



MIGRAINE WORLD SUMMIT

INTERVIEWS WITH WORLD LEADING EXPERTS



TRANSCRIPT

WHY DOESN'T MIGRAINE HAVE A CURE YET?

TISSA WIJERATNE, M.D., FRACP



Introduction (00:00): You quote some of our numbers on mortality, that is true, but one of the criticisms that I hear from migraine patients' partners is, "Migraine doesn't kill you." Well, actually migraine does kill you. But even if migraine doesn't kill you, it definitely kills human joy out of you, and I myself am a patient with migraine, and I could claim a number of days that it killed my joy on those days a hundred percent. So, the reason for not having a cure is, it is such a common, complex human condition with the least funded research, and least respect, and neglect. That's the reason for not having a cure, as such.

Wendy Bohmfalk (00:50): Whether you live in Melbourne, Manhattan, Manchester, or beyond, you may have wondered why migraine has no cure. It's a disabling neurological disease affecting one billion people, yet it's woefully underfunded. To understand what's holding back our progress, we invited one of the authors of the Global Burden of Disease Study, Dr. Tissa Wijeratne, to join us today. Dr. Wijeratne, welcome to the Migraine World Summit.

Dr. Wijeratne (01:20): Wendy, thank you very much. It is my pleasure and honor to be here. You guys are doing such wonderful work in this disabling disorder to raise awareness, and to improve advocacy, and bring a much needed cure for this disorder, eventually.

Wendy Bohmfalk (01:35): Thank you. Thank you, we feel the same way about you. You wrote an article in 2019 that noted: "Migraine is the most burdensome illness in people under the age of 50 and in females. Among people with migraine who experience more than 15 days per month with headache, 20% are occupationally disabled. Migraine with aura is associated with a 20% increased risk of mortality, and the suicide rate among people with cluster headache is 20 times the national average." I'm going straight to the punchline, why is there no cure?

Dr. Wijeratne (02:12): That's a great question, Wendy. Thank you for quoting our paper, also. Let me go back a little bit. You ask these questions because of your brain. I answer these questions because of my brain. Our brains basically make us who we are, but the brain is a very sophisticated, biological computer, if you like. There won't be a PC or Mac that would supersede what our brains are capable of. Our brains consist of just over a hundred billion biological, electrical wires, constantly changing every second, every minute. They talk to each other through what are known as synapses, and we believe that there are over 10 trillion synapses in them. Migraine is a biological disorder — a bona fide, legitimate medical disorder — where you get changes in electrical activity or chemical activity intermittently — basically linking with every other medical disorder that is known to mankind. It is the most complex medical disorder that I can ever think of.

Dr. Wijeratne (03:24): However, it continues to remain the least funded, least respected, most neglected medical disorder worldwide. From north to south, from Europe to Asia, from Asia to Oceania — anywhere you go, the story is the same. So, given that it is such a common human condition, given that it is such a complex



human condition, despite the fact that it causes a leading cause of disability in working class people, who hold this world high — this is not a criticism against all the folks, obviously we respect them. But the bottom line is your plumber, your drivers, your Uber driver, your electrician, your teacher, most of the working class people remain in this working age — and this disorder basically takes the best out of them for the most part. You quote some of our numbers on mortality, that is true, but one of the criticisms that I hear from migraine patients' partners is, "Migraine doesn't kill you." Well, actually migraine does kill you. But even if migraine doesn't kill you, it definitely kills human joy out of you and I, myself, am a patient with migraine, and I could claim a number of days that it killed my joy on those days a hundred percent. So, the reason for not having a cure is, it is such a common, complex human condition, with the least funded research, and least respect, and neglect.

Wendy Bohmfalk (05:05): Well, that was beautifully said, and I'm sure so many people can relate to what you just mentioned, especially about migraine killing our joy. I definitely want to get into a lot more detail about what you've talked about, and maybe we'll start with the Global Burden of Disease Study? I know that you've worked on that, and I'd love for you just to tell us about it, and tell us where migraine fits in.

Dr. Wijeratne (05:26): The Global Burden of Disease Group is a very powerful, coordinated, academic community worldwide; several hundred academics contribute to the Global Burden of Disease Group, and a number of landmark research papers continue to publish in key journals on an annual basis. Again, let me go back to 2017 — where we told the world for the first time at the World Federation of Neurology, World Congress of Neurology, with the concurrent platform presentation — basically telling the world that neurological disorders are the leading cause of disability. The two main disorders that are contributing to this are stroke and migraine — they are intimately interconnected. We'll come to that during the discussion later on. You can see that I work on both fields as much as I can. At that point in time, we realized that headache disorders, specifically migraine, are contributing to the disability significantly; as I said to you, [in] working class people — number one worldwide.

Dr. Wijeratne (06:35): In most countries, migraine is a leading cause of disability across all ages. Say, for an example, where I live in Australia, it is indeed the leading cause of disability above and beyond even stroke, dementia, and heart diseases. The base — there's a way that we calculate disability, but rather than using the terminology that we use, such as disability-adjusted life year and years of lives lost to disability, let me take an example of my own: Let's say that I'm in the middle of an attack of migraine right now. If that is the case, this interview would be the most useless interview that you would be doing with me. That is because in the middle of a migraine, I cannot perform with 100% capacity of my brain. So you only get — you might get 10% of my brain activity or 20% of my brain activity or 30% of my brain activity.



Dr. Wijeratne (07:42): In fact, the Global Burden of Disease Group calculated this to be around 0.43. Let's say, for argument's sake, it is 0.50 — it's almost like a 50% reduction of your ability to do things. Since the 2017 publication, in 2018, we went ahead and looked at headaches and migraine in particular, and we made a slight change on disability adjustment, as headache generally doesn't end up with a lot more deaths compared to stroke and other disorders. And that's how we came to that 0.434 figure, which was mathematically calculated. We were then able to convince the World Health Organization, which is the ultimate body that is advocating for better health for all globally, to come up with its 73rd resolution — which was much awaited — where the World Health Organization accepted the fact and endorsed, with 13 paragraphs, why we need to work in synergy to deal with brain disorders.

Dr. Wijeratne (09:04): Here also, it is important and worth noting that the World Health Organization, accepting the numbers that are there, say that stroke and migraine are the two main contributors to disability worldwide — and, of course, that's as well, worldwide in low- to middle-income countries. These global things have a direct impact and huge repercussions to every country. And this is why I am so excited for all those sleepless nights and all those advocacy works that our colleagues and ourselves have done, finally coming to fruition. Seeing the World Health Organization accepting that brain disorders are the leading cause of death and disability, and migraine is one of the lead things there. Now, the onus is up to us, how we move forward in finding the cure that we are going after. I basically think that this is a curable disease — a curable disease in the sense that we, as humans, we didn't come to this planet to live forever.

Dr. Wijeratne (10:17): We all have a shelf life. You have a shelf life and I have a shelf life. Our job as human beings is to make sure that this shelf life is as joyful as possible to all of us and as useful as possible to all of us. I'll tell you the living example: I told you that I do suffer from migraine. Probably, both my children suffer from migraine also, and I haven't told them this yet. I told them that they get headaches because they spend too much time with computer games and iPads. What you all are doing is fantastic. I think the Migraine World Summit really brought migraine patients to the floor. As a physician who is interested in human health broadly, and more importantly, brain health as a brain specialist, I think the next phase of progress in medicine would rely on how well we incorporate patients into their own management as a partnership. I basically teach my medical students and residents that if you want to get the best outcome for your patients, you really want to get them involved, irrespective of the illness that they have — whether it is migraine, Parkinson's disease, stroke, multiple sclerosis, or COVID-19 — you have to sit with them and make the decisions with them, and take them with you, and let them be involved.

Wendy Bohmfalk (11:51): Going back to the funding piece of it ... So, we do know that migraine received so much less funding than all the other diseases identified by the Global Burden of Disease Study with such a high burden. I'd love to know, I don't know if you can speak to numbers, but how much funding does migraine receive? Is



that funding level similar around the world, and where should it be? Where should we be with funding for research?

Dr. Wijeratne (12:18): That's another great question, Wendy. You know U.S. numbers very well. You know that in the U.S.A., this is significantly less funded — least funded, despite the disability and the rest of the other things associated with it. Guess what? Every other country does much worse than that. I looked at these numbers in Australia — the other main national research funder is the NHMRC [National Health and Medical Research Council]. I looked at the amount of funding that went from 2007 to 2017, over a 10-year period, from their own resources, and I calculated that despite migraine being the number one cause of disability — costing the Australian economy just over \$40 billion in 2018 alone — the NHMRC has only funded less than 0.09% of total funding allocated to migraine. I, myself, submitted well over 10 grant applications. Grant applications are hard, but they got rejected reasonably easily, which is quite unfortunate.

Dr. Wijeratne (13:36): There are reasons behind them. I think we brought migraine to the discussion only after World Brain Day last year in Australia, on a sort of a global mass scale. That's the first time that national radios and national television started to talk about migraine, as far as I can remember. And then ... I'm hoping that the situation that we have seen over the last 10 years, we could hopefully change for the next 10 years, but we still have a lot more work to do. And if the U.S.A., U.K., Australia — these are the countries which have contributed; I'm not saying this with any disrespect for other countries — of course countries like China and other European countries have contributed to the advancement of medicine also — but when you look back over the last 200 years or so, people from these places have contributed significantly to the growth of medicine globally. If these countries are funding this calamity, a disabling disorder this low [of a dollar amount], you can imagine the situation in other countries.

Wendy Bohmfalk (14:56): So why is it so underfunded? I'm glad it seems like we might be coming to a tipping point with it, where it is getting more recognition and there's more awareness, but why historically has it been so underfunded?

Dr. Wijeratne (15:06): I think ... there are several reasons for this. Personally, I think for headaches in particular, we generally have a lay explanation, and you don't necessarily think of a bona fide medical disorder as a cause for the headache. And as a result of that, most patients themselves neglect this as a medical disorder, and then when they eventually choose to go and see a doctor, probably over 90% of the time that lay model gets endorsed. Even in Melbourne, I still see migraine patients being operated on for sinusitis. Even in Melbourne, I still pick up two or three new patients every week with chronic migraine and medication overuse headache. And they have been to doctors for 30, 40 years. And you have seen some publications from a colleague and friend, David Dodick and colleagues, [showing that] even in the sophisticated Mayo Clinic catchment- area-type region, chronic migraine doesn't get diagnosed — not more than 4.5% of the time.



Dr. Wijeratne (16:26): So, all these things — having a lay model, not recognizing this as a medical disorder — make the doctors themselves less interested in this field. I have seen this with my brother. I remember — he's also medical folk — I remember when he was about 17 years of age, with refractory migraine. When we admitted him to a local hospital in the rural city of Sri Lanka where I was living at that time, I was a first-year medical student. I didn't know migraine with aura, migraine without aura. But the local doctor told my parents that he had tried everything that is possible with regard to my brother, and he is in the process of death, and the best that he could do is to give him a side room, and then my parents could bring relatives and others.

Dr. Wijeratne (17:23): Although, I didn't have the courage to disagree with him, I went back to my medical school and I talked to one of my senior professors, seeing whether I could bring him to the university hospital to see whether someone could have a look at him before he died. So we took him to the university hospital. Interestingly enough, the intern medical officer in that hospital, who had taken the clinical history from me and my brother, he made the diagnosis of migraine with aura and refractory migraine, and he controlled his vomiting and he hydrated him. And within about three, four days — I can't remember what he had given him — the symptoms were controlled and he went home. He then went on to study medicine and went in to do a Ph.D. in neurobiology. And now he's working as an academic in a university and a part-time GP also. And he hardly gets migraine attacks now, although we both get our own days where we lose our joy, but they are minimum these days.

Dr. Wijeratne (18:34): I think that is within reach for every single patient with migraine. We are so ripe to find solutions right now, and this is the time to do that. In fact, what COVID-19 has done to us is, it has put us together. This globe is even more global now than ever. I mean, you're on the other side of the world and I'm on the other side of the world, and we are talking to each other through Zoom technology. And I've done the same for the 2020 World Brain Day campaign, visiting well over 60 countries virtually. I think if we work hard, if we work together, I think we can find a solution and we can make our shelf life, in this human life, as useful to us, as well as useful to others, as much as possible, and as joyful as possible to us, as well as others.

Wendy Bohmfalk (19:34): Something else I feel like I should ask, and I just feel like I can't go without asking this question ... So, we know that roughly one in four women experience migraine in their lives — 85% of people with chronic migraine are women, three times as many women have migraine than men as adults. Do you think this could be any reason why the funding for research has been less, historically, than other disease states?

Dr. Wijeratne (19:58): I haven't thought this through in this context, but it is very possible. It is very possible. I mean, the fact of the matter is, when you look back historically, there was gender disparity in the professional appointments, the sporting, the salaries — we could go on talking about them. That is a possibility. I don't think we have convincing evidence to say that is indeed the case, but we all



know that women bear a lot in life compared to men. What we need to do is to work together and fix this mess as a matter of priority, and I think the time is now. We just need to go back to the drawing board and collaborate as much as possible, and find the solutions. I am very convinced that this is within reach for us to control this disorder. And maybe redefine the cure: If migraine is a complex box in your brain, rather than making it a big storm inside your brain all the time, make it the smallest box as much as possible, and keep it aside and live your life and not let migraine run your life.

Dr. Wijeratne (21:34): I think that is within reach, and what we need to do is to promote awareness, promote advocacy, and bring much needed research, as this disorder is holding keys to solutions for most of the disorders affecting us — including stroke and most mental health problems, as far as I'm concerned.

Wendy Bohmfalk (21:57): Where does advocacy fit in? And if someone is interested in becoming an advocate, what are some of the first steps they should take? Certainly sounds like partnering with your doctor is a big part of that, too.

Dr. Wijeratne (22:09): I think advocacy is the most critical component in promoting health care — in anything — and certainly and absolutely in migraine. How does one become an advocate? We have to be an advocate for ourselves to begin with — to promote this disorder's need for recognition and need for treatment, and need for research, and need for education. So, the first thing is, I normally tell my migraine patients that you have to know about migraine just as much as I know about migraine. I don't mean by getting them to read *Cephalalgia* and *Headache* and all those journals. What I mean is, understanding your disorder and the physical aspect of it, and symptoms, and medication overuse headache, and all that information. So that's the first bit. Second bit is, if your doctor is, let's say, not interested in this disorder, for whatever the reason, our job is to make them interested in it.

Dr. Wijeratne (23:24): I'll tell you an example: In Australia, we have developed an eight-hour education module for migraine patients, targeting our general practitioners because we have, like, 40,000 of them. And I tell my patients that if your doctor is not interested in it, take a brochure, take a printout, and then ask them, "You could visit this site, you could take this app, or you could visit the International Headache Society website," and bring them to be interested in those things. So you make them interested in it.

Dr. Wijeratne (24:07): The third thing is, join whatever advocacy bodies that you have. The patient support groups, the regionally ... it's like a Rotary Club and Lions Club. We have to have the social groups where we could raise issues and talk about them. I'll tell you an example from Parkinson's disease: We now know physical things that help Parkinson's disease much more than what we knew, by listening to our patients. If we had two or three things that the patients came and told us that, "Well, doctor, we could do this, we could do *this*, that would help us to improve our balance." In fact, one of the academic physiotherapists in the Netherlands has



designed a poster with almost 40 things that patients could do. But as physicians, we only had, like, three or two over the last 200 years since we knew about Parkinson's disease. Same would be true for migraine, also.

Wendy Bohmfalk (25:07): So, just to end things, I would ask what else is on the horizon in terms of research? You mentioned you have children. I have children as well, who I think have inherited migraine. Do you think it's going to be possible to eradicate migraine before, perhaps, our grandchildren inherit it?

Dr. Wijeratne (25:25): I think, as I said, I think it is possible. As I said before, our job is ... I'll give you an example: When I consult with a migraine patient, I share two screens with them, or two screenshots. I show them a storm, a picture of a storm. Then I show them a picture of a brain and a very tiny red dot in the middle of the brain. Most of my patients are actually in the storm setting, and I am on the other side, who is also a migraine patient, or patient with migraine. When I do get migraine, my migraine is that little red box. It just kills my joy only occasionally now, compared to years before. I tell my patient that if we work together, if both of us do what we are supposed to be doing, and if you get your family — the physician does what he or she is supposed to be doing — and if you get your family to support you, you can be this — your brain can be this red dot also. And that is what we need to do.

Dr. Wijeratne (26:31): I think for that, we must get patients involved; they must become advocates for this disorder. And for this, we have to improve education. And for this, we have to improve research. You asked me what is on the horizon. I think what I learned over the last 10 months, since COVID-19 came on board, is — before this interview, I told you that I learned more medicine during the last 10 months than what I learned during the last 30 years, since my high school days. That is because for the first time, we have seen the direct relationship between the biological underpinnings and disease mechanisms in place in biologically compromised patients, in particular.

Dr. Wijeratne (27:26): I think we will be able to translate this to migraine, also. The brain is the most complex, sophisticated biological computer that was ever built on this planet, during human life. And this disorder is a disorder affecting its chemical changes and electrical changes. So the solution has to come — how we tackle these changes — by collaborating with the patients from a multiple-systems point of view. I can see some literature appearing on this theme, and I can see that groups are regrouping on this theme. And I am eternally optimistic that this is something that we can achieve during our lifetime.

Wendy Bohmfalk (28:16): That's a perfect place to stop. What a great message of hope and optimism, and just a good reminder, too, of how complex of a machine we're dealing with. And I'm glad we've got the right minds working on this. So, Dr. Wijeratne, thank you so much for joining us today with the Migraine World Summit.



Dr. Wijeratne (28:34): Thank you so much. Thank you so much for all the wonderful work that you all have been doing. And I normally subscribe to the Migraine World Summit, and I distribute things to my patients. Keep up the good work, and we must get patients involved. That's the only way that we can untangle this calamity and mysterious disorder.

Wendy Bohmfalk (28:58): Wonderful. Thank you again.