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Author(s)	Hynes, Sinéad M.; Ghahari, Setareh; Forwell, Susan J.
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1 **Title:** “Waiting for Science to Catch up with Practice”: Examination of ten-year YouTube
2 trends in discussions of chronic cerebral spinal venous insufficiency treatment for multiple
3 sclerosis.

4 **Running Head:** YouTube Discussions of CCSVI Treatment for MS

5 **Authors:** Sinéad M. Hynes, PhD, BSc (Hons); Setareh Ghahari, PhD, MSc, BSc; Susan J.
6 Forwell, PhD, OT(C), FCAOT.

7 **Affiliations:**

8 Sinéad M. Hynes; Discipline of Occupational Therapy, College of Medicine, Nursing and
9 Health Sciences, Áras Moyola, National University of Ireland, Galway, Ireland.

10 Setareh Ghahari; School of Rehabilitation Therapy, Queen’s University, Kingston, Canada;
11 Department of Occupational Therapy, University of Social Welfare and Rehabilitation
12 Sciences, Tehran, Iran.

13 Susan J. Forwell; Department of Occupational Science and Occupational Therapy, University
14 of British Columbia, Vancouver, Canada.

15 **Correspondence:** Sinéad Hynes, PhD; Phone: +4435391495624, Email:
16 sinead.hynes@nuigalway.ie

17

18

19 **ABSTRACT**

20 *Objective:* The objective of this longitudinal study examined, first, whether people with
21 multiple sclerosis who previously advocated for angioplasty to treat chronic cerebral spinal
22 venous insufficiency (CCSVI) through YouTube continued reporting benefits. Second, it
23 examined a new cohort reporting on CCSVI treatment; and third, whether perspectives have
24 changed. *Method:* YouTube videos from August 2011 to January 2019 related to CCSVI
25 were retrieved. Once retrieved, all videos were compiled, classified and analysed. Categorical
26 data were reported and a pre-determined code-book was used to code videos. Data from the
27 videos were extracted and analysed using discourse analysis. *Results:* 1293 videos related to
28 CCSVI were uploaded by 54 people with multiple sclerosis who met the inclusion criteria.
29 YouTube videos uploaded by people with multiple sclerosis have shifted in volume and
30 message. The initial surge in interest in CCSVI treatment has diminished, but there still exists
31 strong advocates for its use. There appears to be inconsistency between positive results,
32 actual improvements in symptoms, and the overall messages reported. Very little long-term
33 data was available as the procedure is relatively new. *Conclusion:* Practitioners may be faced
34 with pressure to provide unproven treatments in future and should be understanding but
35 evidence-driven when supporting multiple sclerosis therapies.

36

37 **INTRODUCTION**

38 Multiple sclerosis (MS) is a progressive demyelinating disease of the brain and spinal cord
39 [1] and is the most common neurological condition that has a disabling effect on young and
40 middle-aged adults [2]. There is currently no known cure for MS. Interventions used to treat
41 MS are typically pharmaceutical therapies and behavioural strategies. The pharmaceuticals are
42 used for relapse management (the mainstay of which is corticosteroids; [3]), to minimize the
43 course of the disease (using a number of injectable and oral disease modifying therapies), and
44 to manage symptoms of MS (such as fatigue, spasticity, and urinary problems). The
45 behavioural interventions focus on remedial, adaptive and self-management techniques to
46 support daily function. None of the treatments, however, halt the progression or offer a cure
47 for MS. As a result, people are looking to alternative beneficial treatments.

48 In 2009, it was proposed by Zamboni et al. [4] that MS may be caused by, or significantly
49 associated with, stenosis of the extracranial venous drainage system- known as chronic
50 cerebrospinal venous insufficiency (CCSVI). It was suggested that percutaneous transluminal
51 angioplasty of the extracranial veins that treated CCSVI was an effective alternative
52 treatment for MS – even go as far as terming it “Liberation treatment”. To support this
53 alternative treatment, Zamboni et al. [5] carried out an unblinded and uncontrolled trial of
54 CCSVI treatment and reported improved quality of life and disability status in persons with
55 MS. This research received unprecedented media attention and had been referred to as a
56 “medical miracle” by health professionals and patients alike [6]. Since this first study there
57 have been over 100 studies [7-10] undertaken to determine the efficacy of the angioplasty
58 treatment for CCSVI and its impact on MS. Despite the lack of clear evidence of
59 effectiveness, CCSVI-related interventions were offered by private hospitals and clinics
60 globally to people willing and able to pay the costs. Procedures took place outside of clinical
61 trials and resulted in a number of side-effects and significant safety concerns [11]. Social

62 media discussions, campaigns and pressure on the topic were tremendous [12]. Calls for
63 clinical trials and strong lobbying by patients, especially in British Columbia, Canada where
64 the prevalence of MS is very high, [13; 14] resulted in government and private donor funded
65 trials of CCSVI treatment.

66 In a review of the literature on CCSVI and MS, Tsivgoulis et al. [7] found that the majority of
67 studies failed to reproduce the high prevalence of CCSVI in MS initially reported [5].

68 Tsivgoulis et al. [7] were critical of what they called a “*poorly reproducible and clinically*
69 *irrelevant sonographic construct*” (pp: 8) and provided very clear recommendations from
70 their review:

71 “*‘Liberation treatment’ has no proven efficacy, may exacerbate underlying disease*
72 *activity and has been complicated with serious adverse events. ‘Liberation treatment’*
73 *should stop being offered to MS patients even in settings of randomised controlled*
74 *trials, while further unnecessary expenditure of scarce funding resources needs to be*
75 *discontinued*” (pp:8).

76 They recommended instead that clinicians speak to their patients about the dangers of CCSVI
77 treatment and its lack of efficacy. They reported that the sensationalising of the treatment had
78 led to many patients receiving an unnecessary and invasive treatment. Since then, Traboulsee
79 and colleagues [15] conducted an assessor-blinded, case-control, multicentre study and found
80 no link between MS and CCSVI. They used catheter venography (CV), thought to be more
81 sensitive and specific than the ultrasound criteria used by Zamboni et al. [5]. Specifically,
82 they found that 2% of people with MS, 2% of unaffected siblings, and 3% of unrelated
83 controls tested positive for CCSVI. Overall findings of the trial [16], do not support the
84 CCSVI theory. They found no difference between controls and people with MS in terms of
85 narrowed neck veins. They also reported that compared to CV, magnetic resonance

86 venography has poor interobserver agreement and poor specificity. Siddiqui et al. [17]
87 reported results of a safety and efficacy double-blinded trial of venous angioplasty in people
88 with MS. They concluded that the intervention was not effective and should not be used as it
89 may exacerbate underlying disease activity. Bourdette and Cohen [18] echoed the sentiment
90 of Tsivgoulis et al. [7] and Siddiqui et al. [17], and referred to the venous angioplasty for
91 treatment of MS as an “*ineffective treatment that is based on an incorrect theory*” (pp:388).
92 Regardless of the results of the trials, the significant lobbying efforts and the ability to gain
93 momentum was partly made possible by social media, and demonstrates the power and
94 influence of social media on current research priorities [12; 19].

95 Ghahari and Forwell [20] examined the social media movement (specifically on
96 <http://www.youtube.com>) for messages regarding CCSVI treatment. The study was initiated
97 immediately following the 2009 airing of an episode about CCSVI on “The Fifth Estate”, a
98 weekly television programme on the national broadcaster Canadian Broadcasting Centre
99 (CBC). The authors reviewed YouTube videos for the period of December 2009 to July 2011,
100 and found that strong positive views were reported by people with MS. Furthermore, they
101 found that health professionals who were commenting on the procedure were largely positive
102 in their reports. They also observed that the initial burst of positivity towards the treatment
103 was maintained to the end of the study period of 2011. There appears to be limited
104 examination or follow-up on the current views of people with MS regarding the treatment,
105 given the overwhelming evidence against its use [19]. This is important given the influence
106 that social media reports can have on patients – social media is being used more and more for
107 supplementing information provided by health care professionals and for interacting with
108 peers about health-related concerns.[21]. This study, therefore, aimed to understand the view
109 of patients about CCSVI since 2011. This study is important for health professionals in order
110 to be aware of current health care trends with patients with MS.

111 The objective of the study was to determine if people with MS continue to report benefits of
112 CCSVI treatment on YouTube, and if perspectives have changed. We had two key research
113 questions.

- 114 1. What message was conveyed through YouTube on CCSVI and its treatment?
- 115 2. How does this message and volume of videos being uploaded compare to the
116 previous study [20]?

117

118 **METHODS AND PROCEDURES**

119 This study used a longitudinal design. Data was collected from YouTube between August
120 2011 and January 2019. YouTube was selected as the preferred social media platform as it
121 allows for the examination of videos of varying lengths, it can be used to track progress if
122 multiple videos are uploaded over time and it is free to use and to upload onto. Using videos
123 over written testimonials (e.g. blogs) allows for more objective measure of function, although
124 caveats to this exist as it is still possible to falsely report through the medium of video. This
125 research is primarily quantitative in nature but includes aspects of qualitative methodology
126 used to analyse messages in the videos collected.

127 For the data collection the methodology from Ghahari and Forwell [20] was used. This was to
128 allow for comparisons between the datasets. First, data from videos were collected. This
129 included all data presented in the video – visual, audio and written information. Second, the
130 collected data were classified using a pre-defined codebook (see data analysis for details).
131 Third, the dominant messages from the collected data were extracted using the discourse
132 analysis.

133 Unlike Ghahari and Forwell [20] who looked at people with MS and HCP, here we only
134 interested in the perspective of people with MS, because they were driving the demand for

135 research and treatment of CCSVI. For this reason, only videos uploaded by people with MS
136 were included.

137

138 ***Data collection***

139 All videos were sourced through <http://www.youtube.com/> between August 2011 and January
140 2019. Search terms included “CCSVI”, “*chronic cerebral spinal venous insufficiency*”,
141 “*liberation therapy*”, “*liberation and MS*”, “*Zamboni treatment*” or a combination.

142 To answer our research questions, we conducted a rigorous review in order to collect two
143 sets of data.

144 1. Set 1- a search was carried out for videos uploaded between August 2011 to
145 January 2019 by persons with MS (n=224) who had previously uploaded
146 videos from November 2009 to July 2011 as identified by Ghahari and
147 Forwell [20] dataset.

148 2. Set 2- we searched for videos uploaded by persons with MS who had uploaded
149 videos between August 2011 and January 2019 but were not in dataset by
150 Ghahari & Forwell [20].

151 Inclusion criteria: All included videos had pre and post CCSVI treatment results; included
152 person with MS; and were in English.

153 Exclusion criteria: Videos were not included if they were conference proceedings, television,
154 radio programmes or promotional videos, or were uploaded by patients who were also
155 specialists, as no health professional videos were included.

156 We searched the dataset from Ghahari and Forwell [20] (n=224) on YouTube for new videos
157 that had been uploaded since the previous study [20] ended (August 1st 2011- January 30th
158 2019). We found 52.7% (118) of people had not uploaded new videos related to CCSVI, or

159 had removed the videos that were previously available to view, or made them private. 106
160 people had uploaded (at least one) new video after August 2011.
161 Through coding of the videos for the 106 people, another 76 were excluded for reasons such
162 as the videos being a public presentation, or about a different treatment (see Figure 1). Only
163 videos describing patient progress following CCSVI treatment were included, leaving a total
164 of 30 videos (from 30 people). This constituted set one data. Some people had uploaded
165 multiple videos (range 1-67) but in order to have equal representation from each person the
166 last video uploaded was chosen for extraction and analysis in the case of multiple uploads
167 (one video per person).

168 [Insert Figure 1 approximately here]

169 Set two data included videos uploaded by persons with MS who had not previously uploaded
170 videos prior to July 2011. Videos uploaded from August 1, 2011 to January 30, 2019 were
171 extracted. The total search results provided 669 videos, of which 645 videos were excluded
172 for the following reasons: 273 were not in English; six were not related to CCSVI/MS; four
173 persons did not have MS; 276 were conference proceedings/ promotional videos (210
174 conference proceedings were reported in the study by & Forwell [20]) ; seven were outside of
175 the time of the search; 12 had no information given on pre/post CCSVI; 43 were duplicate
176 videos; seven were television/radio programmes; and 17 were multiple uploads.

177 This search left a final sample of 24 videos (from 24 people; one video per person was
178 extracted for analysis to allow for balanced representation) related to patient experience of
179 CCSVI treatment.

180

181 ***Instrument***

182 Videos were coded using a pre-defined codebook. The codebook was developed based on
183 that used by Ghahari and Forwell [20]. The codebook was pilot tested on 10% of videos.
184 After the pilot and discussion between the raters, the codebook was adapted for use in this
185 study. It consisted of a list of 29 individual symptoms. If the codes were reported by less than
186 two person with MS they were collapsed into one category and coded as “Other”. Coding by
187 symptom was categorised as “Decrease in function”, “Improvement”, “No
188 change/fluctuation”, “Not reported” as it was evident from watching the video. Other details
189 such as time since angioplasty procedure, whether the person had multiple procedures,
190 mobility status, change in work status or leisure participation were recorded. Raters were
191 asked to rate the overall message in the video as “Positive”, “Negative”, “Neutral” or “None
192 of the Above” and to provide a statement by the person with MS to justify this. Inter-rater
193 reliability between the two raters was assessed on 20% of videos at the beginning of the
194 analysis process. The percent agreement statistic is reported here as it is directly interpretable.
195 We acknowledge its limitation in not accounting for the possibility that raters guessed on
196 scores which may lead to an over-estimation of the true agreement [22]. Taking that into
197 account it has been recommended as being a reliable determinant of interrater reliability
198 when raters are well trained and little guessing is likely to exist [22] which is true here. We
199 set a minimum acceptable level at above 75% agreement with 90% being considered high
200 [23]. Agreement of 94% was achieved here and was considered high.

201

202 ***Data analysis***

203 Once all videos were extracted they were compiled and analysed as one group (set one + set
204 two). Categorical data relating to video length and number of uploads were entered into and
205 analysed using SPSS (IBM, version 22). Comparisons with videos by Ghahari and Forwell
206 [20] was also carried out using SPSS.

207 Two raters were involved in the analysis of the videos. One rater had no background
208 knowledge of MS and the other rater was a researcher who was a health care professional.
209 Messages from the videos were analysed using discourse analysis [24; 25] in order to identify
210 the overarching messages within the videos. Discourse analysis was used in the previous
211 study [20] and was shown to be an effective method for approaching data from social media
212 as it allows for individual and group/public discourse. The use of language is of concern and
213 an interpretative analysis of the data took place [25] in order to find themes within the video
214 data.

215

216 ***Ethical Approval:***

217 This study was exempt from ethical approval as all data used was publicly available and no
218 data was directly collected from participants.

219

220

221 **RESULTS**

222 This study included 30 videos in set one and 24 videos in set two, giving a total of 54 videos
223 (from 54 people).

224 ***Key Messages in the videos***

225 Sixty-three percent (34) of videos by persons with MS gave a positive report of the treatment,
226 13% (7) were negative, 13% (7) videos did not provide a clear opinion on the treatment and
227 11% (6) of videos did not provide a view.

228 Following CCSVI treatment, 8% people had returned to full-time work/education; 2% had
229 returned to part-time work/education; and 90% did not report on this. No change in leisure
230 activities was reported by 84% of people, while 16% of individuals reported either taking up

231 new hobbies or being able to participate in hobbies they had not been able to enjoy for some
232 time. The list of hobbies was as follows: working out, gardening, fishing, watching movies,
233 holding pet birds, running, camping, cycling, and horse-riding. People did not always explain
234 why they had not previously been able to participate in that leisure activity, e.g. watching
235 movies. This aspect was not reported in the earlier study [20] but there was an improvement
236 immediately (<1 month) post-CCSVI reported in 12.5% of people in the area of “Activity
237 Participation” which may have encompassed leisure, work and education.
238 Changes in individual symptoms were reported by many people. Overall there were 29
239 symptoms listed in the codebook. Of these only eight symptoms were reported by two or
240 more people, as well as reports of whether an increase in function, decrease in function or no
241 change was reported. These results are shown in Table 1.

242

243 [Insert Table 1 approximately here]

244

245 The most common symptoms that were reported to have improved were overall health,
246 balance, strength and stiffness; while interestingly they were also the most commonly
247 reported symptoms to have worsened. People also noted how they were mobilising but it was
248 not always clear if this signified an increase or decrease in function, or if there had been no
249 change. 26% of people were mobilising independently, 8% reported running, 6% were using
250 a cane, 10% were using a wheelchair, 10% were using a walker and 40% did not report how
251 they were get around.

252

253 *Changes in volume and characteristics of videos*

254 During the study period of 89 months and an average of 0.61 people with MS uploading
255 CCSVI videos each month. Ghahari and Forwell [20] had 224 persons with MS uploading

256 videos over 22 months which was 10.18 people each month uploading CCSVI videos. This
257 equates to a decrease of 94% in the number of people uploading videos in the current study
258 compared to in Ghahari and Forwell [20].

259 A total of 399 videos had been uploaded by the 54 people included in the study. These
260 persons with MS uploaded a mean of 7.39 videos (SD 12.2) each with a range of 1-67 videos
261 uploaded by each person as shown in Figure 2.

262

263 [Insert Figure 2 approximately here]

264

265 The mean time between uploading their first and last CCSVI video was 558.3 days (SD
266 611.8). The standard deviation here indicates quite a large variance in the length in time with
267 a range of between 0 (for people who only uploaded one video) and 2920 days. Some people
268 had uploaded their CCSVI video on the day that they had their surgery while others, the
269 video was uploaded much later (range 0-1465 days). The mean time since CCSVI treatment
270 was 535.9 days (SD 488.4). The average length of each video was 7 minutes 12 seconds with
271 a range of 53:16-01:14.

272

273 ***Describing the CCSVI experience***

274 Although the majority (63%) of the reports of CCSVI treatment were positive, the overall
275 commentaries were often conflicting and not always supportive of the treatment. It is also
276 evident that even the comments that are unsupportive of the treatment continue to have a
277 positive spin, as demonstrated in the following:

278 *“I haven't been able yet to experience the fabulousness that I know is going to come”.*

279 [26]

280 This optimistic view of the treatment was also seen in a number of people who reported
281 positively on their second treatment, even if the results from the first treatment were quite
282 poor. Some people reported on their initial improvement of function, even when this was
283 followed by a gradual decrease in function.

284 There were comments related to the treatment that could not be categorised as “positive” or
285 “negative”. This was the case when a video reported no change. One person described the
286 period following her treatment as:

287 *“The best six months of my life but as we know people are re-stinosing”*. [27]

288 This indicates that she had positive results but they were short-lived. There was some caution
289 reported, emphasising that the treatment might not be effective for everyone:

290 *“Obviously the biggest caveat to the whole thing is that it does not work for*
291 *everybody but for those that it does, it brings hope into a pretty bleak future when all*
292 *else has failed.”* [28].

293 Not all people with MS provided commentary on their view of their improvements, some just
294 videoed themselves completing various tasks or exercises.

295 Of the 54 videos, 16% had a second angioplasty procedure and 4% had a third or fourth
296 procedure, while 34% were recommending alternative treatments (see Table 2). The most
297 common treatments were related to either changing diet (suggested in six videos) or having a
298 stem cell transplant (suggested in five videos).

299

300 [Insert Table 2 approximately here]

301

302 **DISCUSSION**

303 The objective of this study was to examine what message is being conveyed through
304 YouTube on CCSVI and its treatment and how this compares to previous research [20]. The
305 study results found a change in the volume of messages being uploaded on the topic but not
306 necessarily a change in the message being conveyed. The messages on the topic do, however,
307 appear to be more moderated in comparison to the previous study [20].

308 We found a rather conflicting message regarding CCSVI treatment, as presented by people
309 with MS on YouTube. There are still positive results being reported about CCSVI treatment
310 by the YouTube users with MS who were included in this study. Viewed alone, this would
311 suggest positivity about this treatment still exists after ten years since this treatment first
312 received its publicity in both scientific and popular media [4; 5]. There are, however, many
313 other factors to consider before making such assumptions.

314 The first thing to consider is the volume of videos being uploaded has decreased significantly
315 – 94% fewer videos can be found online in recent years of people with MS who are reporting
316 on their CCSVI treatment than before August 2011 [20]. Prior to when this search was
317 conducted CCSVI was a very hot topic, such that public interest in the treatment grew rapidly
318 during the first year [12]. As with all new trends, a fall-off in interest is to be expected but as
319 this particular movement had such a powerful following and strong online presence it is
320 striking that this fall-off has been so significant. There are several suggestions as to why this
321 may be. It could be that people campaigning for trials in CCSVI have had their requests
322 granted. Randomised controlled trials of the treatment are being conducted in numerous
323 locations, including a multi-centre trial of balloon angioplasty in Canada (ClinicalTrials.gov
324 Identifier: NCT01864941) [29] which was largely due to strong public pressure. People may
325 be satisfied that their views have been considered and acted upon and no longer see the need
326 to use social media as a campaigning tool.

327 Another reason why there may be fewer videos being uploaded may be that people who have
328 had the treatment have stopped uploading videos as they are now too busy in their daily lives
329 to be making videos like before. This, however, does not account for the drop in before/after
330 videos as this should also have been the case when the treatment was new, circa 2009. It may
331 justify the lack of videos reporting long term benefits of treatment, since people may not want
332 to spend time reporting on their treatment as they are living their lives. There are very few
333 videos reporting on the results of CCSVI treatment two years or more post-surgery. This
334 could also be because the results have not been encouraging and people may be less likely to
335 report on negative results. If this was the case then it would be similar to the results of
336 clinical trials that have been reported on to date [17]. It may also be that given the results of
337 RCTs, patients are not putting themselves at undue risk by having the procedure. Bourdette
338 and Cohen [18] go so far as to recommend the end of all investigations of the treatment as
339 they are confident that it is ineffective and it is “*placing participants at risk of complications*
340 *without a reasonable hope of benefit*” (pp: 388). Now that the data exists it is likely that
341 people are considering the results when making health decisions.

342 Secondly, although 63% of comments made by people with MS about specific symptoms are
343 positive, the overall comments in many cases are contradictory and not supportive of
344 treatment. People reported on the benefits that they derived from the treatment but this was
345 often followed by a statement indicating that the benefits were no longer present. Similar to
346 the results seen here, in a group of participants in Canada interviewed 24 months post-surgery
347 there was an initial reporting of improvements but these improvements were reported not to
348 have been sustained over time [30]. Additionally 11% of participants reported complications
349 during the surgery and a further 17% reporting complications within a month of surgery. In
350 this study we found very little discussion around safety when people spoke about their
351 experience of the treatment or their decision to have it. In the previous study [20] people were

352 in fact mentioning safety concerns following the news of the deaths of two Canadians who
353 had the procedure. There has, in more recent research, been some discussion around the risks
354 associated with the treatment by patients themselves [30].

355 Interestingly, health, balance, strength and stiffness were both the most commonly reported
356 symptoms to improve and worsen following CCSVI treatment. This suggests that CCSVI is
357 not having consistent effects on people's health. Expectations of the treatment do seem to
358 have diminished somewhat and there is more caution when people are reporting on results.
359 Although 63% of people have reported improvements in function in the current study, this is
360 down from 86% found by Ghahari and Forwell [20]. Finally, other treatments are now being
361 suggested by people either in combination with or instead of CCSVI treatment. Some of the
362 suggested treatments are invasive (e.g. stem cells) but several are not (e.g. exercise and diet
363 change).

364 As is the case with any study of this nature, there are inherent limitations to the generalisation
365 of the findings. It is important to keep in mind that what is being reported on is data obtained
366 from YouTube videos reporting on CCSVI treatment for MS. We do not claim that these
367 results are reflective of all people who have had the treatment or that they report on the
368 effectiveness of the treatment. We are reporting solely on the trends in YouTube discussions
369 around CCSVI treatment and MS on YouTube.

370 Some of the challenges that come with this type of research include difficulties with carrying
371 out accurate searches as videos may be removed or made private and restrictions exist on the
372 website for filtering irrelevant material. Also, reporting bias cannot be controlled for. There
373 appeared to be a positive reporting bias in the videos that were uploaded, since many videos
374 (which did not meet our inclusion criteria) were labelled "Pre-CCSVI" but were not
375 followed-up with "Post-CCSVI" videos. There could be a number of reasons for this but the

376 pressure to report positively or not report at all could have been a key factor here. Missing
377 data is a limitation of this type of research as people are reporting on many different issues.
378 Having consistent data and getting clear answers to the research questions of interest is not
379 possible with this type of retrospective study. It is also not possible to carry out a formal
380 analysis of the commentaries given by people as no interview schedule was followed, and if
381 attempted, data could be easily skewed. Given the limitations of this study it was important
382 that a consistent approach to analysis was taken and an analysis plan that included
383 development of a codebook, which ensured high inter-rater reliability, was followed by
384 authors prior to beginning analysis.

385

386 **CONCLUSION**

387 While YouTube videos uploaded by people with MS have shifted in volume and, to some
388 extent, message, it appears that at least online the debate regarding this controversial
389 procedure continues. The impact of these discussions for HCP and people with MS needs to
390 be acknowledged in light of the availability of risky treatments abroad. Longer-term results of
391 CCSVI treatment have been scant and for many disappointing, but positive short-term results
392 are still being reported by YouTube users.

393 Although the focus here was on the YouTube platform, various forms of social media appear
394 to play a key role in health decision making for many people with MS. Health care
395 professionals need to be aware of this and encourage debate and discussion around treatment
396 options with patients. They may be faced with pressure by patients to provide unproven or
397 experimental treatments in the future. It is important that health care professionals be
398 understanding of the patient perspective but also evidence-driven when supporting therapies
399 in MS.

400

401 **DISCLOSURE OF INTEREST**

402 The authors report no conflicts of interest.

403

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409

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501 **TABLE 1** Examples of symptoms being reported by people with MS in YouTube videos.

Symptom	Not reported	No Change	Decreased function	Improved function
Overall Health	24 (44%)	8 (15%)	7 (13%)	15 (28%)
Balance	34 (63%)	1 (2%)	5 (9%)	14 (26%)
Strength	37 (69%)	0 (0%)	6 (11%)	11 (20%)
Stiffness	39 (72%)	0 (0%)	5 (9%)	10 (19%)
Clear Head	47 (87%)	0 (0%)	3 (6%)	4 (7%)
Pain	42 (78%)	2 (4%)	4 (7%)	6 (11%)
Fatigue	41 (76%)	0 (0%)	4 (7%)	9 (17%)

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506 **TABLE 2** Alternative treatments being suggested by people with MS in YouTube videos.

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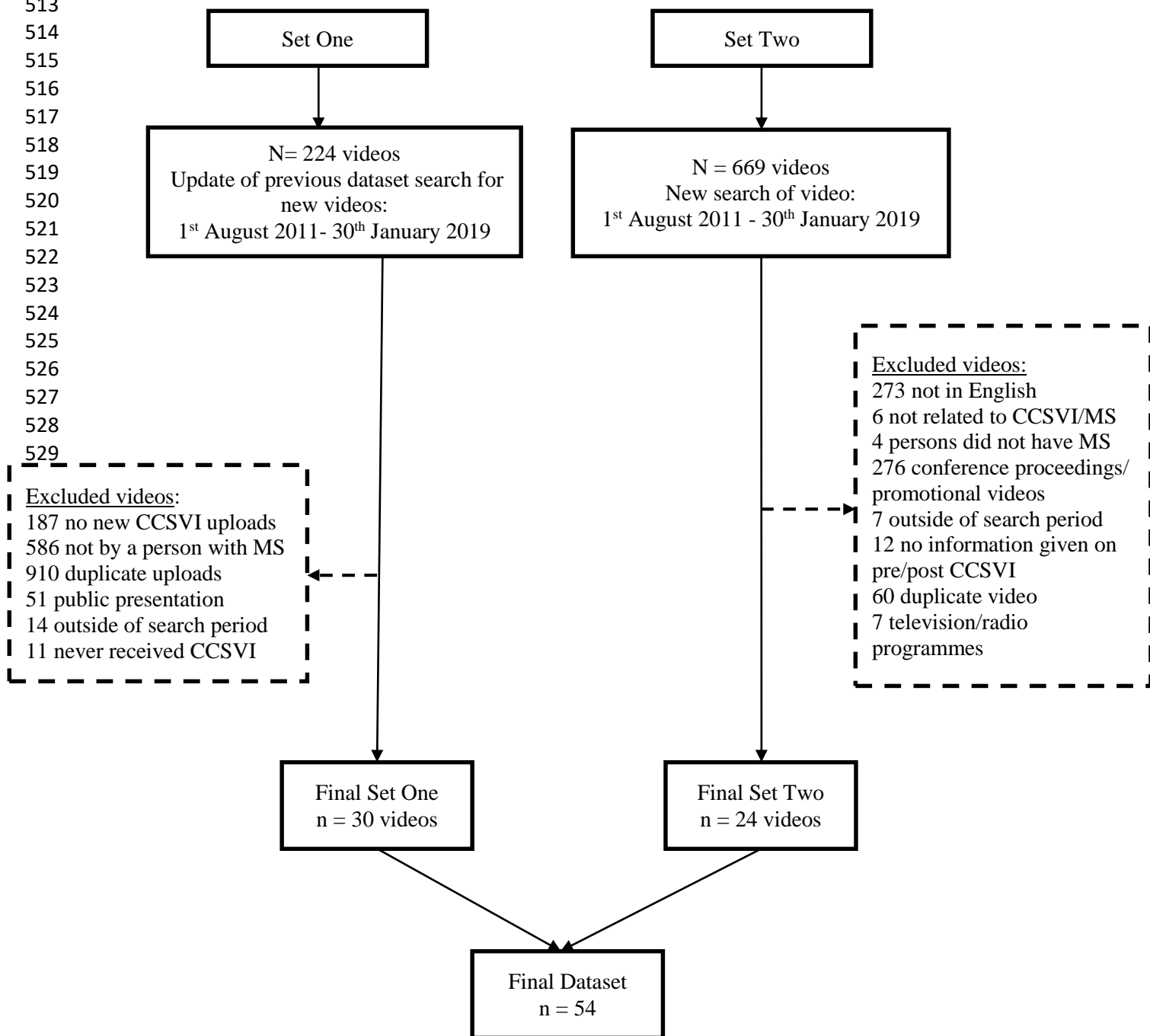
Treatment	Number of videos	Details
Diet change	6	Vegan Diet Terry Wahl's Diet Paleo Diet Gluten-free Diet
Stem cell	5	Stem cell
Other	6	Acupuncture Exercise Medication change
Not reported	33	

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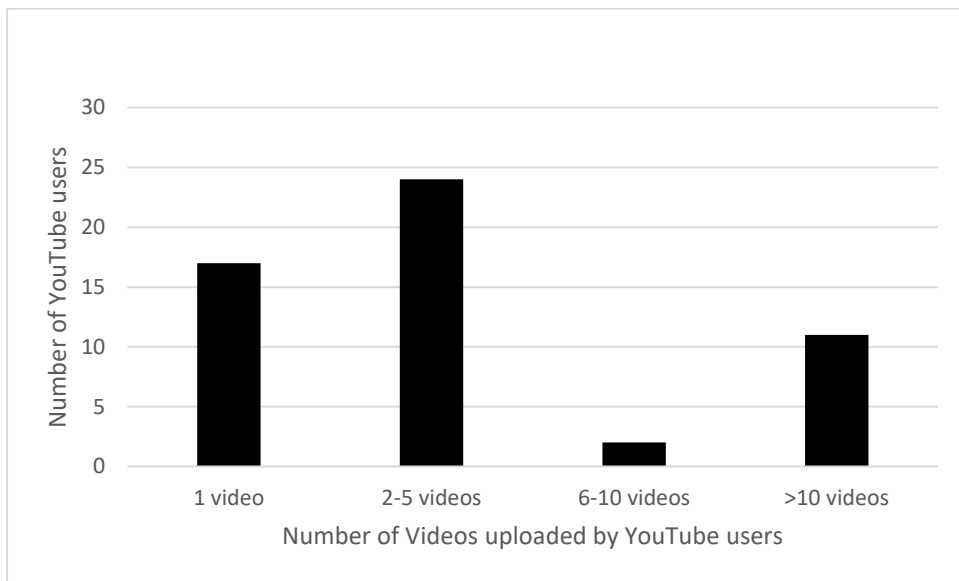
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511 **FIGURE 1** Flow diagram of videos included in the study.
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FIGURE 2 *Number of videos uploaded by person with MS in the study.*



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