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Occupational Therapy Approach to Assessment and Intervention in Dementia Recorded May 19, 2020

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OccupationalTherapy.com Course #4757

- [Fawn] Today's topic is Occupational Therapy Approach to Assessment and Intervention in Dementia. Our presenter today is Julia Wood. Ms. Wood received her master's degree in occupational therapy from the University of Minnesota, and her bachelor of science in exercise science and wellness from Ball State University. She completed a clinical internship in neurological rehabilitation at the Mayo Clinic Hospital, St. Mary's campus. She serves as the occupational therapist at the Dan Aaron Parkinson's Rehabilitation Center, and in multidisciplinary clinics for neurological movement disorders at the University of Pennsylvania's Parkinson's Disease and Movement Disorder Center for Excellence. She serves as faculty for the Parkinson Foundation, Allied Team Training for Parkinson's program, and is a clinical training and certification faculty member for LSVT BIG. Ms. Wood acts as a facilitator for the Parkinson's Disease SELF program, an ambassador for the Davis Phinney Foundation, and serves in planning committees for the World Parkinson's Congress. Welcome back, Julia, so happy to have you.

- Thank you so much, Fawn, and thank you so much to everybody joining us today. I'm really excited to share this presentation. And something that I grow more and more passionate about all the time, which is really helping out our patient population with dementia, which is definitely growing. So, the outcomes today that we're gonna be talking through is really, I want you to understand the changes that you can see happen in different levels and different diagnoses of dementia with Alzheimer's, Parkinson's disease, dementia, Lewy body dementia, and frontotemporal dementia. And we're gonna get into appropriate screening and outcome measures that you can use to really make a client centered approach to your treatment. As well as then later on in the presentation, discussing the use of occupation-based and task oriented treatments, once again, to really make sure that our treatment is always client centered. But the one big outcome that I don't have listed on the screen here today is that in the research I was doing for this presentation, I noted in an article that when occupational therapists were surveyed, less than half felt that they were confident or

even somewhat confident in being able to address and help people with dementia. And you'll notice as we talk through today what the research shows as far as interventions for dementia, it's really our wheelhouse. So, our unique skill sets as OTs is what's needed, as outside of medications and treatments, we need to use our skillset. So I hope that at the end of today, my big goal is that you'll all feel that you recognize the ways that you could help and really be an integral part of improving quality of life and treatment for these individuals.

Okay. So, my disclosure, I don't really have anything to disclose as far as financial relationships. And so let's just hop to it. So, what is dementia? Well, we know that it basically is a clinical syndrome. So there's not a blood test. There's not even often any type of a brain test until after someone has passed, so, post-mortem. So it is a clinical syndrome, and there can be a lot of different manifestations and presentations that we see. It's chronic, and it's considered to be acquired loss of two or more cognitive abilities. So you can see this across different domains of cognition, visuospatial function, executive function, aspects of memory and language and attention, and it's caused by brain disease or an injury. So the decline in these abilities is considered to be from a prior level of function, so we're looking at a significant change. And the big difference to note is if we're thinking about mild cognitive impairment that we sometimes see with Parkinson's disease or different conditions, when we think of dementia, it impairs the ability of someone to function day to day, either in their self care or IOL or occupational interest and social engagement. But recently it's important to note that clinically you notice the diagnosis has always been based on this two or more cognitive abilities. But recently the DSM-5 is noting that dementia can involve impairment in a single domain with someone. So that's important to keep in mind as well.

So, the most common form of dementia that we see, or the most common condition, is definitely Alzheimer's disease. And this is a progressive neurological disorder that is

irreversible, and you see a loss of neurons in the hippocampus and the cortex. So, if you think about functionally what this can impact, we see significant changes with Alzheimer's in memory. Also with judgment and insight and decision making. There can be changes to language and also issues with orientation to their environment. So it is the most common neurodegenerative condition. It constitutes two thirds of dementia cases overall. The prevalence is about 1% of people in ages 65 to 69. But look at how that jumps up. It goes up to 40 to 50% when we get into our individuals that are older, 95 years or older. So you can think about in between that range from 69 to 95, how it's continuing to increase. About 7% of the early onset cases are familial, and there is an autosomal dominant genetic pairing. So, this is something to really keep an eye on.

Probably a lot of you out there are possibly seeing patients in your practice with Alzheimer's, or you might have family members as well. Next is Parkinson's disease dementia. And so this is going to really accompany Parkinson's disease, and I'll offset it a little bit too, we're about to talk about dementia with Lewy bodies. And both of those presentations, I didn't really wanna get into a pathophysiology lecture 'cause that's a whole other topic for another time, they involve the presence of Lewy bodies. But it depends on where those deposits of Lewy bodies are in the brain, which is a buildup of an alpha-synuclein protein in the brain that causes the presentation that you see. So, with Parkinson's disease dementia, this comes on later in the diagnosis. So someone's had changes to their movement first. They've had some rigidity or tremor or slowness in their movement. And then over the course of that Parkinsonism, they develop a dementia presentation. So, they'll have changes to executive function, some changes to memory can be possible. Their clock-drawing will often be impaired. You'll see visuospatial deficits as well as impaired attention. And hallucinations will become prevalent in 45 to 65% of cases, where if you compare that to just Parkinson's disease, where people can also have some hallucinations separate even from dementia, we see that in about 25 cases of PDD.

So then if we compare and contrast that to dementia with Lewy bodies, dementia with Lewy bodies, and sometimes you'll see patients will come in and they might be diagnosed with one and then it switches to the other. I had a gentleman recently that was originally diagnosed with Parkinson's disease. And then based on the presentation that we were really seeing, it was switched to dementia with Lewy bodies because his cognitive symptoms and his cognitive presentation had really appeared first. So we're looking at these core clinical features. And some of these are really gonna overlap with Parkinson's because of that Lewy body connection. So, we'll see a REM behavioral sleep disorder, and that may precede the cognitive decline. There's more and more evidence that suggests that these changes to REM sleep happen long before the presence and onset of Parkinson's and dementia with Lewy bodies. You'll also notice a lot of fluctuations in cognition. So, their alertness, their attention really varies. And you can see this often in your treatment sessions when you're working with these individuals, or sometimes the family will really report a lot of confusion around why are they able to do this sometimes, and then at other times you see a big difference in their function. And they'll have recurrent visual hallucinations. And these tend to be very well formed and detailed. I have had clients who, one lady saw little people, that was her hallucination, and she could describe them for you. Another saw babies, or small children are common. I haven't had a lot of people that they are scary a lot of times, but they are very well formed, and they can really describe them to you. So they'll have one or more also of these cardinal features of Parkinsonism, so that bradykinesia or slowness of movement, they'll have decreased amplitude to their movement and speed. They may have a rest tremor as well, or pill rolling, where when the hand is at rest, you can see a tremor presentation, and they'll often have some rigidity as well. So they have changes to their cognition as well as to their movement.

So, we know that what's essential for them to really make this clinical diagnosis is that presentation of dementia, where their cognitive changes are impacting their daily function. They'll have deficits that are really similar to the same ones we see with

Parkinson's disease dementia, so, attention, executive function, visuospatial. But as I said earlier, the difference is these onset very early and are very prominent in the condition. Where with Parkinson's, they tend to kind of slowly build over time. A memory impairment may not occur early in the disease, but often over time, you're going to see those changes to memory with DLB as well. So, then frontotemporal dementia or FTD is one that is starting to get a lot more, I think, attention and awareness and research. And we'll talk about kind of, there's some conditions that this co-presents with as well as on its own. And there's three major clinical variants that you may see in your practice. The behavioral is most common, and we'll get into some more details of what that looks like in a moment. There's also a variant that really impacts language more. And then the last is motor.

So, for the diagnosis, they have to have this history of progression of behavioral changes. Often there's a family history as well. You're looking at their behavior during interviews. Neuro-psych testing is often done, they do different labs and neuroimaging. And the important thing to note with this one is it's the most common form of dementia for individuals who are younger, so under the age of 60. The closer I get to 60, the younger that gets, by the way. So, 40% of those who are diagnosed with FTD have a family history of at least one other relative who has some form of a neurodegenerative disease. And then 10% have a gene mutation, and I'll talk a little bit more about that. It's really hard for me to stay off of the pathophysiology, but I know I wanna get into assessment and treatment. So with this behavioral variant, it looks like my L moved there, I apologize. It's not a behavira one, it's behavioral variant. So what we start to see are these declines in social appropriate behavior. Poor self control and disinhibition. And this is a change from baseline.

So, a woman that I had recently had started to have a lot of trouble at work. And luckily she had worked at her job for some time, and so some of her coworkers actually reached out to her family and said, "We're a little concerned." she was starting to be

angry and have these kind of outbursts at people, and really acting inappropriately at work and having poor judgment. And this was something that her coworkers had never seen from her before, and they became concerned. And so then the family was able to intervene. But also, I wonder sometimes if this sometimes goes unnoticed and people don't know, and maybe you just get terminated from your job. Or people maybe distance themselves from these people in their life because they don't know what's causing the problems. And we often start to see a lot of apathy, too, and a real disinterest in things that they've previously been interested in. The decline in executive function, if people are still working, which if you think about under the age of 60, most people still are, it can really start to impact their performance at work. We'll often see, too, some changes in how they interact with others. There's a lack of empathy. And like I said, maybe some anger and difficulty controlling their behavior that they haven't had before. They may have compulsive or ritualistic behaviors and start to perseverate. And the really interesting one, too, is there can be some changes to their eating behaviors. They might start to really compulsively eat or overeat. They may suddenly have an affinity for foods that they didn't eat previously.

We had a gentleman in a while ago, and his wife said he'd never really been one to eat potato chips or junk food. And all of a sudden he would take out entire bags of chips and junk food, and just very compulsive in his eating, it was very unusual for her. So then if we look at the language variant, what we typically see is a primary progressive aphasia. So they'll have this ongoing loss of ability to speak, but also to understand speech, and it can impact their ability to read and write as well. So there is a logopenic variant where you see some difficulty finding the right words, so like a verbal fluency type of presentation. There can be a semantic variant where there's a loss of the meaning of words, they don't really understand and relate to what a word means, and even simple words that were in their language previously. And we can also see this nonfluent agrammatic variant which decreases in speech with these increased grammar impairments.

So, we had a gentleman a while ago, and I know our speech therapist was working more with him. And he was someone that was an English professor and really, grammar was a big thing, and all of a sudden his grammar really changed. And that was what the family first noticed. So as you can imagine, when we see this language variant, this is a great time to really work with our colleagues who are speech language pathologists as well. So then if we look at the motor variant, and this is really interesting. So back in 2011, they first identified that there's this ALS FTD spectrum disorder that you can see. So previous to that, it was really thought that amyotrophic lateral sclerosis or ALS, Lou Gehrig's disease was just a motor disorder, and there was no cognitive presentation present. But around 2011, they started to note, and it started to show up in the research that we were seeing people with this FTD and like a behavioral variant that was coming forward, or cognitive variant as well. So, important to note that for those of you that maybe treat ALS, you may see people sometimes, because what will happen is often they've been diagnosed with FTD first, and then the motor neuron changes will start to happen, you'll start to see those motor changes with their weakness and whatnot.

So you'll notice here, though, that the Parkinsonism is the most common variant that we see for people that have the behavioral variant. So once again, that's your slowness of movement. That's your rigidity and possibly even a rest tremor. And some of these folks will have some features of the atypical Parkinsonisms. So, corticobasal syndrome where you see some cognitive changes and also affect usually to one side of the body. Alien limb presentation, difficulty with ideo-kinetic apraxia. Also progressive supranuclear palsy, we see those changes to visual fields and visual tracking. So sometimes they'll have some of these features, too. One of our neurologists calls it a salad bar presentation. He says, "You see a little of this and a little of that, "and start to see features "of a lot of different conditions." And we also know with this motor variant that up to 40% of them will have this mild motor neuron disease. So they may have

muscle atrophy, weakness, fasciculations with lower motor neuron presentation. The upper motor neuron, of course, we get your spasticity, your plantar response, hyperreflexia.

So these are just some things to look out for. Sometimes you'll see a lot of crossover in different conditions that you may treat with FTD. And I think that this is the dementia diagnosis that we're starting to see come on more and more in our awareness and in the research. So, let's talk about the caregivers a little bit. We've talked about a lot about what this means for people living with it. As you can imagine, there's a real increase in physical health problems for caregivers, and mental health problems as well. They may start to really disregard their own physical health. I had a patient a year or so ago that his wife literally was having heart trouble. And when the ambulance came to get her, she refused to be taken to the hospital 'cause she would have had to have left him, and he had Parkinson's disease dementia. She could have died. She got very lucky that she was able to wait, have her daughter come and get her, have somebody stay with her husband so she could get to the hospital. But it could have had a very different outcome.

And then as you can imagine, depression, anxiety, stress, all of these become mental health problems often for caregivers dealing with these complex conditions. And if they're still working, and especially if you think of FTD, for example, and the age of onset, often they are trying to maintain their own employment. So that can become more difficult. And this can result in financial difficulties. A lot of times people say, oh, well, you can take FMLA. Well, the Family Medical Leave Act typically is not paid. So yes, you can have the time off, but then you lose your income as well. They experience barriers to their own leisure engagement often. I found this recently with a woman that she was really into dragon boating here, which is very cool, there's a lot of rowing here in Philadelphia. And she had had to give that up because of the level of care that her husband required. So that was something as an occupational therapist I needed to

look at, was her health and wellbeing as well. And you'll start to see difficulty with family interactions. And sometimes this is around the family not understanding the changes that are going on, maybe to their language or to their behavior. Maybe the family being uncomfortable with it. I've always said that I feel culturally, and some of you may agree or disagree with me on this, when we can see why someone has had a change, they have difficulty walking or standing, or a stroke and their arm doesn't work, I think we have a lot more sensitivity. But we can't see the wheels turning upstairs.

So often people are uncomfortable with mental health issues, behavior changes, cognitive changes. And as you can imagine, when you take all of these factors into consideration, caregivers really face a reduction in their own quality of life. So, this is an important thing for us to look at as well and view it as a team dynamic. So then what do we see as far as the impact on participation for the people with the condition? It's gonna take them longer to complete their task. Even simple things like grooming or dressing often take a lot longer, and this can become very, very frustrating, both for the individual with dementia as well as for the care partner. They'll have difficulty with new learning. So we wanna be really aware of that and not just try to give them a button aid or some type of assistive device or adaptive utensil, because that's going to have a new learning aspect involved. They may have impairments to their communications, so unmet needs, we'll talk about later, become a real source of psychological symptoms with this, too. So, if you can't communicate your needs, it's hard for those around you to meet your needs. And then we can end up with a whole host of issues that can come from that.

We know they have an increased dependency for their self care and for their home management. So if this person maybe lives alone, this can be a real problem. Who's going to help, how do we get that help for them? And then we often see decreased social participation across the board with these conditions. And so the isolation from

that is also not healthy for cognitive function and for quality of life. All right, so let's launch into assessment and talk about this, 'cause I find that this is an area that can be really tricky. How do we assess, what do we assess, what are we looking at? You can kind of look at it from this framework. Basically we want a good old fashion occupational profile. So we have to focus on the key issues that the person with dementia may be reporting or depending on, how profound the dementia and the communication changes are, that the care partner is reporting. And so we really have to dig in and talk a lot and communicate and see what's going on.

So we wanna try to identify what their patterns and routines and roles that they're applying in their daily life are. What are their values and interests? What are their needs? I don't always assume that just because someone maybe can't put their own shirt on, that that's what is important to the person and the care partner. They may be more interested in interacting with the grandkids or something like that. So you've gotta really look at what is important to them. And then identify these areas of concerns and difficulty that are important and meaningful to them, and then that's where we wanna focus our attention. So then that helps us determine what outcome are we looking at? Is this something more directed toward activities of daily living? Is it something that's directed more toward leisure or social engagement or activity engagement? And then we wanna collaborate with the client and the family and really, what are your goals? What do you want to be able to do? I think this schematic, no matter what outcome you're plugging in, I'm gonna give you a lot of options today. But I'm sure you all have some that are your favorites that you might plug into this equation in a different way.

So, some different cognitive screenings you can do. I just kind of sum these up on one slide, because once again, we probably all have ones we use. Often what you may find, too, I know in our center, by the time they come to me, they've usually had some type of a cognitive screening or a neuropsychiatric assessment. And so I may not need

to spend my time on that, I might be able to just access that in the medical record and see where that is, if it was a MOCA that was done or whatever the assessment was. And then I can use my time more on focusing on their participation aspects. So the MOCA is great, as you all know. It requires a training, I think as of September of this year, you have to pay to be trained. It's actually a really quick and painless process, for those of you who haven't done it, you should consider it. The short blessed is another option. If you're looking at the dementia rating scale, like you really wanna know if this person is mild or moderate or severe, you can get into some of the cognitive rating scales or dementia rating scales.

The CLQ, the Cognitive Linguistic Quick Scale, say that four times fast, I find is often more used by speech language pathologists. And I also feel it's anything but quick. But it's good, so keep it in mind. Of course, the good old Mini Mental, and then the SLUMS as well. So if you feel like you need to do some type of a cognitive assessment, there's a lot that are available out there for you to use. So this is one that I like a lot. I put a couple of links there for files that hopefully you can find. One is a media file where you can just kind of tick the box on it, and it produces the results for you. And then the other is a paper and pencil version. So this is more Alzheimer's specific, right? So, this is gonna look at competencies for Alzheimer's and just your basic ADLs and your instrumental ADLs. It can be completed by the caregiver as a questionnaire. So if you wanted them to complete that even outside of your time, 'cause I know a lot of times I get questions from people, how am I supposed to get all these assessments done in the amount of time that I have for an evaluation? So this is one you could send out ahead of time or send home with the individual to do as a questionnaire. And you can do it as a structured interview if you want, or have them fill it out on their own. There's a shorter 19 item version that's just more basic ADL, so that's more severe Alzheimer's patients. There's a longer 23 item that gets a little bit more into interest and leisure engagement if you like, so you can take a look at some of those activities as well.

The Activity Card Sort I like a lot. I think it's underused in therapy. It is a little expensive, though, I understand. I think it's around \$140. And I have heard of people kind of making their own and that it's not really a standardized assessment, but it's more like a picture interest inventory, if you will. But it has photographs of individuals performing different activities. It really helps you hone in on client centered intervention and look at their interests. Helps you guide a discussion about what their current interests are, and maybe prior interest in roles. And then you are able to measure the changes in participation. So there's a misunderstanding sometimes that it's not an assessment, that it's just an activity, but it is actually, it can assess participation as well. The Modified Interest Inventory comes from the good old MOHO, back to school we go. So, this is a way to look at strengths and interests and past engagement and activities. Things they've done currently, things that they maybe would like to do in the future or did in the past. The main focus, as you all recall, is on leisure interests and looking at things that might influence their activity choices. And I brought in here that it can be used by adolescents or adults, 'cause some of you might be more familiar with it if you've worked in kind of a pediatric or young adult setting. But all of these things, just kind of keep them in the back of your mind. They're gonna come up later when we start talking about some of the interventions that are evidence based.

So, the Routine Task Inventory, as well, is another way to look at, how do you kind of see a functional level of cognition, right? And so we're trying to observe their performance in their context, or you can use it to get perception to performance of the client or the caregiver using it as a checklist. So it kind of gives you a little flexibility that way. And it's based on the Allen cognitive levels. So, I put a link here for you to be able to access it, this one can be a nice way to really take a functional look at cognition. The PASS I've learned more and more about, and I have to admit, I put it in more and more slide decks all the time, because what's great about it is you really can customize it. When I first discovered it, I thought you had to do the entire 26 task, and I was like, how am I supposed to do that? But you do realize that you can customize it

and just use the ones that you want. There is a clinic based version and also a home based version. Each of the sub tasks you're rating based on independence, safety, and adequacy, which is nice, 'cause safety with these guys becomes a real issue. And so you can customize it as well to kind of make up your own domain as well. So it walks you through kind of a blank template, where if there's specific tasks that you want to be able to measure that isn't covered in it, then you can create your own format as well.

The Barthel index is an oldie, but goodie. I use this actually a lot with my ALS patients, or kind of more profound and severe dementias. So if I'm looking at just, I wanna get a quick snapshot of self care and their functional mobility, I just interview the care partner and the client together. It's widely used in geriatric settings, it's got good reliability and validity. So you can observe the activities, if you prefer, you can use it as more self report or more of a care partner or even a home health aid report. So a lot of variance there in how you can administer it. The Bayer Activities of Daily Living Scale is another kind of functional cognition assessment. So you're looking at how their short and longterm memory and also performance in different environments impacts their ADL performance and self care. So, this one is one that I've, I'll be honest, I just discovered it recently and just started playing around with it, but I thought I wanted to include it just so you guys could take a look at it and see what you thought, as well. I'm still kind of jury out on how I feel about it, it is a little long, but it does seem to give a lot good information as well.

Goal attainment scaling is coming on more and more in the literature, you'll see it come up later in one of the studies that I present. And so this is a great way of really taking the needs and interests of that patient and whatever their goals are, and completely tailoring your intervention. So you'll notice zero there is the expected level. It's where you think that patient is going to be able to get to with whatever the task is. I give the example here of lower body dressing. And then they might get a plus one, so they end

up doing even better than you thought, or a plus two, much better. And you kind of define what those levels are. But then you'll notice, too, there's a minus one and a minus two if they do less than expected. So, this is something I think that if you feel you're a little bit at a loss of what outcome to use but you know what this person's goals are, you really wanna zero in on that. This can be a great tool. So then we do know, too, I didn't get into this a lot, but especially with some of the Parkinsonism that we see with people, the changes to their movements and some of the impulsivity, even, with some of the conditions, and weakness with the motor variants of FTD, there can be falls from time to time.

So I put the TUG in here 'cause I think this is a nice one because it's pretty quick and simple. You have someone stand up from a chair, walk, turn around, come back and sit down, and it gives you some great information on their falls risk. You can also do a cognitive dual task with it or a motor dual task where you ask them to name animals or count backwards or whatever you want them to do. Depending, of course, on the cognitive level, you would wanna make sure that you made the task appropriate. So that can be a great assessment of their falls risk. Another simple one if someone is more severe and they're reporting a lot of falls, then I can do the five time sit to stand, where they're just standing up and sitting down from a chair five times. So, this is a great one if you just wanna get a quick kind of balance assessment that's easy to cue and give. This can be a nice thing. But also, it can just be a time to collaborate. If you feel like your plate is full with all of the issues that you have to deal with for this person's participation and quality of life, then maybe we hand this off to our PT colleagues.

There's some talk in some of the studies I'm gonna present today of environmental assessment, and the HEAP is one actually that Laura Gitlin cites. So, you're looking at different items to really sum up hazards, adaptations, level of clutter and comfort in the home in up to eight areas. And so it relies on kind of a structured observation, so this is

really more for our home care therapist self-reports. I did have a colleague who said one time that she would sometimes have people take a video of their home, and she would try to use this as well. She was in an outpatient setting. So, this is an option if you want a standardized environmental assessment. And also, part of that caregiver discussion we talked about earlier, if I feel that caregiver burden is really impacting the quality of life for the patient and is a problem, then often I'll do some type of a caregiver assessment. So, the COPM, the Canadian Occupational Performance Measure can be used that way for sure. And these are some of the other indexes that you can use to look at the burden of the caregiver and kind of see over time, do your interventions actually help them with their quality of life improve?

All right, so let's get into intervention. And then we can talk questions at the end, too. So how can occupational therapy help? This is the one that breaks my heart, that less than half of us think we can do anything. So we can really do that strengths based approach, right? And focus on the strengths of the client, promote their wellness, and promote wellness even at the care providers as well. We can enrich their quality of life by maximizing their performance in whatever it is that they want to do. It's important to note here, and I'm gonna soapbox this next one a little bit, I apologize, but I'll definitely drill the point home. Remediation of cognitive skills is not expected. So when we talk about remediation, we're not talking about improving their MOCA score or improving their cognitive function in some way. OTs can incorporate routine exercise into interventions, and we can improve their performance in a task based approach, right? In their ADLs, their functional mobility, we can help them restore range of motion if they're having rigidity problems, look at issues with their strength, maybe their endurance, but we're not trying to remediate their cognitive skills. We can also provide supports for their habits and routines that are working well, so we really help them stay independent as long as possible.

And then also we can look at modification of the home, so we can ensure safe and supportive environments, including verbal cuing strategies for the care partners, and also caregivers, so maybe they're home health aides. And we can try to find as many social supports for the individual with dementia and their care partner, as well. So there's a lot we can do. All right, so if we're talking about cognitive rehabilitation, and this sometimes comes up, it's important to know what it is and what it isn't. So, cognitive restoration or cognitive retraining, as I just mentioned, is that repetitive practice of tasks that's gonna require some targeted cognitive processes, with the goal of strengthening those. So, doing a paper and pencil word finding activity or a memory game to try to improve that aspect of their cognition. This is not shown to translate to function in people with dementias, so this is not the approach we wanna take. But a strategy based approach where we're giving different compensatory strategies or looking at how the person can accomplish their desired task and their activities, regardless of whatever the cognitive problem might be, by using those metacognitive problem solving compensatory strategies, that is the angle we wanna take.

So we can use strategy. And then those things are healthy for their cognition. It is good for them to engage in activity. We know how important those things are. But we wanna look at how we tailor our interventions. So, just to kind of drill that point home a little bit, this is an article from 2017 that looked at an evidence based occupational therapy approach for dementia, what our clinical guidelines tell us, and what this means for practice. And I had to pull this quote out 'cause I thought it was really, really good. So we should avoid spending time on activities that have not demonstrated improved outcomes for the person with dementia, such as cognitive retraining. And I hope none of you out there have been doing that, but I have had assessments I've seen come in from other therapists where they're going to improve their score on the MOCA by using the Dynavision. And that's not a realistic goal for that person.

So what is realistic, though? What we do know, this is a great article, this Bennett article. So when we look at kind of a systematic review, most of the studies had an approach to assessment and intervention just like we talked about, that focused on both the care partner or the carer and the person with dementia. And then you individually tailor and make your interventions goal directed. So, I know it's gonna start to seem like a broken record 'cause this is so much which of what comes out of the literature. The carer and the person with dementia are supported to choose the activities that they want to improve. And that could be activities of daily living, or it could be other meaningful activities. Listening to music together, going to concerts. Like I said, interacting with grandchildren. Carers need to be coached and trained so that they can then problem solve, present, cue, know how to simplify activities, use the strategies that we've given them, and generalize these strategies so that they can not only modify the environment to keep the person safe and independent as much as possible, but also support their activity engagement.

So, a lot of care partner training. Carers also receive training in information to address their own concerns. So, their stress management. Understanding dementia also, 'cause a lot of times people don't understand. We do have to not assume that they understand why the person is behaving or acting this way, we have to really try to educate. So they found that the average number of sessions for occupational therapy was around eight sessions. The median was, its range was one to 12. There was one trial that did 24 sessions. And the sessions were more than likely an hour to one and a half hours. And the total intervention time usually ranged between eight and 12 hours.

So this kind of gives you an idea if you're looking at how to set up your plan of care, I put this in here as a way for you to kind of think about approaching that to start. The timeframe was generally over anywhere from five weeks to six months. And then there was one study that provided interventions across a two year timeframe. So we really are thinking about often kind of a longer plan of care. So, the efficacy from that study,

what they found is that people who received these eight to 12 hours, that average of eight sessions, of that multicomponent OT had improvements in their ability to carry out their activities of daily living and instrumental activities of daily living. What was interesting, too, is they had fewer of these behavioral issues and psychological symptoms. And the carers even reported an improved quality of life. So, the maybe 50% of you out there that didn't know you could help with dementia, this is what we can do, and the research shows it. I get excited about that, sorry, I think we're awesome.

So, then let's get a little bit into some specific ideas here, so I wanna dig a little bit deeper. So, when we look at our role in managing these neuropsychiatric symptoms, 'cause when you look in the literature when you interview these families, this is often what is the biggest problem, right? So this DICE method, where we describe, investigate, create, and evaluate, is a great way to do a patient centered approach. And this really helps inform our clinical reasoning. So you can take this as kind of a framework. I've used this with students in the past to really help them optimize their treatment plans. So, describe, what do we want? We wanna really review the person's abilities. We wanna look at their environment and how it's set up. We wanna look at how the caregiver and the person with dementia communicate and interact. And we wanna look at any demands on activities that they're doing. Maybe they're trying to get dressed seated edge of bed, and that's a problem for balance or coordination. Wanna look at those activity demands. And once again, this is so our wheelhouse here, we've got our performance skills, body function, structures, this is back to just our domain of practice, right?

So in addition to that in person evaluation, we need to really encourage the caregivers to record any issues they have and the context, write a diary, video tape, maybe, and give us things, email, but really keep that communication and get as much description as we can. Investigate, so important. Sometimes I feel like I'm some type of detective

or sleuth, and I'm working and trying to understand these individuals more. So we wanna assess their cognitive level using standardized assessments, as I said, if we don't have that assessment already. We wanna interview the caregiver and really understand what were the roles and hobbies and occupations. Maybe participation in religion or different organizations. What's their role in their family? We really wanna understand who this person is so that we can inquire as to what motivates them. We can't really know that if we don't know what they're into. We also wanna know what times of day is the patient more active and alert. Is there any pattern to those cognitive fluctuations that we sometimes see with DLB?

And we also have to look at their range of motion, strength, their mobility, including their falls risk. That was why I put those assessments in earlier. We wanna look at the environment in which those neuropsychological symptoms kind of creep up, what is the environment like? And then we have to be creative. We've gotta really put on our thinking cap. We wanna educate the caregiver as much as possible about dementia and these behavioral symptoms. We wanna build skills for communication, modify the environment so that we can really take out as many of those external contributors to their behavior. We wanna help the caregiver understand the functional level. So, what are their limitations? What are their strengths? Are there simple cues that they can give to really help introduce activities as a way to minimize these neuropsychiatric changes? How can they make therapeutic use of self, really, which we're very informed in, in how they're caring for their loved one? And we can look at ways that they can simplify the environment to really help them function the best way as possible, reducing confusion, and make everything as supportive for both. And then we wanna evaluate at the end.

So, it's a very fluid process, I would say. We wanna know what worked, what didn't work, did they implement the strategy correctly? What were the changes in status that maybe made it difficult? Was it not the right strategy at the right time? We have to

really kind of get in there and be open to hear maybe criticism or different things that maybe weren't so effective, and then be flexible. It might be the time, too, if the cognition is worsening, the condition is really progressing, that we need to report that to the physician. And it might be time for home services if they were seeing as an outpatient, or maybe different community resources need to be investigated if there's been a decline. So then if we look at the Tailored Activities Program, and if you haven't looked at Gitlin's research, Laura Gitlin, it's fantastic. And this is really looking at, this was the home version. There has been an outpatient study that looked at this as well. But you're looking at up to eight sessions over three months, once again, just to kind of make you think about your plan of care. They evaluated the person with dementia, also the caregiver in the living environment. They developed these activity prescriptions that were really tailored to the individual. And then they also trained the caregiver to manage their own stressors and really optimize their function and manage the behavioral and psychological symptoms of the individual while also taking care of their personal stressors. There was a lot of education for caregivers on developing realistic expectations, and I cannot stress this enough. We can't assume that caregivers understand. They often underestimate the abilities. They also have a poor understanding often of how dementia impacts someone's behavior.

So we have to really make sure they know the person isn't just being naughty, that it's impulsivity or lack of judgment, so that they can understand and be more empathetic. So, when you look at phase one with a tailored activities, we're doing an assessment, right? This is gonna be the first one to two sessions that you do. You may do a standardized assessment to evaluate the person with dementia. Also the caregiver, maybe one of those caregiver burden assessments. Also looking at the environment. You're gonna collaborate, then, to identify three activities of interest. I've used this a lot, I find it very effective, The activities that are gonna be tailored to the capabilities in the context for that individual. And then we're also gonna really focus on that education about the disease process and give the caregiver some simple stress

reduction techniques so they can cope with their own stressors. When we implement this, we're looking at sessions three through six of those eight sessions. We're gonna share the assessment results with a caregiver, let 'em know what we found. We're gonna give them a tight document of these activity prescriptions, which give them the activity, the goal, look at the person's abilities and what the steps are to implementing it. We're gonna demonstrate for the care partner how to set it up, how to implement it. We're gonna have the caregiver practice the strategy, so they might need some help with initiation, helping that person get going with the activity. And then we're gonna use our own task analysis and our observation skills to modify their prescription as needed. And then the caregiver's gonna practice with the person with dementia in between sessions and kind of report back to us and let us know how it went. So then in phase three, we're hoping for generalization.

So this is the last two sessions. We're gonna assist the caregiver in ways to identify aspects of simplification that might be needed with progression of the condition. We're gonna help the caregiver kind of brainstorm ways that they could generalize that activity to other care challenges they might be having. And we might even involve some type of training and strategies to simplify their communication, often slowing down their cuing, which we'll talk about, or adapting the environment. So, when we're looking at mild to moderate or severe stages of dementia, we know that as the disease progresses, there's going to be less time spent in activity, and they're going to need more support for it, right?

So with mild dementia, they found in this study that people were doing more complex arts and crafts and cognitive activities just for brain health. They spent 28 minutes on average in the activity, but they still required, if you notice, cuing from someone about 68% of the time for sequencing the steps, initiation. With moderate dementia, there was more engagement in music and entertainment, and domestic and homemaking tasks. And then the time, you notice, decreased to 24 minutes. But the cuing increased

to 78%, so we're starting to see more supports needed. When we get to severe dementia, we're looking at more just simple physical exercises, maybe sensory type activities. And it's gonna be around 15 minutes. And then cuing once again of that 78% of time. So, we wanna really keep focused, though, that even with severe dementia, they can continue to participate in activity, and we wanna focus on that and make sure that we address that.

So, some considerations for the TAP program. You wanna really align their preserved functional and cognitive abilities with their environment and their interests so that you can maximize their engagement. Look at their previous and current interests. Try to help promote a sense of self, even in severe dementia. Consider the stage of the disease when you're choosing that activity and that setup. Educate and train the caregivers, and how they need to cue and communicate to really help foster this engagement. And then consider also the time of day for the person. So maybe mornings are good and end of day is a little harder. So looking at the demand level of the activities that you prescribe is very important. All right, so this is one that looks at goal oriented cognitive rehabilitation for dementias. This is what I was mentioning with that goal attainment scaling. And so they found that when they just really set goal attainment scaling around what the individual with Parkinson's disease dementia and the care partner wanted them to do, they did see improvement in their function. And they compared this to a relaxation therapy, and they found that there was a better improvement for the care partner and the individual with PDD. So it showed that cognitive rehab is feasible in this task oriented goal directed approach. And they found for the care partners, even, the health status changes, quality of life changes, were maintained even six months following the study. So we can really get in there and center on the individual with dementia and their care partner and make some significant changes.

So I like this quote 'cause I think it kind of sums it up. When we do person centered approaches which optimize the environment and activities, we support their caregivers. We really look at what is needs and goal based. We enable their own self management where it's appropriate and possible. And we give this responsive case management service model, those are the models that are most effective. So we all can do that, and I'm sure you're all doing it, and we can make a lot of good change. So, some treatment strategies. I think I've already covered the first one, looking at that strengths based approach. Errorless learning is one that you sometimes see coming up in the literature, focusing on how someone's doing the activity rather than them thinking about how to do it, trying to prevent errors, so they just get to practice that task. This one's so important at the bottom, speaking clearly and slowly, which I'm getting worse and worse at doing as this is going on, because I have a lot of content still to get through. So don't follow my lead right now when you're working with your patients. But we know they have that increased processing time. I will sometimes use one of those sand timers, where you flip it, and it shows the sands draining out for care partners. So they can see that sometimes it can be 20 to 30 seconds with dementias after you give a cue before they respond. So it's allowing that. And I also give them the example that if you try to open a window on the computer and you get that spinny wheel, we've all seen it. And then you push it even more because you get anxious and you're trying to open it, it slows it down even more.

So trying to not overload the person with cues. So, some strategies for that. Presenting one step or idea at a time. Speak calmly and in a normal tone of voice, which I'm probably not doing right now. Speak slowly and simply, too, keeping your cues and language as simple as possible. This is both for us and for the care partners when working with these individuals. If you need to repeat something, use the same words, try not to rephrase, because then it's like all new information coming in. As much as possible, stand in front of them and maintain a level of eye contact. You'll notice with the progression of dementias, the gaze lowers a lot of times, and there's more of a

stare toward the floor. Sometimes we have to get down to be in their eye level. If you're trying to get their attention, gently touch their arm or their shoulder. Always approach them from the front so you don't startle them.

And then I love this one, utilizing colors. So, I took a course many years ago from a fantastic occupational therapist named Lanny Butler. And he called himself the little green man, 'cause he would always wear neon green, because that is the color that they respond to for individuals with dementia the most. So if you're giving a reminder sign or something that you're trying to get their attention, neon green, if you can, is a good way to go. So, some strategies here. We wanna facilitate routines, look at how to foster gradual transitions. Music can sometimes be part of this, playing a certain song when it's time to do their exercise or activity, or a certain song when it's time to go out of the home for their therapy appointments or take a shower. Coaching both the care partner and the individual with dementia on frequent reorientation. So, working with them to reorient when needed. Keeping that contact with family and friends via Zoom or Skype or phone calls, but really helping others help them stay oriented. Once again, we're back to those meaningful hobbies. Putting things in a predictable place so they're not looking or struggling in the environment to find what they need. Using picture labels, maintaining a calendar, one of those clocks that says, today is, and it's Thursday, May whatever. So they can really see that highly visible in their environment. Trying to keep the clutter and distractions down.

Establishing some cognitive stimulation activities, we'll talk about that a little bit more. Simplifying the environment, and also addressing their lighting issues. So, safety, we wanna look at their medication management. Are they able to safely use home appliances? I had a lady that was getting pretty scary with the toaster and the microwave and we had to talk about that. They might need GPS monitoring or better door alarms for wandering. We might need to limit their access to firearms and assess their fitness to drive, for sure. But we also wanna look for any signs of elder abuse. And

I sadly have to say, I have had this happen before. And we wanna address the need for supervision when necessary and talk with a doctor, talk with a family if they need 24 seven supervision, how to make that happen. So I'm not gonna go through these, these are some of the non-pharmacologic approaches. You'll notice a lot of family planning or financial planning and health care planning, so working with our social work colleagues as well, trying to optimize their sleep and their exercise and their social engagement.

And once again, participation in meaningful activities, sorry to beat the drum too much. Sundowning is important to note. This can be with those changes of light, so if it starts to become dusk. Trying to reduce noise and clutter and number of people in the room, maybe distracting them with an activity or a snack. Keeping early evening a quiet time of day, or scheduling a call with a family member to help them stay oriented. But also sometimes closing the curtains and blinds when it starts to get darker and using increased light. So, these are some tips to prevent sundowning that you'll notice here. Good sleep at night, daytime rest, but keeping the naps short. Physical exercise, avoiding alcohol. So you can kind of take a look at those if sundowning is a problem and do some education strategies with the care partner. As far as cognitive stimulation, what types of groups or activities can they do? Maybe book clubs, or maybe they like to play games or trivia with their family or grandkids, looking at music related activities. And really then training the care partner and the home health aides in how to administer these things.

Music & Memory is a great program, I'm just gonna touch on it briefly. But it helps you and your colleagues. You can do an online training for your entire facility if you want. How to set up personalized music playlists for individuals with dementia, and this is so much fun. I've had such a great time doing this for people. And sometimes some sad times. I had a lady with Capgras syndrome where she didn't recognize her husband a lot of times as part of her Parkinson's disease dementia. And they created a playlist of

all the songs through their life, from what they danced to at their wedding to what they listened to on road trips with their kids. And I have to admit, I was sobbing like a baby and looked like an idiot by the end of the session because I was just so emotionally touched. But it was a really beautiful thing and it really helped a lot with her orientation, so check that program out.

Another thing you can look at is creating life stories. This is a type of reminiscence therapy. I had somebody recently, the child that was an adult child was doing this with her father with Parkinson's disease dementia. And she was so grateful 'cause she really got to know so much about him, and even being his daughter there were things she didn't know. So it helps people with dementia to share their stories and reestablish their sense of identity. Can really help with communication between family members or carers with an individual with dementia. And it really creates this beautiful, I think, intergenerational connection to life, so I put some resources there for you with that as well.

So let's talk about a case example. So this was an 80 year old gentleman that had been diagnosed about six months before I saw him with dementia with Lewy bodies. And he wonderfully lived in a single level home, which was an apartment, and it had access to an exercise facility within the building. He had a lot of strengths. He had a supportive spouse and family. He had the financial means to get help as he needed. And so it was kind of one of those dream scenarios that we don't always have, I admit. His challenges, though, he started to have a lot of rigidity and kind of the Parkinsonism type symptoms. He was having freezing of gait, so that's where he would try to initiate walking and would get really stuck. Or he would stand up from a chair and then be stuck before he could move. This was causing difficulty with his transfers, also with his bed mobility and with dressing. And he was starting to really, he and his wife both, not socially engage. So in a second I'll show, well, actually, I'll go ahead and move forward and then we'll go back to it.

So this is the one that that goal attainment scaling was based on, actually. This was one of the outcomes that I did for him, was looking at, a big goal for him was just being able to do his lower body dressing. And so to address that, what I had to do was he was sitting edge of bed, which made it really hard for him to reach down and get his pants, he was having some loss of balance with that. We found that if he was seated in an armchair and if his wife presented his pants in his lap with them, like he would put them on, we went through a strategy of a big lift to the leg, kind of that big amplitude, since there's still that Parkinsonism aspect, simplified verbal cues for her to give him after she set him up for dressing. And she really needed that no more than one verbal cue. He was able to obtain that where she was just able to say, big movements, and he could do it. So that was how we addressed his lower body dressing. I'll go back to this, some other issues, she had financial means, but she felt bad about leaving him. So we talked about her getting some help in the home. I gave her a passive range of motion program. We did task oriented training for all of his transfers and also worked with physical therapy. So we really just addressed all of the issues and checked them off one at a time.

And I realize I ran out of time, so I'm gonna take you forward. So this is the summary, I think we went through all of this really well. I'm just gonna let you kind of go through that on your own, 'cause I know you may have questions and wanna get back to your day. But please know, you're all perfectly suited to make these person centered approaches like we've talked about, these goals based, promoting self management, and we can really support quality of life for these individuals and their families and make such a huge difference. And there are some resources I put for you as well. But then I'm gonna let Fawn come on, she's probably gonna kick me off here soon.

- [Fawn] Hello, I'm back here, we have some questions. The first coming in is, how do you personally handle individuals that act aggressively during therapy?

- Oh, that's a great question. I mean, I have to admit we've had people that we feared they would, but it's never actually happened. We do have a way at our site, anyway, that we can call for help, essentially. The people that we've had that we feared aggression I have to admit where there were Huntington's disease patients that have a level of dementia associated also. And so we made sure that we were not treating in a private enclosed space, we were out in the main treatment area. I had a therapy aide who was close by. I partitioned myself where I had a table blocking myself from the patient when we were doing the clinical interview and put some things like that in place. There's not any simple answer to that, unfortunately, I think it's really looking at the situation as it comes. Your safety is always so important. But definitely, I think that if you can talk with your practice manager, see what supports you can have in place, putting some physical barriers when appropriate between you and the patient so that you can keep yourself safe if needed. Oh, and then I'm sorry, I should add to that too, I'm sorry, can I add one thing really quickly? I think keeping your therapeutic use of self very level. The more calm that you can keep yourself, I think that can help. It doesn't always fix if someone's getting aggressive. But keeping everything in the environment, too, very calm. Maybe having some quiet music or sound buffers can be helpful as well. Sorry to interrupt, Fawn.

- [Fawn] No problem. Can you please provide an example of an activity prescription?

- Absolutely. So I did one of these awhile ago with a gentleman that he is really into art, his whole life, he was an art curator, very fascinating. And I have to tell you, his wife was deceased, and he had no family that would come with him. So I had to be a little bit of a detective. When I talked about that investigate and the DICE method, I was online, looking him up. I oddly found an interview that I won't say who did it, but a very prominent person had interviewed him, and I was like, "Wow." And this was like two years before I started treating him, so I was really able to gain insight into his interest. I

know we're not always gonna be able to get that. So his activity prescription consisted of this. He had art books that he had written. And so the aides were to sit and go through the books with him. They would ask questions about them, he would show the pictures, tell them things about it as well. He liked movies, that was once a week, really, that he went to a movie, and I had to let them know, they were taking him to movies, the home health aides, that they liked. I think they took him to see "Superfly." And I'm like, this isn't a "Superfly" kind of gentleman. He's a little bit more on the Tony Morrison documentary, or Van Gogh. So I had to really educate as far as within the movies, what that looked like. His daily activity prescriptions were the art books, that was one, daily walks that he would take at the same time every day in this park that he really enjoyed a lot. And then also, he had music that he would listen to, too. Different classical pieces that he liked. So his music was usually in the afternoon when he would start to sundown a little bit. They would close the curtains, they would have the lights brighter, they would have the music on. And so those were his three activity prescriptions that he did per day. So they can be very simple, his dementia was pretty significant. He also had different classes in the community that he went to, exercise classes and group activities and things. And occasionally he would go back to the museum that he had worked in and interact with different colleagues there as well. Great question.

- [Fawn] Wow, those are great examples. How about a strategy based approach? What is a good resource for ideas?

- Oh, goodness. The Gitlin article I talked about, if you look up Laura Gitlin's research, there is one that she actually does a case study. And she really talks about what the person did, what the activity prescription was, what some of the strategies were. So, basically it's good old fashioned OT, I would say. It's getting in there and really looking at, how do you simplify the demands of it? What do they need to be simplified? Is it cognitive? Is it motor, like say, with Parkinson's for example, sometimes it's hard for

them to reach back with their arm into a sleeve. That may be something that they can get the first sleeve in, they're gonna need assistance for it. So the strategy may still involve the care partner to some level, but you've gotta really look at where does the task break down, and how do I make this as simplified as possible to need as little help as possible? Another example would be bed mobility, like the gentleman I just talked about. With his, he had trouble with the amplitude of movement to roll over and get out of bed. When we put a bed rail on his bed, and I had her put some bright green tape even on it 'cause they had nightlights in the room, he remembered to reach over and grab the bed rail and would come up to sitting. She still had to cue him, then, to stand. So she had to verbally cue him. But what she was having to do before that was physically lift him out of bed. So it was really looking at, what parts of the task can the person do with more of a verbal cue or an environmental support compared to what they need physical support for? So the strategy is really whatever is going to take down and make them as independent and self managing as possible, but it's really gonna vary with the individual.

- [Fawn] I'm gonna take one more question so that I am mindful of everyone's time today. And you can feel free to reach out to her at her email there for any questions we don't get to. The last one I wanna ask is, have you used the space retrieval technique with dementia patients, and if so, can you give information on your experience with it?

- I'm not familiar with the space retrieval technique, I have to admit. I'd be really curious, yeah, great question. But I'm sorry.

- [Fawn] I have a course on our site, so if anyone's more interested in that topic, it actually might not be quite in the library, but it should be shortly. We had a course last week on it. It's taught by a speech language pathologist, but it's definitely applicable to our therapy. It is basically spacing out retrieval of things that you've given them in their memory and then spacing it out over time to reinforce our treatment. So, yeah, so you

guys can check that out. I don't have anything else right now. I just, like I said, want to be mindful of everyone's time. So if you could reach out to her for any more questions, that would be great. And thank you so much, Julia, for your time today.

- Thank you, sorry for going over. Thank you all for your time.