



“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

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