

The internet racing ahead of the scientific evidence

The case of "liberation treatment" for multiple sclerosis

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ABSTRACT

Multiple sclerosis (MS) is a chronic neurological disease that typically affects young adults. A recent publication suggested that MS might originate from insufficient blood drainage in certain areas of the central nervous system. The condition was named chronic cerebrospinal venous insufficiency (CCSVI). Other papers have not confirmed these findings and, therefore, the matter remains controversial. Nineteen months after the original publication on CCSVI and MS, another 22 papers have been published addressing the matter. No clinical trials have been carried out on the subject and there is no evidence-based indication to perform surgical vascular procedures in MS patients. However, over the same nineteen-month period, the internet discussion on the subject of CCSVI and MS has led to countless websites advertising treatment using vascular surgery for patients with MS all over the world. The treatment based on the CCSVI theory has appealingly been called "liberation treatment", thus making it difficult to explain to patients why a treatment that has been highly praised (on the internet) cannot be recommended based on partial medical results that await confirmation.

Key words: multiple sclerosis, vascular, etiology, vascular insufficiency.

A corrida da internet na frente da evidência científica: o caso do "tratamento de liberação" para esclerose múltipla

RESUMO

Esclerose múltipla (EM) é uma doença neurológica crônica que tipicamente afeta adultos jovens. Uma recente publicação sugeriu que EM poderia se originar por insuficiência da drenagem sanguínea em certas áreas do sistema nervoso central. Esta condição foi denominada insuficiência venosa cerebrospinal crônica (CCSVI). Outros artigos não confirmaram estes achados e, portanto, o tema continua controverso. Dezenove meses após a publicação original sobre CCSVI e EM, outros 22 trabalhos foram publicados sobre este tema. Nenhum estudo clínico foi feito e não existe evidência para a realização de procedimentos cirúrgicos vasculares em pacientes com EM. No entanto, neste mesmo período de dezenove meses, a discussão na internet sobre o assunto CCSVI e EM levou a uma quantidade incontável de websites anunciando tratamento por cirurgia vascular para pacientes com EM no mundo todo. O tratamento baseado na teoria de CCSVI tem sido chamado de "tratamento de liberação", tornando difícil explicar aos pacientes porque um tratamento tão elogiado (na internet) não pode ser recomendado com base nos resultados médicos parciais que ainda aguardam confirmação.

Palavras-chave: esclerose múltipla, vascular, etiologia, insuficiência vascular.

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In April 2009, the Journal of Neurology, Neurosurgery and Psychiatry (impact factor=4.869) published a paper from Zamboni et al. presenting a new theory on

the genesis of multiple sclerosis (MS)¹. MS is a chronic inflammatory and degenerative disease of the central nervous system that is believed to be related to autoim-

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munity. Zamboni et al.¹ presented overwhelming evidence of the existence of an association between MS and chronic cerebrospinal venous insufficiency (CCSVI), thus casting a completely different light on the origin of MS. They concluded their paper by calling for more studies in order to confirm these findings.

Subsequently, other papers on this subject have been published, but some of them have failed to confirm Zamboni's original findings. There have not been any clinical trials and therefore, at best, the matter remains controversial.

Meanwhile, the internet has built up its own picture of CCSVI and MS. The CCSVI theory is presented as the ultimate truth and Zamboni is described as the martyr in a large conspiracy to deny treatment to patients, while the endovascular approach is sought by patients as the "liberation" from MS.

The aim of the present paper was to compare the present state of scientific knowledge on the subject of CCSVI and MS with the information circulating on the internet on this subject.

METHOD

The terms "CCSVI multiple sclerosis" and "CCSVI" were used for both the medical search and for search engine investigations. The search date was November 3, 2010. For scientific papers on the subject, the access was via PubMed (<http://www.ncbi.nlm.nih.gov/pubmed>). For the internet search, www.google.com and www.yahoo.com were accessed.

RESULTS

Medical papers

Up to November 2010, 22 more papers had been published addressing the matter, subsequent to Zamboni's original paper. Zamboni participated in thirteen of these publications: two reviews^{2,3}, one prospective study on the benefits of endovascular treatment for MS patients⁴, one study on the reproducibility of the vascular findings⁵, three studies on cerebrospinal fluid (CSF) dynamics and CCSVI⁶⁻⁸, one study regarding magnetic resonance imaging⁹, one study on transcranial magnetic stimulation¹⁰, one study on the genetics of MS and CCSVI¹¹, one study on the clinical form of the disease and image correlation¹², and one study on fatigue and CCSVI¹³. One of these papers presents a pilot, single-center, non-randomized, open study on endovascular surgery with very impressive results from 25 patients with the relapsing-remitting form of MS⁴. Eight papers authored or co-authored by Zamboni are in *International Angiology*, showing that the topic has now moved out of the original medical specialty and into another. Actually, the April 2010 issue of *International Angiology* is en-

tirely devoted to aspects of CCSVI. In this issue of *International Angiology*, nine original articles, two editorials and one case report are presented suggesting that CCSVI and MS are indeed related. Five more papers were also published by different authors in the April issue of *International Angiology*, supporting Zamboni's findings¹⁴⁻¹⁸.

The other five papers on the subject of CCSVI and MS presented data and/or discussions refuting the association of these two conditions. They were all published in journals of neurology¹⁹⁻²³ and concluded that the subject is still controversial. The authors of these last five papers recommended more studies and clinical trials, and warned against surgical procedures on such patients at this stage.

The internet access

The Google search for "CCSVI multiple sclerosis" yielded over 650,000 results. The top result was a link to a clinic offering CCSVI evaluation services and MS liberation therapy (www.ccsvi-online.com), followed by the CCSVI Foundation (www.ccsvifoundation.org), which on its front page, reported on a patient who was denied the "liberation" treatment and filed a human rights complaint. Other links on the initial Google page led to pages explaining that there was a plot among neurologists to avoid referring patients to vascular surgeons because neurologists refused to believe in CCSVI (www.multiplesclerosissurgery.com). In addition, links to www.youtube.com presented over 700 videos of successful "liberation" treatment. The search on Yahoo! yielded over 80,000 results, including www.ccsvi-multiple-sclerosis.com, in which doctors willing to perform the liberation treatment could be located around the world, and www.ccsvi-for-ms.org, which advertised using the slogan "Liberation from Multiple Sclerosis - Free yourself".

Both Google and Yahoo! have several links accessing Facebook. The social network www.facebook.com contains dozens of discussion forums and social/charity events relating to CCSVI and MS. The largest CCSVI community on Facebook has nearly 30,000 participants. Although several participants are dubious about "liberation" treatment or have undergone it without success, the tone of the discussion is extremely optimistic.

DISCUSSION

MS is a chronic neurological disease that affects young adults and may lead to severe neurological disabilities. The search for new treatments is immense, and the efforts of research groups all over the world have led to fascinating insights on MS genesis and possibilities of treatment, over the last decade.

Zamboni's group is one of the many teams working on a variety of ideas regarding the origins of MS.

Whether MS patients have associated CCSVI and whether vascular surgery is a possible treatment for MS remain to be proven. Although MS is a classical neurological disease and Zamboni's first paper on CCSVI was published in a neurological journal¹, the discussion is typically moving over to angiology journals now.

Several clinical trials and major studies are now being organized with the aim of confirming this theory and assessing the role of vascular surgery in the treatment of MS. Good clinical practice recommends that only treatments with evidence-based results should be put into practice, and invasive surgical procedures require very specific indications. Although it is understandable that young adults with a chronic neurological disease will seek the state-of-the-art treatment for their disease, it is unacceptable that an invasive and unproven procedure should sprout in the internet in the way that "liberation treatment" has done. While only 23 papers have been written on the subject, thousands of websites have been claiming that CCSVI is the proven cause of MS. A single open pilot study on only 25 patients undergoing surgical vascular procedures has led several clinics all over the world to offer "liberation treatment". During the European Congress of Multiple Sclerosis (ECTRIMS) in October 2010, in Gothenburg, Sweden, Zamboni explained that the term "liberation" originated from a radiologist talking about blood vessels with insufficient blood flow. The talk of "blood flow liberation in the vessel" mutated into "liberation treatment for MS" in very little time.

New theories on MS genesis are most welcome, since there is still a long way to go before such a complex and devastating disease can be fully understood. Zamboni's theory is not yet proven and cannot be recommended as a definitive treatment for MS. For the moment, all that can be concluded is that the medical evidence and internet information are running apart from each other. The internet-based information is racing along much faster than evidence-based medicine, but this does not mean, as many seem to think, that "liberation" treatment is the answer for patients with MS.

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