

A Critique of Andre Picard's Recent Article on CCSVI and Mr Mostic's Death

Ashton Embry, November 24, 2010

I quit writing rebuttals to badly written and erroneous articles on MS and CCSVI because there have been so many of them lately that, to do so, would have taken all my time. However Andre Picard's recent article in the Globe and Mail entitled "***MS is a bedevilling disease with no simple answers***" (<http://www.theglobeandmail.com/news/national/ms-is-a-bedevilling-disease-with-no-simple-answers/article1807128/>) contains so many problematic statements that I felt a strong need to critique it despite the fact I have far better things to do.

Andre's begins his article with the inflammatory claim that "***Mahir Mostic, 35, died because he bought into the hype***". This claim is not supportable given the facts of his death. Mr Mostic died because he was refused proper health care in Ontario upon his return from Costa Rica, not because he got a potentially very helpful therapy.

As an analogy, imagine if someone accidentally shot themselves in the leg with an unregistered handgun. When they went to the emergency department at an Ontario hospital they were refused treatment because the gun was not legal. They then died of blood loss while driving to the USA to seek care at a private facility. Andre would claim the person died because he owned an illegal firearm and mistakenly wounded himself whereas the real reason was the lack of proper and timely health care in Ontario.

The next problematic statement is "***The expectations for the so-called Zamboni procedure have become so grossly inflated that the bubble was due to burst***". The expectations of persons with MS for venous angioplasty are: 1) It may have a beneficial effect on one or more of their symptoms in the short term. 2) It may help to significantly slow their disease progression in the long term. The first expectation is highly realistic given what is known of the results of the first 10,000+ procedures (1/3 have noticeable immediate improvements) and the second expectation is reasonable from a theoretical point of view. It is critical to view these potential benefits in the current situation of the lack of any MS therapies available in Canada which have little if any possibility of meeting either expectation.

"The media, of course, are being blamed for fuelling the hype. In response to Mr. Mostic's death, some have already said there is blood on our hands." is also a deceptive statement. The only people blaming the media are likely the neurologists and MS societies who were desperately trying to keep the concept of CCSVI under wraps in the fall of 2009. When CTV let the CCSVI cat out of the bag, they were most displeased and still have nothing good to say about the CTV

documentary or its producers. I can only repeat that Mr Mostic died because of inadequate care in Canada, not because he got a potentially useful treatment. The media had absolutely no hand in his death and, any claim it did, has no substance.

Andre goes on to describe the initial CTV/Globe and Mail reports which were very responsible journalism that broke a major and most important story. He then claims that the reported story was greatly distorted such that ***“In the blogosphere, however, the provisos evaporated and the “liberation” treatment was billed as a miracle cure.”*** This may be true in a few isolated spots but, in general, most people with MS are much more realistic than Andre would seem to think. The vast majority did not see venous angioplasty as the fabled cure for MS but viewed it simply as a treatment that offers the possibility of symptom relief and slowed disease progression. Notably, the results of the treatments done so far have indeed born out the promise of significant symptom relief for thousands of persons with MS (including my son). Only time will tell if CCSVI treatment also slows disease progression.

Andre could not resist using the standard and baseless line that ***“Many were willing to invest their life savings”***. Given that CCSVI treatment in most cases costs ~ \$12,000 including travel and hotel, I truly doubt if such a sum represents the life savings of any of those who have gotten such treatment. However, this false but powerful image of a person with MS spending their last dime on an unproven treatment is a favourite of those who want to denigrate CCSVI treatment.

“Those crippled by MS began walking – seemingly on water.” These sensational words also reveal a lot about Andre’s views and prejudices. There is no doubt that some people have regained their ability to walk following CCSVI treatment but it is well known and accepted that most who were confined to a wheelchair before the treatment remained that way afterwards. The very fact that some have regained their ability to walk is remarkable, given no other MS therapy over the last 160 years has been able to provide such a benefit.

Those who urged caution were shouted down, dismissed as pawns for Big Pharma.” I don’t recall anyone being shouted down for suggesting caution but I certainly recall long, uninterrupted interviews and widely circulated articles by persons receiving large sums of money from pharmaceutical companies trying to claim CCSVI was a hoax and equivalent to snake oil. These people with such an obvious conflict of interest (mainly neurologists and MS society officials) are not pawns but rather are handsomely rewarded skills for the pharmaceutical industry. I can understand why they want CCSVI to disappear because CCSVI treatment may slow or even halt the pharmaceutical gravy train.

Next up is the ugly side of journalism: the inclusion of a major error which creates a false understanding of an important issue. Andre writes ***“A study done in***

Buffalo, N.Y., found that 62 per cent of MS patients had blockages in their necks; but so did 45 per cent of people without MS” . Of course, if this were true, one would wonder if CCSVI is a big player in MS. The real facts are that the Buffalo researchers found CCSVI in 62% of persons with MS and only 25% of healthy controls (not 45%). Such data strongly support the association of CCSVI with MS, an established and most important relationship that Andre’s erroneous figures suggest is not correct.

Here is another disingenuous line. **“Arteries collapsed in about half of those who underwent angioplasty and stents were required.”** First of all, CCSVI treatment is done on veins not arteries and Andre’s lack of understanding of the difference between the two is worrisome. I was pleased to see this very telling, fundamental error was eventually corrected in the online version of the article. Secondly, we currently have no good information of the extent of restenosis which may be as high as 50% or as low as 20%. That is why we need some proper research to determine this important number. Using the high end of the range to disparage CCSVI treatment, as Andre has done, is not acceptable and is why statistics have a bad reputation. Importantly, everyone who gets venous angioplasty is well aware that restenosis may occur.

Andre’s statement that **“weeks after the procedure, blockages reappeared; many suffered dangerous blood clots, a common side effect of stenting.”** suggests he is privy to data few other have. How he knows that **“many suffered dangerous blot clots”** is beyond me. There have been a few reports of clots but, given that well over 10,000 procedures have been done and few serious side effects have been reported, I can only assume Andre is once again playing fast and loose with the facts and is exaggerating for effect. Of course, if he indeed has some hard data on this issue, it would be most helpful if he shared it with the MS community.

His statement that **“The story of “liberation” is a brutal reminder that any intervention – drugs, surgery, etc. – that has a potential benefit has an equal or greater potential for harm”** once again gives a false impression of reality and is basically not true. Every action has a potential downside and when considering an action we always weigh the chance of benefit versus the chance of harm. There is absolutely no doubt that the chance for significant benefit from venous angioplasty is hugely greater than the chance of significant harm. Tens of thousands of persons with MS will get venous angioplasty over the next few years because, when the odds are in your favour, you go for it. Andre’s suggestion that venous angioplasty **“has an equal or greater potential for harm”** is nothing more than baseless fear-mongering.

Andre’s summary statement **“Liberation procedure may yet prove to be an effective treatment for a subset of MS patients, but the scientific evidence is not there now”** raises a few issues. The good news is that venous angioplasty (a less pejorative name for CCSVI treatment) has already proven to

be an effective treatment for thousands of persons with MS in terms of relief of a number of serious symptoms such as fatigue, brain fog and balance. Five to ten years from now we may well have the results of one or more proper clinical trials which will document this phenomenon. Such trials will also provide some hard numbers which will be valuable. However, it is nonsensical to expect a person with a nasty, progressive disease to wait many years for the fine details to be established by slow, methodical research before seeking a very safe treatment using established techniques and technology. I have little doubt, if Andre or a close loved one were diagnosed with MS tomorrow, they would be seeking CCSVI treatment the following day. It is only common sense.

In conclusion, MS is indeed “**a bedevilling..disease**” as Andre says and I can assure Andre that few, if any, persons with MS are expecting that it “**can be miraculously cured with a little plumbing of the neck.**” However, most persons with MS recognize the facts that

- 1) If they have MS, there is at least a 90% chance they have impaired venous drainage from the brain.
- 2) It is most likely that impaired drainage from the brain is not good for one's health.
- 3) There is a reasonable chance that some MS symptoms may well be relieved by resolving such impaired drainage by way of venous angioplasty.

The next time Andre decides to write about CCSVI and MS, I hope he will be less superficial and sensational and will be better informed on the science of CCSVI and what is happening out there in the real world.