

Tireless Efforts in Meaningful Brain Injury Research

2020 Brain Injury Alliance of New Jersey (BIANJ) honoree Dr. Nancy Chiaravalloti

Recorded April 2020 [Listen to it here.](#)

- NANCY
CHIARAVALLOTI: 00:05
- The best parts of my job are the days when I can spend time with people who have a brain injury and their caregivers. And I'm able to learn what their lives are like and what they're facing in their everyday life.
- ERICA WEBER: 00:20
- I'm Dr. Erica Webber, a research scientist in the Center for Traumatic Brain Injury Research here at Kessler Foundation, and I'm joined today by my colleague Dr. Nancy Chiaravalloti who is the Director for the Center for Traumatic Brain Injury Research and The Center for Neuropsychology at Neuroscience Research at Kessler Foundation. Dr. Chiaravalloti was recently awarded the title of Research Innovation champion by the Brain Injury Alliance of New Jersey at their recent gala. So we want to welcome Dr. Chiaravalloti and say congratulations.
- CHIARAVALLOTI: 00:53
- Thank you for having me, and thank you for the congratulations. It was a huge honor to be honored for something that I love doing every day.
- WEBER: 01:02
- That's great. You've been at Brain Injury Research for a number of years. Now, tell us how did you get involved in brain injury research?
- CHIARAVALLOTI: 01:11
- I've done cognitive rehabilitation research since finishing my fellowship at Kessler Foundation. In the context of doing that research, I designed a cognitive rehabilitation protocol, and I tested that protocol initially with persons who have multiple sclerosis. Through that initial research, we found the treatment to be effective for helping persons with multiple sclerosis overcome the memory deficits that they were having. So in the context of applying for a large grant, I was invited to submit a modification of that protocol directed to persons who have traumatic brain injury, and that was my first foray into traumatic brain injury research. That was back in 2007.
- WEBER: 02:01
- Oh, wow. So it sounds like it was more of a transition, that it wasn't necessarily your first research area, but that you were able to find that a lot of what you were doing was easily translatable and would be helpful to people with brain injury.
- CHIARAVALLOTI: 02:15
- Correct. Going back in my career, my dissertation work was done in epilepsy. My fellowship work was done in multiple sclerosis, and I had continued my multiple sclerosis work to start my research career. And then the traumatic brain injury work came after that because the cognitive rehabilitation protocol that we were testing, called the Modified Story Memory Technique, was showing such nice effects in this other population that had memory problems. The natural inclination was to try to take that technique and apply it in a population that-- in another population that also had memory deficits, and that's how I started to do the traumatic brain injury work that I continue to do today.

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- WEBER: 02:59 Sounds like you've really taken that and ran with it because now you have numerous cognitive rehabilitation trials that are completed and on-going. And so what started with one branch has kind of led into its own separate end of the tree it sounds like.
- CHIARAVALLOTI: 03:18 That's true. The Modified Story Memory Technique was initially started as a pilot study when I was a fellow in persons with multiple sclerosis. Given that the data was promising, we took that data and submitted for a larger grant in multiple sclerosis. We then adapted it to be appropriate for persons with traumatic brain injury, and we did a large study in persons with traumatic brain injury. We've since modified it in a few different ways. One is we created a group administration for the Modified Story Memory Technique, and that is because many clinicians really wanted to be able to do cognitive remediation in a group therapy format rather than an individual format for pay reasons as well as because of the way their practice ran. So we modified it, and we're currently conducting a trial on the efficacy of the group administered version. We also modified it to be appropriate for pediatric population, which as you might imagine, can be somewhat challenging because of the different levels of understanding, different levels of vocabulary, different exposure to the world. So we modified it for young persons, and we're currently conducting a trial funded by the New Jersey Commission for Brain Injury Research on the Modified Story Memory Technique in pediatric patients with traumatic brain injury. And then we're also conducting research on it in spinal cord injury. Individuals with spinal cord injury also struggle with cognitive deficits although very different from the cognitive deficits persons with TBI encounter. However, they do have underlying memory problems that can be-- we hope can be alleviated through the story memory technique. So we're currently conducting a trial in spinal cord injury. And then finally, we are testing the Modified Story Memory Technique in a population of persons who are aging normally as well as persons with mild cognitive impairment. As we all know, that is a huge population of people that are struggling or could be struggling with memory problems. And if we can identify this as an effective means to treat those memory problems, that would be a beautiful contribution to the literature and really help to treat those patients effectively. So what started out as one small pilot study has really grown to many, many different studies applied to different populations in hopes of really being able to impact all of these populations, not just where we initially initiated the work.
- WEBER: 05:52 Absolutely. It sounds like each individual population has been able to help contribute to the next down the line, and I'm sure that you've learned things over the years conducting this work that help fine-tune and restructure the treatment so that it can be most useful to people who are going to be using it in clinic. And as I understand it, there are a number of brain injury clinics that are using the Modified Story Memory Technique.
- CHIARAVALLOTI: 06:21 That's absolutely true. So as we conducted this work, we learned that different adaptations were necessary for the treatment to work in different populations. So the patients respond differently depending on whether they have multiple sclerosis or have traumatic brain injury, and the treatment really needs to be adapted to be able

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to most effectively treat a population that we're working with at a given time. So for traumatic brain injury, in particular, the treatment is being used at several different clinics across the world actually, and they are working with persons with traumatic brain injury, and we're getting feedback on what works in a clinical setting and what doesn't work and how it needs to be adapted. The treatment protocol itself is a very structured protocol, and the examiner follows a manual where they're guided through the treatment. However, clinician judgment is absolutely necessary, and that is really what drives the treatment because different doses of treatment are necessary based on the type and degree of cognitive deficits in any given individual's experience.

WEBER: 07:31

That makes absolute sense, and also even though it is a very structured protocol, there is some wiggle room for making sure that the individual is getting out of the treatment what he or she wants to get out. Is that right that you had made some amendments to the protocol in order to make sure that was built in?

CHIARAVALLOTI: 07:51

That's absolutely true because different people have different goals and they have different lifestyles. So one person may struggle with a particular memory deficit in their daily life such as remembering items when they go to the supermarket whereas another person may not do that at all, and they may be more in an office setting and they may be learning different skills on different days, and they may need assistance in being able to learn and remember information that context. So the way this treatment has been prepared is that the person actually brings to the treatment their memory challenges in their daily life, and that's incorporated into the treatment in the later sessions. And that enables us to really focus on generalization of the treatment effect to everyday life. So what that means is when we teach something in a cognitive rehabilitation session, we want that to be applied to someone's daily life effectively. And that's what these sessions enable the person to do. It helps teach the person: here's a skill we're teaching you. Now take this, and here's a setting in your everyday life where you can actually apply it, and here's how you do that. It's kind of facilitate that transition from an office setting to real-world setting because it's really the real world that everyone cares about. They don't care how they perform in a nice quiet office setting.

WEBER: 09:17

And I know that you're also the director of the brain injury research lab at Kessler. So I imagine there's a lot of other settings that are currently going on that you have a role in and some that I believe also work with caregivers. So I am sure you end up hearing kind of through the grapevine about how these sorts of studies impact the individual in their everyday life but also in the caregivers and the system structure of an individual with brain injury.

CHIARAVALLOTI: 09:50

Definitely. We have a lot of different TBI research going on at Kessler Foundation. The biggest of the research studies is the TBI model system. That's a federally-funded research and clinical system. It's funded by The National Institute of Disability Independent Living and Rehabilitation Research referred to as NIDOR which is part of the federal government. And what that allows us to do is follow people from the time that they're injured every five years until they no longer allow us to follow them

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anymore. So we call them for years, and that gives us data regarding outcome. And we're one of 16 centers nationwide. We contribute that data to a large national data set that's available to the public. So that's a huge contribution to TBI research in general because it really enables people to ask a lot of different questions from a data set, and it supplies that data set to the public. Within that study, there are also sub-studies. So part of that TBI model system is what we call modular projects which are projects where one center proposes an idea and then up to five, six, seven other centers across the country join in and collect data on that idea, and you work on that project together. So we're involved in several modular projects. And then in addition to that, we have independent research ongoing in traumatic brain injury. I have a line of cognitive rehabilitation research that I continue that's not the story memory technique but other cognitive rehabilitation protocols. But then I also have several research scientists that I work with that conduct their own line of research, and I'm involved in those lines of research as well. In that sense, I'm more of a-- I have more of a consultant role where I'm advising, helping where I can, but the investigator themselves are the ones that are really driving the research. So I'm in more of an assistive role in that type of work. So there's a lot of different types of TBI research going on at the foundation, and there's any number of things that a person could get involved in if they wanted to get involved in TBI research either as someone who's living with a TBI, a caregiver or a healthy individual because we always need someone who doesn't have a brain injury to complete our research studies as well because that's how we know what's different about the person who does have the brain injury. So there are a lot of different opportunities for people who might want to get involved in this work.

WEBER: 12:30

It sounds like there's quite a bit going on in that you're involved from many different levels. And it sounds like from the TBI model system data collection site that you have close relationships than with the clinical care that individuals in Northern New Jersey would receive after they have a traumatic brain injury.

CHIARAVALLOTI: 12:50

That's true. We have a very close relationship with the traumatic brain injury staff at Kessler Institute for Rehabilitation because we work hand in hand so they're doing clinical work. They may have questions. They may need some assistance with some of the research or data analysis, and we jump in and help. We're conducting research. We need clinical personnel to help us in making clinical decisions or other aspects of grant preparation or study procedures, and they're always there to help. So we really work together in addressing the different issues that we're all addressing from our unique perspectives. There's a team of staff at Kessler Institute for Rehabilitation that are heavily involved in the TBI model system. And honestly, we couldn't do that grant without them.

WEBER: 13:38

And that's a great way to conduct research because it sounds like you're always being able to hear what is really needed on the front lines from those who are really seeing these patients from the very beginning of their injury through many years living with chronic injury. But you can really hear directly from the providers what is really needed in their clinic to help their patients get back to everyday life.

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- CHIARAVALLOTI: 14:04 That's true. The only people who really know what is needed to improve the rehabilitation of persons with traumatic brain injury and what their real struggles are are the patient themselves, their caregivers, and the clinicians that work with them. So we garner a lot of guidance from both the clinicians as well as the caregivers and the patients themselves to really direct our research and identify the next steps in the research that we're doing.
- WEBER: 14:34 And what have you found the most interesting about working with individuals with brain injury, and what would you say that you've learned from working with this population?
- CHIARAVALLOTI: 14:43 I think when I think about what I've learned over the past 15 years there's a lot I've learned, but I think one of the most important things is about resilience. Hearing their stories is really quite sobering because you really hear what they've gone through and how they struggle every day, what their challenges are, and how they face those challenges, the unique ways that they've learned to successfully overcome obstacles that they face every single day. So I think one of the biggest things I've learned is how to face challenges in a way to overcome them so that they don't become obstacles, that they remain challenges.
- WEBER: 15:39 And it sounds like you wear very many hats in your role at Kessler between being a director and researcher and mentor. But working with the brain injury community, what do you enjoy most about your job?
- CHIARAVALLOTI: 15:56 The best parts of my job are the days when I can spend time with consumers, with people who have brain injury, and their caregivers. And I'm able to learn what their lives are like and what they're facing in their everyday life. And I really enjoy that for a couple of reasons. One is because I'm motivated by hearing their stories. So when I hear how far someone's come from where they started after their injury and how much better they are, that motivates me to continue. Or if I hear that someone really benefited from the treatment that they received during a research study that they did with me, that motivates me to keep working toward the goal I'm working toward, which is to try to minimize these cognitive deficits and really improve someone's quality of life. So that's one reason that I really enjoy working with the individuals who are living with brain injury as well as their caregivers because it motivates me to continue on. But the second reason is that when I hear their stories, that directs my future research. So if I'm in a conversation with someone about the treatment that they might have completed in one of my research studies, they often will tell me what they liked and what they didn't like and what helped and what didn't help and what they're left with after the treatment. So they may say, "Well, yes, I completed your treatment and it was really great and it helped me with this. It helped me with that. But then I really still struggled with this." So that gives me an idea of what else we need to face, what the next research study is, what the next treatment we need to devise is so that we can then directly tackle the next obstacle that person might be dealing with.

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- WEBER: 17:45 Getting your next research idea from how the challenges of your previous research is definitely the definition of being a research innovator. So we can understand that this award was very well granted.
- CHIARAVALLOTI: 17:58 Thank you, and I also want to thank the Brain Injury Alliance of New Jersey because it really was a tremendous honor. I'm only sorry that due to circumstances I wasn't able to accept the award in person. But I look forward to going to all their future galas as their mission is really an incredible mission to support and advocate for individuals with brain injury and really to raise awareness through education and through prevention so they do some really incredible work, and I would hope that others can support the work that they do as well. I thank them for this tremendous honor.
- WEBER: 18:32 Thank you so much for talking to with us, Dr. Chiaravalloti, and we look forward to seeing more of your future research coming out soon.
- CHIARAVALLOTI: 18:39 Thank you.
- ANNOUNCER: 18:41 Be sure and check out Dr. 'Chiaravalloti's research innovation champion and acceptance videos, TBI consumer resources, and research study opportunities by clicking on the links in the program notes of this podcast. For more information, go to Kesslerfoundation.org. Tuned into our podcast series lately? Join our listeners in 90 countries who enjoy learning about the work of Kessler Foundation. Follow us on Facebook, Twitter, and Instagram. Listen to us on Apple Podcasts, Spotify, SoundCloud, or wherever you get your podcasts. This podcast was recorded on Tuesday, April 28, 2020, remotely, and was edited and produced by Joan Bank-Smith, creative producer for Kessler Foundation.