

Social media can alter research priorities, study says

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Widespread demands in Canada for clinical trials for a controversial treatment for multiple sclerosis show the growing power of the Internet and social media to influence research priorities, according to a paper published today in *Nature*.

Paulo Zamboni, an Italian surgeon, suggested in 2008 that MS was not an autoimmune disease but rather a vascular disease caused by blockages in the brain. He proposed unblocking the veins by mechanically widening them – what he calls the "liberation procedure."

His hypothesis got little public attention, except in Canada, where more than 500 Facebook pages, groups or events devoted to the theory have been created with tens of thousands of followers. A poll shows more than half of Canadians are familiar with the theory. Stories about it have appeared in the media almost weekly since *The Globe and Mail*, a national newspaper, wrote about it in November 2009 and it was featured on the CTV public affairs program W5.

Researchers at Memorial University in St. John's, Nfld., and St. Michael's Hospital in Toronto note the reports have sparked a national debate about whether publicly funded trials should be conducted and whether MS patients should have immediate, publicly funded access to the vein-widening treatment known as venoplasty.

This is despite the fact that virtually none of the country's MS physicians and researchers, nor the [Multiple Sclerosis](#) Society of Canada, have

advocated either, and several studies have failed to replicate Zamboni's original findings.

"Indeed, the case indicates the unprecedented pressures scientists, politicians and funders worldwide can now face to alter research priorities even in the absence of credible scientific evidence," the authors wrote.

The paper's lead author is Dr. Roger Chafe, director of the Janeway Pediatric Research Unit, which conducts clinical and applied health research within the Discipline of Pediatrics, Faculty of Medicine at Memorial University. His co-authors include Dr. Arthur Slutsky, vice-president of research at St. Michael's Hospital, and Dr. Andreas Laupacis, executive director of the hospital's Li Ka Shing Knowledge Institute.

The authors said that in this new [social media](#) environment, researchers and clinicians need to engage more actively with the public to articulate the importance of science in determining the benefits and harm of novel treatments – and to ensure that patients' concerns and priorities are heard.

They said unconventional and unproven treatments have long been proposed and tried for many terrible diseases. "Now tools such as Facebook and YouTube make it considerably more likely that patients learn about such therapies, without necessarily learning about their potential limitations."

The authors wrote that a clear lesson from the Zamboni example is that the traditional approaches for communicating scientific findings to the public and policy advisers such as reports, briefing notes, news releases and news conferences, are insufficient. "When patient groups are using social media to advocate and mobilize, scientists must employ similarly

effective tools to communicate."

More effort are needed to improving the scientific literary of the public, politicians and the media, the authors wrote, and to engaging a public that is no longer deferential to experts.

Provided by St. Michael's Hospital

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