



IDEAL RRTC Disability Webinar Series



Investigating Disability factors and promoting Environmental Access for healthy Living Rehabilitation Research Training Center

Webinar: *Aging with Cerebral Palsy: Health Outcomes and Management*

Q&A with Heidi Haapala, MD; Mark Peterson, PhD; and Michelle Meade, PhD

	Question	Answer
1	Can you differentiate the indicators of CP (cerebral palsy) vs MS (multiple sclerosis)?	<i>Dr. Haapala:</i> "Cerebral Palsy is a condition that occurs at or around birth and Multiple Sclerosis is an adult onset condition. There are similar issues that people with Cerebral Palsy and Multiple Sclerosis can face like muscle spasticity and difficulties with mobility. So, one of them is an adult onset disability that is quite variable and the other is childhood onset."
2	What is the physiological reason for why spasticity increases during the aging process for the person with CP?	<i>Dr. Haapala:</i> "So we think some of the reasons that spasticity worsens is as muscles get weak, sometimes they get tighter and more spastic. One of the best things I recommend to patients as part of their spasticity treatment is strengthening - often done first in conjunction with a physical therapist as it needs to be done under a controlled setting to start. But I have had good results for some of my patients if they're able to do strengthening with physical therapy. So that may be one of the main reasons, I'm not sure if that answers the question."
3	It sounds like you only included privately insured patients in these studies? If so, why is that? A very large percentage of people with disabilities have only Medicaid or Medicare...	<i>Dr. Peterson:</i> "So it's actually a really good question and one that I was hoping someone would ask, so because of the limitations of the constraints of the webinar we didn't have time to dive into each of the individual studies. First, we are working on several studies looking at both Medicare and Medicaid data but our original funding was to look at privately insured individuals and so that's how we started our work. The MEPS work that I originally published is publically available and it's all individuals whether or not they have any kind of insurance. So, the most recent studies in the last three years have all been privately insured. So, one could assume that if you're studying individuals with private insurance they may or may not be, but they may be higher functioning healthier segment of the population. They may not be but we have to start looking at that and that's something we can start looking at. Therefore, our estimates may be conservative estimates." <i>Dr. Meade:</i> "Just to add to that - the idea that often with the Medicare and Medicaid population, they have less resources in general. So, when we begin to think about the limitations of just using private insurance samples, you probably think that those are individuals who are healthier, that they may have better access to nutrition, more financial resources or education as associated with that, and that the outcomes when the research is done with the Medicaid and Medicare populations will likely show an even greater extent of chronic conditions."
4	People are saying the recommendations are great, but	



IDEAL RRTC Disability Webinar Series



<p>there's a shortage of CP knowledgeable providers. Have you given thought on how to build capacity for physicians to be more knowledgeable on this front?</p>	<p><i>Dr. Meade:</i> "I think this is an ongoing issue with providers working with individuals with development disabilities beyond pediatric providers, individuals generally who are comfortable working with individuals with disabilities out of specialty areas. And so, this is an ongoing focus both of the RRTC and where the field in general needs to go. We want to enhance knowledge across the continuum. These are factors that are integrated into the Affordable Care Act, but I think they're just beginning to get enacted. In the future, we hope to have CE courses that are direct to providers. Also, programs like the LEND program in which providers get training and experience working with individuals with CP are important but currently are threatened by federal budget cuts. And so while there is more awareness of the importance of education and capacity building for healthcare providers, there's also threats to the actual enactment of those processes. And I don't Heidi what you've seen with some of these issues."</p> <p><i>Dr. Haapala:</i> "Yeah, I think it's a valid concern... I do feel like MedPeds providers, so physicians who are trained in both internal medicine and pediatrics, are often the most open and least affected or worried about somebody not knowing what you do with somebody with a disability because they are more familiar with taking care of children with chronic health conditions and as they transition into adulthood. So sometimes I make recommendations to my patients for an internist who also had a pediatric background like a MedPeds person. But yes, this is an area where we still have a lot of work to do."</p> <p><i>Dr. Peterson:</i> "Yeah, so just to follow up on that I think that raising awareness, not just our own choir of people who work and rehab populations, our physician colleagues, our researchers, other researchers, raising awareness in that audience is one thing but we have to raise awareness - both public awareness and clinical awareness - of people who do not necessarily always see patients who have cerebral palsy. So that's really important and I think that has some impact on public policy and healthcare infrastructure for people with CP across the lifespan. I recently got a review from a journal that said, 'Why are you studying adults with CP? This is a pediatric condition.' So, to me, there's a really huge disconnect between what we're doing and trying to accomplish and what a lot of people out there are doing out there. So, I think the public and clinical awareness needs to be improved, and that will really bolster the healthcare infrastructure of people with CP in the future."</p>
<p>5 We had a couple questions around people who - for reasons like access</p>	



IDEAL RRTC Disability Webinar Series



	<p>to doctors or not really finding a knowledgeable doctor - may have fallen out of the practice of going to the doctor or may resist going to the doctor to address any concerns they have as they age. Do you have any recommendations that you want to offer around this?</p>	<p><i>Dr. Haapala:</i> “I think just trying to get recommendations from family members if they have a good primary care doctor because you really need a primary care doctor. And trying to find somebody who will at least listen to you and who you feel comfortable talking to is the first step. I think if you can communicate with your physician and they're open to listening to you then that will make the biggest difference.”</p> <p><i>Dr. Meade:</i> “And I've heard that in working with other individuals with other disabilities that sometimes it's finding a primary care provider who will learn even if they don't have that base knowledge. There is other expertise who they can find if they're willing to listen but there is a concern about how much time healthcare providers need to invest in order to get up to speed. So sometimes other ancillary providers and their clinicians, physicians' assistants may have more time to establish a relationship, listen to everything that's going on, and then partner with a clinician to find the appropriate treatment.”</p>
6	<p>I am a 40-year-old with cerebral palsy, have you found anything to be helpful with an increase in fatigue?</p>	<p><i>Dr. Haapala:</i> “Fatigue has many causes and it is difficult to assess reasons for fatigue without more information. For all of my patients, the first items we discuss are sleep and energy conservation. Good quality sleep is very important for overall health, pain management and allowing for enough energy during the day. If there are concerns for issues with sleep, such as sleep apnea, this should be evaluated by your physician. In addition to adequate sleep, your daily activities should not be such that you are working at or beyond your capacity. Pacing and taking breaks are important to allow you to have enough energy to function throughout the day.”</p> <p><i>Dr. Peterson:</i> “We are very interested in trying to better understand the relationships between pain, fatigue, and sleep abnormalities in persons with CP. There is a large body of evidence that links sleep deprivation with both chronic pain and fatigue, as well as psychological comorbidities (e.g., depression and anxiety). This work is in progress, but our recommendations are to prioritize regular physical activity participation with attempts at preserving/ensuring adequate sleep (i.e., at least 7-8 hours per night).”</p>
7	<p>What kind problems arise in terms of health care during the transition to adult health care systems? Also, what are the best ways for people with severe CP to minimize sedentary time?</p>	<p><i>Dr. Haapala:</i> “Finding health care providers who see adults with CP is the main barrier to transition for many patients. The most important factor is to find a primary care physician to address your health care needs and make sure you are getting good preventive care. They can then help you find specialists for other health issues you may have. In regard to sedentary time, any movement is important, so try to find ways to move throughout the day, using whatever movement you have. You can set a reminder for every 20-30 minutes to remind you to shift your weight or move your arms or legs.”</p>



IDEAL RRTC Disability Webinar Series



		<p><i>Dr. Peterson:</i> “Reducing sedentary behavior is much simpler than trying to increase physical activity. Any body movements involving large muscle groups would represent reduced sedentary behavior. When standing is not possible, then periodic movement of arms and legs that activate prime mover muscles (e.g., quadriceps, hamstrings, shoulders, lats, pecs, core muscles) is important. This can be accomplished with or without partner assistance to create manual resistance. It can also be done alone by using one's body weight as a resistance.”</p>
8	<p>Individuals with CP have mobility and movement limitations, so independent exercise without assistance can be difficult. In addition, due to the muscular and orthopedic structure, some specialized training is necessary for the assistants who may work with individuals with CP. Young adults are at the prime of their career and before the onset of these comorbid conditions, they can get focused on careers which are inherently sedentary (and have less demands of movement or mobility), so what is your advice to these individuals? How do we reconcile? Finding the right assistance is challenging.</p>	<p><i>Dr. Haapala:</i> “One of the ways I work with my patients to increase activity is to send them to physical therapy (PT) to work on specific goals and help with developing a home exercise program (which may include use of gym equipment). For example, I may refer someone to PT to work on improving their strength with a goal of improving their independence with transferring or working on weight bearing. As part of that therapy, I will often ask the PT to work with caregivers to train them in transfers or with assisting with a home exercise program. The PT may also be able to train them on some exercise machines so they can find a way to exercise after PT is completed. For adults, the goal of PT is to address a specific problem and train you on a self-management program. PT is not a long-term treatment in and of itself.”</p> <p><i>Dr. Peterson:</i> “I agree that finding the right assistance is challenging. I also agree that careers that are inherently sedentary is a problem, but this problem is not specific to people with CP. For all of us, finding creative ways to fragment sedentariness during our daily jobs is very important. Standing desks are useful, but not always practical. I suggest setting a timer/reminder to alert the need to stand up or move. There are many apps and devices that offer this type of intervention. It is very important remember that exercise and reducing sedentary behavior are two independent points of intervention. We all need to think about how to approach both on a daily basis to optimize functional preservation, as well as physical and mental health.”</p>
9	<p>What are the gender differences in Cardiovascular Disease (CVD)?</p>	<p><i>Dr. Peterson:</i> “Generally speaking, men are at greater risk for CVD than women. There is little evidence to support that this is different for individuals with CP.”</p>



IDEAL RRTC Disability Webinar Series



10	<p>This has been very informative. I am an occupational therapist in and working seating and mobility. I have noticed that many of my adult clients have not maintained medical care after aging out of the pediatric medical model. My interests are in maintaining life participation and reducing risk of isolation. Living in a low resource state (Montana) are there strategies to relay information to assist with better medical care for my adult populations that have fallen out of the medical model and resist going to the doctor?</p>	<p><i>Dr. Haapala:</i> “Fear of medical professionals or resistance to therapy is common for many of my patients. Many times, my patients have had constant therapy, interventions and bracing up until their teen years and fear getting back into that environment. One of the issues I talk about with my patients is that they are the ones who get to decide how little or how much support, medications or intervention they want. I see my job as providing them with information on health and function, educating them about options to manage the issues they are facing (difficulty walking, spasticity, pain, fatigue) and having a two-way discussion to determine how to best proceed. My overall goal is to provide information and tools for optimizing function and health long term. Many times, I start small and progress slowly, always checking in with the patient as to their specific goals. If I see an area of concern, I will often take the time to provide my viewpoint but it is up to the patient to decide how to proceed. I think it is very important that the patient feels their concerns are heard and that they have the ability to fully participate in treatment decisions.”</p>
11	<p>Can you comment at all about your finding of a higher incidence of dementia in adults with CP? By what means was that diagnosis identified and what are your thoughts about this finding?</p>	<p><i>Dr. Peterson:</i> “Our findings for this were directly from administrative claims data. Those data come directly from a medical diagnosis, which is coded using International Classification of Diseases, and provided to insurance carriers. We are able to leverage these claims data to explore any disease of interest. As to my thoughts about this finding, I was/am not surprised by this because we are finding similar findings across other domains of cognitive health outcomes in CP. This extends concerns about the issues of "premature" or "accelerated" aging in other organ systems (muscle, bone, cardiovascular, etc.) to the central nervous system. It also highlights the need for early screening and interventions to preserve cognitive function across the lifespan.”</p>
12	<p>Should I look at Athetoid CP separately since they move all the time?</p>	<p><i>Dr. Haapala:</i> “The main area is to consider the cervical spine and evaluate for cervical stenosis (narrowing of the spinal canal) or myelopathy (compression of the spinal cord). Cervical stenosis can happen to anyone, but is more common with athetoid CP.”</p>
13	<p>What about menopause?</p>	<p><i>Dr. Haapala:</i> We do not have any separate information about that at this time.”</p>
14	<p>Waist circumference may be hard to interpret in people with scoliosis or who are unable to stretch erect. Is there an adaptation for seated waist circumference for example?</p>	<p><i>Dr. Peterson:</i> “This is a terrific question and one that is often raised. While there is not a current published adaptation for WC in a seated position, we are in the process of trying to adapt WC to be assessed in a supine position. Unfortunately, there is no perfect way to get around this issue of scoliosis with a simple anthropometric measurement. In a perfect scenario, we'd be able to get imaging on trunk to determine adiposity depots; however, this is not feasible. Thus, better efforts are certainly needed to extend and improve anthropometric measures of central adiposity.”</p>



IDEAL RRTC Disability Webinar Series



15	<p>Have you documented a high rate of side effects with SSRI antidepressants and CP? Even one dose gives me immobilizing spasticity and I have heard the same thing from several other people. (If it's relevant, I experience the same effect with any medication containing dextromethorphan.) Do you know of any alternatives to SSRIs for people with depression/anxiety and CP that do not increase spasticity?</p>	<p><i>Dr. Haapala:</i> "Some SSRIs can cause worsening spasticity. Fluoxetine seems to be one of the ones that causes the most problems. There are not any articles published yet that I am aware of, but at one of the national meetings, a psychiatrist presented some of his clinical recommendations. He noticed that citalopram (Celexa) seemed to have the lowest risk of worsening spasticity for most of the patients he treated. This may not be the same for all individuals as medication side effects can vary."</p>
16	<p>I don't think there is any evidence about disuse osteoporosis, but I am wondering what others are doing for it aside from exercise and Calcium/Vitamin D.</p>	<p><i>Dr. Haapala:</i> "Lack of weight bearing or limited weight bearing does lead to low bone density. The first treatments are weight bearing, calcium and vitamin D as you noted. In addition, evaluation by an endocrinologist may be useful if there is concern for osteoporosis and fractures. There are many different medication options for treating osteoporosis and it is important to work with a specialist who understands when to start and stop a medication and understands which medication to choose."</p> <p><i>Dr. Peterson:</i> "I cannot underscore enough the importance of strength training to improve and maintain musculoskeletal health in CP. While general physical activity is important for cardiometabolic health, strength training to load muscle and bone is vital for preservation of both tissues."</p>
17	<p>Is there information about repeated Botox use and adverse outcomes such as fractures or muscle problems?</p>	<p><i>Dr. Haapala:</i> "There is not a lot of information as yet, but there was an article published recently that highlighted some concerns as to long term use of botulinum toxin. It is a medication that can be helpful, but use should be considered carefully and goals of treatment set up ahead of time."</p> <p><i>Dr. Peterson:</i> "The information is very scarce. I will refer to a recent review on this topic: "Sarcopenia, Cerebral Palsy, and Botulinum Toxin Type A"</p>
18	<p>Additional test needed during annual physical, that may not be standard beyond bone density and waist measurement?</p>	<p><i>Dr. Peterson:</i> "I would highly recommend a standard lipid panel and possibly fasted glucose and insulin."</p>
19	<p>Can you recommend some specific strength training guides that we can use? Most are written for people without disabilities and are difficult to use or follow.</p>	<p><i>Dr. Peterson:</i> "See our published guidelines for persons with CP: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4942358/"</p>



IDEAL RRTC Disability Webinar Series



20	Is there a list of PCP who are truly knowledgeable about health needs of adults with CP. Most specialists or PCP are focused on pediatrics, as you know.	<i>Dr. Haapala:</i> “Possibly on the AACPDM's site. However, this list would not be inclusive. Often a physician who is Med/Peds (did a combined Internal medicine and pediatric residency) trained is used to treating both children and adults and is a good choice. Family physicians also treat children and adults and can be a good fit.”
21	I have had a normal bone density scan but you mentioned a full body scan to check for fat, does one just ask their doctor for that?	<i>Dr. Haapala:</i> “The scan to check body fat is a research technique This is not yet available clinically.”
22	Do you know of a network of physical therapists who want to work with adults? I have had a hard time finding physical therapy as an adult and it almost seems as important to keep function. Stretching myself is not effective.	<i>Dr. Haapala:</i> “I do not know of a network of PTs. The AACPDM's website may have some information. What I usually tell my patients is to look for a PT trained in neurorehabilitation. These therapists work with individuals who have had neurologic injuries, such as a stroke or brain injury. They are familiar with muscle weakness and spasticity and can usually treat CP. For more musculoskeletal type problems a PT trained in manual therapy may also be a good fit.”
23	How can we connect after the webinar?	<i>Dr. Peterson:</i> “By email: mdpeterz@med.umich.edu ”
24	Can you describe any examples of weight-bearing exercises for an adult with CP who uses a power wheelchair most of the time?	<i>Dr. Haapala:</i> “This is a difficult question as there are so many different levels of power wheelchair users. Many of my patients in a power wheelchair can use a stander for weight bearing. Some also use the NuStep, which can provide resistance if set up correctly.” <i>Dr. Peterson:</i> “The National Center on Health, Physical Activity and Disability (NCHPAD) is an invaluable source of information pertaining to physical activity in persons with physical disabilities. Please check out their resources at: https://www.nchpad.org/Aboutus .”
25	Medicare/Medicaid refuses to cover a standing wheelchair, because according to them, it is medically unnecessary to stand after the age of 20. Any suggestions?	<i>Dr. Haapala:</i> “The age limit of 20 for use of standers is not set in stone. We had a patient challenge Medicare and she was eventually able to get a stander covered. As a result of her work, there is a precedent to not discriminate based on age. However, depending on your specific functional level and medical issues, a stander may be more appropriate than a standing wheelchair. A standing wheelchair can work well for some, but if there are problems with scoliosis, the seating system on a standing wheelchair is not as customizable and may not meet your needs for the rest of the time you are using it.”



The contents of this webinar was developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (90RTHF0001). NIDILRR is a Human Services (HHS). The contents of this webinar does not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.