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Chair

Mr. Neil Ellis

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• (1540)

[English]

The Chair (Mr. Neil Ellis (Bay of Quinte, Lib.)): Good afternoon, everybody. I now call the meeting to order.

Pursuant to Standing Order 108(2), a study of the effects of mefloquine use among Canadian veterans, today we have two witnesses appearing as individuals: Dr. Jonathan Douglas, a psychologist with Central Ontario Psychology; and Dr. Penelope Suter, an optometrist. She is on a video conference from Bakersfield, California.

Dr. Suter, welcome. We'll start with your opening statement.

Dr. Penelope Suter (Optometrist, As an Individual): Thank you and good afternoon.

I'm a private practice optometrist with a specialty in neuro-optometry. I received my doctoral degree from the University of California at Berkeley.

My interest in the brain and vision began early in my career. After receiving my optometry degree, I spent 22 years doing part-time visually evoked potential research, measuring brain responses to visual stimuli, as co-director of the vision laboratory at the California State University in Bakersfield.

In my private practice I have been practising, writing and lecturing in the field of neuro-optometry for nearly 25 years. My co-editor Dr. Lisa Harvey and I published what is considered the most comprehensive text reference book to date on vision rehabilitation following brain injury. We worked hard to include both the basic science and clinical science involved in visual dysfunction and visual rehabilitation following brain injury.

Neuro-optometrists are interested in testing and treating visual function, including eye movements, eye coordination, visual perception of objects and visual perception of space and motion, as well as how we integrate those visual percepts with the other senses and the motor system so that we can move through space and act on objects. Visual processing is so distributed throughout the brain that it is difficult to injure the brain without some visual consequence.

I am here today not as an expert in mefloquine toxicity and the visual system, although I am happy to share what I know on the subject. I'm not sure that we have experts on the visual system and mefloquine toxicity at this point. However, I am here as a neuro-optometrist who has diagnosed hundreds of patients who have subtle

vision deficits resulting from acquired brain stem injury that can mimic or exacerbate the symptoms of post-traumatic stress disorder—PTSD—or other psychological diagnoses.

Quinolones have been shown to cause brain stem lesions. I am here because just like the patients I see with subtle vision dysfunction resulting from other acquired brain stem injury, patients with mefloquine toxicity are at risk of being diagnosed with PTSD or other stress- or anxiety-related disorders when they actually suffer from neurologic vision deficits. I am here to tell you that every patient who suffers mefloquine toxicity and has PTSD-like symptoms, or difficulty reading, or photophobia, or difficulty with balance or dizziness, or feelings of disorientation or anxiety, needs a neuro-optometric workup. Neuro-optometrists and neuro-otologists can test for biological markers of brain injury that other professionals simply do not.

Ordinarily, our visual system and our vestibular system work together to create the perception of a stable physical world around us so that we can move through it with confidence. However, imagine suddenly living in a physical environment that moves and shifts just a little as you move your eyes—not enough for you to be able to say, “Oh, the floor just dropped three inches when I looked to the right”, but just enough to make you feel a little uneasy or queasy, or startled or disoriented, or where the space around you shifts, expanding on one side and contracting on the other.

When you walk toward an object that is straight ahead of you, you find that you're always veering to one side because your visual perception of straight ahead has been shifted from the reality of the physical straight ahead. All of these visual symptoms are common following acquired brain stem injury. They cause difficulty with balance and feelings of disorientation and anxiety because the physical world that we depend on to stay stable under our feet, in our hands and in our visual perception is no longer reliable.

If you have a visual problem that destabilizes the perception of the physical world around you, as I have described, the vestibular system will attempt to keep you upright. If you look to the right side and your visual system says, “Oh, something shifted,” and you get startled, your vestibular system will say, “It's okay. I know where upright is. I know where gravity is,” and it will rescue you. If you have a vestibular problem, the visual system can help stabilize you.

Some of you may remember having drunk enough alcohol to have closed your eyes and have the world start spinning, and then you opened your eyes to make it stop. That is your visual system rescuing you from your vestibular system. If, however, you have both a vestibular and a destabilizing visual deficit, then you suddenly live in an amusement park funhouse.

I want you to think for just a moment, if you were to wake up in a world that was that distorted, how you would try to explain that to your doctor to get help. What words would you use? What would you say? You don't have that spinning dizziness that you get with severe vestibular vertigo. Do you think that once you tried to explain it to them you would be sent to a neuro-optometrist to diagnose your subtle visual deficits creating this instability or exacerbating this instability, or do you think you would be sent to counselling, psychology or psychiatry?

Most of you have probably never heard of neuro-optometry before these meetings, and the same is true for your physicians. This is a common problem for many patients with mild acquired brain injury who can go for years or for a lifetime without ever getting diagnosed. It is certainly possible to have PTSD concurrently with subtle brain stem injury-related visual and/or vestibular deficits, but the treatment is very different for these diagnoses, and patients with mefloquine toxicity deserve accurate diagnosis and treatment with neuro-optometry and neuro-otology.

That's really what I wanted to come talk to you about today. Thank you for the opportunity.

• (1545)

The Chair: Thank you.

Dr. Douglas.

Dr. Jonathan Douglas (Psychologist, Central Ontario Psychology, As an Individual): Thank you for giving me this opportunity today. It's quite humbling, as I do not consider myself an expert in quinism. Instead, I'm an expert in operational stress injuries, or OSIs—diagnoses that arise from the stress of military training and operations, including PTSD, depression, and adjustment reactions, and any of the myriad other problems that arise as a result of being thrust into extremely demanding situations.

I'm very pleased that the committee will be hearing from the real experts on quinism. In particular, I have learned much from Dr. Remington Nevin, who has studied quinism extensively and will be able to teach you much more than I can about the neurological damage that it causes.

I'm here today primarily because I have listened to veterans. Through doing so, I have learned about the challenges associated with mefloquine, including the difficulty that diagnosing it can represent.

I have worked with veterans for about 15 years now, and as part of my work I have completed many psychological disability assessments. For most of these, the issues associated with quinism have simply not been on my radar. It's not something there's much awareness of in my field.

To diagnose an operational stress injury, I begin with a clinical interview. I need to understand the veteran's presenting symptoms,

and I gather a history so that I can understand how the veteran was functioning before and after exposure to the military. I look at the operational history of the veterans, including what tours they went on and the traumatic events that occurred. We look at physical injuries, including exposure to blasts, as well as any other physical issues that might arise from the rigours of training and deployment. I review what documentation I have available, which is often pretty scant, and I administer psychological tests. From these, I'm able to identify the veteran's symptoms, and in combination with the history, I can draw conclusions about the diagnosis and its probable link to military service.

I'd like to take a moment to review the diagnostic criteria for PTSD. You may already be reasonably familiar with these, but please bear with me, as I think it's worth reviewing them in this context. The diagnosis of PTSD is distinctive among psychiatric diagnoses. That's because diagnosis begins not with the symptoms presented by the patient but with an examination of an event.

Criterion A is directly experiencing or witnessing actual or threatened death, serious injury or violence. In the course of their careers, many, if not most, veterans will experience an event that meets criterion A; however, they don't all end up with PTSD. They must experience the following symptoms, which arise following the event.

Criterion B requires one intrusion symptom from among the following: intrusive memories of the event, recurring dreams in which the content or mood of the dream can reflect the trauma, dissociative reactions such as flashbacks in which the person feels or acts as if the event is happening again, intense or prolonged psychological distress at exposure to reminders of the event, or physiological reactions to reminders of the event.

Criterion C requires one avoidance symptom—either efforts to avoid distressing memories, thoughts or feelings associated with the event, or efforts to avoid external reminders of the event, such as people, places, conversations, activities or situations.

Criterion D references two symptoms of negative alteration in cognition or mood, including the inability to remember some aspects of the event; exaggerated negative beliefs about oneself, others or the world, such as, "I'm broken, I'll never get better" or "No one can be trusted"; distorted beliefs about the cause of the event, leading to blame of self or others; a persistent negative emotional state such as fear, anger, guilt or shame; withdrawal from activities; feeling detached or estranged from others; and the inability to experience positive emotions.

Criterion E references two symptoms of alteration in arousal and reactivity, including irritability or angry outbursts, reckless or self-destructive behaviour, hypervigilance, an exaggerated startle response, problems with concentration and sleep disturbance.

Criteria B through E represent the symptoms of PTSD, and in each case, there should be evidence that the symptom began, or at least worsened, following the trauma. In these symptoms, you'll find the echoes of other OSIs, including depression or anxiety disorders. Substance abuse can be used to self-medicate and mask many of these symptoms. Those who have strong reactions to events that don't meet criterion A might be diagnosed as having an adjustment disorder. All of these are common OSIs.

● (1550)

For our purposes, there is one more important criterion for PTSD. Criterion H says that these symptoms must not be attributable to the physiological effects of a substance such as mefloquine.

That final criterion is pretty much universal in DSM-5. It is found among the diagnostic criteria for most disorders. It's so common that it's actually easily overlooked. When you're dealing with psychological trauma, it's rare to see someone in clinical practice whose symptoms can be attributable solely to the effects of a substance. In fact, before I had heard of mefloquine I was not aware of any substance that could mimic PTSD.

This substance was often prescribed in proximity to a traumatic event. When we look at the symptoms of quinism, we're going to see that they mimic many of the symptoms of PTSD and other OSIs.

According to the work of Dr. Nevin, the adverse effects of mefloquine can include the following psychiatric symptoms: anxiety; depression; panic attacks; severe mood swings; agitation; aggression; restlessness; mania, such as racing thoughts, irritability, paranoia or excessive goal-driven behaviour or euphoria; psychosis, including paranoia, delusions and hallucinations; dissociative symptoms, such as derealization and depersonalization; or sleep disturbance, including terrifying, intense nightmares or sleep paralysis, an experience like being awake in a body that will not move, often accompanied with a terrifying hallucination.

With varying degrees of frequency, all of these symptoms can and do present as sequelae to exposure to psychological trauma. They also represent the prodromal presentation of mefloquine, those symptoms that may appear with initial toxicity or as a side effect, an adverse reaction to the drug. They may also persist beyond the application of the drug, in some cases for years.

I am thinking of two veterans I have worked with. Both meet criterion A for PTSD and both present with an unusual feature that I rarely see in OSIs: hallucinations. Only one was exposed to mefloquine, and he experienced the full prodromal reaction—nights of severe terror punctuated with what seemed to be auditory hallucinations of animals screaming in the forest around him. Today he suffers from tinnitus and a persistent auditory hallucination consisting of mumbling voices, along with other more typical symptoms such as irritability, anxiety and mood disturbance.

It was years after his initial diagnosis of PTSD that the issue of mefloquine came up, and that was the first time I had ever heard of the word. I only heard about it because he brought it to my attention. As we've seen, PTSD should not be diagnosed when the symptoms can be explained by the impact of a substance such as mefloquine. Does this mean that his diagnosis is not accurate? Frankly, it's

possible, but I think the question may be more complex than a simple yes or no answer.

One of the challenges in clarifying the diagnostic conundrum is that veterans may not always be able to accurately reconstruct the order in which events occurred, particularly such vague events as the emergence of a psychological symptom.

Let's consider a possible timeline. A soldier is deployed overseas on his first tour of duty. There are no prior exposures to traumas. To prevent the malaria, the soldier receives a course of mefloquine. He and his buddies joke about how rough their Friday nights are after they receive their weekly dose of the drug, but they're either not aware of the risks of continuing to take it or they dutifully push through. Almost immediately after treatment, the soldier is exposed to a war zone, with all the horrors that entails. When the subsequent symptoms arise and persist, are they solely due to the mefloquine or are they solely due to the exposure to the trauma?

Soldiers are not always the greatest historians. After years of pushing their emotions to the side and ignoring discomfort, it can be difficult for them to remember precisely when a symptom arose. In the midst of a war zone it's only natural to be anxious, vigilant and irritable. Years may pass before the psychological injury is assessed. How are we to say whether the symptoms are due to quinism or to trauma?

There are some symptoms more neurological in nature that might be helpful, things such as difficulty with balance, vision, vertigo or tinnitus, which do not typically present solely as the result of PTSD. Again, though, these have their own confounding variables, including the impact of blast injuries and concussions.

● (1555)

Of course, if the mefloquine was not taken on the first tour, but after the soldier was already exposed to chronic trauma, then exposure to mefloquine may or may not account for subsequent symptoms.

The interaction between quinism and OSIs may prove to be quite complex. Consider, for example, recent research on how MDMA, or ecstasy, can help veterans overcome traumatic memories. In a nutshell, a drug that induces feelings of warmth and compassion is paired with a traumatic memory, which helps to settle the anxiety provoked by that memory, with lasting effects.

Is it not possible that quinism does the opposite—a drug that provokes a chronic state of anxiety, when paired with a traumatic event, leads to a greater likelihood of PTSD?

In some tragic circumstances, there may be another source of trauma. Actions taken while under the influence of the drug could lead to horrific moral injuries. I understand that soldiers in the Airborne Regiment in Somalia were given mefloquine. Imagine being such a soldier. You might find yourself asking how you came to violate your values and your duty by acting violently and illegally. Though it may not meet criterion A, perhaps the reaction to the drug is a kind of trauma in itself. Is there anything more traumatic than having your very self, including your values and your sense of reality, stripped away?

Our understanding of quinism is in its infancy. We have yet to grapple with its impact on the diagnosis, misdiagnosis, overlapping diagnosis or exacerbation of operational stress injuries, in part because too few of us are sufficiently aware of the need to screen for mefloquine exposure and subsequent reactions to that exposure.

In our ignorance, we're also at risk of creating sanctuary traumas. A sanctuary trauma occurs when someone expects to find help and support, but instead experiences invalidation and rejection. Research shows that the experience of such injustice can have a severe impact on recovery from physical and psychological injuries.

Therefore, it's imperative that the veterans coming forward with stories of quinism have access to well-informed case managers and clinicians, and that means we must disseminate what we know and do the research necessary to learn more, so that we know best how to assess and treat this complex condition.

Certainly, we need to start asking the questions, both as clinicians and researchers. I am grateful that the ministry is taking the questions that need to be asked. I hope that I've been of some help to you in that quest.

Thank you for your time.

• (1600)

The Chair: Thank you.

We have Ms. Wagantall for six minutes.

Mrs. Cathay Wagantall (Yorkton—Melville, CPC): Thank you, Chair.

Thank you, Dr. Douglas and Dr. Suter, for being here today. It means a great deal to us to have you both here. You have significant experience that I think is making us very aware that we do need to pursue this further.

On that, the surgeon general's report on mefloquine in conclusion number seven stated, "We did not identify any evidence (that met our inclusion criteria) addressing potential long term adverse effects of mefloquine"; yet in contrast, in 2014 the European Medicines Agency concluded, "There is enough evidence...supporting a causal relationship between mefloquine and the occurrence of long lasting and even persistent neuropsychiatric side effects."

This to me just shows the need for more research. How do each of you reconcile two such very different reports being presented to us?

Dr. Jonathan Douglas: I know I'm aware of it. I believe that both Australia and the U.K. have identified mefloquine quite positively as a significant risk factor for neuropsychiatric disorders.

I would tend to agree that the research is in its infancy, as I said. Clearly more needs to be done, but I think if we listen to the veterans and the stories that they're telling us, what we learn is that there is this very significant reaction. It's not simply exposure to mefloquine, and perhaps that's the confounding variable here. If you only look at whether the veteran was exposed, then that might wash out in the statistics. If you look at the veterans who have developed that reaction, the initial reaction to taking the mefloquine, that's going to predict the longer term impact. Perhaps that's the piece that has been confusing here.

Mrs. Cathay Wagantall: It's choosing to home in specifically on those who indicate that they had a severe reaction.

Dr. Jonathan Douglas: Exactly.

Mrs. Cathay Wagantall: What about you, Dr. Suter? You've indicated that you've worked with individuals dealing with these issues of visual and brain injuries. What is your take from what you've experienced with the effects of mefloquine?

Dr. Penelope Suter: First of all, I don't believe that there's a very good awareness about mefloquine in my profession. There are a number of neuro-optometrists who have worked with patients with mefloquine toxicity. I have a few cases, but in calling my colleagues in preparation for today, what I found is that the information is disappearing from the records. A lot of the people who we saw, we saw back in 2011 and 2012 in the U.S., and those records are being purged by doctors.

We have not done a good job of getting the visual consequences out into the literature. It's been not a small issue for the people who are involved, but it's a smallish issue in terms of the overall look at brain injury.

Mrs. Cathay Wagantall: Okay.

Dr. Penelope Suter: Optometry is notoriously poor at getting the research out because we are traditionally a clinical profession, I think, so—

Mrs. Cathay Wagantall: All right. Sorry.

Dr. Penelope Suter: No, go ahead.

Mrs. Cathay Wagantall: I just want to ask one more question.

Within the Canadian Armed Forces, mefloquine accounts for less than 5% of malarial prevention prescriptions now. Since June 2017, mefloquine has been recommended only when members requested it themselves. I believe this, to a large extent, is due to the work that we've been able to do to date in Canada to draw better awareness to the impacts of this drug.

It's only used when they request it or when other drugs aren't able to be used. That sounds very good to me, but there's a huge gap in dealing with those who have suffered in the past when they were required to take this drug within Canada.

Dr. Douglas, what would you say to this? This is a new directive for future use but what about other measures in regard to Canadian Armed Forces members and veterans who were required to take it, who are facing injuries, and nothing has been done significantly by anyone to draw their attention to this?

•(1605)

Dr. Jonathan Douglas: I think it's a very significant issue and I think it has a relatively simple solution, which is to reach out to veterans and simply ask them if they have had an anti-malarial drug in the past. Was it a weekly dosage one? That would tend to lean it towards having been mefloquine. Did they have any kind of significant reactions to that drug at the time?

From what I've heard, it's a fairly common reaction. I know the research is estimating that somewhere around 14% of people exposed to mefloquine may have that prodromal reaction.

It may very well be that a fair number of people have been missed. They may not be connecting something like an ongoing psychotic reaction, for example, to military service. It might be helpful for them to receive that information.

The Chair: Thank you.

Mr. Eyolfson.

Mr. Doug Eyolfson (Charleswood—St. James—Assiniboia—Headingley, Lib.): Thank you, Mr. Chair.

Thank you both for coming.

Dr. Suter, you spoke about the alterations in perceptions that you can get when you have any problem with the brain stem, and I understand something about the neuro-pathways. Are you aware of what the evidence is that there are specific effects on the brain stem by mefloquine that are causing these changes?

Dr. Penelope Suter: The research that I looked at was that there are micro-lesions that do not show up on imaging that can occur with quinolone use.

Truthfully, again, as I said, I was asked to come because I have some cases of mefloquine toxicity in my practice and because I have expertise in the brain stem brain injury, but—

Mr. Doug Eyolfson: I'm sorry to cut you off. I have very little time.

What was the diagnostic criteria to say that these patients had mefloquine toxicity?

Dr. Penelope Suter: They came in previously diagnosed by other doctors. I believe they were mainly diagnosed by the neuro-otologists who saw them prior to their seeing us.

Mr. Doug Eyolfson: Okay. You talked about a cohort of patients or incidents that had happened. You said these records were purged by doctors. Could you clarify that statement?

Dr. Penelope Suter: These records, and I think—

Mr. Doug Eyolfson: What records were those, again, just so I'm clear?

Dr. Penelope Suter: They were the clinical patient files.

Mr. Doug Eyolfson: These were purged.

Dr. Penelope Suter: In the United States you only have to keep records for clinical patient files for three years after you see the patient if they're an adult. It's standard procedure to purge records after three or four years.

Mr. Doug Eyolfson: Okay, so this wasn't a deliberate purging of records for—

Dr. Penelope Suter: No, I'm sorry.

Mr. Doug Eyolfson: It was just that these records were deleted. I'm not sure purged is the right word when you get rid of records as per protocol after a number of years.

Dr. Penelope Suter: I apologize for not choosing my words more carefully.

Mr. Doug Eyolfson: Thank you. I just wanted to clarify what that was about.

Dr. Douglas, you mentioned, and we've heard this from some people, that PTSD can be diagnosed when in fact it's mefloquine toxicity.

How do you tell the difference? How do you know it isn't PTSD when a patient comes in?

Dr. Jonathan Douglas: I know that in this area, there's been a lot of talk about the concept that this is misdiagnosed. To be honest, I'm not completely convinced of that because, as I said, mefloquine is often used in a context in which there are exposures to traumas. We look at the diagnosis of PTSD. We have to be able to say that it's not due to the effects of a medication. Certainly in the past that question's not even been asked, so I think there may very well be such cases and that's going to be quite challenging.

The reality is that they're often given at the same time. If we look at the criteria for PTSD—here is the event and things got worse following it—it's going to be very challenging to separate these two things, in my opinion.

I think it's a complex picture, and it's not really necessarily so much one of misdiagnosis but it could very well be one of mefloquine making the psychological reactions to trauma significantly worse. It can be much more complex than just either-or.

•(1610)

Mr. Doug Eyolfson: Thank you.

Are you aware of any data comparing the diagnosis of PTSD in combat veterans to those who have had mefloquine and those who haven't?

Dr. Jonathan Douglas: Yes, I am. Dr. Nevin who will be coming, I believe on May 1, will be able to speak to that, but some of the research that I can recall showed something like close to 180% more diagnosis of PTSD in those who were mefloquine-exposed with a prodromal reaction.

Mr. Doug Eyolfson: Okay.

Would you be able to forward us the actual references, the papers, that state that?

Dr. Jonathan Douglas: Certainly.

Mr. Doug Eyolfson: Thank you very much. I appreciate that.

Dr. Jonathan Douglas: You can follow up with Dr. Nevin, as well.

Mr. Doug Eyolfson: Sure. All right. Thank you very much.

That's all I have. Thank you.

The Chair: Ms. Blaney.

Ms. Rachel Blaney (North Island—Powell River, NDP): Thank you both for being here today.

One of the things I've heard loud and clear through this process is that research is needed, and how much we don't know is the issue at hand.

Could I ask both of you to tell us what research is specifically needed in Canada?

Dr. Jonathan Douglas: Since it's a Canadian question, I guess I'll take it.

Number one, how many soldiers have been exposed? They spoke about the issue of clinical records in clinical practice being purged. It's routine in the military that I learn of people whose medical records are missing or inadequate. In some cases, they've been redacted. It's very difficult. Plus there is simply the reality that a public health medication such as mefloquine may not even appear in anybody's medical records. The records themselves may not be a very effective strategy for identifying who was exposed. The records may simply not be there.

About the only thing we can do is ask veterans. I think we need to ask them whether they were exposed to this medication or a similar medication and whether they had that reaction. From there, we can start to get a sense of how many veterans have been so exposed. From there, we can look at the comparative rates in the presentation and the diagnoses of psychological disabilities, and we'll be able to start understanding a little bit more.

Finally, I think we need to really look at issues of treatment. Dr. Suter has some great ideas about some avenues for treatment that are not very well understood and not very well known. We need to really explore any number of options that might lead to some more effective treatment. Medications might be an answer, but they might also not be an answer if they are a complicating factor with these kinds of brain disorders in the context of psychiatric medications. They may not work the way they ordinarily would in a brain that has not been exposed to mefloquine.

It's going to be complex and a lot of research needs to be done.

Ms. Rachel Blaney: You talked earlier, Dr. Douglas, about the screening process. I'm just wondering if you could talk to us about mefloquine. Is there a screening process? How do you know? You talked earlier about the fact that it's not necessarily in the records, and you also spoke about something that I think is really important, which is the lack of awareness.

Dr. Jonathan Douglas: Right.

Ms. Rachel Blaney: You learned about this because one of your patients informed you—

Dr. Jonathan Douglas: Yes.

Ms. Rachel Blaney: I guess I'm asking two questions. What is the screening process, and in terms of awareness—and both of you have

spoken about awareness—how do we do that so that we're making people more aware that, when they're talking to veterans, these are the important questions to ask?

• (1615)

Dr. Jonathan Douglas: Again Dr. Nevin has written papers on the screening, and it's really quite simple: Have you been exposed to this medication, and did you have this reaction to it? It's as simple as that in terms of understanding. Now we're identifying those who had that prodromal reaction—which is to say the symptoms that appeared when they were on the medication—which then sets them at risk of having persistent reactions.

Ms. Rachel Blaney: Okay.

For the awareness piece, how do we build awareness so that people know to ask that question?

Dr. Jonathan Douglas: I think you're doing it right now. I think paying attention to the issue is an important thing. We need to get the information out to veterans. We need to get the information out to those clinicians who work with Veterans Affairs and communicate that way.

If you look at veterans affairs in the United States, the VA, they do a pretty good job of communicating constantly with the clinicians who work with Veterans Health Administration.

In the case of Veterans Affairs Canada, I don't see a lot of communication going out from VAC to the clinicians on the street, and that can be a bit of a challenge. We're sort of training ourselves in a sense, and of course, that leaves a lot of gaps. Having even some form of newsletter coming from Veterans Affairs to the providers would be a very effective strategy for communicating to those who are on the front lines.

Ms. Rachel Blaney: Thank you. I think that's really important.

I have one last question, and I don't even know if it's a question as much as a statement, but I would like to hear your response. What I understand from all of this is that we don't even know how many veterans have taken mefloquine. We don't even have the numbers.

Dr. Jonathan Douglas: To the best of my knowledge, we don't. No.

Ms. Rachel Blaney: Okay. How do we even start? As was said earlier, it's this cohort—and over a period of time it has lessened—that we need to care for in a respectful way, but we don't even know who they are.

Dr. Jonathan Douglas: Yes.

Dr. Nevin suggests that Somalia forward is the era he's looking at, at least with respect to American veterans. I'm not sure if that would apply directly to Canada or not, but it sounds about right. If we started from 1990 forward...? Honestly, I don't know when the drug was released. I don't know when it started getting used by veterans, or soldiers at the time. There are a lot of question marks in my own mind certainly.

Ms. Rachel Blaney: Thank you so much.

The Chair: Mr. Bratina.

Mr. Bob Bratina (Hamilton East—Stoney Creek, Lib.): Thank you both for joining us.

Dr. Suter, your discussion on the optic nerve hit a nerve with me, especially with the remarkable numbers—with around 70% of all sensory input fibres to the brain beginning in the eye.

Is that correct?

Dr. Penelope Suter: That's correct.

Mr. Bob Bratina: That's as opposed to every other source in the brain.

In your connection with veterans and so on, is there anything in a normal examination that ever leads you to suspect there are issues beyond the ones that you are treating for?

Dr. Penelope Suter: I kind of owe an apology to Dr. Douglas and his colleagues in that I made it sound as if psych is not a huge part of treatment for the veterans or anybody with a brain injury. I think it's because psych is a place where people immediately turn. I wanted to emphasize what I think is being missed more so.

I really feel strongly that Dr. Douglas's mention about needing strong case management in these cases is part of the solution. It would be a “down the road” step in terms of getting the information we need to find out about mefloquine toxicity—how it is intertwined and how much of it is intertwined with PTSD or other psych diagnoses that go along with mefloquine toxicity versus straight neurologic or neuro-optometric symptoms that aren't being masked. When I'm working with patients with brain injuries, veterans or not—most of mine are not veterans—it's really important to have a multidisciplinary approach. In fact, our book is titled *Vision Rehabilitation: Multidisciplinary Care of the Patient Following Brain Injury*.

• (1620)

Mr. Bob Bratina: I see.

Unlike my colleague, I'm not a doctor. When I hear you talk about micro-lesions that don't show up in brain scans, let me ask you this: How do they show up? How do you know that there are micro-lesions there that you can't see?

Sorry for sounding simple on that, but it's not my field.

Dr. Penelope Suter: No, not at all.

Again, I'm not a mefloquine toxicity expert. The research that I saw was actually with rat studies. They just sectioned the brain stem so that they could see them under the microscope. I don't know if there is a way to tell in a human being if that is occurring. However, the symptoms are the signs. Not the symptoms...well, it's both. Vestibular neurotoxicity and the visual deficits that we are very familiar with from other brain stem injury in humans all point to brain stem lesions.

Mr. Bob Bratina: I get it. Thank you.

Dr. Douglas, on your point of knowing how many did or didn't, whenever I now meet with veterans, the first thing I ask them is where they served. For instance, I just came back from Africa and I had to take a malarial drug. If they say Somalia or some African location—others say India, Afghanistan and so on—I ask if they took the drug.

I would assume there is a way of accumulating how many of our soldiers were in malarial postings.

Dr. Jonathan Douglas: Yes, do it by asking them. Absolutely.

Mr. Bob Bratina: Do you think it would be sufficient for Veterans Affairs to acknowledge the relationship between the mental health problem that the veteran is having and the military service?

We're dealing with veterans now, not active members.

Dr. Jonathan Douglas: Right.

Mr. Bob Bratina: We want to do the best for them, so we want to accumulate our knowledge of the issues they are dealing with.

Is it necessary to bring the mefloquine into that discussion at the veteran's level, in terms of the benefits they might potentially receive?

Dr. Jonathan Douglas: My understanding is that Veterans Affairs takes an approach that basically says, “Is there a diagnosable condition? Is it attributable to military service? To what degree is their impairment arising from that?”

I think what I gather, reading between the lines of Dr. Nevin's research, is that the issue may be somewhat different in the United States, where they might put more emphasis on it having to be PTSD. If it's a generalized anxiety disorder, they're not going to cover that. I don't think Veterans Affairs is so fine-tuned about it. They just want to know that there's a link to military service. In that regard, I think you're correct. With respect to treatment, it's quite a different matter. From there, I think we really have to train the practitioners and ensure there is some kind of a knowledge of how to diagnose this.

There may also be the issue of people who have never served in a traumatic situation, and they are very harshly judged by their peers: “Nothing ever happened to that guy. How come he's seeking out a disability pension?” Such people may be shamed into silence and may not be seeking disability pensions.

I think it's very important that we be able to acknowledge that it's not just a general disability. We also have to be reaching out to these people and letting them know about the benefits. They may be suffering from something that is service related even in the absence of having been exposed to a specific trauma.

• (1625)

Mr. Bob Bratina: They may be in a theatre but not in combat but still expressing....

Dr. Jonathan Douglas: Right, exactly.

The Chair: Thank you.

Mr. Samson.

Mr. Darrell Samson (Sackville—Preston—Chezzetcook, Lib.): Thank you.

Thank you for both for your presentations today. It's very helpful as we move forward in this study.

I'll start with Dr. Suter.

You made reference at the beginning of your presentation to there being no experts out there for mefloquine. Can you expand on that a little? I believe it's important as we move forward.

Dr. Penelope Suter: I believe what I said was that there are no experts out there on mefloquine toxicity in vision.

With regard to the visual consequences, the brain stem is an area where the vestibular system coordinates with the visual system in terms of keeping us balanced and helping us understand what's around us, keeping us oriented. I do not believe we have anybody who has had enough cases that they have put out the information in terms of the visual consequences.

I think that Dr. Nevin has done an amazing job of getting the vestibular consequences published and out there. He has also mentioned.... Really, he has been pushing to get people to neuro-optometry because he recognizes that it's vestibular and visual.

That was what I meant. The people who are working with these patients in vision have not, I think, looked at enough cases nor published those cases.

Mr. Darrell Samson: Is there an area we should focus on and research? Is there a recommendation that you would make?

Dr. Penelope Suter: Yes, there are particular symptoms and signs that have shown up in the patients we see. A lot of it has to do with coordinating with the vestibular system. For instance, the patients we see with mefloquine toxicity that I'm aware of tend to have what we call vertical phorias, or the two eyes want to be pointed a little bit up and down instead of on the same plane. That makes horizontal surfaces ambiguous to your brain, because your two eyes are not giving you the same information. Those vertical phorias in brain stem injury tend to change when you look from left to right, so you get different information about horizontal surfaces as you move your eyes. Vertical phorias seem to be an issue. The convergence insufficiency, where you are having trouble pulling your eyes inward as is necessary for reading, tends to be an issue. It's also a brain stem-related function.

Then, of course, there's coordinating the vestibular system—for instance, one of my patients had difficulty moving his eyes. When he moved his eyes from looking far to looking near, he would go into a tumbling vertigo, so we were trying to figure that out. It turned out that he had both the vestibular neuropathy and a vertical phoria that changed from distance to near, such that one eye was up at distance and the other eye was up at near. There was no opportunity for his visual system to stabilize the vestibular system.

Mr. Darrell Samson: Thank you.

Dr. Douglas, it is nice to see you again. I think we all agree around the table that tracking is probably the most challenging thing we need to be doing more of, so that we have the facts and we can draw on those facts and then find solutions to the issues on the table. I think we can put systems together to track; there is no question about that.

When the other countries like Australia and...?

•(1630)

Dr. Jonathan Douglas: The U.K.

Mr. Darrell Samson: Yes, it's the U.K. They have done some research and they are saying that there are some links, but I don't get the direct link. They are saying that there are possibilities but it's not directly PTSD. Can you expand on that? When I look at those studies it's not as clear as night and day that it's directly an effect.

Dr. Jonathan Douglas: Yes. As I say, unfortunately, I'm really not an expert. I would direct that question to Dr. Nevin. I think he might be much more familiar with it than I would be, but it is my understanding that essentially what it boils down to is this: Those who are exposed to mefloquine and have had that prodromal reaction to mefloquine are substantially more likely to be diagnosed with a psychiatric disability.

Mr. Darrell Samson: But we don't know what numbers that is based on because we're not doing the tracking.

Dr. Jonathan Douglas: In Canada we're not doing the tracking, no.

Mr. Darrell Samson: No, not as much as we....

Dr. Jonathan Douglas: Exactly.

Mr. Darrell Samson: Okay. That's all from me.

The Chair: Mr. Kitchen.

Mr. Robert Kitchen (Souris—Moose Mountain, CPC): Thank you both for being here today. I've learned something new because I was not aware of neuro-optometry, so I appreciate that.

I could spend hours talking with you, Dr. Suter, about many things, but I'm limited on time so I will try to be as quick as I can.

We talked about quinolones, basically, dealing with their having caused brain stem injuries. We know that there are 12 cranial nerves and basically 10 of them come from the brain stem and two of them don't. As for the oculomotor nerve—and I'm assuming that's where the interaction between vision, which you've been looking at, and the oculomotor disturbances is—I'm wondering if you could expand a bit more on that for us.

Dr. Penelope Suter: In those cranial nerves that are coming off the brain stem, the information is kind of flowing from the bottom. The eighth cranial nerve is your vestibular nucleus. Then the information comes up to the sixth, the fourth and the third, all of which involve coordinating your eye muscles. The vestibular system tells us where our head is going so that the information then moves up the brain stem so that we can coordinate head and eye movements and keep our fixation stable, even though our head is moving. I think that is a huge part of what is happening here, that you're ending up with interruptions in that pathway.

Mr. Robert Kitchen: When you're seeing patients who have been on mefloquine, how are you testing it? What are you looking for when you do this with that specific patient?

Dr. Penelope Suter: With any brain injury patient, we are looking very carefully at eye alignment. With the traditional eye exam, you don't really look at eye alignment very carefully. If they're not complaining of double vision, then you don't test out the fine details.

There are techniques whereby you separate the vision from the two eyes. You have one eye seeing a line and one eye seeing a line and you just say, "Tell me when it lines up." You can measure very accurately what the misalignment is in all kinds of different fields of gaze. We usually measure nine fields of gaze, because it changes in nine fields of gaze.

There are, then, instruments that are simple and easy to use, which any practitioner can use. This might be something that would be good to make standard for your optometrists or your vision specialists who are testing veterans.

Mr. Robert Kitchen: Okay, thank you.

I think we've all heard and you both have indicated that the reality is that we need to make certain we're doing the proper diagnosis, whether it's of PTSD or of mefloquine toxicity. That's ultimately what we're looking at—what diagnoses we need. Obviously we need more research along those lines.

On that note—and Dr. Douglas, you touched a little bit on this when you pointed out to us the criteria—when we're looking at the criteria, and particularly when you talked about someone being exposed to an event, if you were exposed to that event and you had other factors on top of it, what would be the potential that we could see a greater reaction, greater responses?

Dr. Jonathan Douglas: I think the potential is certainly there, absolutely. For example, PTSD tends to be cumulative, so if you have more and more exposures to trauma, you can absorb so many and then you'll get the one that breaks the camel's back. Obviously there are multiple factors. Life at home can add more stress and then make PTSD more likely and lead to a stronger reaction. As I said, I think something like mefloquine could very well make it more likely that someone's going to have a traumatic reaction to a given event.

• (1635)

Mr. Robert Kitchen: Are you aware of any specific medications that might react with mefloquine?

Dr. Jonathan Douglas: I'm not aware. That would be outside of my purview, for sure.

Mr. Robert Kitchen: What about strength of dosage?

Dr. Jonathan Douglas: That could also be an issue, but again, I'm not the right person for that question.

Mr. Robert Kitchen: But those would be things worthwhile researching, isn't that correct?

Dr. Jonathan Douglas: Absolutely, yes.

Mr. Robert Kitchen: Definitely we would want to know this. I see it when I travel overseas. We see it not only in our military population, but in the civilian population who travel overseas. Often our doctors are prescribing the first thing that comes along, and it's mefloquine.

In fact, when I went to Pakistan, that was the first medication my physician offered me. Knowing what I know, I chose doxycycline, but the reality is that not everybody knows that information. It has a big impact for them. We hear of civilians travelling in Asia, especially the Australians, who say.... When my son was overseas in Thailand, and he said he was taking it, they told him to get off it, because they're aware of it but Canadians aren't.

Dr. Jonathan Douglas: Yes, exactly.

Mr. Robert Kitchen: Your comments about awareness are, I think, appropriate. Not only VAC but other agencies should be notifying not only our physicians but our pharmacists, because ultimately our pharmacists....

Dr. Jonathan Douglas: Yes.

Mr. Robert Kitchen: Are you aware of how much training a pharmacist might be able to get in this area?

Dr. Jonathan Douglas: I have no awareness.

Mr. Robert Kitchen: That's something we need to look at, because the pharmacists are the ones giving it out. If all of a sudden it's 100 milligrams that is being asked for and they don't have that pill, do they go to different strengths, different levels?

Dr. Jonathan Douglas: Yes, I agree that this is absolutely an issue that applies to civilians as well.

The Chair: Thank you.

Mr. Chen.

Mr. Shaun Chen (Scarborough North, Lib.): Thank you, Mr. Chair. I want to thank Dr. Douglas and Dr. Suter for joining us today and providing their testimony.

I want to begin by reading from the 2014 report by the European Medicines Agency. It stated, "There is enough evidence from the presented drug safety reports, the submitted literature report and the FDA assessment report supporting a causal relationship between mefloquine and the occurrence of long lasting and even persistent neuropsychiatric side effects." Certainly, both of our witnesses provided much testimony today.

Within our Canadian Armed Forces, currently, mefloquine is used for less than 5% of malaria prevention prescriptions. From my understanding, since June 2017, it is only prescribed to members of the Canadian Armed Forces when it is specifically requested, or when other options are deemed a contraindication. What is your thinking, what is your assessment of how the armed forces is currently prescribing this drug?

Dr. Jonathan Douglas: It's certainly a good idea to encourage different medications over mefloquine. All of the quinine-based drugs carry at least some risk. Mefloquine's risk, from what I gather, seems to be unique, but none of them are entirely without some risk. I would be concerned about people requesting mefloquine specifically and I'd be curious as to know why. Are people getting the informed consent they need to make a decision about whether or not mefloquine should be the drug of choice here? What's behind someone saying, "I'd like to take mefloquine"? Based on what I know about it, it seems to be a fairly surprising choice.

Mr. Shaun Chen: That's an excellent question in terms of why somebody would ask specifically for mefloquine. As far as I can see, there's no literature to look at that question. That would certainly be a good research question to put out there.

You mentioned other drugs, but that they also carry risk. As you mentioned earlier, there could be underlying conditions or a buildup of different events in, for example, a soldier's career where he or she actually hits that point where they break the camel's back and they reach that critical point of PTSD.

With respect to the other drugs, can you speak to the neurological or psychiatric conditions as well as experiences that are potentially traumatic? What are the potential risks with other types of medications that are used for malaria?

• (1640)

Dr. Jonathan Douglas: I'm afraid I simply can't give you an informed answer. I'm the wrong professional for that. I'm not sufficiently aware of other medications and their risks.

Mr. Shaun Chen: Dr. Suter, do you have anything to add?

Dr. Penelope Suter: I know there are other chloroquinines that are used routinely for things like rheumatoid arthritis or autoimmune disorders. What we look at there is macular toxicity. With some of those drugs, you've never heard of psychiatric issues with them. Mefloquine does seem to be somewhat unique. It almost sounds like anything would be safer, truthfully.

Mr. Shaun Chen: I know we've talked about the research questions you put out there of how many soldiers have been exposed. What do you think would be some of the broader research questions, because these drugs are used by folks who are outside of the Canadian Armed Forces?

What type of research do you think would be very helpful for us, as a community, to move forward on this issue in the interest of public safety?

Dr. Jonathan Douglas: It's an excellent question. I think it's a much more challenging one to identify people in the community who may have been exposed to the medication.

Perhaps pharmaceutical records might lead to people who have received mefloquine in the past. Again, I think we might be up against the challenge of how long records are kept. I know in my own field it's 10 years for keeping records. I'm not sure if that would apply. That's from my own college of psychologists, so I'm not sure how long pharmaceutical records would be held. I suspect a lot of the people who are exposed to mefloquine probably took it as long as 15 or 20 years ago.

It would be interesting to correlate the rates of psychiatric disability among those who have been so exposed perhaps through census or something like that, where you might ask such research questions. Did you ever take an anti-malarial drug? We could correlate that with the reactions, because it's not simply exposure. It's exposure plus that reaction. Then correlate that with subsequent psychological or psychiatric disability.

Mr. Shaun Chen: Thank you.

The Chair: Ms. Wagantall.

Mrs. Cathay Wagantall: Thank you, Chair.

Dr. Douglas, in your bio it states that you have expertise in sanctuary trauma, which is the psychological mechanism by which invalidation, dismissal and betrayal by authorities not only

perpetuates both physical and psychological injuries but actually impedes healing and makes the injury substantially worse.

As we've been studying a lot of issues around veterans, I have sensed over and over again that a great deal of the added stress, illness and trauma is due to having to try to prove that they are ill and this whole question of benefit of the doubt.

Could you speak to that a little as to the issues around mefloquine? There's a lot of information out there. We know it's there. We know we need more study, but in the meantime, what is your sense on this specifically for veterans who were forced to use this drug, had no recourse and are suffering now?

Dr. Jonathan Douglas: The issue of sanctuary trauma are very important to me. I work with Badge of Life Canada, an organization devoted to helping police officers and corrections officers. I often speak on this topic at considerable length. It's almost hard for me to speak on it shortly, but I will do my best.

• (1645)

Mrs. Cathay Wagantall: There's no problem; you have time.

Dr. Jonathan Douglas: It has a great deal of research behind it. Again, it's not a concept that is very well understood, but the idea is that the level of injustice somebody experiences subsequent to an injury predicts very strongly the duration of that disability. It predicts that, independent of the severity of the physical injury that occurs. It applies to both psychological and physical illnesses.

I have absolutely no doubt that it's a very common reaction really in anyone who's up against that system that says, "Prove to me you're sick." That person's going to experience that at some point. Some people are going to be embittered by that experience and, as a result of that, their injuries are going to get worse.

It's difficult to balance. We need to have good, solid information when we give somebody a disability pension. We don't want to give people disability pensions simply because they ask for them, obviously.

Mrs. Cathay Wagantall: Absolutely.

Dr. Jonathan Douglas: But we also have to recognize that putting up too many barriers actually makes the disability worse, which increases the costs to the system, never mind the personal costs to the individual who's suffering.

Mrs. Cathay Wagantall: Exactly.

Dr. Jonathan Douglas: I think when it comes to dealing with mefloquine, what we have to be able to do is to move quickly to a place where we can offer some kind of validation that we get it, we're hearing it, we're paying attention to it and we're listening to it. That's number one.

Number two, it's not really true that this thing is undiagnosable at this point. It really can be diagnosed. If we say they can't be diagnosed with PTSD because of the exclusion in criterion H regarding its being attributable to a medication, if we say that it's not PTSD, then, okay, it's a trauma-related disorder, it's an anxiety disorder or it's a mood disorder. We can come up with other labels. There's always a label for someone who's suffering psychologically and has a significant impairment. That's going to be a diagnosable condition of one form or another.

Mrs. Cathay Wagantall: On that note, then, we know that Health Canada quietly upgraded the label to be more visible, to give more attention to the fact that if any of these conditions are happening to you, you must quit using this drug.

Dr. Jonathan Douglas: Right.

Mrs. Cathay Wagantall: So that's an improvement, but have either of you received any training or literature from Health Canada indicating that mefloquine poisoning is a condition that should be screened for?

Dr. Jonathan Douglas: I wouldn't, as I don't prescribe.

Mrs. Cathay Wagantall: What about yourself, Dr. Suter?

Dr. Penelope Suter: I'm actually from the U.S.

Mrs. Cathay Wagantall: Oh, that's right. You can't help me there.

Dr. Penelope Suter: No, sorry.

Mrs. Cathay Wagantall: As far as our veterans are concerned, I know a lot of them have heard of these upgrades in announcements from the surgeon general and from Health Canada, yet there has been no communication whatsoever to the veterans themselves to try to deal with these issues.

Dr. Jonathan Douglas: Correct.

Mrs. Cathay Wagantall: From your perspective, again, that causes even greater duress because it creates even more of a wall. Then you talked about suicides.

I'm hearing over and over again from our veterans about the number of suicides taking place in Canada, due to illness and due to—they would say as well—such a heightened level of frustration.

Dr. Jonathan Douglas: Absolutely. In fact, this speaks again to the issue of what we should be researching. Mefloquine exposure with a prodromal reaction and risk of suicide, that's retrospective research that could be done, and it would certainly be very important to understand the potential impact that mefloquine may have had on veteran suicide.

The Chair: Thank you.

Ms. Blaney, you have three minutes.

Ms. Rachel Blaney: Thank you for speaking about the informed choice of taking mefloquine. We heard earlier about the 5%, or less than 5%.

What is the process that they're being asked to follow and are they being given the proper information before they make the decision to take mefloquine? Is that something that you would recommend that this committee look into?

Dr. Jonathan Douglas: Yes. I think that's a very significant issue and it goes much beyond simply mefloquine. It's the issue of a

soldier's right to consent to medical treatment, and it's a challenging one. We're sending people into an area where they may be exposed to certain diseases and we have these medications. We want to protect the soldiers—we have an obligation to protect the soldiers. Are they able to make an informed consent?

I'm not the expert here, but my understanding is that if you get ordered to take that drug, you take that drug. I know that in the United States, from what Dr. Nevin was writing, frequently the drug inserts that say to stop taking it if you're getting certain reactions were not being provided to soldiers, so the information was not being provided. Even if it were being provided, were they actually empowered to say, "I have to stop taking this"? These are very challenging issues when we're dealing with a captive population that may not have the same freedom of consent to a medical treatment as any other citizen would.

• (1650)

Ms. Rachel Blaney: Thank you. I think that's a really important part to consider.

You also talked about some veterans not disclosing because their experience is that this feels like what we think PTSD is but they weren't in active combat and they didn't see those things, so they wonder why they are having this reaction. I'm just curious about what you think about the education process to let people know that this could be why they're having that.

I also want to know, in that context, if you've ever worked with someone who was diagnosed with PTSD but later on found out that it was actually mefloquine toxicity, and figured out how to address the issue.

Dr. Jonathan Douglas: To date, I believe I've worked with three people who have been mefloquine exposed, two of whom had the prodromal reaction. One of them is a more recent one, so I was able to catch that and say what was going on there. The other one was the one who introduced me to the concept of mefloquine toxicity. In that particular case—I think that's sort of my standard—that fellow had been diagnosed some years before I'd ever heard the word.

In my opinion, the diagnosis of PTSD is not inaccurate in his situation, but we'd have to look at that case by case. We may very well have people out there who have been so identified, who are not actually suffering from PTSD. As I say, I think it's complex.

Ms. Rachel Blaney: It is complex and making sure people are getting the correct treatment is something that we should all be concerned about.

Dr. Jonathan Douglas: Absolutely. In terms of the treatment, certainly, I think the psychological treatment of anxiety, depression and these kinds of issues that people are presenting with are going to be beneficial. We're going to help people cope more effectively, regardless of the source of the anxiety.

It's not like that treatment is going to be wasted, but we might very well find that certain people are not responding as effectively to treatment as we might otherwise hope, and the mefloquine exposure and the reaction are in fact holding them back. What do we do with those people? I'm going to be sending them to a neuro-optometrist from now on.

What other options are there? We really do have to come up with some good answers for what we do with these people.

Ms. Rachel Blaney: That's right. Thank you so much.

The Chair: That ends our time for testimony today.

On behalf of the committee, I'd like to thank both of you for taking time out of your day to testify today.

That's the end of the meeting.

Dr. Jonathan Douglas: Thank you very much.

The Chair: We're adjourned.

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