Dementia Dialogue; Season 3, Episode 22

Changing Roles in Dementia Reasearch: From subjects to participants
Transcript of interview with Jill Czuczman and Rick Swartz.

David - Welcome to Dementia Dialogue. The week of March 15th to 21st is Brain Awareness Week with a focus on brain science.

Today's episode is one of two where we are exploring the relationship between research participants and researchers, moving from an expert/subject model to an investigator/participant model.

Jill Czuczman's husband, David, has frontotemporal dementia and is a participant in a research project. Jill is an active care partner and research partner and serves on the Patient Community Advisory Committee for the project.

Rick Swartz is a clinical physician and researcher at Sunnybrook Hospital and the University of Toronto. He co-leads the Ontario Neurodegenerative Disease Research Initiative. I spoke separately with Jill and Rick last week.

Jill - He was officially diagnosed in 2015, but it took six years for him to get the diagnosis

David - In that six year period, how long a search was it to get that diagnosis that you were confident in?

Jill - It was quite intense. We saw nine different specialists and he had a multitude of misdiagnosis, a multitude of different drugs, a multitude of invasive testing, all to come back to what the original thought was, could this possibly be FTD, that was thrown around at the very beginning? And it took until I found that doctor, I had heard her speaking and it was Dr. Sandra Black. I heard her talking and she was talking about FTD. And I just went back to my family doctor and said, "This is who we need to go see because it checks all the boxes". And we walked in and she said, "Can I see his two MRI scans that he had had?"
I said, "Sure. Here they are". And she said, "I can tell you definitively he has FTD'".

I've often said it's really a choice, and I learned that through a support group at the beginning. I struggled so much then couldn't find a support group for young onset. Finally I found a group with five ladies. Through that, I realized that you have a choice; a choice to see the negative every day or to wake up and try to find the positive in the day. And you go day by day.

David - So the subject today is around research, and I'm wondering whether you might think back a few years, when you and your husband or your husband perhaps initiated the idea of getting involved in some kind of research project. What was on your mind at that time? What prompted you? And then how did you go about finding a research project that, suited you?

Jill - I think the main thing being given a diagnosis of a terminal illness, you lose all control. You have no control over anything anymore, and you have to choose to accept that or not.

We together chose to accept that. And through Dr. Black, she mentioned that there was something called The ONDRI Study (Ontario Neurodegenerative Research Initiative) that included things like eye tracking at the Kensington Eye Clinic, included a gate sort of section, included genetic testing, an MRI scan, spinal tap.

Some of it was pretty invasive and David, right away from the beginning said, “Absolutely not. I want nothing to do with that. That's just not good”.

After we talked about it for a little while, I think I convinced him that if there's any kind of control we can have, it's that we can control and help someone else hopefully. I’ve often said that you can remove yourself emotionally from all of this. The scientific part of this is so fascinating and amazing.

David - Talk about that a little bit more, if you don't mind. What kind of feedback or information would you gain along the way, either in respect to David or in respect to the overall population of subjects in that study?

Jill - So there's so many connections in neurodegenerative disease. And the more I read, the more I realized how interconnected they all are. And for me, knowledge became power. I started to read more and more and get more and more interested in it. And in that sense, it was almost calming to me to understand it. We always felt very supported. I still feel so supported at Sunnybrook. I can't say enough great things. Being in the right place makes all the difference.

David - Now, when you are going in for these annual tests, after your experience were you contacted to see how that day went for you or if there are any questions that came to you after that day, how would the results have been reported to you, that kind of post test experience, if you will?

Jill - Right. Unfortunately, the results are not given to you. It's a blind study.

David - OK, well, when you mention the genetic counseling then was mostly an informational experience, not specific to the results of your husband's test.

Jill - They did. They did tell us the results. And they were very open to if you had any questions or any concerns, please call right away. They would answer anything.

David - So otherwise, like on the results of the lumbar puncture or the blood tests and that kind of thing, that data is entered into the pool of data for the study rather than being any reported back to you in any individual way to mark your husband's progress or change in situation.

On the other hand, if there was some kind of unusual finding, then that would have been brought to your attention or?

Jill - To the neurologist.

David - In terms of the genetic testing, I'm interested in knowing about that in terms of impact on David's family, if you know his siblings, if he has any or also on your children, has that been a point of discussion as that information unfolded?

Jill – Oh definitely. Yes. And luckily, we went to a great genetics counseling. They do have counseling for you. Even just to do the ONDRI tests we were set up with a genetic counselor and she explained everything ahead of time, explained what samples they were looking for, what genome types they were looking for, specifically with FTD, but they were also screening for Alzheimer's and other ones.

It was a big discussion with our children and I have it with them every once in a while, even with the eye tracking or the gate they could have picked out from that, Alzheimer's related or Parkinson's related, that could have come up. You have to be prepared for that in some ways. They do tell you that these things could arise.

The more I learn about it the more I want to help or I want to do so I joined the PCAC (Patient-Community Advisory Committee). I've started a Facebook group for those from frontotemporal dementia in Durham region. Any kind of other research projects we were part of, the second part of the ONDRI study was something called the Remind Study, and that was wearables that were actually worn in home. And you were sent home with these monitors on for seven days.

The results from that, because I'm on the PCAC we got to see a little presentation on it. And it's fascinating what they can see and what information they're gaining from those tests. That to me is just so exciting. And I think, yeah, there's going to be huge changes coming.

David - Could you describe a little bit more of what your role is in the PCAC, what benefit do you derive from it? What contribution do you make, the frequency of meetings?

Jill - So definitely joining the PCAC, which I did probably about a year and a half ago, was an opportunity for me to raise awareness for young onset FTD. It would give me a voice. And through that voice, I have now found myself in the co-chair position.

Very quickly they were asking me if I would be willing to do an interview, would I be willing to do my story? And I said, “Sure, I'm happy to tell people”. Now, I've lost that sort of… at the beginning when you're diagnosed, especially with young onset dementia, there's so much shame and kind of stigma attached to it because people don't understand there's not enough information about it.

Through the PCAC, I was able to promote the self-care and talk to other people about that. It's not much time involved. There's usually a meeting once a month. As the co-chair now I have a second meeting, I attend the executive meeting where I get to learn about what's new and what's happening with the doctors perspectives and all the researchers. We do need, definitely, they're looking for more people. We need more representations from study participants and caregivers. And the whole part of the PCAC is that it's patient based. They're listening to the patients, what they need and trying to help that and pass that along to all the other different areas.

David - So the discussion around the table in the PCAC is broader than just The ONDRI Study. It's really talking about the total, your total experience.

Jill - Definitely. They're very open to different questions we have, as study participants or as caregivers. They want to know our opinion on things. They really do listen and made

me feel like I am useful. A lot of times as a caregiver, you feel pretty useless, day in, day out.

David - So what your experience been, communicated to some of these scientists or physicians, has the potential to inform some of their future work or their current work?

Jill - Definitely. I mean, as I explained to them, when you go to these appointments, you have months and months worth of information that you want to share with them. And you have twenty minutes maybe if you're lucky to do that. And there's so much more that you want to say and do at an appointment. And it's great to have the audience of the PCAC to listen and to make a difference. I was going to say, “I hope my voice is now used for the good to help people that don't have a voice”. A lot of people with dementia do not have a voice.

Quite often the research projects for dementia did not involve drugs, they're more observational studies. I think that's a great thing that eliminates the whole idea if you're getting the placebo or not. I think that would cause a lot of stress to a lot of people. And there was quite a few, I know at one point there was a lot of brain stimulation tests. That, too, would be you would have to weigj your risks and your outcomes of that.

In terms of things like genetic studies, I said before, I'm all for knowledge. The more know that more you can understand and the less you're blindsided by things. I think that's very important. And there's so much stress just around being a caregiver to add to your stress by fearing things in the future, I find that kind of a waste of time. They say, “Don't look back, just keep moving forward”. And I think to move forward you need more knowledge. And you're going to get that by participating in a study. Definitely. Definitely you’re going to learn more.

When you go to these neurology appointments, they are quite long. So you have a lot of downtime. And I think they could use the downtime a little bit more efficiently by presenting you with the option of going into a study, at the beginning of your appointment, instead of at the end of the appointment. And a lot of times the neurologist will come in and say, “Oh, well, there's this study to study this study. Are you interested?” And you've already had your appointment. You've been sitting there for a few hours, you want to go home and talk about it, but they kind of want an answer. So I think if they presented it to you earlier in the appointment, you have time to think about it. And then you could ask questions when you were actually in front of the neurologist. That would be one.

The other thing would be I wish that they could share all of the information. So whatever they learn, whether it's good, bad or otherwise, I think it's so important that a family doctor would be involved, any of the other clinics that you go to, any of the other clinicians involved. I think it would be fantastic if they could all share the information.

David - Jill, have you raised this issue that we're just talking about, about sharing information at the advisory committee?

Jill - Definitely. We talk about it all the time and they're very keen on it. They're trying their best to turn around the information as quickly as they can.

David - Well, I want to thank you very much for this conversation, for you taking the time with your husband to contribute to that study and to go beyond that and to be involved so

much in the patient advisory committee. And I'm sure your contribution will make a difference in subsequent work. So thank you for that.

ONDRI has evolved and Rick describes how a new study is taking shape.

Rick - So my name is Rick Swartz. I'm a neurologist at Sunnybrook Hospital at the University of Toronto. I'm also an academic. So I'm a clinician scientist and I do a lot of research in stroke. That's my clinical specialty. I'm a stroke neurologist and my special interest is in vascular cognitive impairment. So the impact of stroke and vascular risk factors on thinking and memory and function, some of those longer term impacts of stroke. And in part through that I'm involved in ONDRI, in this iteration of ONDRI now as one of the co-leads of ONDRI more broadly.

So, ONDRI for the Ontario Neurodegenerative Research Initiative, O.N.D.R.I.
And that really is meant to cover the broad range of conditions that affect the brain and spinal cord and that kind of evolve over time. That's what neurodegenerative really refers to. So that includes the condition known as mild cognitive impairment, which sometimes can progress to Alzheimer's, but not always. Obviously, Alzheimer's disease is sort of the prototypical one people think about. And then Parkinson's Disease, ALS, or Lou Gehrig's disease, which is Amyotrophic Lateral Sclerosis, is what the ALS stands for and Frontotemporal Dementia, as well as vascular cognitive stroke and the vascular contributions both in people who present with stroke but sometimes we also see vascular contributions across those other disorders.

So ONDRI really spreads all of those conditions. And as you say, that's one of the key defining features, is that we're looking across diseases. Certainly there's lots of room to contribute within disease knowledge and discovery. But part of the innovation here is collecting standardized data, all of the same types of information, across disorders.

So phase one was what we call like a deep endophenotype, and we're really trying to characterize across these conditions. And so they were five hundred and twenty participants in the initial ONDRI study, each also who had at least one study partner that they enrolled in the study with. So we have some data that's specific even to study partners, things like caregiving burden and stress, burnout kind of measures and those five hundred and twenty participants are across those different cohorts. And as much as they were able were followed over time at baseline year one, in year two, some of them, we enrolled the stroke cohort particularly quickly so we were able to get up to three years for most of this cohort.

And we collected the same detailed data across diseases and over time, so mentally and on the website, we describe that with the visualization of the Rubik's Cube. So you have an MRI square and you have a detailed neuropsychological square and you have a gate and balance activity square and so on: genetics, eye tracking, retinal imaging, all sorts of deep characterization. Each of those is a square. Each disorder is a row. And then you get the depth over time.

So it was a relatively small sample in that five hundred and twenty. But those volunteers were extremely dedicated and really provided a great deal of information and went through all of these different assessment platforms to provide this really rich data set.

David - So if I follow the Rubik's Cube, you've mentioned about five or six tests or data points of data measurement.

Rick - Yeah, so we call them platforms. There's a genetic platform looking at genetic markers. There's neuropsychology, so memory and thinking tasks and concentration, that kind of stuff. There was neuroimaging. Obviously within each of these platforms, there's a number of different pieces of data. I mentioned gait and balance, eye tracking, retinal imaging and clinical data. So we have a clinical platform, which is function; day to day function and mood and sleep in those kinds of more clinical demographic information. So across each of these platforms, multiple different data sets across diseases and over time.

David - Were there any challenges in recruiting people? You mentioned the stroke cohort came forward pretty quickly. Were there challenges in other disease conditions?

Rick - Absolutely. I mean, as we were just describing, it's a fairly intensive protocol. So it really called for about four days of volunteer time. So people who are busy with grandchildren or busy with careers still sometimes even trying to manage that, in the background of their disorder or their care partner may also have been very busy to commit to something like that. So it was a big ask.

Obviously, people had to be willing to do MRIs over and above the clinical MRIs and provide blood samples and things like that. So it was a bit of a challenge in that sense because we were asking a fair bit of volunteers. Because of what we were asking, it did narrow the field a little bit. So people had to be not too severe in order to complete all the different assessments and obviously had to have a study partner who was willing to engage as well.

So the needs of the study sometimes dictate, the kinds of questions you want to ask, sometimes narrow the field a little bit.

David - There's been a growing consciousness about the importance of gender, race and socioeconomic status in terms of the impact, the differentiation of the impact of a disease, depending on some of those factors. Were you able to build in to your recruitment anything along that line around the characteristics of in those conditions, or is that something for another time?

Rick - So this is something that obviously we're more focused on in the current iteration, the 10 years ago, that was less of a focus. I think more societally. Obviously, there was sex and gender was a key issue. And it was interesting that we did see a more skewed distribution, we saw more men enrolled than women than we expected. We're not exactly sure of all the reasons. Maybe it was because of the requirement for a study partner that older women, sadly, are sometimes less likely to have older men beside them who are healthy enough to volunteer as study partner. So that could have biased things. We haven't entirely figured out the sources of bias there.

In this study we're looking at involving patients more as partners. And the term I like to use is a Research Care Partnership where the research actually can be used to help inform care decisions or daily decisions that patients or support or family members or loved ones can use to help them in their day to day decision making or potentially even that their physicians can use.

And so we're building into this study a few key elements. One is a permission to be re-contacted. So we're going to ask people explicitly to say, “Can we actually reach out to you and tell you about new things that are going on and tell you about some of our findings and say thank you?”

We are giving feedback to participants on the wearable data that we collect, and we're asking them for feedback on our feedback to say, “How are you using this? Does this help you in your day to day activity? What would be better?”

There’s on the order of somewhere between 80 and 100 researchers, clinicians, students, trainees at different levels, and then they do come and go to some degree, especially the trainees.

David - Is there any active effort on the part of the leaders to monitor the kind of the researcher/participants relationship? Or is there an opportunity where the participant might be able to provide feedback to you on how they feel about their experience in the research project?

Rick - In the new form, in the new project, there's specifically that opportunity for feedback. And in some of the pilot projects that we've done over the last couple of years, there's been that debriefing process at the end. It's going to be as we scale up in numbers, the debriefing is going to be a little bit more formal, less face to face. So we call it the PCAC the Patient and Community Advisory Committee. We certainly, as the researchers and clinicians, we look to our PCAC members and especially those with lived experience to give sort of a unique lens on the research. So we have our scientists come and not go hardcore into the science, but really talk about the “so what?” of it all and the high level what are we finding?

And actually we're partnering very early on now, so we've engaged them from the beginning in the Hands Ontario platform and project and the hypotheses and the approaches, the need for feedback and how we want not too much feedback, but trying to titrate that to the needs of the communities that we're looking to work with. They've been instrumental there. And so one of our platforms is actually health services research and using the administrative data at the Institute of Clinical and Evaluative Sciences, they come on a fairly regular basis and update the PCAC about sort of not only what they found, but what they're proposing to do and get feedback and impressions. The individuals tell us, “Oh, I've struggled with this” and sometimes that informs the questions. And the agencies tell us, “This would really help us to advocate for change at the government level” or something so we can use that partnership to make the research that we're doing that much more relevant, both to individuals and it's sort of societal impact.

That's been a key priority for us. I mean, I think fundamentally we don't want this whole process of engaging patients and family members and participants in research. We want this to be a real partnership. So we're not looking for participants to be disease experts or scientific platform or methodological experts. But every single patient who's living with one of these disorders is an expert in what it takes to live with these disorders.

David - I want to thank you very much.

Of particular significance to me is Jill’s emphasis on the concept of choice in confronting her husband's situation. Very similar to our previous episode with Merna Norman.

I'm encouraged by Rick's positive attitude in including participants in the research enterprise and the direction that ONDRI is taking in this regard.

More information on the ONDRI project can be found on our website. As well, on our website is a link to the Alzheimer Society of Canada, where you will find the results of a Canadian project to establish research priorities in the dementia field. It was undertaken with the input of people with lived experience.

Thanks to the Ontario Brain Institute for sponsoring this episode and to the Center for Research on Aging and Health at Lakehead University and the Public Health Agency of Canada for their continuing support.

My name is David Harvey.