



PODCAST

Current Research Updates in Rehabilitation in MS

Episode 174 – Podcast Transcript

[[0:00]] [Music] Stephanie Buxhoeveden: Welcome to the Can Do MS Podcast. I'm your host, Stephanie Buxhoeveden. I live with MS and I'm also a clinician and MS researcher. Today we're excited to welcome our guest, Dr. Kathy Zackowski. She's an occupational therapist and has a PhD in movement science. She spent over 20 years researching MS and caring for patients, and now she serves as the Associate Vice President of Research at the National MS Society. We're excited to learn more from her on rehabilitation, both what is currently happening in this space as well as what's on the horizon. Hi, Kathy. Thank you so much for being here today.

[[0:55]] Dr. Kathy Zackowski: Thanks for having me. I'm excited to talk with you.

[[0:59]] Stephanie: Awesome. Can you start by explaining what rehabilitation means and why it's such an important aspect of care?

[[1:07]] Dr. Kathy: Yeah. Rehabilitation, I mean, it is such a broad category. So, let me, let me kind of start with what I think is the true definition. So, it's an active process in which you and your team work together to identify and execute a plan to strengthen and maintain your ability to perform in areas that are important to you. And that means at home, at work, at school, or in your community. And I think it has to be that long, because really that is... the-the idea is really rehabilitation that can affect all aspects of your life. Um, and it's the only... it is like the truly the treatment that is customized for what, you know, what particular areas each person needs to work on. Um, very different than, um, a medication that you might take, which might be for a particular symptom, um, or might be to curb, you know, progression for MS. But rehabilitation is really different in that the goal is to help you do things, to do things that you wanna do [noise] and need to do despite having MS.

[[2:10]] Stephanie: Absolutely, and it's so important because it's really comes down to quality of life. And because everyone with MS is so different, rehabilitation can be a little bit confusing. So, can you explain what kinds of MS symptoms you can address in rehabilitation?

[[2:26]] Dr. Kathy: Really there, you know, there's no limit. So, I would say any... i-if you have symptoms that are making your life hard to navigate, those are things you should talk about with your physician. Um, but they could be physical issues like weakness or spasticity and pain, but it could also be sensory. So, you might just have

tingling in your arms or legs at times. It could also be cognitive issue-issues, like memory problems, or it could be this, you know, symptom of fatigue that no one can quite put their finger on how to define or how to treat. But those are the things you need to bring up to your physician because there are experts in rehabilitation that have trained to address those symptoms in different ways. So, maybe physical therapy, most people know, you know, what they do, but you know, they want to identify and help you move, walk, balance, um, um, safely, um, all among, you know, while you're doing your life, your hobbies and your interests.

Um, I think occupational therapy is another important aspect of rehabilitation. Um, and occupational therapists want to teach you or help you to take care of yourself to how you care for your home, how you care for your family. That's the, where the word occupational comes from. It's not about your job, it's about how you occupy your time. So, anything that occupies your time and you're having trouble with, you should bring that to your OT. I mean, this could be sleep, it could be exercise, it could be eating, it could be sex, it could be, uh, how you eliminate waste every day. And, uh, these things are very important to daily life. And there are experts who have thought about it and have, um, ideas for how to address them. So, I mentioned PT and OT, um, I also want to mention speech language pathology. Really important in MS too, you know, they can screen for swallowing difficulties. They look for speech and voice changes, as well as, um, thinking skills. Um, there's also psychologists and neuropsychologists. They're slightly different, but they're both there to help a person adapt and make lifestyle choices that promote good health. That could mean, you know, working on stress reduction, um, um, thinking of strategies to, um, address, um, uh, issues that they're having at home.

And then last, I want to mention that there is a physician that is a, that is a specialist in rehab, and that is a physiatrist. There, there's not a lot of them, but there are some physiatrists who specialize specifically in MS. Um, and so their job is really to help sort of manage and make the team, uh, make sure you have all the, all the people on your team that you need, um, to address any of the symptoms that you might have.

[(5:15)] Stephanie: Yes, I love physiatrists. We used to have one in my office where I worked at in an MS center, and they were absolutely amazing. I think you touched on a few really important points, and that is first start by identifying what you're struggling with the most, because it's hard to tell, right? I've had MS for a long time. I have not always been able to put my finger on what the issue was. I just know that I usually love going to work. And then one day I started like dreading it and it-it wasn't, 'cause I didn't love work, but it was 'cause it was just getting so hard to do. And talking with my team helped me figure out ways to work around symptoms. So, then I got back to not having to be thinking about how hard it was all the time, and I just went back to doing it. Um, and that's a little vague, but it was the same thing too with my walking, which actually came to your lab at Hopkins, right? Because I was...

[(6:11)] Dr. Kathy: I remember that.

[(6:12)] Stephanie: ... yeah. Short...

[(6:13)] Dr. Kathy: [Laughter]

[(6:13)] Stephanie: ... I mean, short distances were fine, but it was those like long distances that were giving me trouble. And, you know, there wasn't like a specific PT regimen that I went through after that, but it was just so helpful to understand what was happening and why it was happening. And if you know what symptoms are at the root of the discomfort or the challenge, even just understanding those symptoms help you work with them better.

[(6:39)] Dr. Kathy: Yeah. And not... right, and being a, being... you-you, I think sometimes if you are, um, part of a study, you sort of learn what it, you know, what aspects of that movement are important for you to change or maybe you can't change them. So, we need to think of a strategy to overcome that. Even just... I think people often will try to ignore symptoms because they're like, oh, this isn't really that... there's nothing I know to do about it. That's where I think rehab could really be enlightening and that you need to find a therapist just as carefully as you find a physician, um, that cares about MS, wants to problem solve with you. Um, and so that you can really address the things that are important to you.

[(7:21)] Stephanie: A hundred percent. Problem solving is so important. Even if, like you said, we can't 100% solve the problem, it does take some of the fear out of it, right? So if you understand, okay, this is my body, this is my symptom, I go out on a hundred degree day, I'm gonna feel a certain type of way, and that's okay. I understand that about my body, I'm gonna cool off. It's gonna be alright. And then you bring that like anxiety about the symptoms down, I think. And it's just being in tune with your body and knowing yourself.

[(7:49)] Dr. Kathy: And it gives you a little feeling of control, right?

[(7:51)] Stephanie: Yeah.

[(7:51)] Dr. Kathy: Because the reality is like, you don't have control over those symptoms. So, you can develop strategies that give you a little bit more, at least expectation of-of what, you know, knowing what to expect and knowing what you can control. [Noise]

[(8:05)] Stephanie: Oh, yeah. It's a huge confidence booster.

[(8:07)] Dr. Kathy: Yeah.

[(8:07)] Stephanie: So, tell me a little bit about how technology is transforming MS. Rehab.

[(8:13)] Dr. Kathy: Yeah, this is a really exciting area, I think. Um, there are, you know, the first thing that always comes to mind is the use of wearable sensor data. You know, the watches that we all wear the narrator[?] ring, the Oura ring like, you know, captures so much information. But the beauty of this is that it helps you personally, you know, keep track of or monitor how much you move. Um, it also can be used in research and now they're trying to, you know, they're using it as biomarkers. So, it's a way to capture not just what you're doing in a laboratory, but what you're doing all day and all night. And that could be important pertinent information, um, for understanding where your issues are really coming from or how to treat them. But I did look up a couple of things that I-I wanted to mention a couple of, um, technology or aspects of technology that people might find interesting.

So, there's one study that was done in Germany, um, a small trial using an internet-based cognitive behavioral therapy program to reduce depression in people with MS. You might have heard of it, it's called deprexis. Um, they-they did a larger study as well. So, um, with over 279 people with MS who had depressive symptoms. And they did this at five centers in Germany, one in the US. Um, and they randomized people. So, they were... you didn't know which group you'd be in to receive either that a standalone program of deprexis or you were guided by a therapist that was a second group or a control group that did not receive the program. And what they found after 12 weeks is that, um, there was a significant reduction of depressive symptoms, improvement in quality of life, um, all, um, whether, it-it, not in the control group that didn't receive the treatment, but in both of the groups, the standalone program or the one guided by a therapist. So, I think that's very interesting because it suggests that there are things, uh, for depression that you can do on-, that are available, um, online. And so, the use of technology really allows this kind of treatment to be shared with people, you know, around the world. Um, and the fact that they tested it in such a large study was really, I thought, really interesting.

[(10:22)] Stephanie: Yeah. That's amazing. I mean, cognitive behavioral therapy to be able to get that online, there's such a shortage of mental health providers and it can help with so many symptoms beyond just depression, fatigue, pain, sleep.

[(10:35)] Dr. Kathy: Right, right. And it, you know, I think it also makes it so you can, if you can do it in your, in a, you know, luxury of your own home, you can find the place that you can, um, find a quiet spot where you can work on things and you can decide to do it on some days and not others, depending on, you know, what, what you have going on. So, I like that flexibility, I guess that this offers. Can I tell you about another

one?

[(10:56)] Stephanie: Yes, please. [Laughter]

[(10:58)] Dr. Kathy: [Laughter]. So, there's one... this is interesting. So, um, brain stimulation has been around for a while and-and it's approved to address a depression. And it-it's a, you stimulate a part of your brain, it doesn't, nothing, no needles or anything go into your brain. It's just a pulse that, um, like you apply kind of this weak current to the brain through the scalp. So, this one group found that brain stimulation can improve cognition in MS. So, it's a small study, it's coming out of UC, San Francisco, um, a postdoctoral fellow and their mentor worked on this. And they found that using brain stimulation, um, a single 20-minute session on 60 people with MS, um, and 30 of them got the single session of stem, brainstem and 30 of them got a sham, which just means you didn't really get, uh, you get the same feeling, but it's not, it's not doing anything to your brain.

And they found that processing speed improved significantly for the people who receive the stimulation. Um, and now what they're doing next is to, they're gonna do it in a larger study and see if repeated sessions would be even more helpful. 'cause now brain stimulation can even be applied at home. So, it doesn't have to be done remote, I, sorry, in a laboratory. Um, this study was done in a laboratory, but-but there are brain stimulation, um, devices that are definitely something you could do at home. So, I-I feel like it's just another example of how technology is really not, you know, is-is really trying to, um, bridge that gap between, um, I don't know, use of technology for your job versus use of technology to help your rehab. I think it's a really, it's a really cool bridge.

[(12:36)] Stephanie: Yeah. Very cool. And just getting started really.

[(12:39)] Dr. Kathy: Yeah. Yeah, exactly. I'm glad there are people interested in doing this and-and, uh, we'll, you know, hopefully we'll get to this at the end. Uh, but I, you know, I think we need people to volunteer for these studies too.

[(12:51)] Stephanie: Yes, absolutely. And we can talk about that now.

[(12:54)] Dr. Kathy: [Laughter]

[(12:54)] Stephanie: Um, [laughter] so it's exciting. Obviously, there are these technologies and exciting new endeavors to help out with rehabilitation. What if you were interested in being part of those studies, how would you go about doing that?

[(13:08)] Dr. Kathy: Yeah, I really encourage people to, um, to-to think about being part of a research study. So, as someone who did research for so many years, it,

recruitment is really, really an issue. And if we don't get people recruited to the studies, then we aren't gonna learn, um, how and when those interventions are most effective. So, um, so for example, we know exercise is important, right? Everyone, we should be exercising, but we need to study, you know, what are the critical elements about exercising that personally help you or help your neighbor? Um, and the only way to do that is to study it. And that means recruiting larger groups of people. And so, I really, I... to benefit the MS community overall, we, I-I really encourage, um, people with MS to read about studies, think about them and make sure that it's something you're comfortable doing. But-but be curious and, um, volunteer if it's possible.

[(14:06)] Stephanie: Yeah. And some places that they could find out more would be maybe the place that they get their MS treatment, um, national MS society's research webpage, clinicaltrials.gov, that sort of...

[(14:16)] Dr. Kathy: Yeah.

[(14:17)] Stephanie: Yeah.

[(14:17)] Dr. Kathy: I mean definitely there's... yeah, you can... I-I would say, you know, you can ask, right? Your, at your own clinic. Um, the National MS Society has a webpage that describes this, but yeah, the, um, clinicaltrials.gov is like a really great place. 'cause you can put in the key word of something you're even interested in. I'm interested in fatigue and you can see all fatigue in MS and you can go see all the studies going on right now that are looking at fatigue and MS and then sort of read enough about it and then just reach out to the person who's running the study or whatever email that is offered there. 'cause um, you know, you, there are a lot of inclusion exclusion criteria. So, you kind of have to, um, you know, be aware that you might not be the best fit, but you won't know that if you don't reach out and-and give it a try.

[(15:03)] Stephanie: Absolutely. And I've volunteered for some exercise studies for fatigue and it was, dare I say, fun...

[(15:10)] Dr. Kathy: [Laughter]

[(15:10)] Stephanie: ... because [laughter], I got to take part in this intervention and get this program and you get a lot of one-on-one time with the researchers and the study staff and you spend time learning about yourself and your body. And again, it all comes back to where we started in this conversation where the more you understand your symptoms and how to manage them or about, you know, circumstances where they might be a little more unmanageable, but then you get the confidence that you can go forth and just live your life despite these challenges or, you know, as I like to

say, live with it...

[(15:41)] Dr. Kathy: Yeah. Right.

[(15:42)] Stephanie: ... not despite it.

[(15:43)] Dr. Kathy: Don't let it... right. And don't let it run you. Right. The other thing I think that is a big benefit that I'm not sure people appreciate all the time is that when you re-, when you participate in a clinical trial, you're also informing the scientists about what's important. You know? And so, scientists don't really understand MS, they don't understand the lived experience of MS. So, you're, you know, when people with MS, you know, volunteer to be in these studies, that's the, a critical way to be teaching science about what's important to the MS [inaudible]

[(16:14)] Stephanie: Absolutely. And I think participating in research is one way of doing this. Next question I'm about to ask you, but um, so what are some common barriers that MS patients face when trying to access rehab and what steps can they take to overcome these challenges? Right. So, participating in research, for instance, might be one, but what are some others?

[(16:36)] Dr. Kathy: Uh, so I-I think a big issue with rehabilitation is just the time and effort of getting to, somewhere to do it. Um, so transportation to a clinic. Um, and for those kinds of issues, you know, uh, if you don't have family or friends that can get you to the clinic, you know, speak with your provider or speak to that clinic, the therapy clinic and ask them about transportation options, they often will-will have suggestions for you. Um, 'cause you're not alone in this. There are lots of people who have trouble getting to a clinic. Um, time is also what is told to me a lot. This is why taking a drug is just so much more appealing 'cause you just do it and it's done. But rehabilitation really takes time. Um, so, uh, you can ask, you know, you can be sure you communicate well with the people on your rehab team so that they can kind of organize the appointments in a way that makes sense for you. Um, whether that means back to back or just on certain days of the week, um, because you really, no one has time to do it all. You have to make choices. And the more you can communicate that to your rehab team, the more you know your goal, um, can, your goals can be reached.

Um, another thing I feel like it's important about a barrier is maybe having limited English, because I think that might make people hesitant to even make the appointment. 'cause it's hard, um, to get your-your, to communicate. So, um, try, I guess kind of the obvious things would be to try to find a therapist or a clinic that has bilingual staff. Um, but even if you don't know that when you call the clinic, you can ask them, um, about interpreting services. 'cause um, many, at least large, um, medical centers have interpretation or interpreting services that are available, um, at

no cost to you as the patient. So, I would just... I-I think those are, you know, I think that should not stop you from being able to participate in rehabilitation and, and, you know, get the benefits.

[(18:34)] Stephanie: Absolutely. And sometimes it can just be hard to find somebody with MS experience in rehab. Right? Uh, I know that has been a challenge for me in the past, but in the description of this podcast, we can link to some resources from different teams of people who, if you don't have somebody locally, at least you can watch some of our webinars or read some of the articles and try to get a little bit of help that way. And oftentimes, you know, when you go to rehab, you're not signing up for a really long-term program. It can just be quick few tips to manage fatigue with occupational therapy or the—the quickest rehab visit I ever had was I was having some swallowing issues and they just like, they were like, well, just tuck your chin—chin to your chest as you swallow and problem solve forever [laughter]. Like literally, literally it was just one...

[(19:26)] Dr. Kathy: Yeah, yeah.

[(19:26)] Stephanie: ... little tip from a speech language that, therapist that made a huge difference. So...

[(19:31)] Dr. Kathy: Right. And I worry that if you don't know that, right, you could go years and think... and—and you know, the mental, you know, the mental anguish, I don't know if that's too dramatic...

[(19:40)] Stephanie: Yeah.

[(19:40)] Dr. Kathy: ... but that goes with sort of thinking, oh my gosh, this is such, this is so frustrating that I can't do this and not knowing this one tip. And I think that says it about rehab. Like it, some things are simple like that. Some things are long term...

[(19:53)] Stephanie: Absolutely.

[(19:53)] Dr. Kathy: ... um, but you don't know that until you try and you find a—a—a, I think finding a therapist that really knows MS, even if they're, don't know MS, but they have neurology training. I think that would be other, um, sort of key word to think about when you're looking for someone. Also, the APTA, which is the American Physical Therapy Association, if you go to their website, I think it's just apta.org, they have a little link that says find a therapist and you can, you can click that, put your, I think your zip [noise] code in. And then there are different specialties within PT. So, one of them is neurology, and so those are the PTs in your area with neurology background. And so, I think there are, you know, places to—to—to ask and to go to try to find that right person. I find people put a lot of effort into finding the right

neurologist really, really research that. But it's really hard. Um, and people don't often... they often think rehab doesn't work, but it might be just that they went to a therapist that doesn't really understand MS and so they don't know how to help you. Um, just like a neurologist who doesn't know MS wouldn't be as helpful as someone who knows.

[(21:02)] Stephanie: A hundred percent. Could not agree more. What exciting developments are currently being researched in MS Rehab and what are you personally excited to see about this field?

[(21:12)] Dr. Kathy: I think what's really exciting is this idea of remote delivery of interventions and the-the-the variety of remote delivery options, um, given the barriers we just talked about of getting somewhere even, right. So, this remote delivery idea really can provide some opportunities. It allows people to, um, participate no matter what their age or their experience is. Um, so I wanted... I did, um, kind of want to highlight a couple of, um, interventions that are being studied right now. Um, and so, so to give, I think it sort of makes it exciting to think about what's to come in the future. So, one study, um, they are... So, it's a study about exercise, but what is unique and maybe more innovative about this particular study is that they're looking, um, they're focusing on people that have more limitations of movement and they are combining symptoms. So, they're not just looking at exercise, they're also, they're, to improve function, but they're looking at exercise to improve cognition.

So, this is a, um, this is being done out of the University of Illinois, Chicago, um, and it's a 16-week exercise, tele rehabilitation training program. Um, and they're combining aerobic exercise and resistance training. Um, and then there's this active control, like I've talked about before, like, so that this is what their comparison is. And the active control gets the same amount of attention, but they don't do exercise, they just do stretching. [Noise] Um, and I-I think what's really nice is that the exercise delivery is-is, um, remote. Um, it allows this to be much more accessible. So, the results aren't out yet, but I think it's going to be interesting to see, um, how this can, um, how people who have more limitations can participate in exercise. I think too often our-our rehab studies are really focused on people who have mild symptoms. I don't even know if I can define mild, right? Probably all symptoms feel terrible, but-but this is really focused on people who are pretty limited. Um, and those are the people that perhaps even need rehab the most, but are, it's so hard to access. So, I liked that this group really focused on that-that group.

[(23:25)] Stephanie: Yes. A group that's so often left behind in researched. It's really important and exciting.

[(23:30)] Dr. Kathy: Yeah. Can I tell you about another one?

[(23:32)] Stephanie: Yes. [Laughter].

[(23:33)] Dr. Kathy: [Laughter] so there's... this is, this is a totally different kind of study. So, this is just sort of step one, but this is the title. It's a digital toolkit for enhancing resilience among MS caregivers. So, this comes out of Canada, um, Queen's University and the University of Ottawa. Um, and they are trying, the... what they're doing is exploring the perspectives of, um, of users that includes caregivers, people with MS clinicians, and asking them what are the areas that someone, a caregiver might need to, um, help themselves and promote their own wellbeing. Um, and what they've found so far is they've done one study, um, of the interviews, and now they're putting together this digital toolkit and the recommendations that they found, um, I kind of highlighted a couple of them. One was just the need for content that focuses on, um, understanding the disease itself, content that, um, will teach, um, caregivers about the-the trajectory of MS. So, how over time things can change, and about management options and skills that the caregivers need to learn, um, or maintain in order to, um, help the person they're-they're providing care to while they're promoting their own wellbeing. So, I-I feel like caregivers often so often get forgotten, and this is one group that really focused on them. And I think it-it's-it's really great because it's also digital. So, again, it's accessible to people theoretically all over the world if, you know, as long as you have a computer. Um, but it, so I-I feel like it-it's, the findings will guide, um, um, I think how caregivers are treated in the future.

[(25:20)] Stephanie: Absolutely. I think that's really exciting. Is there anything else you want to mention that we didn't already get to?

[(25:26)] Dr. Kathy: No, just to-to not be intimidated by the idea that rehabilitation is so complicated. Just, um, ask, talk about it, talk to your doctors about it, talk to your nurses about it. Often, um, different people have a different, you know, set of networks or different, um, you know, uh, things they can share about how rehabilitation might have helped them or their patients. And really getting to the right people is pretty much the critical element, I think, to-to sort of appreciating what rehab can bring to people.

[(25:58)] Stephanie: Definitely. That's for sure the hardest part about it. But nothing's more important than quality of life. And this is a lifelong disease. You're gonna have to figure out how to work with your symptoms. And I cannot emphasize enough how many simple tips, more complicated rehab programs, I myself have done, research studies I've participated in, and it's probably what has made the biggest difference in my quality of life. [Music] And so, if it's scary and intimidating, I encourage you to stick with it because it's really worth it.

[(26:33)] Dr. Kathy: Yeah, I agree. I completely agree. And I hope, um, it, yeah, there

are definitely a lot of resources can do, has some wonderful resources. Um, national MS society. So, um, explore and ask, talk about it with people, ask questions to your friends.

[(26:47)] Stephanie: Awesome. And we will include a lot of that down in the description of the podcast. Thank you, Kathy, for being here and for sharing your expertise with us.

[(26:56)] Dr. Kathy: Thanks for having me. It's really great to talk about this. I feel really strongly about this particular topic, so...

[(27:01)] Stephanie: [Laughter]

[(27:01)] Dr. Kathy: ... thank you for including me.

[(27:02)] Stephanie: Good. Great. Thank you. Thank you for listening to this episode of the Can Do MS podcast. If you liked this episode, please leave us a rating and review on Apple Podcasts or Spotify. We really appreciate your feedback. We'd also like to thank all of our generous sponsors for their support of this episode of the Can Do MS podcast. Until next time, be well and have a great day. [Music]

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