Social Determinants of Health in TM

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[00:00:05] **Ka-Ho Wong:** So, first of all, thank you SRNA for inviting us to come over to actually talk about my project or my passion, which is social determinants of health in myelopathy and transverse myelitis. Here's my disclosure: This study is actually funded by SRNA. So, thank you again, SRNA, for funding this project.

[00:00:26] I wanted to talk about what is social determinants of health. So, social determinants of health are factors that does affect our health outcomes, but it's not traditionally caused by medical characteristics. It's really your sex, work, educations, and things like that. So, in the Healthy People 2030, they actually categorized five different factors that is called social determinants of health factors.

[00:00:59] So, these are the five factors that we have often seen. And then furthermore, they have talked about how these factors could be subcategorized even more. So, it's not just these overall five factors, but there's even more to it. So, even education, specifically, there's different types of education barriers that patients will be affected as well too.

[00:01:26] So, what are we doing in social determinants of health in neurology? Actually, in neurology and other diseases, there's a lot of different things that people are talking about as well too. So, even the NIH or the National Institutes of Health -- specifically the NINDS -- has talked about different types of recommendations of how to deal with social determinants of health, how to address those as well.

[00:01:54] And to the extents, they actually made a framework for us to follow when we're studying social determinants of health. How do we follow those four neurological disorders as well? Which is this super complicated thing that I'm just going to call 'our framework' that we could follow as well too. Well, great. So, what about rare neuroimmune disorders? What are we doing?

[00:02:23] So, I did some PubMed search through a couple of thousand literature. In NMOSDs, there's a couple papers out there that is talking about the effects of social determinants of health and predicting time of aquaporin-4 NMOSD. They did find that it is predictive factors. And then, recently, one of our colleagues in Cleveland Clinic has done what we call a neighborhood disadvantage.

[00:02:54] Because a lot of the time, social determinants of health, it's not individual factors. It's neighborhood factors: it's where you live, your upbringing, and things like that. And what he has found too is, if you live in a traditional disadvantaged area, you're more likely to have a time of delayed diagnosis as well and choice of therapy.

[00:03:20] And then, this is another study that they have done as well and see if stress is actually a factor and socio-economic status, if that's a factor in neuromyelitis optica. And they have found that stress actually increases the risk of neuromyelitis optica. What about these other diseases or what Dr. Greenberg calls transverse myelitis plus syndrome yesterday?

[00:03:47] We actually have not found any articles in there, but this is based off of our PubMed research. Because of that, we're actually implementing a couple studies going on. So, the first study, it's actually what we call the SDOH factors in the Transverse Myelitis Outcome Project, which is funded by SRNA.

[00:04:13] So, this is actually, we use the VA, which is a Veterans Affair cohort to look at all of our transverse myelitis patients and see if social determinants of health factors or different social determinants of health factors are affecting their outcomes as well. So, remember, we were talking about that there's five main categories that we include. Well, the three that we circled are actually the main three categories that we're really focusing on or really studying in this specific project.

[00:04:48] So, what have we found? So, there's a total about just over a 1000 patients. Again, remember, this is the VA cohort, so it is a little bit older. It's the 64 years old of median age, predominantly white. Again, that's pretty common in the VA cohort. And so, we can see there's different types of etiology that we are focusing on.

[00:05:13] And then, the outcomes that we're looking at, it's their Median Modified Ranking Scale. So, what a Modified Ranking Scale is: it's a format, it's a clinical outcome that we could use to measure how the patients are doing. So, in a Modified Ranking Scale of three, it's you need some assistance in some of your daily activity as well. And then, we would look at it at your follow-up as well. What is your Modified Ranking Scale, which is at a three as well too.

[00:05:43] So, we're currently still capturing more data on the social determinants of health piece, but some of the stuff that I didn't put in the slides is, we're looking at the medical and hospital quality and access in those areas, the median income in those areas as well too, and we're also looking at different types of, so insurance, given that because we're at the VA insurance usually tends to be a single payer system, but there's also other types of insurance that VA could accept as well too.

[00:06:21] So, we're still actively looking at different data points on that as well. So, I talked a lot about how neighborhood is going to affect your outcomes. Then we also have a separate project that is looking at individual social determinants of health outcome as well too.

[00:06:40] So, how are your traditional disadvantage affect your outcome as well too. So, in Utah, we're actually implementing this survey study as well too. So, we have deployed a social determinants of health stakeholders committee where it allows us to sit together and talk about what are some of the factors that are most important for some of our patients as well too. And this is more of a broad spectrum of different types of neurologic diseases.

[00:07:17] So, some of the factors that we're including in this survey studies are: social and ethnicity, social stigma, education attainment, transportation access, socioeconomic status, the neighborhood in that area, and the source of information or barriers of communications because a lot of the time, we know that we're

afraid of talking to a neurologist. I'm not a neurologist, so even when I talk to a neurologist, I'm like, "I don't know if I want to share all these information with you as well too."

[00:07:48] So, we're looking at those as barriers, and then we're also actively looking at what about the patient-reported outcomes. Are any of these barriers related to your reported outcomes as well too? And then, retrospectively, what that means is we're going to go back to your notes and then look and see your clinical outcomes, and we're also looking and see if the physicians-reported symptoms matches what you reported as symptoms as well too.

[00:08:15] So, those are some of the stuff that we're doing. This is a survey that we're doing. We welcome anybody who are interested to do this survey to just scan the QR code to do it as well too because this would be very helpful for us to understand how social determinants of health affects different types of rare neuroimmune disease as well too.

[00:08:38] So, here's some preliminary results that we have here. So, again, this is just a very small sample size that we have done in Utah. We have found that a lot of people actually have a lot of great support system from spiritual and community in the state of Utah or around the surrounding states. Family supports are huge as well too. And then distance in clinics, we actually have a half and half. Some of them travel from 25 miles or more away.

[00:09:10] Again, in Utah, we're the only academic centers in the six surrounding states. So oftentimes, a lot of patients comes from different areas. What this Median ADI is, it's an Area Deprivation Index. So, that's actually a map created by University of Wisconsin. They do a composite scale where they allow different types of social factors and calculate a scale from 0 to 100. Zero, it's where you live, you know, in Beverly Hills, and 100 is the most disadvantaged area where we live.

[00:09:49] And then, we found that the pain level as well too, it's in five as well. And then, we did the PROMIS-29, which is the patient-reported outcome. We cut it into three different sections, and we can see that the chunks are divided pretty evenly as well, and we did a prediction model. So, the PROMIS-29 again, is just a self-reported outcome.

[00:10:20] What we have found is age is a big predictor for poor PROMIS-29 or for a poor self-reported outcome. And then, we looked at the clinical outcome as well too. What we have found is, insurance was a predictor for poor clinical outcome, which is not a surprise for any of us. So, a lot of our projects are still in the preliminary phase, and I just want to thank you everyone for all of it. And then, just wanted to leave a quote from Martin Luther King for you all to read. Thank you.

[00:11:25] **Audience Member 1:** I didn't see on your slide. I'm blind. What were the social determinants of health that you all measured there?

[00:11:31] **Ka-Ho Wong:** So, the first project at the VA projects, we mostly measured the healthcare quality and healthcare access, and we also measured the socioeconomic status in those areas. So, the median income in those areas, and things like that. Because, again, that was focusing in the neighborhood, what do they have in that neighborhood. The second one, we catch a wide net. So, we measured basically every single social determinants of health factors we could think about in a public health perspective.

[00:12:08] **Audience Member 2:** And this was after their diagnosis?

[00:12:10] **Ka-Ho Wong:** This is after their diagnosis. Yes.

[00:12:12] **Audience Member 1:** And with the NIH declaring disability as one of their social determinants, did you factor that in?

[00:12:18] **Ka-Ho Wong:** Yes, we did.

[00:12:19] **Audience Member 1:** Okay.

[00:12:20] **Ka-Ho Wong:** Yeah.

[00:12:24] **Audience Member 3:** Hi. So, I have tons of questions for you, so I'll find you later. I don't want to keep everybody. But I'm thinking about your population in Utah and it's fairly homogeneous.

[00:12:36] **Ka-Ho Wong:** You can just say it's very white. Yes.

[00:12:39] **Audience Member 3:** And I'm pretty sure, but I'm wondering if you were to have a different population, given that there's certain other global factors like race and ethnicity that affect social determinants of health overall, if you anticipate that you would have different outcomes with, say, a population like Cleveland Clinic.

[00:13:04] **Ka-Ho Wong:** Yes. I do think so. So, we are actually actively looking to see if we can expand to different racial and ethnic group as well too. And then, on top of it, we wanted to expand that into different geographic areas. So, that's why it's super important for us to share this survey out to different people as well too.

[00:13:27] Because the main purpose of this survey was looking to see if social determinants of health affect your reported outcome, not what the physicians reports because we have seen there's differences between what the physicians reports versus what you report a lot of the time. So, what we're focusing on in that second project, which is a survey project, is how are our patients filling it?

[00:13:56] **Audience Member 4:** A question for you regarding the VA survey. Are you going to be doing another VA survey?

[00:14:03] **Ka-Ho Wong:** So, the VA one, it's actually what we call a retrospective analysis. So, a lot of the data is based off of what we capture, but we absolutely would be very interested to do a VA survey as well during the long run.

[00:14:19] **Audience Member 4:** So, in the next VA survey, are you going to also ask about their military service and see if they were in places where there was some impact on, like, the burns and other things?

[00:14:30] **Ka-Ho Wong:** Yes. Absolutely. Absolutely. Yeah. So, I think the VA piece that we would also be very interested is the stress because we have seen that stress actually affects the NMOSD outcomes as well too. So, given that the stress would be completely different than what a general population would have. So, we'll be very interested in that area as well.