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| Title | "Waiting for Science to Catch up with Practice": an examination of 10-year YouTube trends in discussions of chronic cerebral spinal venous insufficiency treatment for multiple sclerosis |
| Author(s) | Hynes, Sinéad M.; Ghahari, Setareh; Forwell, Susan J. |
| Publication Date | 2019-03-26 |
| Publication Information | Hynes, Sinéad M., Ghahari, Setareh, & Forwell, Susan J. (2019). "Waiting for Science to Catch up with Practice": an examination of 10-year YouTube trends in discussions of chronic cerebral spinal venous insufficiency treatment for multiple sclerosis. Informatics for Health and Social Care, doi: 10.1080/17538157.2019.1582052 |
| Publisher | Taylor & Francis |
| Link to publisher's version | https://doi.org/10.1080/17538157.2019.1582052 |
| Item record | http://hdl.handle.net/10379/15072 |
| DOI | http://dx.doi.org/10.1080/17538157.2019.1582052 |

Downloaded 2024-04-26T20:03:13Z

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Title: “Waiting for Science to Catch up with Practice”: Examination of ten-year YouTube trends in discussions of chronic cerebral spinal venous insufficiency treatment for multiple sclerosis.

Running Head: YouTube Discussions of CCSVI Treatment for MS

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

Affiliations:

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

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

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

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

ABSTRACT

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

INTRODUCTION

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

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

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

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

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

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

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

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

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

METHODS AND PROCEDURES

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

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

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

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

Data collection

All videos were sourced through <http://www.youtube.com/> between August 2011 and January 2019. Search terms included “CCSVI”, “*chronic cerebral spinal venous insufficiency*”, “*liberation therapy*”, “*liberation and MS*”, “*Zamboni treatment*” or a combination. To answer our research questions, we conducted a rigorous review in order to collect two sets of data.

1. Set 1- a search was carried out for videos uploaded between August 2011 to January 2019 by persons with MS (n=224) who had previously uploaded videos from November 2009 to July 2011 as identified by Ghahari and Forwell [20] dataset.
2. Set 2- we searched for videos uploaded by persons with MS who had uploaded videos between August 2011 and January 2019 but were not in dataset by Ghahari & Forwell [20].

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

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

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

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

[Insert Figure 1 approximately here]

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

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

Instrument

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

Data analysis

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

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

Ethical Approval:

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

RESULTS

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

Key Messages in the videos

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

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

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

[Insert Table 1 approximately here]

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

Changes in volume and characteristics of videos

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

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

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

[Insert Figure 2 approximately here]

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

Describing the CCSVI experience

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

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

[26]

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

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

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

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

“Obviously the biggest caveat to the whole thing is that 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.” [28].

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

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

[Insert Table 2 approximately here]

DISCUSSION

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

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

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

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

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

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

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

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

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

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

CONCLUSION

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

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

400

401 **DISCLOSURE OF INTEREST**

402 The authors report no conflicts of interest.

403

404 **ACKNOWLEDGEMENTS**

405 This research is funded in part by a National MS Society Post-doctoral Fellowship Award

406 No. MB 0016.

407 Thanks to Amy Villablanca who assisted with the study through data cleaning and analysis of

408 videos. Thank you to Sara Morassaei for her helpful comments on the paper.

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

| 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 | |

FIGURE 1 Flow diagram of videos included in the study.

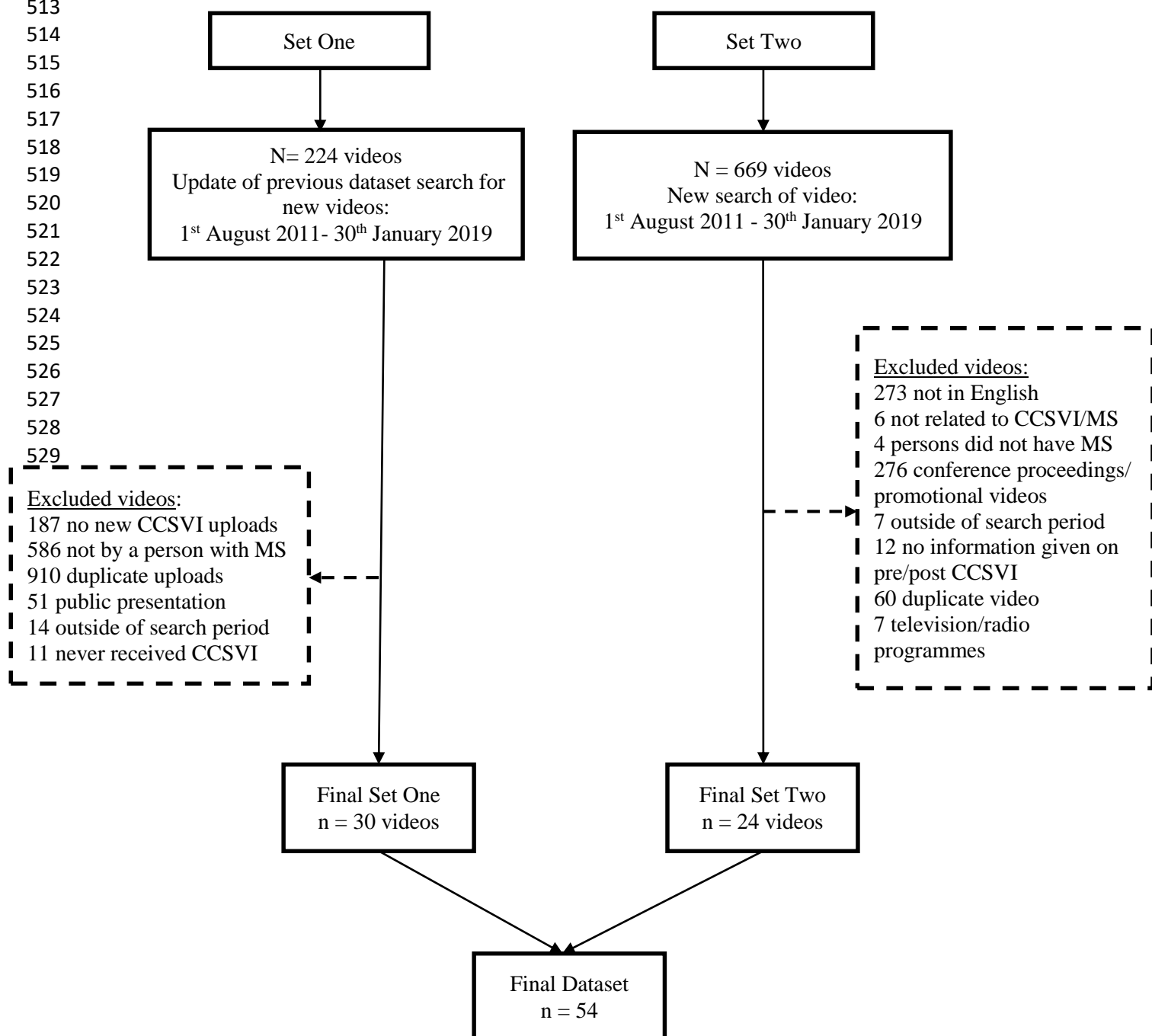


FIGURE 2 *Number of videos uploaded by person with MS in the study.*

