

Close-minded Negativity by MS Doctors Does Not Equate to Scientific Skepticism

Ashton Embry, Sept 30th, 2010

Introduction

I read with great interest the Toronto Star article entitled “MS doctors attacked for their skepticism” which was published on September 24, 2010. I especially enjoyed the comments of the various MS doctors on their feelings and views on the reactions of persons with MS to CCSVI and to the doctors themselves. It would seem, by way of this article, the MS doctors (neurologists and researchers) are now trying to convince the media/public that they have been unfairly treated by some of their patients and that their only fault regarding CCSVI is to offer a “healthy” skeptical viewpoint.

In this essay, I would like to point out some of the information the MS doctors conveniently left out about their previous actions and why such actions were in a large part responsible for the hostility they have been experiencing. The main body of the text will be making the case that the MS doctors have reacted to the CCSVI concept and the potential value for MS of treating CCSVI, not with scientific skepticism, but with close-minded negativity. Finally, I’ll wrap-up with a few thoughts on why the discovery of CCSVI in persons with MS may have triggered such a reaction in the MS neurological community and how we might improve the situation.

Verbal Abuse of MS Neurologists

There is no doubt that Mark Freedman is the most reviled MS neurologist in the entire world and he has been trashed on numerous websites. I personally do not believe in *ad hominem* attacks and think there is no place in the world of science for such nasty, emotional responses. Mark has been subjected to many such attacks and a nice sampling is provided in the Star article. Mark naturally asks “*What did I do — to warrant this kind of aggressiveness from their part?*”. The answer to why he has been singled out for the most vicious attacks is rather straightforward.

In February, 2010, a few months after a CTV documentary brought the linkage of CCSVI and MS to the attention of the world, Mark publicly called CCSVI a hoax which is equivalent to saying that Dr Zamboni is a fraudster. This was the first mean-spirited, personal attack associated with CCSVI. So it is completely understandable that, once Mark opened the door to nasty name calling, he should not be surprised that persons with MS fired back at him with similar malicious taunts. I must admit I laughed out loud when I read Mark was called “*The King of All Turds*”. However, I don’t think any name that Mark has been called over the last 8 months is as outrageous or unethical as

publicly implying that a fellow medical researcher is a fraudster. His lack of an apology to Dr Zamboni has only made matters worse.

It is worth noting that MS neurologists continue to bad mouth interventional radiologists who are doing venous angioplasty for persons with MS. Dr David Spence of the University of Western Ontario has been the most spiteful and has publicly referred to IRs as unscrupulous charlatans, quacks and scoundrels. Recently Pat Coyle, a prominent neurologist from upstate New York, has called IRs “opportunists”. This ongoing bashing of interventional radiologists by neurologists, which started with Mark Freedman inferring Dr Zamboni is a fraud, only encourages the hateful comments from both sides of the CCSVI debate. However, I find it very hypocritical of the neurologists and MS researchers to pretend they are victims in this ugly and unprofessional name-calling war when they are really active participants.

Neurologists have undoubtedly been the target of verbal abuse by their patients (muttered or otherwise). This has occurred most often when they have not provided balanced, objective information on CCSVI and MS and have curtly dismissed the concept with a flippant remark. It is not hard to understand a negative reaction by the patients in such a scenario. I can readily imagine the frustration a person, who is spiralling into disability, must feel when their neurologist refuses to provide objective, non-judgmental information on a potential treatment which has seemingly helped many others. Such frustration and anger are magnified by the fact that the drug treatments strongly promoted by the neurologists have little, if any effect, on disease progression.

In summary, if neurologists want to have a positive reaction from their patients, they should consider providing solid, thorough, science-based information on CCSVI and MS. It would also help if they kept personal judgements and negativity to a minimum. I know for a fact that persons with MS who have experienced this relatively rare, yet reasonable, approach have not left their neurologist’s office in a huff.

Close-Minded Negativity or Healthy Skepticism

What is “healthy skepticism?”

The main theme of the Star article is that the MS doctors feel they have been maligned and misunderstood when they told their patients there is nothing to CCSVI and to not bother being tested, and definitely not treated, for the condition. They seem to think such a viewpoint represents “healthy” skepticism which is a key part of the scientific process.

I agree that a scientist must, above all, be a skeptical empiricist which means, when a hypothesis is made, the scientist should doubt its validity until enough scientific data are gathered to provide solid support for the hypothesis. The first ingredient of such

skepticism is to consider the theoretical likelihood of the hypothesis (rational criticism) and to actively pursue the compilation of available data so as to quickly assess its merits and to see if it meets the minimum requirement for further attention. If it appears that the hypothesis is reasonable from a theoretical point of view, and there are some solid data which support it, the next step is to promote the gathering of new data which will provide “acid tests” of the hypothesis’ validity.

I would stress that scientific skepticism of a new hypothesis does not entail a firm and unflinching belief that it is wrong until the acid tests eventually show otherwise. Skepticism involves open-mindedness which sees the hypothesis as possibly being valid. As part of this open-mindedness, it is essential to keep examining the available data in an objective fashion until the answer is clear.

My final remark is that science can never say anything is absolutely true or is absolutely wrong. It only provides probabilities such as the hypothesis is very likely correct or it is almost assuredly wrong. It is worth gathering data and keeping an open mind until either of these two end members is reached. Even then, new data may cause the question of validity to be reopened at any time.

Close-minded negativity

In sharp contrast to healthy skepticism, close-minded negativity is not useful in science. It basically entails a refusal to objectively appraise both the theoretical appeal and the available empirical data for a new hypothesis. In this approach the hypothesis is seen as definitely being wrong or perhaps even a hoax. You can usually recognize close-minded negativity by general comments like “everyone’s knows it is wrong”, “it’s simply impossible” and “there are no data which support it”.

Those who practice this approach also are against research which might properly test the hypothesis and will often focus on minor bits of information which are not in perfect accord with the hypothesis. Such data are then construed as “disproving” the hypothesis. One of the biggest giveaways is the studious avoidance by those practicing close-minded negativity of any data which support the hypothesis.

The current science of CCSVI and MS

The concept of a vascular component as part of the MS disease process has been considered for about 150 years because it is theoretically reasonable and there were indications that veins were involved in MS from the time it was recognized as a disease. However, the hypothesis was never taken seriously by most because only a small amount of circumstantial data was available. The new findings of Paolo Zamboni and others that significant vascular problems are highly associated with MS have caused the vascular hypothesis to be seriously re-examined. At this time it has not been proven

beyond any reasonable doubt one way or the other if CCSVI is an important factor in the MS disease process and that treating it will be of value. However, some aspects of the relationship between CCSVI and MS have been well established beyond a reasonable doubt and thus open-mindedness and continued data gathering and analysis must rule the day from a skeptical point of view

CCSVI was shown to be highly associated with MS by Zamboni's original work and, importantly, this was confirmed by the very large and reliable University of Buffalo study (500 subjects blinded to evaluators) which found CCSVI was three times more common in persons with MS than in healthy controls. Any lingering doubt regarding this high association has been removed by the 5000 + CCSVI treatments which have been done worldwide in various centres throughout the world over the last 10 months. All published reports have found 90%+ of MS patients had CCSVI as demonstrated by selective venography, the gold standard for CCSVI detection. Notably, no treatment centre has ever found that more than a small percentage of persons with MS do not have CCSVI.

The question of whether or not CCSVI is part of the MS disease process is not as well established. However, the high association in combination with both the congenital origin of most of the vascular anomalies and the biologically plausible mechanisms that link the effects of CCSVI to the MS disease process (e.g. iron deposition, venocentricity of lesions, hypoperfusion, upregulation of endothelial adhesion molecules) indicate it is much more likely than not that CCSVI is a key part of the MS disease process. The reasoning behind this is that the accepted three main ingredients for strongly suspecting a "causal" relationship between a pathology and a disease are: 1) high association, 2) appearance of pathology before the disease process begins and 3) biological plausible mechanisms linking the two. The CCSVI/MS relationship fulfills all three. Clinical trial research, which demonstrates the relief of CCSVI also lessens the MS disease process, is required if this very probable causal relationship between CCSVI and MS is to be established beyond a reasonable doubt.

Finally, the question of whether or not CCSVI treatment is of value for persons with MS remains very open. The current data, which consist of positive results from the Zamboni pilot trial and many hundreds of documented positive experiences from persons who have had CCSVI treatment, indicate that the treatment may well have efficacy but such data, although very encouraging, are far from convincing for a skeptical scientist.

These data, in combination with the established high association of CCSVI and MS, and the probable role of CCSVI as part the MS disease process, are sufficient to dictate that a proper clinical trial to test the effectiveness of CCSVI treatment is **urgently** required so that the hypothesis can be either accepted and used to guide actions or rejected and forgotten. Robert Maggisano, a vascular surgeon, said it best at a recent Parliamentary Subcommittee Hearing when he testified that *"we need to get going on this, so that*

within a year or two we can let our MS population know the answer.” And there is no doubt persons with MS need to know the answer as soon as possible given the unrelenting progression of MS and the accompanying increase in serious disabilities.

With the above background on where the science now stands in regards to CCSVI and MS, we can now look at the remarks and actions of the MS doctors interviewed in the Star article to see if they are truly “healthy skeptics” or are better seen as “nattering nabobs of negativity”.

MS Doctors and Negativity

The question of whether or not Mark Freedman has exhibited healthy skepticism or close-minded negativity is not hard to answer. When one publicly declares CCSVI, which has a great deal of empirical data and theoretical reasoning to support it, a hoax, there is no question about this being a quintessential example of close-minded negativity. Mark has never offered any criticism of the CCSVI science and does not appear to know much about it. Mark also is quoted as claiming that *“breathless reporting fed the outcry for liberation treatment, overpowering their reasoned caution”*. Actually it was not the reporting but the impressive science that was the foundation of the great interest in CCSVI. Furthermore, Mark has never offered any “reasoned” caution and, I doubt if it would be possible, given the very safe nature of venous angioplasty. Finally, Mark has never tried to find out for himself if CCSVI is a real phenomenon or not. A quick visit to a CCSVI treatment centre, or even a CCSVI research centre like the University of Buffalo, would provide him with a clear view of the reality of CCSVI in persons with MS. Such avoidance again demonstrates Mark’s close-minded negativity.

Anthony Traboulee is the head of the MS clinic at UBC and is quoted in the Star article as *“feeling that he and others are being penalized for being honest about skepticism, to let people know that yes, this is interesting, but gosh, there isn’t a heck of a lot of evidence”*. If Anthony was truly skeptical, he would have been reading the 100+ articles related to CCSVI and MS and would have realized there actually is “a heck of a lot of evidence” regarding CCSVI and MS. Furthermore, he would not have voted against the need for a CCSVI treatment trial as part of the CIHR/MSSC committee (Beaudet Committee) because a skeptical person wants to get the “acid test” done as soon as possible because that is the only way to remove lingering doubts.

Anthony is also quoted as saying that *“Maybe it’s not the cure and people don’t want to hear that messaging”*. This statement has no substance to it and Anthony should realize that that very few, if any, persons with MS see CCSVI treatment as the fabled “cure” for MS. Persons with MS see CCSVI treatment as a therapy which has the potential to reduce symptoms of MS. I suspect this is a message that Anthony does not want to

hear. I have no doubt he had his hands over his ears when vascular doctors, who are doing CCSVI treatment, publicly stated that 1/3 of their patients have had significant improvement and 1/3 have had moderate improvements. Anthony prefers to use absurd extremes (people with MS do not want to hear CCSVI is not the cure) to avoid the main issue at hand. Again, this is another classic tactic of close-minded negativity.

Alexandre Prat is a young MS researcher who is quoted as saying “*that there are a number of scientific truths that have been presented and that do not support the claims of these Italian scientists*”. As discussed earlier, there is no such thing as “scientific truth” and it is shocking that a bona fide research scientist would make say such a thing. However, a baseless pronouncement of the existence of mythical scientific truth which disproves the CCSVI/MS relationship certainly fits very well with close-minded negativity. Regardless, I can only hope Alexandre will investigate the philosophy of science and I especially refer him to the works of David Hume, the 18th century Scottish philosopher.

Another MS researcher who is quoted in the Star article is Peter Stys of the University of Calgary. He has been researching methods of neuro-protection for about 25 years and only relatively recently has he concentrated on MS. All he can muster is the classic, negative generalization of “*the science is just not there*”. I assume Peter has not taken the time to actually look at what is actually there or else he would not have made such a baseless statement. Perhaps he is avoiding all the data on CCSVI and MS so that he can escape having to agree that CCSVI research should be a higher priority than neuro-protection research which, after 25 years, has yielded no tangible benefits for persons with MS.

The last MS doctor quoted is Katherine Knox who is the head of the Saskatoon MS Clinic. She notes that “*she takes the time to explain her concerns with the experimental treatment — including the risk of blood clots and that a stent in the jugular vein could travel to the heart as it did for one patient*”. I doubt if Katherine also takes the time to mention that since the one serious adverse effect of a stent migration, 5000 treatments have been done with only a few very minor problems which were quickly addressed. Once again, a complete emphasis on one, very early, negative event out of 5000 treatments is not a skeptical response but is basically fear-mongering which is another component of close-minded negativity.

I could provide many examples of MS doctors exhibiting classic, close-minded negativity and I would be hard pressed to provide any examples of “healthy” skepticism. As mentioned previously, such skepticism requires open-mindedness and this is one quality that does not appear to exist in the fraternity of MS neurologists and researchers

when it comes to CCSVI. The best example of such a lack of open-mindedness is the MS doctor-driven recommendation of the Beaudet Committee to not do any CCSVI treatment research. Healthy skeptics want to see the key research done so that a clear decision can be made on the validity of an important hypothesis whereas negativity mongers want to ensure there is no chance of a positive result being produced.

Another classic example of the close-minded negativity of the MS clinicians and researchers is their firm denial that the impressive and undeniable physical improvements enjoyed by thousands of persons with MS following CCSVI treatment are not real but are simply “placebo effect”. The absurdity of such a position is apparent to anyone who has watched a person who could barely walk before CCSVI treatment run 10 kilometres weeks after treatment. In fact, most of the reported improvements could not possibly be “placebo effect” and the use of this term to rationalize the documented improvements is yet another manifestation of the blind and inhumane negativity of the MS doctors. A scientific skeptic would be closely investigating the experiential accounts of persons with MS who have had had CCSVI treatment to determine their nature.

Why MS doctors have adopted close-minded negativity

Close-minded negativity is often adopted by an individual or group of individuals when it is apparent a hypothesis will result in problems for them if it proves to be acceptable and suited to guiding future actions. It is no secret that CCSVI treatment has the potential to replace current drug therapies which are very lucrative for many MS doctors by way of funding, honoraria, and gifts from drug companies. Furthermore, interventional radiologists rather than neurologists may become the primary care providers for persons with MS with the advent of CCSVI treatment. This would result in a further loss of income and status for the MS doctors.

The MS researchers are very negative about CCSVI because it will command a huge amount of research money once it is accepted as a part of the MS disease process. This will result in far less money for the pet projects of the current researchers whose expertise resides in the immunological aspects of MS rather than the vascular ones. This fear of lost research money has been voiced on a number of occasions by MS researchers, including Mark Freedman.

Overall, the spectre of CCSVI being accepted as a key part of MS and as the primary target for MS treatment is not a happy one for the current MS doctors and researchers. Thus, it is somewhat natural, although a little discouraging, they have taken a close-minded, negative approach to it. In contrast, interventional radiologists, who are being smeared by neurologists as quacks, frauds and opportunities, are taking a healthy,

skeptical approach. They are proceeding with open-minded caution and are starting to organize treatment trials so that a clear answer will be attained as soon as possible.

How MS doctors can become healthy skeptics

If the MS doctors, who are bemoaning the fact that their patients and the public don't understand them, want to really become respected, healthy skeptics, I would suggest they actively start trying to see for themselves if CCSVI is a real phenomenon in MS and if CCSVI treatment is a safe, straightforward procedure. This can be achieved by simply spending a few days at an established CCSVI treatment facility such as the prestigious Arizona Heart Institute in Phoenix, Gary Siskin's Clinic in Albany, NY or Marian Simka's Clinic in Poland. There are many others to choose from and most are doing three to six CCSVI treatments a day.

At a clinic, the MS doctors could examine the venography for each patient and clearly see whether or not the venous anomalies which constitute CCSVI are present. Following this, they could watch the restoration of venous flow by way of venous angioplasty. Finally, they might well also see the positive effects of the treatment on the symptoms of the patients. Right now the situation is similar to doctors in Canada debating if a heart transplant was possible, while at the same time 100 heart transplants were being done throughout the world every day. This disconnect from reality by the MS doctors due to their close-minded negativity is definitely a problem.

To help alleviate this unfortunate situation, Direct-MS is prepared to help fund trips to CCSVI clinics by the five doctors interviewed in the Star article. Our charity sees such an initiative as being an effective way to help reverse the close-minded negativity which pervades the MS neurological community. We also call on the other main MS charity in Canada, the MS Society of Canada, to join us in this initiative and to share the funding costs. MSSC has repeatedly claimed they want to do everything possible to help persons with MS but their past actions on CCSVI have made many persons with MS skeptical of the veracity of such a statement. Their participation in this initiative, of helping some prominent, Canadian, MS doctors and researchers see for themselves if CCSVI is real or not, will go a long way to demonstrate that MSSC really has the best interests of persons with MS as their # 1 priority when it comes to CCSVI.

Summary

The claim by MS doctors and researchers that they are simply skeptical of CCSVI and the value of CCSVI treatment has no support. The statements and actions of the MS doctors and researchers demonstrate that they have taken a close-minded, negative approach and that they are studiously avoiding examining the available data and the

results of ongoing clinical treatments for CCSVI. Furthermore, their claim that they are the innocent targets of malicious slander is also at odds with reality. Neurologists actively continue to slander interventional radiologists doing venous angioplasty. The latest public slur was delivered by a clinical neurologist during a CCSVI debate in Ireland (24/09/10) in which he called IRs charlatans, a favourite insult of neurologists in regards to IRs.

It is clear that ongoing, widespread, and sometime voracious, criticism of MS doctors is due mainly to their blind negativity in regards to CCSVI and to their unprofessional name calling in regards to interventional radiologists who are doing venous angioplasty. It has nothing to do with falsely perceived and completely absent scientific skepticism.

To help rectify the serious problem of the close-minded negativity of the MS neurological community, Direct-MS is offering to help fund five MS doctors to visit CCSVI treatment centres. This will provide an opportunity for the doctors to see for themselves the reality of CCSVI, the safety and ease of CCSVI treatment, and the types of improvements enjoyed by some after the treatment. MSSC is invited to join this necessary and potentially game-changing initiative.