



Can Do MS Podcast Transcript

Dr. Terry Wahls: A Look At Current Research Episode 112

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Dr. Rosalind Kalb: Welcome back to another episode of the Can Do MS Podcast. I'm your host Dr. Rosalind Kalb. Today, I'm excited to welcome back Dr. Terry Wahls for episode 112.

If you didn't catch our first conversation with Dr. Wahls, be sure to go back and check out episode 107 for the full picture of Dr. Wahls' journey. Today, we're going to talk about what Dr. Wahls is currently working on.

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Welcome back, Terry. I'm glad we are having an opportunity to continue our conversation.

Dr. Terry Wahls: Oh, thank you so much for having me.

Roz Kalb: Okay. What I want to do now is turn to your current research, which I know you're very, very excited about, The Efficacy of Diet on Quality of Life in MS. Can you tell us what that study is specifically looking at and how it builds on your prior work?

Terry Wahls: Okay, so, uh, I, I'm thrilled, we had a donor, actually a patient of mine who was grateful say she wanted to support our research. And so, she gave us a substantial gift, which is allowing us to follow people for 2 years, including with MRIs. And the question is, what is the effect of diet on quality of life, on fatigue, on walking function, hand function, vision function, and on brain structure as measured by MRIs?

We'll have 3 arms. And one arm is usual diet where people get monthly tips from us, that basically encourage them to eat more these radical things known as vegetables, reduce the sugar, cooking videos and tips. So, that's the control arm.

The 2 interventions arms, one is the ketogenic diet that uses olive oil, which I think is much more heart-healthy and heart-friendly than a lot of the ketogenic diets that are... lean so hard on butter and cheese. And then the other arm is the modified paleo diet

that we used in the study that was funded by the MS Society. We're continuing to investigate diet. And what's... how it's building is we now get to follow people for 2 years and we're adding MRIs.

And, you know what, I do want to make clear that we don't know if we're going to see any difference because the, you know, the people want to be in diet studies, want to be in diet studies because they want to fix their diet. And so, they're not quite like the general public who's eating the standard American diet. It's quite, quite possible that our usual care arm with the monthly tips that we're going to give them to improve their diet, actually do improve their diet. And we know that people who enroll in dietary studies want to improve their diet. So even the control arms, uh, if they don't get many tips, still improve their diet. So, it's possible that all 3 diets are going to do better, between the enrollment in the 24 months. It's possible that the keto diet may stand out the best or the paleo diet may stand out the best.

Roz Kalb: Could you just define what you mean by quality of life?

Terry Wahls: Well, what we are going to use for our definition, will take a little survey of 45 questions, the MS Quality of Life survey, that people will answer. And it has been analyzed to measure our Mental Health Quality of Life in terms of mood and our social functioning. It also measures our Physical Health Quality of Life in terms of what we can do physically in terms of our daily life. Doing things like vacuuming, moving furniture, taking walks, how well our hands work. And really from my point of view as a patient who has experienced profound disability, I think quality of life measures are profoundly important. And to me as a patient, I cared a whole lot more about, could I function, then I did about what my neurologist said about my, uh, brain structure in my MRI. And I think that's probably true of most people with MS. What we care about is, can we do the things that we want to do? And that's what I really like about this measure, is it lets people answer the question, can you do the stuff you really want to do?

Roz Kalb: Yeah, no, I rea... I really like that as the clearest best definition of quality of life. So, thank you for sharing that. So, I'm sure there are listeners to this podcast who are interested in participating in your study. Are you recruiting?

Terry Wahls: We hope. Yes, we hope. Well, a lot of people are interested in being in our study because we want to recruit 156 people. Now, as of last week, we had 45, which means we still have 111 slots to fill as of last week. And so yes, we are still recruiting. We'd love to have your listeners sign up.

Roz Kalb: What are the criteria for folks who want to be in your study?

Terry Wahls: You have to be between the age of 18 and 70. You must have relapsing-

remitting multiple sclerosis. You need to be willing to come to Iowa, which is in the middle of the country, and come to Iowa City for a visit at month 0, month 3, and month, 24.

Roz Kalb: Three trips to Iowa. Okay.

Terry Wahls: Three trips to Iowa. It's a beautiful state. And you'll have to be willing to be randomized. So that means that you'll come in, you get your baseline assessments, then we go through randomization procedure, and you get informed that you're in group 1, 2 or 3, by the dietitian who will then say and "I'm going to set up a Zoom call with you in the next week to go over the education". That will have about a two-hour Zoom call. Because, you know, there's a lot that you do that first visit with us in terms of the clinical assessments and then the MRI at the blood draw, so we don't... There's a very brief visit with the dietitian, but the big training visit is later because if you try to do it during the study visit, it's too much information people get overwhelmed. So it works out much better if we separate the education out.

Roz Kalb: So how do people get the food that they're going to be eating in your study?

Terry Wahls: Well you're going to, you're going to have to go to the grocery store, get your own food, do some preparations. The intervention arm, we do have an application that people can have a food app for meal planning and recipes. The control arm, there's an app for them as well that we let people have, and that's the Dietary Guidelines app, which it really has some great recipes and guidance on how to reduce the added sugars and have more vegetables and have an overall healthier diet. So, we have some tools. We also, you know, give support. Our dietitians can help the intervention arm. If people have questions, they also get a monthly call to talk about whatever challenges they have with their diet. So lots of resources for all 3 arms to help people meal plan, find recipes, and learn some cooking strategies.

Roz Kalb: So, 2 years is a very long time for a diet study. I do know that from the research I've read...

Terry Wahls: Yeah.

Roz Kalb: ...that that has been a challenge because it's difficult to support people through that long a period of time. So, I guess the dietitians will be helping people stick with the program and...

Terry Wahls: Correct. So, the dietitian will certainly be very helpful. We have group calls that participants are really enjoying. We have a website for each... for the 2 intervention arms where people can again get information and share photos of their meals. People

are enjoying that. I sort of wish we would have figured it out, a way to make a Facebook group for each arm, but the IRB said, "Mm-mm, no way..."

Roz Kalb: Yeah.

Terry Wahls: ...you're not doing that.

Roz Kalb: I love the idea that... of sharing of pictures of the...

Terry Wahls: I mean, that would have been lots of fun. But I certainly understand why the IRB said, "Mm-mm, no way. You can't do that."

Roz Kalb: And so, is people's eating actually monitored? So, I know when you're doing a study and you're comparing...

Terry Wahls: Yes.

Roz Kalb: ...groups, it's really important to know that each group...

Terry Wahls: Yeah, what you...

Roz Kalb: ...is either getting what they think they're getting, were doing what they're supposed to be doing. So how do you monitor that?

Terry Wahls: So ideally, what you do is put people in jail for 2 years and feed them. But of course nobody would sign up for that and nobody's going to fund something so expensive. The next thing that you would do would be 24 hour recalls where you call people and do the recalls. We did not have enough resources to do that. So, then the third thing that you do is a very detailed dietary questionnaire about what you ate in the last month. And so, dietary history questionnaire, number 3, which is developed for a cancer epidemiology, we're using that. I think that will be very effective. So we're getting that at baseline, at 3 months, 12 months, 18 months, and 24 months.

Roz Kalb: To your knowledge, is this the longest diet study that will have been done?

Terry Wahls: Well, this will be the longest diet study in the setting of multiple sclerosis...

Roz Kalb: Okay.

Terry: ...that has been done. It's the longest study that has these clinical outcomes that include vision, an OCTs, MRIs, and the quality of life. We are also, of course, collecting a bunch of blood, a bunch of saliva that we're freezing because, I'll be writing more grants to do microbiome analyses and then metabolome analysis at the end. Or, you know, my lab is in this really wonderfully unique position. And, you know, I think because I am so public about my story and my work and what I do that we have really

grateful donors that have funded a bunch of very interesting innovative pilot studies. And so, you know, I'm very confident that I'll ultimately be able to analyze the microbiome and the metabolome, metabolome, at the end. If I can't get, you know, if I'm not successful for grants, I anticipate that we'll find another donor to help us with that as well.

Roz Kalb: Okay. So, I have one last question for you and this is a personal one about you, really about grit and grace. So, over the course of your career, you have faced a lot of doubt and a lot of criticism, particularly from the neurologic establishment who weren't so...

Terry Wahls: Yeah.

Roz Kalb: ...familiar with the concepts of wellness. How did you find the energy and the patience to just keep moving forward with this? A lot of pushback you've had over the years.

Terry Wahls: An immense amount of pushback. People condemned me. I went on interviews, people were sometimes incredibly harsh. And my response is, you know, they need to do what they think is ethically correct. I have trigeminal neuralgia, incredibly painful. I want it turns on. And in 2007, you know, I could not sit up anymore. My trigeminal neuralgia was more frequent, much more difficult to get turned off. I was just beginning to have brain fog.

And my boss had told me he's reassigned me to a new clinic that I have to start in January, that I knew I couldn't do, couldn't possibly do the work he was describing. So, I was probably going to have to finally take medical disability. And then as we know, I finally get the pieces in place and, you know, my energy comes back. I can sit up in a regular chair and then I can walk using walking sticks, then I can walk without walking sticks, then I can bike.

And my chair of medicine is a rheumatologist. He calls me in. He actually... You know, I came in for every two-year review. And I walked in which he hadn't seen me walk, you know, in 4 years. He's like... and so I explained what happened and Dr. Rothman said, "Terry, you got to write a case report." I'm like, "On me?" "Yeah, yeah, yeah. You got to write a case report." So we got that done. Then he calls me back and says, "You have to do a safety and clinical feasibility study." And I'm like, "But I don't know how to do clinical trials." He goes, "I'll get you the mentors. This is your assignment, you're doing it." So, I salute and say, "Okay." I do that. And we had these amazing results with people who were... cane and walkers, who are now jogging.

And, you know, Roz, in 2007 I thought I was going to become bedridden, demented,

and have to live with intractable trigeminal neuralgia permanently on and I changed my living will. I changed my durable power of attorneys. So that if I stop swallowing... Because when it's on, swallowing and speaking increases the pain. So, if I stop swallowing, there'd be no feeding tube, no IV fluids. And I knew it's going to eventually turn permanently on. So that was the future that I was clearly on track for. And now I'm on a future where I can bike, hike, think clearly, do research.

And I know there are hundreds of thousands of people with progressive MS. And they could choose to wait for that randomized double-blind controlled trials, or they could decide that my message of eat more vegetables, meditate, insist on seeing a physical therapist, getting exercise is, work on your wellness, is worth doing.

And so I would tell my interviewers that you do what you feel is morally correct. I'm going to tell people my story, the research that I'm doing. If they feel like they want to try implementing this stuff with their primary care doc, they certainly can. And eventually, people decided that I'm not so crazy.

Roz Kalb: [chuckles]

Terry Wahls: You know, and they're citing my papers.

Roz Kalb: Well, thank you for being patient with us. You've taught us all a lot to our benefit. So, thank you so much for sharing this information about your current research and this very exciting clinical trial. To our listeners, if you want to learn more about this clinical trial, we've included the links to additional information in the description of this podcast. Again, thank you so much for joining us.

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Terry Wahls: Thank you.

Roz Kalb: Hope to see you again, Dr. Wahls.

Terry Wahls: I hope so.

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Roz Kalb: We've reached the end of another episode of the Can Do MS Podcast. I'm your host, Dr. Rosalind Kalb. Thank you for listening. I'd also like to thank our sponsors for their generous support. And if you liked this episode, please be sure to subscribe to the Can Do MS Podcast and give us a rating and review. Thank you for tuning in.

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