



# “Waiting for the Science to Catch up with the Practice”:

## A More Cautious Trend in Social Media Discussions of CCSVI Treatment for MS

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### BACKGROUND

- It was proposed<sup>1</sup> that MS was caused by or significantly associated with stenosis of the extracranial venous drainage system- known as Chronic Cerebrospinal Venous Insufficiency (CCSVI).
- Zamboni and colleagues<sup>1</sup> carried out an unblinded and uncontrolled trial of CCSVI treatment and reported improved QoL and disability status in participants.
- This research received unprecedented media attention and has been referred to as “liberation therapy”; and a “medical miracle” procedures being offered by private hospitals and clinics outside of clinical trials, despite safety concerns.
- In Traboulee and colleagues<sup>2</sup> assessor-blinded, case-control, multicentre study found no link between MS and CCSVI – such that 2% of people with MS; 2% unaffected siblings; 3% unrelated controls tested positive for CCSVI.
- Throughout this time social media appeared to play a key role in patient discussions around decisions to have CCSVI treatment.

### PURPOSE

**Objective:** To determine if people with MS continue to report benefits of CCSVI treatment on social media, and if perspectives have changed.

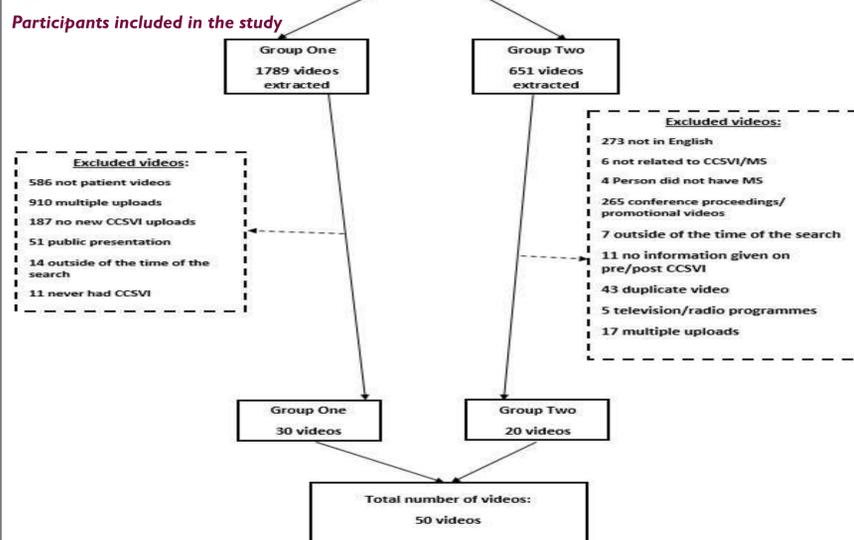
#### Research Questions:

- What message is currently being conveyed through social media on CCSVI Rx?
- Has the volume of videos being uploaded remained constant?
- What alternative treatments are being suggested by participants?
- How do people describe their experience of CCSVI treatment?

### METHODS

- Accessed data from Ghahari & Forwell<sup>3</sup> study in order to follow up on persons with MS who had been uploading videos about CCSVI treatment.
- Performed a new search of videos uploaded by persons with MS who did not upload videos prior to August 2011
- All videos were sourced through www.youtube.com

Figure 1



### METHODS

**Group One:** Of the 1789 videos that were collected by Ghahari & Forwell<sup>3</sup>, we took the last video uploaded by participants leaving 293 videos. From these, new videos were uploaded by 106 participants. Through coding of the videos 74 were excluded. Only videos describing results following CCSVI treatment were included, leaving 30 videos.

**Group Two:** New search of videos were extracted from August 2011 to December 2014.

The following **inclusion criteria** was applied (see Figure 1):

- Pre and post CCSVI treatment videos available
- Participants must have multiple sclerosis
- Videos in English (many of the newer videos uploaded were in Italian)
- No conference proceedings, television, radio programmes or promotional videos.

The **50 videos** met the inclusion criteria and were then analyzed using a pre-defined code book.

### RESULTS

**Research Question 1: the overall message –** Symptom reporting (Table 1);

- 32 videos were positive of the CCSVI Rx [note: some were +ve about Rx, but not necessarily have +ve results]
- 7 videos were negative
- 6 videos were neutral
- 5 videos did not provide an opinion on the treatment

**Research Question 2: volume of videos**

- Participants uploaded a mean of 7.5 videos (SD 12.16) each (range n 1-67) – Figure 3.
- There were 89.34% fewer videos uploaded in this study than in the initial capture
- Mean time since participants had their CCSVI treatment was 535.86 days (SD 488.42; range 0-1465 days)

**Research Question 3: alternative treatments**

- Of the 50 participants, 8 (16%) had had a second procedure and 2 (4%) had a third/forth procedure.
- A variety of alternative treatments were suggested – Table 2

Table 1: Examples of symptoms reported

Symptom	No report	No Change	Decrease	Improve
Overall Health	22 (44%)	8 (16%)	7 (14%)	13 (26%)
Balance	32 (64%)	1 (2%)	5 (10%)	12 (24%)
Strength	34 (68%)	0 (0%)	6 (12%)	10 (20%)
Stiffness	35 (70%)	0 (0%)	5 (10%)	10 (20%)
Clear Head	43 (86%)	0 (0%)	3 (6%)	4 (8%)
Pain	40 (80%)	1 (2%)	4 (8%)	5 (10%)
Fatigue	38 (76%)	0 (0%)	4 (8%)	8 (16%)

Table 2: Alternative treatments suggested

Treatment	Number	Details
Diet change	6	Vegan Diet
		Terry Wahl's Diet
		Paleo Diet
		Gluten-free Diet
Stem cell	5	Stem cell
Other	6	Acupuncture
		Exercise
		Medication change

**Research Question 4: describing the CCSVI experience**

- Although the majority were positive the overall commentaries were conflicting & not always supportive of the Rx.
- Some of the participants' comments on the treatment can be seen in Figure 2 below.

“Liberation therapy gave me my life back”

“It does not work for everybody but for those that it does, it brings hope into a pretty bleak future when all else has failed.”

“Even though I had the remission, I went back down and went further.”

“I don't have MS anymore/ If I needed it again, I'd do it in a heartbeat”

“My results held for about 5.5 months and then like a truck with my name on it-BAM!- I was hit again with all my symptoms and then some.”

“I think it's a blind alley/ I would say save your money and do not pursue CCSVI”

“I still feel the illness but my life has changed for the better in many ways”

“I've decided to wait for the science to catch up with the practice./ It is difficult to see some of the symptoms coming back after initial improvement.”

Figure 2: Participant comments on CCSVI (green=positive; yellow= neutral; red=negative).

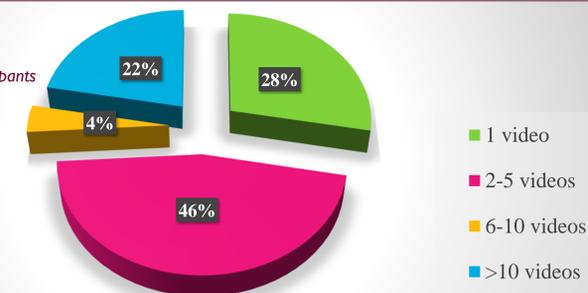
### KEY MESSAGES

- The volume of videos being uploaded has decreased significantly.
- Overall, people continue to report some benefits from the CCSVI treatment.
- Few videos report long term benefits of treatment – 2 years post-CCSVI treatment.
- Expectations of the treatment seem to have diminished.
- Longer-term results have been scant and for many disappointing
- Although many are positive when reporting on specific symptoms the overall comments are contradictory and not supportive of treatment.
- Many videos were uploaded “Pre-CCSVI” but there were no follow-up videos suggesting possible positive reporting bias.
- New treatments are now being suggested.

**Social media plays a key role in health decision making, despite recommendations from health care practitioners.**

Figure 3

Number of videos uploaded by participants



### IMPLICATIONS

Practitioners may be faced with pressure to provide unproven treatments in the future and should be understanding but evidence-driven when supporting therapies in multiple sclerosis.

### REFERENCES

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### ACKNOWLEDGEMENTS

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