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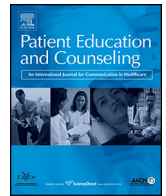
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“People power” or “pester power”? YouTube as a forum for the generation of evidence and patient advocacy[☆]



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ABSTRACT

Objective: Venoplasty has been proposed, alongside the theory of chronic cerebrospinal venous insufficiency (CCSVI), as a treatment for multiple sclerosis (MS). Despite concerns about its efficacy and safety, thousands of patients have undergone the procedure. This paper analyses YouTube videos where patients have shared their treatment experiences.

Methods: Content analysis on the 100 most viewed videos from over 4000 identified in a search for ‘CCSVI’, and qualitative thematic analysis on popular ‘channels’ demonstrating patients’ experiences.

Results: Videos adopt an overwhelmingly positive stance towards CCSVI; many were uploaded by patients and present pre- and/or post-treatment experiences. Patients demonstrate rather than merely describe their symptoms, performing tests on themselves before and after treatment to quantify improvement. Videos combine medical terminology and tests with personal experiences of living with MS.

Conclusion: Social media technologies provide patients with novel opportunities for advocating for particular treatments; generating alternative forms of ‘evidence’ built on a hybrid of personal experience and medical knowledge.

Practice implications: Healthcare practitioners need to engage with new digital forms of content, including online social media. Instead of disregarding sources not considered ‘evidence-based’, practitioners should enhance their understanding of what ‘experiential-evidence’ is deemed significant to patients, particularly in contested areas of healthcare.

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1. Introduction

The internet is frequently discussed as having the potential to revolutionize healthcare. Yet the impact that internet technologies have on people’s health, clinical practice and policy remains unclear. The emergence of the internet as a resource for health information and services has had a mixed reception. It has been hailed as a catalyst for increased patient power, more efficient and effective healthcare [1–4], while concern has been expressed about potential harm due to incomplete or incorrect information [5,6].

Two of the main challenges of studying and designing health-related internet technologies are the speed of technological change, and the diversity of tools, health conditions and contexts.

Broad conclusions, either negative or positive, about the consequences of information technology for health are rarely accurate [7–9]. Instead, detailed analyses of the actual use of particular technologies in particular contexts are required. In this paper we draw on the specific case of YouTube use by patients in relation to a contested theory and treatment for multiple sclerosis (MS) – chronic cerebrospinal venous insufficiency (CCSVI) and the ‘liberation’ procedure – to contribute to discussions on the interaction between internet use and health.

1.1. Multiple sclerosis, CCSVI and the internet

MS, a disorder of the central nervous system, is the most common neurological condition to affect young adults [10]. A number of theories have been investigated to explain the cause of MS, and it is acknowledged that it is a complex condition with multiple aetiological factors implicated, both genetic and environmental. It is widely accepted that MS is an autoimmune disease where the body’s immune system mistakenly attacks the myelin sheath around the nerves in the brain and spinal cord. This demyelination results in diverse symptoms, including visual disturbance, balance and bladder problems, stiffness and loss of

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mobility, cognitive and emotional changes, and, in many cases, permanent disability [10].

In 2006, Italian physician Paolo Zamboni proposed abnormalities in cerebrospinal blood drainage as a possible aetiology for MS [11]. He termed this chronic cerebrospinal venous insufficiency (CCSVI) and suggested that venous angioplasty (venoplasty) of the azygous and jugular veins – referred to as the ‘liberation procedure’ by some of its supporters – might improve symptoms and slow disease progression [12]. Although vascular theories of MS are not new [13], this proposition has been met with both excitement and concern.

Despite the novelty of the research, between 2009 and 2012 thousands of patients across the world underwent venoplasty for CCSVI, sharing their experiences on online social media platforms, including blogs, forums, Facebook and YouTube. This extensive use of social media is frequently mentioned as a key feature of CCSVI patient activism [14,15], and has been criticized as ‘internet-based practice’ in lieu of ‘evidence-based science’ [16]. In spite of the frequent references to CCSVI-related internet use in academic journals and the media, there has been no in-depth study of how people who have had the ‘liberation’ procedure actually use internet technologies and what makes this use so compelling. In this paper we analyze YouTube to explore: (1) how patients use video to share their experiences and opinions of the ‘liberation’ procedure; (2) suggest how healthcare professionals and other relevant parties can respond to this.

1.2. Research on health-related YouTube videos

YouTube is a popular video sharing platform started in 2005. Originally designed to host user generated content, it is now a space where over 4 billion videos are shared on a daily basis by organizations, advertisers, and other broadcasters. A considerable number of health-related videos are available on YouTube, many are produced by charitable organizations, healthcare providers, universities, and commercial organizations; others by individuals affected by, or with a particular interest in, a given condition.

A number of studies have been conducted on health-related YouTube videos: immunization [17–19]; cancer [20,21]; smoking [22,23]; non-suicidal self-injury [24]; partial asphyxiation [25]; epilepsy [26]; cardiopulmonary resuscitation [27]; the H1N1 influenza pandemic [28]; kidney stone disease [29]; organ donation [30]; and multiple sclerosis [31]. The majority of this research is quantitative analyses of videos, user comments and, depending on research interest, demographic information such as number of views, dates uploaded, country of origin, etc. Moreover, they typically focus on assessing whether the videos are ‘useful’ or ‘misleading’ to the public or whether a particular medical intervention or treatment is portrayed ‘positively’ or ‘negatively’.

The conclusions drawn in this work varies and is often specific to the context being studied, but two key themes are of particular relevance here. The first is the prominence of videos focused on people’s experiences. The second is the advice given to healthcare professionals in relation to these videos. In almost all cases the authors suggest that healthcare practitioners need to be aware of these videos and be prepared to respond to patients’ questions about them; that they should engage more actively with this content and where necessary take appropriate measures to minimize the effect of harmful information. In contrast to our own study, most of this literature starts with a priori assumptions about which sources are to be trusted and what is considered ‘useful’ or ‘good’ information. Here, however, we are not interested in assessing the medical accuracy of the CCSVI-related information available on YouTube, but in unwrapping how different forms of evidence are produced in patient-generated videos.

2. Methods

In January 2012 the YouTube search facility was used to retrieve all the videos identified by the search term ‘CCSVI’. Over 4000 videos were returned and the 100 most viewed selected for further analysis. While the number of views does not indicate the number of unique users who see the video, in the absence of more specific metrics this is used as a rough indicator of video popularity. The top 15 videos were analyzed by all three authors. Each author developed their own coding scheme that categorized the videos based on its source, content and how CCSVI was portrayed. After discussion, a combined coding scheme was agreed on. This categorized the videos as either a ‘patient’ or ‘non-patient’ video. A ‘patient’ video focused on the experiences or thoughts of a particular person with MS, while a ‘non-patient’ video was any video that discussed CCSVI in other ways. In addition, categories were developed to classify the content of the videos (e.g. a news report, information and personal thoughts, fundraising) and to assess whether CCSVI (either as a theory or the ‘liberation’ treatment specifically) was portrayed positively, negatively, neutrally or ambiguously.

Two authors (F.M. and B.G.O.) coded the top 100 videos. The first 50 videos were coded separately. Based on this, the categories were refined to ensure that, as much as possible, they were exhaustive and mutually exclusive [32]. Second, the remaining 50 videos were coded using the updated categories. Third, all the videos were re-coded and any discrepancies resolved through discussion. This resulted in the ‘patient’ videos being broken down into one of nine inductively derived categories: informational and personal thoughts; pre CCSVI videos; post CCSVI videos; pre/post video combinations; procedures in clinic; medical images; promotional material; advocacy/fundraising; thank you. Where possible, gender, type of MS and medical treatment, was recorded for each ‘patient’ video. The ‘non-patient’ videos were broken down into five inductively derived categories: medical demonstrations; news reports; conference presentations; promotional material; educational material. Title, channel, number of views, date uploaded, country of origin (if possible), was recorded for all the videos. The results of this are presented in Table 1. Coding was consistent across both coders with a basic percentage agreement inter-coder reliability of 90% [33]. During the coding process 30 videos were excluded because they: (1) were not about CCSVI – 3 videos; (2) were non-English language (videos with English subtitles were kept, as were 8 duplicate videos of a Canadian documentary as its prominence was deemed significant for our analysis (discussed further below)) – 27 videos. This left 70 videos, with views ranging from 7103 to 79,956.

Next, a qualitative thematic analysis was conducted on the 46 ‘patient’ videos. Some ‘patient’ videos belonged to a ‘channel’. For example, six of the videos analyzed belonged to a highly viewed channel created by one patient. In cases like this, we analyzed the entire channel in order to contextualize the videos. Constant comparison coding that focused on *what* patients said as well as *how* they said it was used. For each video we noted key emergent themes, transcribed portions of the video as relevant, and read the comments posted by viewers.

3. Results

The videos adopted an overwhelmingly positive stance towards CCSVI (67/70: 96%); 66% (46/70) were uploaded by patients, most of which presented pre- and/or post-treatment experiences (30/46: 65%). Of the remaining videos, almost half were news reports (11/24: 45%). Within our sample a Canadian documentary produced in 2009 had been uploaded eight times and translated into several languages (Italian, Polish, and Czech). This video

Table 1
Summary of coding results.

| | | | | | | | | |
|-----------------------------------|-------|----------|----------|--------|------|------------------------------|---------------------------------|-----------------|
| Total number of videos | | | | | | | | 70 |
| Most viewed: | | | | | | | | 79,956 |
| Least viewed: | | | | | | | | 7103 |
| Date of newest upload: | | | | | | | | 01-October-11 |
| Date of oldest upload: | | | | | | | | 11-September-09 |
| Type of video | Total | | Positive | | | Ambiguous | | |
| 'Non-patient' video | 24 | | 22 | | | 2 | | |
| News report | 11 | | 11 | | | 0 | | |
| Medical demonstration | 4 | | 4 | | | 0 | | |
| Conference presentation | 4 | | 3 | | | 1 | | |
| Educational material | 3 | | 2 | | | 1 | | |
| Promotional material | 2 | | 2 | | | 0 | | |
| | Total | Positive | Negative | Female | Male | Describes signs and symptoms | Demonstrates signs and symptoms | |
| 'Patient' video | 46 | 45 | 1 | 29 | 17 | 24 | 19 | |
| Post procedure | 14 | 14 | 0 | 11 | 3 | 12 | 6 | |
| Pre and post procedure combined | 12 | 12 | 0 | 8 | 4 | 3 | 10 | |
| Pre procedure | 4 | 3 | 0 | 3 | 1 | 3 | 3 | |
| Information and personal thoughts | 9 | 9 | 1 | 4 | 9 | 5 | 0 | |
| Advocacy and fundraising | 3 | 3 | 0 | 1 | 2 | 0 | 0 | |
| Medical images | 2 | 2 | 0 | 1 | 1 | 0 | 0 | |
| Procedure being done in clinic | 1 | 1 | 0 | 1 | 0 | 1 | 0 | |
| Promotional material | 1 | 1 | 0 | 1 | 0 | 0 | 0 | |

contained interviews with patients as well as with Zamboni; in our sample it had been viewed 150,666 times across its postings. Thus, in the context of CCSVI YouTube is not only used to share personal experiences but, as evidenced by the popularity of this and other videos, these experiences are located in relation to other YouTube videos that reinforce their primarily positive message.

We found that 'patient' videos could be broken down into three sub-types. The first, 'commercial patient experience' videos, focused on individual patients, but were produced by a third party for promotional purposes. The second, 'personal treatment evidence' videos, focused on the 'liberation' procedure and had one or two pre/post videos directly linked to treatment. The third, 'experiential video diaries', belonged to a YouTube channel where patients produced diaries about living with MS and/or CCSVI. In what follows we focus on this qualitative analysis, but situate it in relation to our wider analysis. These 'patient' videos are a rich source of information and can be analyzed in a number of ways. Our focus is on how 'evidence' is presented and discussed for or against CCSVI and the 'liberation' procedure.

3.1. The power of the visual: demonstrating both signs and symptoms

Many of the most highly viewed CCSVI-related videos presented people's experiences pre and post the 'liberation' procedure. Patients not only described their symptoms and improvements, but also *demonstrated* them, performing physical tests to the camera before and after treatment. Walking and mobility changes were quantified visually, with patients' stepping up and down, jumping, tying shoe laces, walking with and without canes. Pre-treatment and post-treatment videos were frequently filmed in the same place, with the same obstacles (e.g. stairs, benches, foyer of house), aiding the viewer in making a direct comparison.

In addition to physically demonstrating symptoms, patients frequently discussed the 'invisible' symptoms of MS. Chronic fatigue and cognitive dysfunction were notable examples as many patients spoke of them as being improved post venoplasty. Many videos referred to 'brain fog' – a subjective description of cognitive dysfunction characterized by memory loss and a lack of ability to think clearly – as a problem that was alleviated post treatment: 'It's like I have a whole fog of cob webs lifted off' (experiential video

diary; female channel 1: video A). Circulation and sensory changes, and the amelioration of vision difficulties and chronic pain were also frequently mentioned: 'I used to have very cold feet. Freezing feet. And they are warm' (commercial patient experience video; female; channel 2; video A). A wide variety of symptoms were discussed across the videos and while changes post treatment differed greatly, they were usually described as being significant to the patient. Moreover, in cases where the improvement was not what the patient had hoped for (i.e. to be able to walk), CCSVI and the 'liberation' procedure were still usually presented in a positive light.

Whereas *symptoms* – 'a disease manifestation of which the patient complains' [33] – were presented in videos, *signs* were also incorporated (especially in personal treatment evidence videos). There is an important distinction between the two in clinical medicine: signs are 'a manifestation of disease perceptible to an observer' [33] and are generally considered to be indicative of some underlying pathology. Subjectively experienced symptoms differ between people, and are elicited during history taking in the medical encounter; signs are normally elicited during a professional's physical examination. Clinical signs shown in the videos through self-examination performed to the camera included nystagmus (involuntary eye movement), intranuclear ophthalmoplegia (problems in eye adduction often resulting in double vision), and balancing and touching fingertips to the nose.

While the demonstration of signs was of varying success (sometimes tests were performed incorrectly or video quality prevented the viewer actually seeing the result), it is significant that elements of formal neurological examinations were performed as online 'proof' with the video poster sometimes directly referencing and imitating tests typically conducted in clinical contexts, noting, for instance, 'this is what your neurologist will get you to do in his office' (personal treatment evidence video; female, channel 3; video A). Tests such as the Romberg test (a component of a neurological examination that involves standing with eyes closed to test balance) or walking heel to toe to check for gait ataxia were common [10]. Although less frequent, patients drew on disability and quality of life measures to provide a more 'objective' measurement of their improvement (e.g. the Kurtzke Expanded Disability Status Scale [34,35]).

3.2. Medical knowledge: perspectives on medication and medical professionals

In addition to drawing on medical terminology and tests, video posters expressed opinions on the medical profession and the pharmaceutical industry. There was a general expression of dissatisfaction over available MS medication; Ampyra (dalfampridine), Tysabri (natalizumab), Methylprednisolone, 'anti-seizure medications', Lipitor (atorvastatin), Beta-interferon, and Copaxone (glatiramer acetate) were all mentioned. Sometimes medications were presented as part of a pharmaceutical industry conspiracy to make money rather than provide legitimate treatments. In a number of videos it was suggested that neurologists and MS Societies were anti-CCSVI because they derived an income from current pharmacologic treatments:

The neurologists make a lot of money because they prescribe medications, they have to be seen regularly by MS sufferers, so if someone goes to have this CCSVI and he is better off, he feels much better, he doesn't need to see them, he makes no money. I think it's all about money. If it's not about money they should do it everywhere in the world (Commercial patient experience video; male; channel 2; video B).

Interactions and relationships with specific professionals were also discussed. Neurologists were often framed in a negative light, although some patients spoke of cases where their neurologist had been interested and if not supportive, then, at least, accepting of their choices. This was in contrast with the disciplines of vascular surgery and interventional radiology that were typically presented more positively. Interestingly, there was minimal negativity or suspicion regarding the potential conflict of interest amongst those who provide the 'liberation' procedure in our sample. In one exception to this, a man expressed concern about the financial incentive and lack of professionalism of a Polish clinic he had visited. The comments posted in response to this video, were very mixed. Some viewers expressed similar concerns about medical tourism, while others criticized what they perceived as a negative attitude to CCSVI.

3.3. Living with MS: the immediacy of everyday life

A third key theme that emerged from our analysis was the personal and emotional immediacy of the videos. This was especially the case in experiential video diaries, but was evident in the other categories. Patients were frequently filmed in their homes, often with family and friends in the background or behind the camera. Family interactions were described repeatedly, from the initial difficulties to the constant adaptation required as function gradually decreased and they became more dependent on family and loved ones. Although it is possible to video oneself, many videos had a family member behind the camera, who provided off camera narration noting, for instance, how much their family members' functioning had declined. This was juxtaposed in several cases with their commentary after the 'liberation' procedure, for example: 'Oh my god, this is amazing... Pretty darn good... that's crazy!' (personal treatment evidence; male, channel 4; video A). While family members often played a pivotal role in recording the effects of treatment, they also gave the viewer a personal perspective on the patient's life, hopes and expectations, making their experience more 'real'.

What it is like living with MS was presented through descriptions of daily life. One patient, created a humorous, yet poignant, 'day in the life of' video to show the lived reality of MS from her perspective. Aspirations, such as returning to work or engaging in leisure pursuits, were discussed in relation to the restrictions MS placed on these activities. Therefore, when actual

symptoms were described and demonstrated they were done so in the context of a person with a life rather than as an anonymous number in a clinical trial. Moreover, in different channels you can view other videos the channel owner has commented on or provided links to. While often MS related, these included other topics of interest, such as music, pets, humorous videos, and so on. Sometimes, video posters engaged in dialogue with each other, explicitly mentioning other people's videos (again, this was most commonly the case in experiential video diaries), creating a sense of community.

This 'subjectivity' did not weaken the legitimacy of the videos, but, judging from the comments posted in response to them, for many people it strengthened it. For instance, in response to a positive pre/post demonstration video: 'god bless u, i am so happy for u. Im getting liberated in a week and you gave me hope & strength, i was about to choke up lol, god bless u! and i am hoping to join you real soon!' (posted in response to personal treatment evidence video; female; channel 5; video A). Discussion between the video poster and viewers was common and in cases of videos done pre or post 'liberation' this was often requests for information about how the patient was doing, well wishes or exclamations about how the video had inspired them to seek out the procedure. While it is not possible to tell from our analysis if these videos are actually affecting patient decision making, the high number of views and extensive comments they receive indicate that, along with other sources of information, they are playing a role. This suggests that patients were making decisions based, at least in part, on what they see on YouTube and their communication with other patients.

4. Discussion and conclusion

4.1. Discussion

The most viewed CCSVI videos on YouTube were overwhelmingly positive towards the theory and the 'liberation' procedure. This contrasts with the skeptical perspective of many in the medical community, a number of research findings and many national MS societies [36–38]. Zamboni and other researchers have, however, continued to publish positive findings [12][39–41]. While the videos we analyzed were markedly positive, we are not suggesting this be read as an assessment of treatment effectiveness – something that remains contested. Indeed, we recognize that there is a bias towards reporting positive results, both in research and the media [42,43]. What we want to highlight is that many people who feel they have had positive effects from venoplasty have communicated this to other patients in very powerful ways through YouTube. Scepticism of big pharma and a sense of dissatisfaction of the available treatment for MS constituted an important theme in our analysis. However, it is necessary to point out that this was a very selective sample of people who had venoplasty and had chosen to share their experiences online. Also, many of the videos had been uploaded during 2009 and 2010, before some of the more recent and less positive research results had been published. This meant that many of the people posting the videos were early adopters of the CCSVI theory. Moreover, while there were similar themes across all three patient video types, a strong anti-neurologist and pharma sentiment was particularly prevalent in the commercial personal experience videos. The experiential video diaries typically provided a more balanced view, with patients discussing their interactions with various professionals and responses to mainstream MS medication and venoplasty over longer periods of time.

Unlike much existing health-related YouTube research, we have not assessed the 'medical' accuracy of the videos analyzed. Instead we are interested in how particular types of evidence are

constituted through these videos. Three key themes emerged from this: (1) the visual medium enabled vivid depictions of pre and post treatment comparisons, often drawing on medical explanations, terminology and tests adapted from clinical practice; (2) patients not only displayed their own medical knowledge, but discussed current MS treatments, medical professionals and big pharma; (3) videos were situated in relation to people's experiences, conferring a sense of authenticity and personal immediacy. Thus, patients drew on medical knowledge in order to explain and reinforce their message, but, at the same time, their status as patients conferred their thoughts, experiences and, in some cases, advice, with a particular type of authority. The evidence generated through these YouTube videos was, therefore, predicated *both* on the language and practices of contemporary biomedicine *and* personal experiences of living with MS. This was most notably actualized in personal experience diaries, through which trust and legitimacy can be particularly developed, enhancing the strength of the evidence portrayed. Consequently, it is extremely important for further research to explore the effects of this exposure to the combination of scientific and personal information provided by social media.

4.2. Conclusion

YouTube allows the dissemination of vivid examples of symptom relief and functional recovery post treatment (in this case post the 'liberation' procedure). It enables patients to visually and emotively demonstrate physical performance and changes in symptoms, turning their experiences into qualitative and quantitative 'evidence' to 'prove' the effectiveness of different treatments. Social media platforms such as YouTube and Facebook enable the aggregation of individual experiences, creating a database of experiences that patients can draw on. Moreover, the sharing of personal experiences online can be used to advocate for policy changes and to prioritize particular research agendas. The increasingly mainstream adoption of social media technologies means that this type of 'people power' advocacy will likely proliferate and be adopted by other groups looking to disseminate their message [14]. In the case of CCSVI this has led to some patients expressing extreme frustration at the slow speed of research and policy change, while many in the medical establishment have expressed an equal frustration about what they perceive as a hijacking of the MS research agenda – seeing online patient activism as 'pester' rather than people power [16].

4.3. Practice implications

The sharing of health experiences on YouTube is part of a general rise in the sharing of experiences on social networking and other sites that is relevant for health professionals. Rather than simply expressing concern about the use of social media in relation to contested and/or alternative treatments it has become important for practitioners and researchers to engage with this content. In many cases, interested patients will seek out information about new and controversial treatments regardless of what they are told in clinical consultations. Instead of dismissing information they do not consider 'evidence-based', healthcare practitioners need to enhance their understanding of the forms of evidence, especially *experiential evidence*, considered significant to patients.

Previous research has highlighted a gap between what MS patients and clinicians rate as important to them [44]; we noted a similar gap between CCSVI research and patient videos. Whereas much CCSVI research focuses on ascertaining the relationship between venous insufficiency and multiple sclerosis at a physiological level, patients, as demonstrated in these videos, are concerned with whether the 'liberation' procedure improves their

symptoms. Videos contained discussions about aetiology, but this was secondary to the description and demonstration of symptomatic improvement as a way to 'prove' the effectiveness of the treatment. By gaining a better understanding of the experiences and priorities of different patients presented in social media, healthcare practitioners may be better able to focus on issues of importance to patients and avoid the polarization that has taken place in the case of CCSVI.

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Conflict of interest

No conflict of interest to declare.

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