Using Social Media to build a Counter-Power Movement: Multiple Sclerosis and CCSVI, a Case Study

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USING SOCIAL MEDIA TO BUILD A COUNTER-POWER MOVEMENT: MULTIPLE SCLEROSIS AND CCSVI, A CASE STUDY

ANTONELLO BOCCHINO

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Abstract

The research is focused on a patient-based social media movement which advocated for clinical research into a discovery rejected by key elements of the medical establishment. This thesis aims to examine how social media interactions empowered patients, what motivated them to become a movement, and the elements which propelled the movement to create alternative patient associations.

This research comprises 62 individual, in-person, audio-recorded interviews with movement activists, and the researcher's autoethnography as the founder and administrator of the movement's Facebook Page. These methods are triangulated with academic publications, newspaper and television news, as well as other publicly-sourced materials relating to the case study.

The research finds that while the movement's activities, from planning through protest, occurred solely on the streets of social media, activists experienced the same passion and urgency as the academic literature has described for on-the-street activists. That is, social media paralleled the "real streets" as a forum for the movement's core activities. The research further finds that the traditional patient associations' initial strategy of stonewalling the contested discovery was undercut by the momentum of the social media movement's activities. They subsequently sought to quell the movement by lambasting social media as well as deploying a co-optation strategy, as described by the activists.

To conclude, social media function as streets and city halls where decisions taken can be implemented in the real world and permit geographically distributed as well as differently abled people to gather in significant numbers. The space where human interactions can foster social life and deepen personal emotional relations could be named the *space of humanity.* This is the space where timeless time and the realities of the counter power experience can happen, independent of whether that space is surrounded by real or digital bricks.

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I declare that all the material contained in this thesis is my own work.

Introduction

(i) “We are free to talk”

It was August 19, 2009, we were told “you are free to talk”. We were a group of multiple sclerosis (MS) patients’ who had undergone an innovative treatment within a controlled study sanctioned by the Human Subjects Institutional Review Board of the University of Buffalo, NY. The new medical theory regarding MS, a chronic disease whose aetiology is unknown, suggested that reactivating the brain and spine’s blood drainage, would give relief to MS patients. It was theorised that a newly-discovered medical condition, Chronic Cerebral Spinal Venous Insufficiency (CCSVI), had a strong connection to MS. Until that day in August I had not searched much on the internet about the treatment I had undergone. I was not familiar with medical terminology, and besides my new life experience following the treatment, I was also in mourning for my late father. I had been informed about all I needed to know by my neurologist which was enough for me. After the announcement that would allow us to talk publicly about our experience, I started to search on the internet for “CCSVI” and “multiple sclerosis” in Italian and English. Among the very few results was an American Facebook Page, called *CCSVI in Multiple Sclerosis*. It had been created a few days before and, unlike Facebook personal profiles, Facebook Pages were visible even to those not signed up to Facebook.

I had heard about Facebook, but I did not know how it worked. I had never felt the need to sign up, even if many acquaintances had asked me to become their friend and were kind of surprised when I told them I did not have a Facebook profile.

Strengthened by my direct experience with the innovative experimental treatment for MS (at that time only a few dozen patients around the world had undergone the treatment), by the forthcoming publication of the first important scientific study on the treatment, by my master's degree in Communications from the University of Bologna (DAMS – Drama, Art and Music Studies), and last but not least by a very good flask of home-made red wine (from my zio [uncle] Mimì), there on the table to accompany my dinner, I considered the idea of creating a Facebook Page about CCSVI and MS in Italian, and I said to myself: "I am in the right position to start something meaningful. Social media requires somebody who knows about communications more than somebody who knows about medicine". I did not know what it could become, but I knew that because of published scientific research, it could go a long way, which is why I took all the precautions to protect my mental health, my personal life and my safety thinking of its possible future development:

> There have been difficult times, times of troublemakers, of fake ... but look, I think it is so difficult to manage such a large group, so huge, that I have never allowed myself to criticize the administrator, that is you, because I believe that, precisely because I too was experiencing pressure, in short, even if as a simple user, at times I felt pressured by other users (Aurora).

Only a handful of people knew who was running the Page. By not allowing myself, the administrator of the Page, to be personally attacked, I would also be able to protect the movement. I did not have any personal objective. I had already undergone the innovative procedure, so I was not looking to earn special attention from the scientists to have it done, nor could I have been bought by the private sector offering me the new procedure. This situation gave me the impartiality needed for the movement. I also knew for sure that I did not want to create a myth of myself.

Besides my interdisciplinary education in communications which gave me insights into the political economy, sociology and psychology of communications, I did not have a plan. I only felt I was the right person to do something. Not just a few wondered why I was doing it, for which personal profit. I have never had the intention to make money out of it. I would be the employer and employee in what I realised was the most exciting unpaid working experience, where I took all the decisions, in charge of the Facebook Page, my only purpose to facilitate the path to the scientific truth about MS and the new treatment. Acting in respect of the law in force, I would be answerable only to myself and my morality.

That same night, 19 August 2009, I opened a Facebook Page entitled *CCSVI nella Sclerosi Multipla* (CCSVI in MS). Within a few months, it had attracted a couple of thousand members. Within one year, it had grown to more than 20,000 members, and by November 2010, there were 30,000 members when in Italy there were 60,000 people diagnosed with MS (AISM, 2010a). By that time, this social movement, born online, had also generated an offline national association which took the name of the Facebook Page:

> But the association, the association is something that was born later. That is, the association was born because when, let's put it this way, the numbers grew, and so we started .... That is, I was dealing with the Emilia Romagna region that the association did not exist (Ginevra).
>
> It was born from there, even if then it took different paths, at times we also found ourselves in disagreement, because it is also right to take independent directives, but in short I believe that the seed was your page, of everything (Aurora).

As the administrator of the Page, and the movement's first activist, I wanted all my activity, including my original photos, my photomontages and translations, to be available to everyone without putting any brand in the image, to be freely shared and distributed without crediting the creator:

> The Facebook Page was the voice, at least in part. Before the various official pages of the association were born and so on, it was the only, the only official page with which one communicated on the CCSVI (Lisa).

I wanted to create a leaderless movement uniquely based on medical publications and public updates from the scientists who first discovered and studied the new theory, aiming to inform patients and, in turn, to petition institutions to fund further research. I wanted patients to determine by themselves the actions to be taken. For example, I have not authored any of the movement's many emails sent to doctors, political institutions, and mass media. They were all proposed and written by activists. Before publishing the letters proposed by activists on the Facebook Page, I checked whether they were polite, whether any statements or scientific data mentioned had been referenced, and with experience I later compiled instructions on how to write a polite email and how to prepare a list of email addresses. I wanted activists to be in charge of the creation and of the activities of the movement, which means that they did not have to wait for me to tell them what to do. The description from a 2021 publication, in the first study conducted by a media scholar on the Italian CCSVI Facebook Page, gives an idea of what happened: "Indeed the subjects of our investigation have succeeded in creating a collaborative network of patients, associations and the doctors themselves, which is unprecedented at least in Italy" (Matteucci, 2021:175), which allowed MS patients and caregivers to be "empowered by the sense of belonging to a group and by making joint decisions on the course of action to be undertaken” (176).

I only sought to facilitate the process of becoming informed and of informing in a way that has been characterised as a connective leadership activity triggering active participation:

> You didn't put yourself forward as a person, it's very important to me, because you didn't propose yourself as a person, it was like a group thing, a splendid thing (Beatrice).
>
> For me the most important thing, the motivation to communicate via computer, with those who were really interested. To understand, for friendships, to be informed of what is happening (Emma).

For example, when at the beginning of 2010 it was clear that there were the prerequisites for developing regionally-based groups (on 15 February 2010 the Page reached 10,000 members), I proposed or I implemented the suggestion to use the Facebook’s Discussion feature on 5 February 2010, (a function abandoned by Facebook at the end of October 2011), to allow activists to gather by region (there are 20 Italian regions). Facebook’s Discussion section was similar to a traditional web forum and, importantly, it was embedded into the Facebook Page. I facilitated activists in creating regional groups without starting them myself. That was the first step towards bringing the activists back to their own streets. In that way activists could organise on the basis of geographical contiguity and meet in person. I was blamed for not creating a group for one small region. I tried to explain why I had not done it, that if the spark does not come from one of the activists of that region, it is not going to work. I then decided to start it because it seemed I was being partial, but unluckily, it did not work. Similarly, one of the activists had the idea to open new

Facebook Pages advocating CCSVI in different languages for potential activists in other countries (where a Page did not already exist), with the hope that MS patients in those countries would take charge of them, but they never took off. The lesson was that whoever wants to start a movement must be the first activist of that movement.

In 2011, shortly after the Arab Spring, I moved to Egypt. On July 29, I was in Tahrir Square, in the Mogamma, a huge old Soviet-style government building, to have my visa renewed. I was leaving the square walking back home to the Dokki district when the Egyptian military forces arrived to evict the last remains of the January Revolution, a few tents under the burning sun with only a handful of people hanging around because it was the first day of Ramadan, when Muslims do not eat or drink from dawn to sunset. At the sound of the first gunshots, I ran towards the relative safety of the lions of Qasr al-Nil Bridge.

In Egypt I worked as a journalist and speaker for the Egyptian State’s Radio Cairo, which broadcast in the Italian language, among others, from the huge building on the banks of the Nile called Maspero, which looked to be the most militarily secure place in Cairo with tanks and armed forces inside and out. In the same building, I also worked as a presenter and teacher for a TV series introducing the Italian language to Egyptian viewers. I worked as social media manager for the Italian Cultural Institute of Cairo, and I privately taught Italian language to the students of Ain Shams University. From 2011 the CCSVI movement was no longer as engaging as it had been in the first two years; independent associations were fully functioning and many studies on the new theory were ongoing or already published. The administration of the Facebook Page was becoming routine, more focused on reporting news on published studies and on the CCSVI associations' activities, than on facilitating the connection of people and the coordination of actions:

> Surely, we need to make a distinction, between what was the social web movement, and social media, to what was then the more structured movement, therefore with the birth of the various associations. At the beginning, space was given, let's say, to requests or in any case to the activities of individuals, mainly of individual users. After the birth of the associations, the page has always maintained a correct neutrality among the associations by relaunching the contents, the activities of all the associations, and therefore this was certainly a positive factor, because it gave visibility to everyone in the same way. So let's say, if I had to remember, make a summary of the page, let's say that I would note these two moments, these two periods, therefore: first period from the aggregation of consent, I mean aggregation of the people. And the second moment, that of the birth of associations (Lorenzo).

My experience in Egypt, which was highly engaging, connecting me constantly to the reality of the uncertain political and civil condition in the aftermath of the Arab Spring (for instance, often riding the Egyptian underground system while going to work, I could smell the tear gas on entering the Tahrir Square station during Autumn 2011), gave me the opportunity to distance myself from the CCSVI movement. I began using social media in a different way, for work at the Italian Institute of Culture, to connect to my students, and for my personal needs, as it was the preferred source of information about which city squares and streets should be avoided, places to be immediately evacuated, sometimes more immediate and functional than the "must leave" SMS texts from the Italian Embassy. In November 2011, while I was teaching an Italian language lesson, some of my students were respectfully quivering with impatience to leave the lesson early so they could substitute their peers, in the round-the-clock Mohamed Mahmoud Street fighting against Egypt's Central

Security Forces, which was one of the many backlashes against the suppression of the January Revolution. I was forced to look at the CCSVI movement in a different light, disembodied from the figure of the administrator and activist of the Facebook Page from which the movement had started. This detachment from the CCSVI movement and the diminution of my activity on the Facebook Page, coupled with my experience of the intensive use of social media with completely different needs and objectives. Then, an article published on *Nature* about the social media patients' pressure into CCSVI medical research (Chafe et al., 2011), brought me to consider commencing scholarly research on the CCSVI movement, from the unique perspective of being the first and an ongoing activist of the Facebook Page.

In August 2013, a few days before the one-day massacre of about 1000 people in Rabaa square on August 14, I left Cairo to start my PhD in London. This thesis draws from my direct activist experience (see Ch. 2), through social media, from four nations of three different continents, and from 62 face-to-face audio-recorded interviews of activists and doctors, related to CCSVI and MS.

(ii) The research

Facebook represents the most significant tool within the world of social media with about one in four people using it at least once a month. This research aims to examine how Facebook's unique functionality - enabling communication that closely mirrors in-person and public interaction - can facilitate the emergence and development of a social movement. For instance, the 'groups' function on Facebook allows for the building of communities of common interest, membership of which is quantifiable. This can be seen as one of the key attributes of a social movement identified by Tilly, i.e., the "'participants' concerted public representation of WUNC: worthiness, unity, numbers, and commitment on the part of themselves and/or their constituencies" (2004:3-4).

My research focuses on a case study of a patient-based counter power social movement in Italy that aimed to inform patients about, as well as promote clinical research into a medical discovery that offered new hope to people with MS, a lifelong condition "that can affect the brain and spinal cord, causing a wide range of potential symptoms, including problems with vision, arm or leg movement, sensation or balance" (NHS, 2022). This medical discovery, which has been strongly contested by the neurological community, concerns the relationship between CCSVI, a syndrome that results from a blockage to the veins that drain blood from the brain and spine, and MS. According to the first interventional scientific study published in 2009 (Zamboni et al., 2009a), more than half of the patients who went through a minimally-invasive procedure to correct the blockage, experienced relief from MS symptoms for as long as the correction lasted.

This Italian patient-based movement emerged and developed on-line through social media. It was initiated in 19 August 2009 as a Facebook Page (*CCSVI nella Sclerosi Multipla,* i.e. CCSVI in MS*)*. By the end November 2009 the Italian Facebook movement had 1000 active members and by February 2010 it had an online membership of 10,000. Its membership in 2022 stands at more than 33,000 members. To my knowledge it is the largest community of those affected by MS and their family/care-givers of its kind in the world. The movement has also given rise to numerous off-line, non-profit-making, legally-recognised Onlus societies (where Onlus stands for non-profit making organization for community work), dedicated to CCSVI (CCSVI Societies). For example, the first Italian national association "*CCSVI nella Sclerosi Multipla* - *Onlus*" (Associazione CCSVI-SM, 2010a), arose directly out of this online movement in April 2010 (less than eight months after the creation of the CCSVI Facebook Page). The association took the same name as the Facebook Page and gave rise to a number of affiliated regional groups.

(iii) Research questions

The three central questions my research seeks to answer are:

1) Which elements of the social media interaction did members of the Italian Facebook Page "*CCSVI nella Sclerosi Multipla*", MS patients and caregivers, identify as important in encouraging them to become engaged, responsible, self-sufficient and active in terms of their level of awareness and understanding of this medical discovery?

2) What were the processes through which members of the Italian Facebook Page came together to form networks and what motivated them to do so (a sense of injustice, a belief in people power, a desire to consolidate their membership in the community or something else)?

3) Were there particular elements that supported members of the Italian Facebook Page in formalizing their activism through the establishment of off-line, legally-recognised societies dedicated to CCSVI?

(iv) Research framework and objectives

In order to give definitional focus to the term social media I draw upon scholarship framing that which differentiates social media tools from other internet tools (boyd and Ellison, 2008), where, as highlighted by Meikle and Young (2012), the critical difference is that social media tools “blur the distinction between personal communication and the broadcast model of messages sent to nobody in particular” (61). I examine the importance of social media’s “making and doing culture”, which gives the psychological frame to the importance of activity and creativity (Gauntlett, 2011), in the building of an on-line social movement, which is connected to the need to relate these activities to Rheingold’s line “Don’t forget to get together in the physical world” (cited in Meikle, 2002:178). While this thesis aims to examine the unique aspects of the social network, it remains sensitive to the importance of considering Net activism as the first step in reaching broader media activism, which is possible today thanks to the reality of media convergence, with its “blurring of distinctions between producers and audiences” (Meikle and Young 2012:104), where “large media corporations still possess the capacity to exercise enormous resources of symbolic, economic and political power” (198).

I also draw upon recent research in the field of social movements to analyse the growth and development of the CCSVI Facebook page and its evolution into a formalized network of CCSVI Societies within Italy. In particular, I examine the factors that led to participants' initial decision to actively engage with the counter-power movement, the processes through which mobilization occurred and finally the elements that led activists to create formal CCSVI associations. By applying a range of carefully selected theoretical tools, to include the use of collective action frames, network theory and collective identity, this research analyses the processes that underpinned the evolution of the CCSVI social movement from its inception.

This thesis analyses the use that patients and caregivers have made of social media as a space where people aggregate, become a movement, discuss, decide and implement influencing activities aiming at changing the *status quo*.

This thesis considers the unique challenges in seeking to build a health-related social movement, including the difficulties in mobilizing patients. It argues that social media can affect research priorities (Chafe et al., 2011), examining the question how and to what extent a social movement can function as a counter-power movement (Castells, 2007; Fuchs, 2014) in affecting medical research priorities which are typically industrially driven by pharmaceutical companies.

(v) Preview of chapters

Chapter 1 frames and defines the theoretical field for the research on the CCSVI Facebook-based social movement. It starts from the definition of social media and their characterisation as sharing industries, which favoured the growing of social movements first, and the spread of fake news after. It follows the theory of social movements underlining the distinction between social media *in* social movements and *social media movements*. It concludes with an overview of research and statements by the medical community on the Italian MS patients' use of social media. The doctors' assessment of social media and patients with MS (a neurological condition), advocating CCSVI (a newly discovered vascular condition) depended on their specialisation. Those with a neurological background tended to view it in a more negative light, whereas those with a vascular background took a more positive view.

Chapter 2 explains the methodology used in this research, including autoethnography and 62 individual, in-person, audio-recorded interviews with movement participants, the latter of which form the real backbone of the research. The interviews, referenced throughout the thesis, have assumed an even greater importance as unique documentation, as after they were recorded in 2014, the associations and the social media movement's activities started to decline.

The subsequent chapters respond directly to the three central research questions posed by this thesis.

Chapter 3 describes the conditions which gave birth to the CCSVI social media movement, and which fuelled its rage and hope. Copious material was disseminated by activists starting in 2009 on blogs and social media to create a consensus encouraging MS patients to join the movement. The chapter reports the public statements of MS associations and neurologists whose opposition to CCSVI was understood by activists as evidence of commodification. Only when the neurological scientific evidence refuting the CCSVI theory was published, did the movement and its associations decline.

Chapter 4 draws from Castells’ 2015 definition of timeless time to expose the importance of human interaction in building a movement. The chapter aims to demonstrate that the experience of timeless time described by the observation of the Occupy Wall Street movement’s activities on the streets, overlaps with that of the CCSVI movement on social media. It considers the common characteristics of the two movements and then describes through the interviews how timeless time was experienced by activists in the CCSVI social media movement.

Chapter 5 draws from Dean’s description of the fantasies of communicative capitalism. After reviewing the global MS drug market, the chapter highlights the fantasies of the CCSVI social media movement, versus its realities. The latter led to a process of co-optation as understood by activists. Following co-optation, the strength of consensus was such that even some administrators of Facebook groups where MS patients could discuss any aspect of MS, felt empowered to ban anyone who mentioned anything related to CCSVI and Zamboni. The cooptation process of the CCSVI case study is then compared to the 2003 anti-war movement described by Dean.

The conclusions propose the definition of a *space of humanity,* a concept that suggests a different paradigm in network society research, which goes beyond the dichotomy between social media spaces and physical on-the-street spaces. Arguably, social media users’ interactions are not more conditioned by algorithms than people’s interactions on the street are conditioned by available means of transportation, architecture and police control. The space of humanity is the digital or physical space where human relations can grow, providing the humus where timeless time can be experienced, potentially allowing for the development of a counter power social movement.

CHAPTER 1. Framing and defining the field

(1) Social media

The emergence of social media represents a departure, a unique opportunity within the communication field, as it signifies the transformation of the media from a means of distribution to a means of communication, as wished for by Bertolt Brecht (1932:42) and then Enzensberger: "The development from a mere distribution medium to a communications medium is technically not a problem. It is consciously prevented for understandable political reasons" (1970:262). In the past, as highlighted by Baudrillard in 1972, such a reality was not possible (1981), because the media were intransitive, not permitting any form of response if not simulated (i.e. readers' letters, audience phone calls, guests, polls), a simulacrum of the people's response. According to Baudrillard, "in primitive societies […] power belongs to the one who can give and *cannot be repaid"* (170). Mass media as a system of social control and power reflects this same principle: everything is organised so that no responses are allowed. Baudrillard reminds us that the mass media system can only be infringed with a reciprocal exchange in which the answer is simultaneous, thereby exposing the ambivalence of the media's message.

Drawing from the Paris uprising of May 1968, Baudrillard identified the street and town walls as the real revolutionary media, a symbolic space for the word unamplified by the media, where everything "was an immediate inscription, given and returned, spoken and answered, mobile in the same space and time, reciprocal and antagonistic” (176). The internet and more precisely social media can be considered a manifestation of this concept, where it is not just one person who speaks while others listen, but rather everyone can speak, and each can decide to whom and what to listen; a virtual equivalent of Hyde Park Corner. Lyon on the other side balanced Baudrillard’s enthusiasm by pointing out the myth of the Information Society and its alleged natural positive and progressive process, that assumes social change is a consequence of technology (1988). He reminded us that, the extent to which the new technologies can change control of the processes of production, who controls the cultural synchronization, and the social goal offered by the new social environment, should be taken into account.

(i) Society, economy and politics

The evolution through which we have arrived at social media tools today, can be condensed into five factors (Richeri, 1995): the shift from the material (physical products) to the immaterial economy (informational products); the transformation of the industrial organization from Fordism to post-Fordism; the end of the Cold War; the realization of technological convergence, brought about by a shift from analogue to digital technology; and the saturation of the market at the beginning of the nineties, when the internet was made of relatively small groups of people interacting in online communities organised around common interests. It was still the time of a text-based internet where anonymous users interacted in MUDs (Multi-User Dungeon, 2016). Dibbell’s ‘A Rape in Cyberspace’ originally published in 1993 in *The Village Voice* provided a deeper understanding of the reality of those virtual communities. The author described those text-based communities of anonymous users or characters, called MUD Object-Oriented (MOO), characterised by an accurate description of the content which defined the purpose of those chatrooms, indicating also the characters present at the moment with whom to interact, like a role-play. The contemporary manifestations of such communities are today's social networks with hundreds of millions of users, resembling more closely a society than a community. At the time of the publication of the article in 1993, the World Wide Web (WWW) was just beginning. The WWW was proposed by Berners Lee in 1989 but the first web site was only implemented at the end of 1990 functioning solely from Berners Lee's computer (Castells, 2001:15). In 1991 a cross-platform browser version of the World Wide Web was created and in April 1993 the WWW software became public with an open license (CERN, 2016).

In September 1993, a few months after the WWW software was released for public use, a Task Force commissioned by the Congress of the U.S. completed its 'Agenda for Action for the National Informational Infrastructure' (The White House, 1993). The purpose of this agenda was to propose the creation of the infrastructure necessary for a digital global market. The first paragraph of its chapter entitled 'The Promise of the NII' illustrates the power of this agenda in prescribing the future, describing a device, the smartphone, which became a reality 15 years later:

> Imagine you had a device that combined a telephone, a TV, a camcorder, and a personal computer. No matter where you went or what time it was, your child could see you and talk to you, you could watch a replay of your team's last game, you could browse the latest additions to the library, or you could find the best prices in town on groceries, furniture, clothes -- whatever you needed (The White House, 1993).

The European Union also recognised the potential for the global market dependent on the new digital infrastructure. In December 1993, a few months after the American Agenda for Action had been published, the EU Commission adopted the White Paper on ‘Growth, competitiveness and employment: The challenges and ways forward into the 21st century’, to promote the use of information technologies for the development of the European economies in the new world that was emerging (Delors, 1993).

Western governments were laying the foundation for the information superhighways, which became a common catch phrase in the early nineties, though by 1995, their promise was already being questioned (Besser, 1995). It can be said that the role of information superhighways in a society based on immaterial exchanges, is comparable to the role of the old communication routes (e.g., physical highways) in a society based on material exchanges. Information superhighways became the globally recognised solution to economic stagnation. In fact, the saturation of the market required the development of a new modality inside the existing economic system (which has been called the New Economy). It was no longer the lack of goods and services which represented the element of scarcity, but the ability to attract and retain the attention of the user-consumer. That is to say, the economy was not limited by the universe of products on the shelf or services for sale, but by the attention of the consumer. Thus, the consumer has been successfully commercialised through the logic of empowerment. Something we know very well today with social media, where the users who produce the material being shared are not the customers, but the product which is sold to advertisers, marketers and developers.

On February 8, 1996, President Bill Clinton signed into law the U.S. ‘Telecommunication Act of 1996’ (U.S. Congress, 1996). The aforementioned Agenda for Action had prepared the ground for this law. Previously, each medium (i.e., radio, TV, telephone, etc.) had developed separately on different networks, but with digital technology information could be stored and transmitted on the same network. The realisation of technological convergence brought about the possibility of a more general media convergence. To foster this evolution, with ‘The Telecommunication Act of 1996’, the American Administration eliminated antitrust barriers so as to permit the integration of different media under a single corporate entity. Barlow (1996) was aware of the changes that were about to be effected by governments and released his ‘Declaration of Independence’ the same day the American law was signed and published. Barlow’s declaration was an expression of the libertarian approaches that have run through the internet since its inception. Bearing all this in mind and looking at the cyber-reality of today, the declaration of independence sounds more like a swan song, a poem, which gave strength to the hope of a different world, and to the misapprehension that the internet is somehow unregulated by state sovereignty; a misapprehension which became a mantra particularly among the cultural industries, which fed on people’s anxieties of being under the control of the authorities (Hesmondhalgh, 2013:126), and arguably aimed to maximise participation in the activities of the new digital environment.

(ii) An historical definition of social media. Technical, social and political background

This ongoing technological convergence eventually gave rise to social media. According to an article published in *Forbes* in 2010 (Bercovici), the term social media was coined in 1995 by Tina Sharkey while she was in charge of community-building at a website *iVillage,* but the only public evidence of her first use of the term is the domain ‘socialmedia.com’ that she bought in 1999 for $10. Among others who claim the first use of the term social media in the early nineties, is Ted Leonsis, then an executive at AOL who said that users should be offered “social media, places where they can be entertained, communicate, and participate in a social environment”, and Darrell Berry, who published online in 1995 a paper entitled ‘Social Media Spaces’. The first use of *social media* is June 2004, when it was announced that the ‘BlogOn’ conference was to be held in July at the University of California Berkeley's Haas Business School, which aimed at “showing how social media will impact business and culture” (Shipley, 2004). The term social media was clearly coined for marketing purposes, far from its later presentation as the key tool of the empowered user. Considering that one of the social media par excellence, Facebook, was created in February 2004 and was restricted to a small number of university students, the term social media used that same year was not describing the social network sites (SNSs) as we know them today, but more broadly “blogs, RSS feeds, aggregators, emerging platforms for user-generated content and profile-based networking services like LinkedIn and Friendster” (Meikle, 2016:5).

In order to give definitional focus to the term social media I intend to draw upon scholarship framing that which differentiates social media tools from other internet tools (boyd and Ellison, 2008), where, as highlighted by Meikle and Young (2012), the critical difference is that social media tools “blur the distinction between personal communication and the broadcast model of messages sent to nobody in particular” (61). Castells described the blur of the communication boundaries of the new digital environment as mass self-communication (2009:55), because it can potentially reach a general audience, as for example a YouTube video. Simultaneously it is self-communication because the message can be self-generated by a single individual, it can be self-directed to a specific receiver and it can be self-selected. Mass self-communication coexists with interpersonal and mass communication and they all complement each other within the same digital device, in audio, video, text and image format.

Meikle gave a broad and at the same time neatly-bound definition of social media, i.e. sharing industries, as follows: “networked database platforms that combine public with personal communication” (2016:6). Sharing industries are networked because of the use of technologies which offer a model of behaviour, but ultimately do not determine their final usage, because social organisation together with technology embodies the network. The terms database and platform denote a business model which exploits the networked digital media. Personal information both private and public, from movies to food preferences, from habits, to websites or geo-localities visited, both intentionally or unintentionally communicated, are stored in a database and used for commercial purposes. The words public and personal communication relate to the cultural and behavioural aspects of social media, in particular to the individual spreading of their own meanings in the space shared with media industries. Meikle explained that not all smartphone apps are social media. For example, Uber, an app that allows users to connect with non-professional taxi drivers, should not be considered social media, because even if it relies on a networked database and on the share economy, it currently lacks personal and public communication. This last aspect interconnects with the use of user-generated content (UGC) and the making and doing culture made by the business model named Web 2.0 (Web 2.0, 2004; O'Reilly, 2005).

Gauntlett examined the importance of social media as a shift from a sit–back–and–be–told culture to a making–and–doing culture (2011). He gave a functional visual representation on the difference between what is called Web 1.0 and Web 2.0. Web 1.0 was characterised by websites which were likely to be “separate gardens”, “by contrast, Web 2.0 is like a collective allotment” (5), where the content is not only produced and shared, but co-produced by social media users. Social media, after all, are media companies that do not themselves actually create any media.

(iii) History of social network sites

This review focuses on only some of the SNSs listed by Sujon (2021:39-42), among them those which could help to explain the social media background relevant to the research on the social media movement examined in this thesis. Mainly profile-centric sites, like Facebook, are reviewed, as well as some media-centric sites, like YouTube (Ellison and boyd, 2013). Location-focused services, public or private sharing of images and augmented reality, have not been used by the CCSVI movement. The only social media used by the CCSVI movement in the early stages was Facebook. The CCSVI Facebook Page was founded in August 2009. In January 2010, a companion Twitter account was founded, but it was never as successful as the Facebook Page. In 2022 it is still operating with about 1000 followers (https://twitter.com/CCSVI_nella_SM). YouTube was used by a few personal profiles to show their symptom improvement following the new therapy, and by some of the CCSVI associations to publish videos of TV news about CCSVI (also foreign news, with subtitles provided in Italian) and of their conferences.

The first example of social media can be recognized in SixDegrees (boyd and Ellison, 2008), which postulated that everybody in the world could be connected through a line of six degrees of acquaintances. It was the first site that made it possible for users to find gathered in a single site a number of interactive characteristics, which were previously separately available in different sites. For example, it made it possible to create profiles and lists of friends which were visible to others. The service closed in 2000. Among the reasons for its closure: there were not yet a critical number of real friends active on the internet, digital video production was not yet popular (Meikle, 2016:10), and the lack of digital cameras made it difficult even to upload photos onto personal profiles (Kirkpatrick, 2010:69). SixDegrees was restricted by technology to a public acknowledgment of acquaintances, without yet allowing the users to produce visual content to be shared and enjoyed, meaning the users ended up not knowing what to do with the site.

Among other SNSs, the most significant in early/mid 2000 in reshaping culture and business on the internet were Friendster, My Space, LinkedIn, YouTube, Twitter and

Facebook. Friendster was launched in 2002 on the assumption that acquaintances were more likely to be a good match for dating than strangers. Users were allowed to browse profiles to the fourth degree, and everybody was allowed to join even if they were not interested in dating, because they might change their mind or involve others interested in it (boyd, 2004:1279). Friendster's decline started one year after its inception, in 2003, because after receiving television coverage, the amount of activity prompted Friendster to face regular technical failures caused by their complex algorithm, which left the users frustrated. Furthermore, Friendster's restrictions on its users' desires, as for example browsing unknown profiles beyond the four degrees instead of just dating acquaintances (boyd, 2006), opened a breach between the site and the users' interest.

The decline of Friendster was parallel to the growth of Myspace, which was launched in 2003, when increasing broadband widths were allowing faster browsing and faster uploading of photos when, at the same time, digital cameras were becoming cheaper (Kirkpatrick, 2010:76). In this new environment MySpace took advantage of the friction created by the severe restrictions imposed on Friendster users: MySpace was open to everybody, also to fake profiles and pseudonyms with every interest including music, and it was willing to adapt to users' demands for their profile. For example, indie-rock bands who were expelled from Friendster for not complying with the regulations, moved to MySpace (boyd and Ellison, 2008).

In between the two, in mid 2003 LinkedIn was founded, but it was business oriented and it was not in competition with Friendster or MySpace: the LinkedIn personal profile was a curriculum vitae and did not involve dating or anything not job-related (Kirkpatrick, 2010:72).

YouTube is a media-centric site distinct from the others here analysed, which are profile-centric. Founded in 2005 (Cloud, 2006), YouTube made it possible to watch videos online without the need to install any software and without signing up. There are user profiles which one needs to have to upload videos, but the main characteristic is being a portal of any kind of video, with a powerful internal search engine (Google bought YouTube in 2006).

Twitter was founded in 2006 (https://twitter.com/jack/status/20) and presented some main differences compared to the other SNSs, positioning itself between the microblogging and the information network (Lapowsky, 2013). Users were allowed to send messages or tweets with a limit of 140 characters because they could also be sent through mobile phones' SMS, that have a limit of 160 characters (the 20 characters difference were for the username). In November 2017, the character limit was increased to 280. Among the other differences with SNSs worth mentioning are the one-way relationship, that is one can follow and receive another user's tweets without needing an acceptance, and the hashtag. Its use allows messages to be collected under a common subject, without the need to search among tweets: all who want to have their say shared publicly on the same matter, use the same hashtag. In this way users don't need many followers to be seen by potentially an unlimited number of people. All tweets sent are public by default - sign up is only required for those who wish to send tweets.

thefacebook.com was created in February 2004 and was meant to be college-student oriented with dedicated features (it required a university e-mail address to join), resembling also a dating site, but since the first weeks, students were using their profile also to express political opinions (Kirkpatrick, 2010:6). The same year of its foundation litigation arose regarding the property of the original idea, which was settled in 2008 (Carlson, 2010). In September 2005, when 85% of the students of the supported colleges had created a profile, the domain facebook.com was bought and the company was renamed Facebook without the initial *the* (Arrington, 2005). The same month it opened to high school students, and later to everyone. The applications built by outside developers were among the unique features that differentiated Facebook from other SNSs: those would allow the users to personalise their profiles together with other tasks (boyd and Ellison, 2008). After a few years Facebook came to distinguish itself from a dating site: various options like the ability to find people in specific localities by gender and relationship situation were removed. Among the other features that characterise Facebook is the Share button and the Like button. The latter in February 2016, after one year of experimentation, was enriched by the reactions: Love, Haha, Wow, Sad and Angry (Bell, 2016). The choice was also a response to facilitate feedback through images, rather than words, for the growing number of smartphones' users (Stinson, 2016). The reasons behind Facebook's success are manifold: the simplicity of use, the many easy to access features, the promotion of trustworthiness and honesty which prompt users to open themselves and expose their views (Shah, 2016).

(2) Sharing industries and post-truth

The medical research on CCSVI, which was approved by ethics committees, peer reviewed and published in renowned medical journals, was defined by some MS top neurologists as a hoax and it was considered a loss of money. Furthermore, it was deemed a sacrifice of the science to the altar of the social media consumer demand (see Ch. 3), even if some of the most important initial studies were published or started well before any CCSVI movement. In fact, the social media consumer demand was the result of the fast spread of the CCSVI movement on internet forums and Facebook in only a couple of months of activity since the creation of the Facebook Page in August 2009. The same fast-growing rate of followers for the CCSVI movement will be publicly recorded in the following years for the followers of political and historical social media movements such as the Arab Springs or the Occupy Wall Street.

The CCSVI movement spread coincided with a few changes in the way web research engines worked. For example, Google decided to return personalised results for each user (I remember how satisfied I was when I always received my Facebook Page as the first result when I searched for CCSVI), and through a similar mechanism Facebook prioritised friends’ posts related to the users’ most recent activity in the personal newsfeed (see Ch. 1.2.iv below). For this reason, I consider fundamental this part of the thesis for understanding under which technical/economical circumstances the CCSVI social media movement spread successfully and why, for many MS patients and caregivers, social media were considered more reliable than medical institutions and mainstream media, which in turn mostly referred to as hoaxes whatever was spreading on social media about CCSVI.

(i) Fake news: complexities of the term

If the internet and social media were initially characterised as platforms for empowering people (Hinton and Hjorth, 2013), since 2015 they have emerged as powerful instruments for spreading fake news (Vosoughi, Roy and Aral, 2018). That is to say, whereas social media were a synonym for protest groups against social injustice, such as Occupy Wall Street and the Arab Spring, they increasingly became a synonym for fake news favouring populism.

Despite the attempts of academics to elaborate the term fake news by using several appropriate definitions to describe the complex phenomenon (boyd, 2017; Marwick, 2017; Marwick and Lewis, 2017; Wardle, 2016; Wardle 2017; Wardle and Derakhshan, 2017), it is and will likely remain the term used by mass media and in popular discourse. The complexity of the phenomenon is partially resolved by analysing the deceivers' intentions. For example, satire delivers fake news with the active complicity and amusement of the audience, whilst propaganda refers to questionable ideas and information propagated for advancing a cause. When false news comes from the mainstream media, aims to educate or at increasing sales, it is called a hoax; if it comes from non-media actors with the intent of manipulating the audience, it is called fake news (Finneman and Thomas, 2018:358).

Ultimately, the term fake news is a journalistic and political umbrella term. Among mainstream media, intended as traditional forms of corporate mass communication as opposed to the internet, fake news is understood to be disinformation purveyed through news sources other than mainstream media. Among politicians, the term fake news has been used to describe coverage of news organisations they find disagreeable (Wardle and Derakhshan, 2017:5). An important distinction taken into account is between disinformation, when false news is deliberately distributed, and misinformation, when the user who shares the information is not aware it is false, the latter typical of sharing on social media. I will limit myself to the use of a few terms as synonyms: fake news, post-truth and disinformation, all referring to the definition of the term "post-truth", designated word of the year in 2016 by the Oxford Dictionaries: "relating to or denoting circumstances in which objective facts are less influential in shaping public opinion than appeals to emotion and personal belief".

Disinformation has existed since the time of the ancient Romans and before the Chinese Empire. The difference today is that fake news is being used intensively to influence the information ecosystem with the aim of affecting political outcomes in democratic countries. Initially in June 2016, during the UK referendum on Brexit. The win for Brexit was in part attributed to widespread circulation of post-truth communication regarding the pros and cons of EU membership. In November 2016, fake news was credited with influencing Trump's victory in the U.S. presidential election (The Guardian, 2018; Weedon, Nuland and Stamos, 2017; Roeder, 2018; Guess, Nyhan and Reifler, 2020), and in December, fake news was alleged to have influenced Italy's referendum on constitutional reform. Subsequent examples include the Italian political elections of March 2018 which were also alleged to have been influenced by fake news (Alto Data Analytics, 2018; Fletcher, Cornia, Graves, and Nielsen, 2018; Fubini, 2018).

(ii) Factors that have facilitated the influence and spread of fake news on social media

Keeping in mind that the CCSVI movement has been considered by some scientists since its inception to be spreading hoaxes and to be turning science priorities over to the will of consumer demand, it is important to examine which factors have facilitated the influence and spread of fake news on social media. I argue that the intensive reach of fake news has two key drivers. The first, that the middle-class crisis, rooted in the 2008 economic catastrophe, has led to mainstream media's inability to counter post-truth communication in influencing public opinion (Harrison, 2017), and the second, that the sharing industries (Meikle, 2016), i.e. social media, have indirectly promoted the spread of fake news (Morozov, 2017).

(iii) First key driver: loss of public trust in the institution of mainstream media

Loss of public trust in the institution of mainstream media has been repeatedly cited as a key factor in its dwindling influence. Participants at a conference 'Investigative journalism in a post-truth world' (Wells, 2017), organised in London in early 2017 argued that certain mainstream newspapers were responsible for degrading public trust in traditional journalism, thereby encouraging the growth of social media as an alternative source for news. One example given was the practice of *monstering* which was fairly common among newspapers in the UK. It is a campaign of denigration and delegitimization of people and groups in the form of a severe reprimand or scolding, or a highly critical verbal attack. At a UNESCO conference in 2017(a) not only did the Pulitzer Prize winning journalist Serge Schmemann confirm that legacy media were in crisis, "largely financial, but also in terms of content, competition, readership" (UNESCO, 2017b), but also the President of the World Editors Forum, Marcelo Rech, stated that the challenges to journalism included: "the lack of public trust in the institution of journalism, the development of echo chambers on social media, and challenges to economic models" (UNESCO, 2017c).

To explore in more detail the factors underlying mainstream media's loss of influence in moving public opinion, I turn to examine the nature and social meaning of the news and the traditional base for mainstream media.

> Reading the morning newspaper is the realist's
> morning prayer. (Hegel, 2002:247)
>
> The man who is tired of London journalism is tired
> of life, Samuel Johnson almost said. (Tiffany, 2012)
>
> When humans are angry and fearful, their critical
> thinking skills diminish. (Wardle, 2017).

Carey explained that the news exists only in historical time (2009). It does not provide information about the world but describes an array of dramatic forces which border on gossip. Thoreau anticipated this view in his novel *Walden; or, Life in the Woods*, when he imagined that the first news coming from Europe through the soon to be operating trans-Atlantic telegraph cable, was going to be that the British Royal family's Princess Adelaide, "has the whooping cough" (Thoreau, 1854:45). In this drama, added Carey, the news "invites our participation on the basis of our assuming, often vicariously, social roles within it" (2009:17). In fact, playing a bit with the terms used by mass media, Stam pointed out that "the news offers: 'tonight's top *stories*, not tonight's top *facts"* (2000:368). Indeed, in 1844 one of the most successful stories of the journalist Edgar Allan Poe published in the *New York Sun*, was about a British man who crossed the Atlantic Ocean in three days on a balloon. It was a hoax that sold a record number of papers (Walsh, 2006). It was not an isolated event that of publishing hoaxes, actually, it was quite a common practice for increasing newspaper sales (Fedler, 1989), which helps us recognise that journalists, before the 20th century, considered themselves as entertainers. News is "something that will make people talk, even when it does not make them act" (Park, 1940:679). Park's analysis can help in interpreting Hegel's quote "Reading the morning newspaper is the realist's morning prayer" (2002:247) as follows: "The function of news is to orient man and society in an actual world … In so far as it succeeds it tends to preserve the sanity of the individual and the performance of the society" (Park, 1940:685).

The common destiny between the fortunes of the middle class and journalism is suggested by Carey. He started from the assumption that the middle class invented a specific form of culture, i.e. the news, in the eighteenth century: the news "as such does not represent a universal taste or necessarily legitimate form of knowledge (Park, 1955:71–88) but an invention in historical time, which like most other human inventions, will dissolve when the class that sponsors it and its possibility of having significance for us evaporates" (2009:17). Furthermore, Carey remarked that: "Like any invented cultural form, news both forms and reflects a particular 'hunger for experience', a desire to do away with the epic, heroic, and traditional in favour of the unique, original, novel, new— news. This ‘hunger’ itself has a history grounded in the changing style and fortunes of the middle class” (17).

These critics argued that not only was the invention of the news a by-product of the rising, literate middle class in the 18th century, but also that the fortunes of legacy media today are closely tied to the fortunes of the middle class. There is undoubtedly a difference between the middle class for whom arguably the news was invented, and the middle class that consumes the news in the 21st century, a difference which is more economical than cultural, as Thoreau reminded us (1854:45). Historically the middle class represented those who were not part of the proletariat or the aristocracy. In 1845 Engels described the middle class as *bourgeoisie*, that means the “possessing class which is differentiated from the so-called aristocracy”. The middle class, he added, was “the class which in France and England is directly and in Germany, figuring as ‘public opinion’, indirectly in possession of political power” (Engels, 1993:14). The middle class in the 18th century had the means to invent, produce and consume the news, and in common with the middle class of the 21st century figured as public opinion when not directly involved in politics, and hungered to know the latest news on the princess’ whooping cough and the like.

Given that today’s middle class appears to anchor traditional journalism, it is worth exploring what constitutes the middle class. Researchers defined the middle class as “those with an income that is two-thirds to double that of the U.S. median household income, after incomes have been adjusted for household size” (Pew Research Center, 2015:2). Among the many definitions, “some experts define the middle class by income, others define it by lifestyle. Still others say it's a state of mind” (Luhby and

Baker, 2018). In fact, to define the middle class using only household income and income inequality "appears rather as an unfortunate *deformation professionelle*" when it extends to more general considerations on social inequality (Goldthorpe, 2010:740). Instead, two main forms of social stratification, class and status, should be taken into account for analysing the position that individuals hold in order to determine their life-chances, life-styles and life-choices, "crucial to the understanding of the different kinds of inequality" of income (732). Not only household income, but also "the role of property and wealth, which is important in identifying the middle class in popular discourse" (Atkinson and Brandolini 2013:77), and the occupational structure, because "it is reasonable to wonder whether a pure income characterization of social classes is analytically satisfactory" in order to measure the strength of the middle class considered pivotal by economists for economic growth, democracy and the political stability of a society (95).

Christine Lagarde, managing director of the International Monetary Fund (IMF) from July 2011 to September 2019, in 2017 officialised the crisis of the middle class in the advanced economies. This had previously been reported by researchers (Pew Research Center, 2015). In 2014 it was reported that "the share of Americans who identify with the middle class has never been lower, dropping to 44% in the latest survey from 53% in 2008" (Kochhar and Morin, 2014). This was the result of the recession hitting harder "middle-skilled white- and blue-collar jobs" (Autor, 2010:2), rather than lower and higher categories, a trend which "is not unique to the United States, but rather is widespread across industrialized economies" (3). Lagarde reported that where the middle class has shrunk "there have been signs of lack of trust, lack of hope, disenchantment with many of the principles and vision that people had for their future" (World Economic Forum, 2017), and warned that inequality and mistrust fuels populism, “saying no to whatever the policy leaders suggest”, added the then Italian Economy and Finance Minister, Padoan (World Economic Forum, 2017).

Supporting the strong ties between the fortunes of journalism and those of the middle class, is the fact that in those industrialized economies where the middle class has shrunk and has lost trust and hope, there was a parallel decline in the circulation of newspapers (WAN-IFRA, 2017). In part the decline it is also due to the rise of the mass use of the internet and social media (Newman, 2011), but there has been a parallel rise of print circulation “in countries with a growing middle class” (WAN-IFRA, 2014), especially in some Asian markets, including India, suggesting a positive correlation between the wealth of the middle class and newspaper circulation despite the increasing use of the internet. The middle-classes’ lack of trust and hope coincides with a general lack of trust in journalism. A Gallup poll in early 2016 found that Americans’ trust in legacy media had fallen to its lowest since 1972 (Swift, 2016). The Edelman Trust Barometer in its 2017 study recorded the “largest-ever drop in trust across the institutions of government, business, media and NGOs” in 2016, with trust in media falling to an all-time low in 17 countries (Edelman, 2017).

According to Katz, “the news is what elites say and what non-elites do” (2014:460). Mainstream media has come to represent the economic establishment by whom the middle class has felt betrayed (Wike, 2016), thus fuelling their disenchantment and pushing them towards alternative news sources, self-referential media, and trust in peers. Parenthetically, in their role as opinion leaders for the lower classes (Lazarsfeld, Berelson and Gaudet, 1948; Katz and Lazarsfeld, 1955; Katz, 1957, Schäfer and Taddicken, 2015; Winter and Neubaum, 2016), the betrayed middle class has influenced the “less active sections of the population”, moving them towards alternative and hidden truths available online, in a mechanism spreading gradually from higher to lower-status individuals (Rogers, 2003), resembling a ‘populism 2.0’ (Gerbaudo, 2015; Fuchs, 2017).

This may help to explain the results of a poll in 2016 which showed that 60% of people believed that a person like themselves had the same credibility as an academic and twice the credibility of a government official (Edelman, 2017). These figures were foreshadowed by Umberto Eco when he said that social media "give the right to speak to legions of idiots who spoke only at the bar after a glass of wine, without damaging the community (…) and that now have the same right of speech as a Nobel Prize winner” (Eco, 2015). The 2.9 billion active users on Facebook in 2021 (Statista, 2022), means that a large part of the global population including Eco’s legions are now active on Facebook, many of them with no knowledge of the internet outside of a smartphone and Facebook, and no cultural tools to call into question alarmist and post-truth news.

By considering the news as an artefact of the middle class in the 18th century (Park, 1940; Carey, 2009), which had as its main target audience the middle class itself, and considering a positive correlation between middle-class dimension/satisfaction and newspapers circulation (WAN-IFRA, 2014, 2017), I argue that there is a strong socio-cultural interdependence between journalism and the middle class, which roots the loss of faith in and attention towards mainstream media, in the middle-class crisis. Thus, it is the crisis of the middle class, i.e. the thinning of the main reference public of major newspapers, which strongly contributes to the Fourth Estate's inability to successfully oppose disinformation. In addition, "people now view media as part of the elite" (Edelman, 2017).

(iv) Second key driver: sharing industries (filter bubble; echo chambers)

I now turn to examine the second driver, that is the economic mechanisms contributing to the spread of fake news on social media, "the motivations of those who create this content" and "the ways this content is being disseminated" (Wardle, 2017).

A powerful economic driver for the creation and spread of fake news is the ability of private individuals to earn money through the use of Google AdSense, the most popular among similar programs, which pays the website owner for each user who has been exposed to or clicked on an ad. An example of how this mechanism operates can be seen in an Italian website dedicated to publishing fake news, which was active well before fake news became a popular slogan. The website "Senza censura" (without censorship), fabricated and published gruesome news stories, with a strong racist component, using explicit titles about terrible crimes, mostly committed by African immigrants, cruelly avenged by the Italian *victims* (https://web.archive.org/web/20150822200158/http://senzacensura.eu:80/2015/07/13/immigrato-violenta-bambina-di-7-anni-il-padre-gli-taglia-le-palle-e-gliele-fa-ingoiare/ "Immigrant rapes 7-year-old girl. The father cuts off his balls and makes him swallow them”). The website attracted 500,000 readers a month. In September 2015, a piece of news was published that drew 500,000 readers in a single week and that finally attracted the attention of the police, who closed down the website and denounced its owner for instigating racial discrimination. In a subsequent interview in a renowned Italian magazine, the website’s owner said he had observed how much attention a well-known Italian right-wing politician would draw using populist speech against immigrants and thought to use that same rhetoric with the sole purpose of making money through Google AdSense (Di Fazio, 2015).

An economic boom in Macedonia in 2016 provides another example of economic interest driving the creation of fake news (Silverman and Alexander, 2016; Ohlheiser, 2016; Sydel, 2016; Smith and Banic, 2016). Over 100 websites owned by Macedonians had published content in favour of Donald Trump’s election for the U.S. presidency. Directed exclusively to an American audience, these sites had American-style names like WorldPoliticus.com, USConservativeToday.com, and USADailyPolitics.com and published mostly unverified content in favour of Trump, as well as fake news disparaging Hillary Clinton. The young Macedonians who ran the websites reported that they did not care about politics or Donald Trump, they just wanted to make money through Google AdSense. The sites were directed at the American public because clicks on advertiser banners by users coming from richer countries like the United States pay a lot more than clicks by Macedonian users. They further reported that the best way to generate traffic from social media was to target Trump supporters who were more likely to be drawn to scandalmongering.

To put it in the words of one of the most famous Americans to fabricate news who was interviewed by *The Washington Post*, who claimed to have earned $20.000 a month with Google AdSense and claimed to hate Trump: “I think Trump is in the White House because of me. His followers don’t fact-check anything — they’ll post everything, believe anything. His campaign manager posted my story about a protester getting paid $3,500 as fact. Like, I made that up. I posted a fake ad on Craigslist” (Dewey, 2016). Another American news fabricator interviewed by *NPR*, was reported to say that: “his writers have tried to write fake news for liberals — but they just never take the bait” (Sydel, 2016). One year later in 2017 the same person stated to Harvard University’s *Nieman Reports*: “This is not an issue isolated to the fringe right. Both sides of the political aisle are susceptible to fake news, and with the recent shift in the balance of power I see liberals as being a prime target for anything negative about President Trump or his administration” (Coler, 2017). In response, in November 2016 the Director of Product Management, Sustainable Ads at Google, announced the introduction of a new ‘AdSense misrepresentative content policy’ pursuant to which action was taken against nearly 200 website owners who were permanently “kicked out” by the AdSense network (Spencer, 2017). However, some of them transferred to use other similar programs to make money such as Publy.net (Rovelli, 2017).

Research published in 2021 confirmed the tendency of the right-wing public as being more profitable for social media (Edelson et al., 2021), and confirmed the successful business model for websites mentioned above, thanks to the advertising revenue from top brands (Skibinski, 2021).

There is yet another aspect to consider in the context of economic incentives to create and spread fake news: science disinformation for improving industrial income. This practice consisted in having a predilection in publishing strictly partisan studies instead of others, and to operate as an extension of a marketing department of companies writing more favourable reviews, disparaging non-industrial research. This practice is denounced by former and current editors of well-established scientific and medical journals like the *British Medical Journal-BMJ* (Smith, 2005), the *New England Journal of Medicine* (Angell, 2009), and *The Lancet* (Horton, 2004 and 2015). A 2016 study found that one industrial clinical trial out of every five, published in the most important medical journals, is designed for marketing, rather than for scientific purposes (Barbour et al.). Another study published in November 2016 stated that the sugar-producing industries fund research demonstrating that sugar is unlikely to cause cardiovascular disease (Kearns et al., 2016). Press releases and public relations do the rest, ensuring exposure in the mass media favoured by the publication of studies in well-established scientific journals. This system indirectly overshadows opposing voices and studies that fail to have the same visibility or do not have public relations agencies.

Sharyl Attkisson, an Emmy award-winning journalist, explained that lobbying activities to influence legislative power have become less important than so-called astroturfing (2016a), which “are most often denounced by journalists in the course of their investigations rather than by academic researchers” (Lits, 2020:167). Astroturfing is a term derived from the English word grassroots, meaning popular social movements born of the people. *Astroturf* is a registered trademark for synthetic grass, so astroturfing refers to fake popular movements where people are paid to campaign in favour of one stance. This term has been in use since the 80s but exploded with the advent of the internet. Astroturfing refers not only to paid political activist campaigners, but also to marketing activities that create a fictitious popular consensus to support the products of certain companies or delegitimize the products of competing companies, ultimately to promote business interests (Henrie and Gilde, 2019). There are agencies that sell fake supporters on social media, who are also very active on Wikipedia, and partisan websites hide their fake news behind the cover of real news, thus making it more likely that users will accept their falsehoods.

Having reviewed some of the economic motives underpinning the creation of fake news, whether for personal, political or industrial interests, I now turn to examine the mechanisms that facilitate its spread on social media: the sharing industries (see definition above in Ch. 1.1).

All social media algorithms work on databases which collect individual users' information starting from email, username and phone number through which access is granted to social media. All data collected and organised in databases are voluntarily shared through users' online activity. To store all data, sharing industries started building new data centres. At the time when its first data centre was built in Europe in 2013, Facebook had to manage approximately 350 million photos published, 4.5 billion "likes" and ten billion messages each day (Kotenko, 2013). Data centres require powerful cooling systems and the first built in Europe by Facebook was set in Sweden, 100 km from the Arctic circle (Harding, 2015), an energy-saving solution that had already been implemented by Google.

All data collected contain users’ preferences on personal life, desires, ideas and politics expressed through words, images, shares and likes, also the time users take to read a text or to look at an image. All those data are interconnected with data from other social media or websites. For example, on most web sites alongside each article is a *share* button on Facebook, Twitter, and LinkedIn. Similarly, the like button that often appears on sites outside of Facebook, gives Facebook the ability to track our readings on that site, even without clicking like, even without logging in to Facebook. All those data are eventually sold to marketers whose creativity is limited by Facebook’s commitment to preserving users’ experience of empowerment and community (Jordan, 2020). However, in order to be of interest for marketing purposes, the databases must be constantly updated. For this reason, social media constantly push their users to post new messages on their timeline, send private messages through messenger, add new friends, become members of new pages, or to transmit feedback using the classic thumbs up of the like button, to which have been added various emoticons to ensure more accurate feedback on users’ thoughts and reactions, with the purpose of being shared with advertising agencies. Paraphrasing Feuerbach’s "we are what we eat" (Cherno, 1963), it can be said that we are what we share. Castells in 2009 said that: “in our society communication protocols are not based on the sharing of culture, but on the culture of sharing" (126). As Meikle said, we can talk about the industry of sharing, because the whole social media system is based on sharing: “The word share is at the heart of social media” (2016:24).

Unsurprisingly, Facebook never mentions this business model in its mission statements, focusing rather on its ability to connect people. The Facebook mission statement has changed several times since 2004 (Reagan, 2009; Kelly, 2017). Since

2018 the mission statement has been: “Give people the power to build community and bring the world closer together” (http://web.archive.org/web/20220220221559/https://about.facebook.com/company-info/). However, the statement in force between 2009 and 2017 is very useful to explain the way Facebook works: “Founded in 2004, Facebook’s mission is to give people the power to share and make the world more open and connected. People use Facebook to stay connected with friends and family, to discover what’s going on in the world, and to share and express what matters to them” (http://web.archive.org/web/20160114234737/https://newsroom.fb.com/company-info/). Based on this mission statement, Meikle elucidated how Facebook represents itself to the world (2016:37). Two sentences, the first of which has as its subject Facebook which offers a space to connect; the second is about people (not users or customers), who use Facebook to communicate and share. There is no mention of Facebook as a company with costs and revenues, exploiting user content for commercial purposes. Rather, Facebook is presented as a public good, and therefore, it is not surprising that most users do not think twice about providing personal data to Facebook, in the same way they would to the city council.

To maximise profits through the collection of data, several mechanisms have been implemented to increase user traffic on social media and research engines, which also facilitates the spread of fake news. In December 2009, Google implemented epochal changes in its search engine, which created what was called a filter bubble (Pariser, 2011). That is, results of searches made by users on Google would for the first time be influenced by the analysis of 57 indicators in relation to the user, including: geolocalities, browser used, previous searches, sites visited, along with a whole series of other personal information that Google was able to collect including from the content of users' private emails sent via Gmail. Thus, since December 2009, while searching for the exact same words in Google's search engine, each user receives personalised results (Holman, 2010), not only in terms of the order of those results but also in their quantity, thus creating a bubble of filtered reality within which the user remains embedded. Echo chambers (Sunstein, 2001, 2007; Garrett, 2009; Del Vicario et al., 2016; Dubois and Blank, 2018) are another powerful mechanism that can facilitate the transmission of fake news, enhanced by the filter bubble algorithm. Echo chambers are groups, or an aggregation of people united by the same interests or worldview, generally "with both very low interest in politics and low media diversity" (Dubois and Blank, 2018:740). Echo chambers facilitate the circulation of certain information more successfully and rapidly, which is what the members of the group want, that is, "listening to louder echoes of their own voices" restricting "themselves to opinions and topics of their own choosing" (Sunstein, 2007:13). This facilitates the users' returning to the same platform because algorithms ensure more pleasing content, including post-truth information, in search engines results or on social media's newsfeed. Recalling the definition of the sharing industries (see above Ch. 1,1), it can be said that the growth of social media has contributed to the rapid spread of fake news.

The following is an example of how well-designed algorithms can create an environment that favours certain behaviours over others. In 2010, researchers in collaboration with Facebook conducted a study of 61 million users in the United States, just before the mid-term, i.e. Congressional elections (Bond et al., 2012). Users were shown different versions of the same message encouraging them to vote.

The research concluded that the version of the message that included images of close friends who had voted, had been more successful in turning out tens of thousands of users. The power of algorithms was further demonstrated in a psychological study published in 2014 conducted by Kramer, Guillory and Hancock, in collaboration with Facebook, which told us how the manipulation of news that appears in users' news feed can affect their emotions (2014). The study's ethics were questioned because users had not been informed of their participation. The results showed to what extent an algorithm is able to make users feel good-humoured or in a bad mood, using minor changes to the news page algorithm, by limiting the amount of positive or negative messages that come from friends' posts. By making the messages that appear in the newsfeed less positive, the user's mood became negative. By making the messages less negative, the user's mood became more positive.

The algorithms that create filter bubbles and echo chambers, facilitate users' ability to access information of interest, not only fake news that feeds peoples' anxieties, but also opportunities for coming together to discuss a certain type of news and possibly organise actions, inside or outside the group to which users belong. Through the algorithms, alternative associative realities such as the CCSVI movement can be created that could not exist outside of the internet, for example due to the geographical distance between the interested parties, or because of immobility among users, that is, not being able to move out of the house due to old age, chronic diseases or accidents.

In addition to users' data being exploited by marketing agencies in order to recommend products, such data can also be of interest for political purposes. An example of Facebook data being used for political ends is Cambridge Analytica, a British/American company that dealt with the analysis of data and strategic communication in electoral processes. It designed a unique methodology to psychologically profile people in great detail through their activities and personal information on Facebook. Cambridge Analytica's services were used by the U.S. presidential candidate, Donald Trump, and they issued a congratulatory press release a day after his victory (Cambridge Analytica, 2016). Trump used the company to reach his potential voters as well as the undecided, devising different messages, based on personal data, such as age, race, political preferences, income, occupation, etc., using updated strategies with immediate effect based on the constant updating of their databases. Most of the information was harvested from 50 million Facebook profiles (Cadwalladr and Graham-Harrison, 2018), which were used to build disinformation operations through personalised messages appearing in each user's newsfeed.

The resentment of the middle class which is sceptical about the future and not any more part of the economy, together with the mourning of the larger lower class which aspired to become middle class, became an easy target for Cambridge Analytica's information operations. Cambridge Analytica's targeting of post-truth communication on social media was psychologically tailored to fuel peoples' resentment towards the system, and they were also helped by representatives of social media giants which were profiting to the tune of millions of dollars (Bartlett, 2017).

Facebook confirmed the existence of information operations influencing public opinion for political purposes and stated that there was a strong will to counter this phenomenon. A Facebook report confirmed the activity of foreign governments in influencing the U.S. electorate during the presidential elections in 2016 (Weedon, Nuland and Stamos, 2017), and further stated that 30,000 Facebook profiles, found to have been acting with malicious political intent, were closed during the 2017 presidential election campaign in France. Social media were under scrutiny for their role in spreading fake news, and Facebook had even been threatened with a 50 million euro fine from the German government (Eddy and Scott, 2017).

(v) Social media deemed responsible for spreading fake news

The challenge for social media is to find a way to curb the spread of fake news without limiting the creation/sharing of data that are their main source of income. To avoid imposing a blanket ban on the sharing of information, which is the sharing industries' main income generator, social media companies such as Facebook have started to cooperate with external organisations to assist them in policing the circulation of fake news. Disinformation will not disappear entirely as it will still be possible to share fake news stories, but the algorithms will give them a lower priority in the visibility list, perhaps to the point that it will be possible to see them only if you go to the personal profile of those who posted them. In addition, warnings about their credibility will appear, with links to alternative articles to offset the false or allegedly false news. This approach will require increased user activity, as users will help to identify and signal fake news stories. Paradoxically, such an approach could provoke an increase in the spread of fake news by those users who are interested in that piece of news, once they understand it has been targeted. In fact, this happened in 2017, in the first known case in which Facebook tested its fact checking system in the San Francisco area. When fact checkers, the Associated Press news agency, and the American urban legend debunker website *Snopes*, highlighted a fake news story (Hunt, 2017), interested users worked harder to share the news and circulate it.

It is worth noting here that not all sites that claim to patrol the news are created equal as there is currently no regulation of these sites or the people who work for them. Indeed, the American *Snopes* site referenced above has been identified as an Astroturfer by Attkisson (2015, 2016b). Like *Snopes*, many debunker sites could be undertaking counterinformation activities in favour of companies that make large investments in marketing, organising alleged activists on social media to promote their own scientific truth, while denigrating dissenting users on personal rather than scientific grounds.

Even if Attkisson’s report can arguably be considered an overstatement, generic debunker sites should probably not take part in ongoing scientific debates and decide who can have a say and on what in a Facebook public debate.

In fact, *Snopes* did take a position against CCSVI in 2016 which was contested by CCSVI activists. An unknown web site which had recently been established with the purpose of click baiting and making money from Google Ad Sense, published an article with a title claiming that “an Italian doctor discovered a “surprisingly simple cure” for multiple sclerosis” for MS. Starting from debunking the claim and the unrelated photograph, *Snopes* went ahead and stated on the basis of a single study, that CCSVI was “conclusively debunked” (https://www.snopes.com/fact-check/italian-doctor-multiple-sclerosis/), despite the fact that scientific research on CCSVI was still ongoing. In turn, in the same article debunking not just a claim but also all the research on CCSVI, *Snopes* mentioned as a real alternative the “dramatic” results published a few months earlier on a stem cell therapy after which a paralysed patient allegedly went back to riding his bike and walking again (the title of the *Telegraph* article, cited by *Snopes* states: “'Miraculous' results from new MS treatment”). This appears to be a typical example of the blending of genres (Kress and Leeuwen, 2001:35), that is, arguing the effectiveness of a therapy and at the same time offering an alternative as if it were effective, though still under experimentation. It did not go unnoticed among activists that a few months later *Snopes*, among others, did not debunk an article claiming: “An Extreme New Treatment Has Cured Patients of MS”, with a scientist from Ottawa Health Research Institute in Canada claiming : “these patients are cured” (https://www.sciencealert.com/this-radical-new-cure-for-ms-reboots-the-immune-system). According to the study, out of 24 patients who were given drugs and stem-cell transplantation, one patient no longer required a wheelchair, but another one died (one of the main researchers was Dr Freedman who called the CCSVI research a hoax, see CH. 3.2.1). CCSVI activists went onto the *Snopes* Facebook Page and on Twitter to inform people about the ongoing scientific debate, but they did not receive any answers. A study conducted in several European countries and published in November 2021 in *The Lancet Neurology*, did not support the use of bone marrow-derived mesenchymal stem cells to treat active multiple sclerosis (Uccelli, Laroni, Ali, Battaglia, Blinkenberg, Brundin, … Freedman, 2021), but on the *Snopes* internal engine search, the article on CCSVI is the only recurrence about debunked cures for MS.

(vi) A socio-cultural dependence between journalism and the middle class

I argue that the main flywheels of the spread of post-truth communications in the western world are as follows: the crisis of the middle class rooted in the 2008 economic crisis which has led to a loss of trust in mainstream media and journalism, prompting a move to alternative, online news sources, coupled with the sharing industries' business model, in which profits depend on the exploitation of users' data collected through the "produsers" (Bruns, 2006) sharing activity, which includes the sharing of post-truth communications.

I propose a strong socio-cultural dependence between journalism and the middle class, rooted in the 18th century when the news was invented for the middle class. This suggests a positive correlation between the fortunes of journalism and the middle class; data shows that where the middle class was prosperous like in some parts of Asia, print circulation was increasing, whereas in the west, where the middle class was shrinking, print circulation was diminishing. In early 2017, the IMF officialised what previous studies had found, which is that the western middle class is not only shrinking, but also losing trust and hope. This loss of trust in media and institutions, confirmed by two independent polls, has been especially true in countries that have seen the middle class shrink and that witnessed "the election of Donald Trump, the Brexit vote and the failed Italian referendum" (Edelman, 2017). Furthermore, mainstream media represents the economic establishment by which the middle class has felt betrayed since the ‘Great Recession’ in 2008, another motivation for turning against it.

I consider the economic interests which underlie the spread of fake news. There is a direct monetary interest in the creation of disinformation, with website owners recognising the draw of fake news and profiting from visitors’ clicks on advertising banners. However, most importantly in the spread of fake news is the sharing industries’ business model, which is based on the collection of data shared by users’ online activities, then organised in databases to be sold to marketers. To enhance users’ activity and the amount of data collected, the sharing industries use algorithms that create filter bubbles and echo chambers. The favourable search responses given by filter bubble algorithms together with resentment towards mainstream media may lead people to prefer search engines over human news editors, thus enhancing the reach of disinformation. Echo chambers can also be crucial in favouring higher sharing activities of fake news thanks to cues like familiarity through the repetition of the message, endorsement of friends and family, self-confirmation bias and a “desire to be vindicated” (Wardle and Derakhshan, 2017:47). An example of the mechanism that amplifies the reach of fake news is the activity of online users serving as gatewatchers (Bruns, 2003), and news editors (Hermida, Fletcher, Korrel and Logan, 2012:821), selecting content for their friends’ news feeds, as well as social media platforms tailoring content for individuals using filter bubbles and echo chambers.

A healthier information ecosystem and a stronger democracy would require higher levels of public trust in traditional media which would work to oppose post-truth communication. This could happen through increasing transparency, both in terms of the chain of command from the owners of the newspapers to the publishers, and about what they do and why they do it, in order to render the reader aware of newspapers' liberty "to suppress and to distort news because of 'the freedom of the press'" (Lynd, 2016:217).

(vii) Media consolidation and the decline of local news

Local news has been strongly "McDonaldized" (Franklin, 2005), as a result of an intensive media convergence, and more specifically as a result of an intensive media consolidation in the last years of the 20th century. For example, internationally, in 5 years from 1990 to 1995, the same number of media merges took place as had taken place in the 30 years from 1960 to 1990 (Castells, 2009:75). In the U.S. alone, from fifty companies leading the media market in 1987, there were only five companies in 2004 (Bagdikian, 2004). Focusing on the newspapers' panorama, at the end of 2019, before the Covid-19 pandemic hit, in the U.S. there were one fourth less newspapers than in 2004, down to 6,700 newspapers from almost 9,000 (Abernathy, 2020:11). Further, 25 major groups owned one third of all newspapers, up from one fifth in 2004. In 2020, the three largest corporations in the U.S. owned 15% of the countries' newspapers, managing more than half of the circulation (34).

The growing number of online local news sites give only the appearance of diversity as either they are owned by the same big corporations that control traditional media, or they do not have the capacity to cover local news, covering on average only 10% of the stories of the U.S. communities (Napoli and Mahone, 2019). Furthermore, independent publications will likely suffer from the dismantling of the net neutrality rules (Rushe and Gambino, 2017), which will likely favour wealthier companies. Empowering traditional media's local news could create a stronger community because local newspapers are reported to produce nearly 50% of original stories, even if they account for only 25% of the outlets in the U.S. communities (Napoli and Mahone, 2019). Community, that is, local news can work as a geolocalized echo chamber which would give citizens more opportunities to be heard and to see themselves represented, a role currently fulfilled by social media. The disappearance of community newspapers means that "the watchdogs of school boards, city councils and quorum courts are gone. The chroniclers of high school sports teams are missing", and it probably means also the impossibility of "putting into local context issues that may have seemed to be national ones" (11), acting as a filter of fake news.

The U.S. Federal Communications Commission (FCC) act of 2017 did not reverse media consolidation. Rather it further loosened media ownership rules, and has been critiqued for letting a single company own multiple newspapers, televisions and radio stations in the same community (Reardon, 2017; Nevins, 2017). Furthermore, the FCC gave greater control to Internet Service Providers (ISPs) in marketing broadband connections (Karr, 2018). This has been criticised for empowering ISPs to favour some web services over others and for penalising poor communities' networks which are not lucrative. However, this media concentration together with the ISPs greater control of the information highways, could provoke the creation of strong competitors opposed to social media giants, which may in turn rely on edited news to counter the uncontrolled spread of fake news.

In the short term, it will be interesting to see how the giants of the web square the circle, that is: on the one hand to limit the number of fake news stories in circulation without oversight becoming a tool of censorship in the hands of governments and multinationals (Marwick, 2017), and on the other hand, to uphold freedom of speech and sharing, their primary source of income. More significant will be the question whether and how governments will choose to sustain the middle class for the sake of a wealthy democracy. Inequalities, relative deprivation and a shrinking middle class could weaken democratic institutions, reduce educational performance, increase crime levels (Davey, 2012), and could "trigger a violent political reaction" (Piketty, 2014:439). Change will require a strong will by the elites to not distance society from the level of civilisation and democracy achieved in the west after the second war world. In 2021 we have an example of Facebook's squaring the circle: after the U.S. administration decided to investigate the origin of Covid-19, Facebook removed the ban enacted a few months earlier on posts claiming that Covid-19 was "man-made or manufactured" (https://www.theguardian.com/technology/2021/may/27/facebook-lifts-ban-on-posts-claiming-covid-19-was-man-made). Interestingly, the lifting of the ban appeared only in the American version of the 'COVID-19 and Vaccine Policy Updates & Protections', it was not reflected in the British and Italian versions of Facebook's policy.

(3) Social movements

The following parts of the literature review include references to interviews with CCSVI movement activists (for details see Chapter 2 - Methodology).

(i) Contentious politics

Social movements as we generally understand them today, did not exist until three centuries ago (Tilly, 2004:3). Until the 1960s, when social movements became more common (Tilly and Tarrow, 2015) researchers focused their attention on the structural source of social movements' contentious politics, where predominantly the working class and more generally all social classes were the key actors of contention. Whilst class was still an important category of theory framing, from the 1960s a new stream of research "questioned the predominance of class in the study of contentious politics and placed a greater emphasis on the political process of contention" (Tilly and Tarrow, 2015:216).

Jordan (2001) tracing the history of activism focused on the transition from the industrial society to the information society, identifying three stages. The first was the rise of the industrial society when movements advocated issues such as women's right to vote, labour rights and anti-slavery. The second stage started with the Bolshevik Revolution where the framework for movements was that of class. In the third stage in the 1960s, class started to diminish in its importance. Instead, issues-driven movements such as feminism and anti-racism called the "new social movements”, re-emerged (27) and by the 1990s there was no movement which could claim to be superior to or more significant than the others.

Tilly recognised that social movements are a major vehicle through which ordinary people can participate in public politics through “repertoires of contention” in a defined place and time. Tilly identified the following as key attributes of a social movement:

> 1. a sustained, organized public effort making collective claims on target authorities {let us call it a campaign};
> 2. employment of combinations from among the following forms of political action: creation of special-purpose associations and coalitions, public meetings, solemn processions, vigils, rallies, demonstrations, petition drives, statements to and in public media, and pamphleteering (call the variable ensemble of performances the social movement repertoire); and
> 3. participants' concerted public representations of WUNC: worthiness, unity, numbers, and commitment on the part of themselves and/or their constituencies (call them WUNC displays) (Tilly, 2004:3).

Social movements, as Tilly and Tarrow added later, draw on “the organizations, networks, traditions, and solidarities that sustain these activities— *social movement bases*” (2015:11, emphasis in the original). Specifically, from the 1970s, the subjects of contentious politics “were defined as they defined themselves” (2015: 216), starting from definitions such as “ecologists”, “animal rights advocates” and moving to the “broader populist imagery” which focused “on the mood of outrage among protesters (*los indignados*); on the breadth of the public they claimed to represent (“the 99 percent”), and on the forms of contention they employed” (217, emphasis in the original), as for example the Occupy Wall Street movement.

Tilly (2004) traced a specific description of contentious politics adapted to social movements:

> Contentious in the sense that social movements involve collective making of claims that, if realized, would conflict with someone else's interests, politics in the sense that governments of one sort or another figure somehow in the claim making, whether as claimants, objects of claims, allies of the objects, or monitors of the contention (3).

The Italian CCSVI movement was also defined as it defined itself, that is as “*CCSVI nella Sclerosi Multipla*”, at times shortened to CCSVI-SM, from the name of the Facebook Page (which then became the name of the new-born association), because the activists were advocating only for additional inquiry into a correlation between CCSVI and MS, and nothing else. Activists also called themselves in an energising and reassuring way, “il Popolo della CCSVI” (“The CCSVI People”, Fig. 1), a term which reflected the enthusiasm of the massive participation at the first successful public conference on CCSVI in Vicenza. The conference was hosted on 23 January 2010, organised by a local MS foundation introducing Zamboni’s theory for the first time in public. There were 1,000 attendees, 400 more than expected, so that they had to quickly set up a nearby hall in the same complex where the conference was projected (Pepe, 2010). Attendance was largely credited to the publicity the conference had received through social media and the CCSVI Facebook Page. The conference was reported by one of Italy’s national TV channels, Mediaset, the following day, marking CCSVI’s first known appearance on national mass media in Italy (Canale5, 2010). The success of the conference was also the start of the development of the movement:

> In January 2010, the idea was born to create a movement a little more, like, organized, and therefore to give an organizational basis to these people who had found themselves on the internet and who asked for different research on multiple sclerosis (Lorenzo).

Figure 1: "Popolo della CCSVI" (The CCSVI People). Drawing from satirical drawer Matitaccia (Giorgio Serra). June 2010. On the left on the walnut shell are pictured Dr Galeotti, Dr Salvi and Prof Zamboni.

Della Porta (2015) identified the main stages of social movements in the changing development of capitalism: *Old social movements* with industrial workers' "class identity with universal norms" hierarchically organised; *New social movements* with the middle class's "single issue identities" organised in a participated network; *Global Justice Movements* of the late 1990s early 2000s, characterised by class coalitions in "plural identities" following deliberative organizational models, which were more likely to involve well-educated and left-wing people; *Anti-austerity* *movements* from the 2008 economic crisis onward (2015:17), where the precariat with citizens' identity, resembled a mass phenomenon which received approval from people of diverse generations and with different educational backgrounds (54). The Anti-austerity movements were also known as "movements of the crisis" (Della Porta and Mattoni, 2014:2). Transformations as the "distribution of power at national and international level" of the early 2000s were reflected in "new forms of protest such as countersummits and transnational boycotts, as well as in internet protest actions" (Della Porta and Diani, 2006:192).

Studies of social movements, why they emerge, how they are sustained and what impact they have on broader society, grew exponentially in the 1980s and Diani (1992) sought to systematise the definitions of the most influential scholars of that period. Diani recalled Touraine (1981) and Melucci's (1989) revelation that collective identity is a "key problem for the study of collective action" (Diani, 1992:18). Diani synthesized that while collective identity played a key role in defining the margins of a social movement, it "does not imply homogeneity of ideas" but a "continuous process of 'realignment' (Snow et al., 1986) and 'negotiation' (Melucci, 1989) between movement actors" (Diani, 1992:9).

Contrary to the movements described by Jordan, where activists could not clearly articulate their plans for the future (2001:138), for the CCSVI activists their plans were crystal clear: more research on CCSVI and its medical intervention available for all MS patients through the Italian NHS. However, there was a heterogeneity of ideas which for the first time in mid-2010 emerged in response to a decision by the administrator to temporarily remove the possibility for activists to post in the CCSVI

Facebook Page (formerly known as Fan Page), following the posting of insults directed at a well –known person who, contrary to what she had promised, declined to talk about CCSVI when invited on national public television:

> I can tell you that we talked about it with the others in our group that I told you about earlier and they too did not agree that you had closed the bulletin board. It was very beautiful before, (…) and we all felt a little involved, now maybe not knowing the newcomers because so many people have joined then maybe you stay more on the sidelines because you don't know who you are dealing with… but the Fan Page was very positive (Giorgia).
>
> I remember the closure of the Fan Page, I was in agreement because in that moment, well, there were the first signs of what we later saw (Mattia).
>
> The administrator certainly knew how to cut, cut ... he knew ... it was necessary, he did well, to cut the possibility of exponential growth, and therefore a loss of control. He gave some, indicated some rules of the virtual world, established things and closed them there. The people present, thanks to a sort of subjection, fear of being eliminated, because there is that kind of fear there, immediately returned to normal, civilized tracks, also because if they had not the administrator would have thrown them out. However it worked, it worked well, so much so that the page continued to grow and always live in a flourishing way (Dario).

Furthermore, social movements endure “even when collective effervescence is over, and that this is not immediately followed by institutionalisation (see e.g. Melucci, 1984 and 1989; Tarrow, 1989)” (Diani, 1992:11). Diani noticed that collective identities may change and give birth to dissimilar social movements, “or provide a persistent, though latent, basis for a new upsurge of mobilisation campaigns under the same heading”, in that a social movement might be going through a “latency” phase even if they are not acting on the public stage (16). The synthetic definition of social movement that Diani put forward was:

> A social movement is a network of informal interactions between a plurality of individuals, groups and/or organizations, engaged in a political or cultural conflict, on the basis of a shared collective identity” (13). This implies that social movements are not “necessarily anti-systemic actors” (18), leaving “more specific connotations to the analysis of specific conflicts (19).

In line with Diani’s argument on the alignment of heterogenous ideas, Melucci defined collective identities as “an interactive and shared definition produced by a number of individuals (or groups at a more complex level) concerning the *orientations* of their action and the *field* of opportunities and constraints in which such action is to take place” (1996:70, emphasis in the original).

Others attempts at a definition have sought to conceptualize social movements as:

> Collectivities acting with some degree of organization and continuity outside of institutional or organizational channels for the purpose of challenging or defending extant authority, whether it is institutionally or culturally based, in the group, organization, society, culture, or world order of which they are a part (Snow, Soule and Kriesi, 2004:11).

Sidney Tarrow simplified the definition of social movements to: “collective challenges, based on common purposes and social solidarities, in sustained interaction with elites, opponents, and authorities” (Tarrow, 2011:9). Tarrow’s definition was more inclusive of movements such as the CCSVI movement, which was not political, nor antisystem. In fact, most if not all the Italian scientific research backing up the CCSVI theory was conducted within Servizio Sanitario Nazionale (Italian National Health Service, Italian NHS) facilities, and publicly funded by the State. Tarrow made a distinction between social movements and political parties, where the latter end the “capacity for disruption” (138) of the social movements’ bases internalising them into organisations, and when the former contributes in the success of the parties they helped in the elections (218) “that can precipitate their own decline” (169). New hybrid forms of social movement organizations from the 1960s gave the opportunity to “maintain a sustained interaction with allies, authorities, and supporters” with umbrella organizations, while decentralised social movements could “create networks of trust that are free to develop their own programs and engage in forms of action appropriate to their settings” (139). In the case of the CCSVI movement, instead of developing into a political party, it developed into a legal association. The institutional organisation of this association, necessary to interact with medical and state institutions, required a controlled behaviour in public on behalf of those activists who were in charge of the association (see Ch. 4.5):

> For example, when those who joined the board of the association went back to write on your Facebook Page, it was quite another thing. Before there was not all the presumption shown in the association’s Facebook Page, they commented in another way (Giorgia).
>
> Now, I always read everything that happens on the original Facebook Page, I try to follow it as much as possible, but differently than before I interact little publicly, in chat, perhaps privately with those I know, I let myself go a little more. What I would change, I don't know, maybe nothing. It seems to me that, all in all, then along the way we learned to use this tool, so I would say that also the way we are using Facebook now through the association, it is productive in short (Aurora).

The social movements’ bases were not all internalised into institutional organisations, at least not the Facebook Page from which the activists created the association with the same name. The original CCSVI Facebook Page maintained its independence and offered the possibility of speech with no constraints also for those who had joined the associations:

> I had used that page, and therefore for me it was the origin, that is, I had done things, some relationships were born from there, they started from there, so ... I owed the information to that page. The information was not to be withheld, the information had to be there, that's it. And that was a mistake in my opinion, it was a mistake politically, but politically not in the reductive sense of the term, in the noble sense, politically in the noble sense, in short, right? Because it's like denying where you come from, instead you don't have to deny where you come from. Absolutely (Ginevra).

What then contributed to further reduce the capacity for disruption of the movement was the unsuccessful cohabitation among several CCSVI associations that were created after the first one:

> Basically, everyone has their own way of working, everyone has their own way of expressing themselves, each contributing in their own way, each slowing down the work of the others in their own way. And this is something that goes against patients, goes against research, and goes against any self-respecting associative spirit. But unfortunately, we have fallen into a vice from which we cannot get out (Vittoria).

Tilly and Tarrow made a distinction between social movement bases and social movement campaigns and they defined the activities of the social movements as “a sustained campaign of claim making, using repeated performances that advertise the claim, based on organizations, networks, traditions, and solidarities that sustain these activities” (2015:11). According to this definition, the social movement bases entailed “movement organizations, networks, participants, and the accumulated cultural artifacts, memories, and traditions that contribute to social movement campaigns”, while the campaigns are defined as “sustained challenge to power holders, in the name of a population living under the jurisdiction of those power holders, by means of concerted public displays of worthiness, unity, numbers, and commitment, using such means as public meetings, demonstrations, petitions, and press releases" (148). Underlining the differences had the purpose of making "systematic comparison across type of contention", examining "transitions between different forms of contention", and the purpose of enlightening "the difference between the bases on which contentious politics builds and the campaigns that launch those politics" (148-149). The distinction helped "to sort out the organizations, networks, participants, and traditions that make up a social movement and constitute a movement campaign" (149).

Tilly and Tarrow listed a series of mechanisms and processes that captured the dynamic of contention. Mechanisms were intended as a "delimited class of changes that alter relations among specified sets of elements in identical or closely similar ways over a variety of situations", while processes were defined as "regular combinations and sequences of mechanisms that produce similar (generally more complex and contingent) transformations of those elements" (2015:29). Those which were considered the most common mechanisms were: "Brokerage: production of a new connection between previously unconnected sites. Diffusion: spread of a form of contention, an issue, or a way of framing it from one site to another. Coordinated action: two or more actors' engagement in mutual signalling and parallel making of claims on the same object" (31). When the three mechanisms were combined, they constituted one version of process called "new coordination" (35); when a coordination process led to a higher level of coordination, it became a process called "upward scale shift" (35). Among mechanisms and processes that influenced the spatial and temporal life of contentious episodes, Tilly and Tarrow listed: social appropriation, boundary activation, certification, identity shift, competition, escalation and radicalization (36). A mechanism characterized as a "set of tools that a state uses in order to oppose challengers" (38) were repression and social control. Other processes that recur often were mobilization and demobilization (38).

Della Porta and Diani (2006) distinguished the forms of repertoires of action in three logics: "the logic of numbers, which seeks to display the strength of support for a movement; the logic of material damage, based on the capacity to interrupt everyday routine; and the logic of bearing witness, which seeks to demonstrate the emotional commitment of protestors" (192).

(ii) Framing perspective

The growing literature on social movements has given rise to a number of analytical frameworks that help to explain in particular the roots of mobilization as well as the mechanisms that contribute to their longevity. One of the most widely-accepted theories regarding social movements is drawn from sociology and uses a framing perspective to critically examine them. While the concept of framing was originally devised by Goffman in 1974, it has been developed considerably in the intervening years (cited in Benford, 1997).

In their 'Framing Processes and Social Movements: An Overview and Assessment', Benford and Snow (2000) set out the key parameters of this perspective. They noted that the scholarship on framing processes arose largely to fill a gap in the literature relating to “the struggle over the production of mobilizing and countermobilizing ideas and meaning” (613). Consequently, actors within a social movement were seen as being “actively engaged in the production and maintenance of meaning for constituents, antagonists, and bystanders or observers” (613). In other words, these actors, “along with the media, local governments, and the state”, were considered to be engaged “in what has been referred to as "the politics of signification" (Hall 1982)” (2000:613).

According to Benford and Snow, this signifying work or meaning construction denoted “an active, processual phenomenon that implies agency and contention at the level of reality construction” (2000:614). In other words, collective action frames were the product of a dynamic, evolving process involving the work of movement activists to generate interpretive frames that may not only differ from existing ones but may challenge them.

Collective action frames were designed to simplify and condense aspects of the *world out there*, in ways that are "intended to mobilize potential adherents and constituents, to garner bystander support, and to demobilize antagonists" (Snow and Benford, 1988:198). Thus, collective action frames could be characterized as “action-oriented sets of beliefs and meanings that inspire and legitimate the activities and campaigns of a social movement organization” (Benford and Snow, 2000:614). Crucially, "[c]ollective action frames are not merely aggregations of individual attitudes and perceptions but also the outcome of negotiating shared meaning" (Gamson, W. A. cited in Benford and Snow, 2000:614).

The framing process has been conceptualized thus: movement actors first develop or negotiate a shared understanding of the problem they wish to address and make attributions in terms of blame (this is known as diagnostic framing). In the next step (known as prognostic framing) they set forth various solutions to the alternatives to the problem as identified. In the third and final step they seek ways to characterize the situation so as to provide a rationale to others to act in concert to bring about change (so-called "motivational framing", Benford and Snow, 2000:615).

Through the semi-structured interviews as well as my direct activist experience with the CCSVI movement actors, this thesis recalls the activists' sense of the evolution of the movement and how it relates to the aforementioned concept of framing.

This thesis further aims to examine the role and significance of collective identity in building and sustaining the CCSVI social movement, drawing on work by Polletta and Jasper (2001), among others, who note that collective identity may help to shed light on people's motivation to act. The literature suggests that collective identity may be better than other theories at capturing the "pleasures and obligations that actually persuade people to mobilize" (284).

Diani and Bison (2004) described collective identity as being "essential inasmuch as a movement cannot be reduced to any specific event or campaign, nor to a specific coalition". They characterised collective identity as a process "strongly associated with recognition and the creation of connectedness", bringing with it a "sense of common purpose and shared commitment to a cause" (283–284). This is important because the CCSVI movement can not be tied to a single campaign, in fact there have been many campaigns and events, not all managed or executed by the same coalition, but with a shared commitment to the cause. While in the pre-digital era there were a limited number of activists defining the orientation and the field of the action, Della Porta and Pavan (2018) noted that “the diffusion of digital media and their extensive use as tools of protest and activism have enlarged the spaces and enriched the contributions that shape collective identities” (33).

For the CCSVI movement digital media have been fundamental, not only for their contribution in shaping collective identity, but also for the spatial existence of the collective identity itself, in occupying a space. At the inception of the CCSVI movement there were a limited number of patients with MS all over Italy who could have been interested in the new theory of CCSVI and willing to mobilise for that:

> I must have joined in September 2009. Almost immediately. Yes. There was everything (...) yes, we started to follow, I started to follow the Facebook Page, all information, in part also to help in trying to spread the Page as much as possible as a meeting place for people with this problem or in any case interested in this issue (Lorenzo).

In comparison, political movements and most of the movements studied in the academic literature could draw from larger audiences who might be interested in the cause. Compared to the estimated 60.000 people with MS in Italy in 2010, who could also have had different degrees of physical and mental disabilities, generally the audiences of the movements studied by researchers might be as large as the working class or the general population of a nation, when for example advocating for animal rights, human rights or for “the 99 percent”.

This thesis also aims to examine scholarship relating to the importance of social networks in building and sustaining social movements. Diani noted that studies "have long suggested that embeddedness in social networks not only matters for recruitment, but also discourages leaving, and supports continued participation" (2004:342). However, scholarship on the importance of networks has also shown that for recruitment, it is not essential to be directly linked to movement participants: "Lack of direct ties may be overcome if prospective participants are embedded in organizational networks, compatible with the campaign/organization they are considering joining" (Diani, 2004:345).

(iii) Social media in social movements

The case study of the CCSVI Facebook Page has two distinctive features that can be of particular interest to network theorists: firstly, it represents an autoethnographic study, charting the course of mobilization and participation over several years since 2009, focusing on the movement's first year of activity. As Diani has noted, most extant studies of network and participation "are still based on data collected at a single point in time" (352). Secondly, the case study provides an opportunity to explore the role and significance of virtual ties in network theory. As Diani observed current scholarship on the importance of virtual ties in building social movements is still "too rare to be conclusive" (2004:352). Furthermore, this research deepens the analysis of the ties between movements and social media, examining how movements are built, nurtured and maintained through social media.

Kavada (2015) analysed scholars' arguments on the positive and negative aspects of the use of social media in social movements. On the negative side social media are considered responsible for creating a "type of collective action that requires 'only ephemeral engagements from participants'" (Kavada, 2015:873), contributing to the "displacement and dispersion of critical energy" (Dean, 2012:126), facilitating "mobilizations based on shallow commitments that fail to build long-standing relationships" (Kavada, 2015:873). This was not the case for the CCSVI movement. Firstly, without social media the theory of CCSVI would have, at best, become a sub-category of an unreachable by-many and not-so-social internet forum, as happened before it landed on Facebook. In fact, the first recurrence of the words "Zamboni" or "CCSVI" in one of the most famous American MS forums, was on 30 November 2007 in a post presenting the scientific research on CCSVI. That was almost two years before Facebook became a platform for informing people about CCSVI (https://web.archive.org/web/20210314195421/https://www.thisisms.com/forum/search.php?keywords=zamboni+CCSVI&terms=any&author=&sc=1&sf=all&sr=posts&sk=t&sd=a&st=0&ch=-1&t=0&submit=Search). Secondly, for the CCSVI movement social media did not create only ephemeral engagement for MS sufferers who "used social media to walk" (see Ch. 4.4 below), if it is true that they were responsible for shifting medical research priority funding (Chafe et al., 2011). As one of the most engaged activists declared about getting to know other highly-engaged activists:

> Facebook has created this channel, that is even friendship by phone, which is not making a phone call every five years, I mean, it becomes a telephone relationship, also because with Facebook you know a person. Yes, you know them by writing, you phone them, but on Facebook you also have the chance to see their photos, how they look like, that is, that's what Facebook gave me, many of these

> people who are here now at this conference, I have seen their photos, they have seen mine, where I live, that is I imagined them… can I say a name? I have never seen Tim, but having seen their photos in that city, while going somewhere, or Dick ... or Harry, I seem to know them even though we have never physically met (Martina).

It is perhaps not social media that are responsible for ephemeral engagements. Rather, people are responsible for the choices they make to get involved or not. It could be that the social media groups examined in prior research were wrongly categorised as movements whilst, in fact, they only were social media discussion groups at best, that did not succeed in becoming a movement. We only know of their failure because their attempts left behind a digital imprint searchable online. We can not compare how many attempts at building a movement were made before the advent of the internet, because only disruptive or functional demonstrations have been recorded by mass media, which could become searchable and part of a study. The people who attended physical meetings but who did not respond to a request to mobilise, or those at best constituting a casual choreography of street marches because they happened to be there and joined, they could as well be considered participants with ephemeral but unrecorded engagement.

The University of Bologna in Italy, an open-air campus embedded in the everyday life of the city, was in the nineties and likely still is, full of ephemeral engagements in aspiring movements which enriched student life. Some of them became real - for example a students’ movement called Panther Movement that occupied and self-managed a University building in Bologna including a library for years (the famous “occupied 36”, from the number of the door). Most of the movements did not take off and appeared to be theatrical happenings or moments of discussion without any follow up. To know about the extracurricular University life, it was enough to walk through Piazza Verdi for possible protests to join or walk *sotto i Portici* checking leaflets attached to the wall reporting news, at least once a day, which could be described as comparable to checking a Facebook newsfeed.

Also on the negative side, Kavada credited Fenton and Barassi (2011) and Juris' suggestions (2012) that proprietary platforms were not suited to facilitate collective cohesion and mutual identity because they were built to emphasise the individual interactions, and referred to Fuchs' observation (2014) on corporate surveillance profiting from users' data and activities. In the CCSVI case the enhanced individual interaction is what rendered the social media users more responsible and engaged in building the movement. Corporate surveillance should not be considered a necessary obstacle to building movements as long as its only purpose is profiting from users' attention, rather than to censor them (see Ch. 1.2 above).

In addition to Kavada's negatives, Coretti and Pica's work (2015) should be considered, where they described how the changes in Facebook's communication protocols in 2011 "increasingly promotes top-down flows of communication, which (…) progressively decreased the plurality of voices within the movement's page" (963). This change also had an impact on the Italian CCSVI Facebook Page, which had been open to users' posts since its inception (as an administrator, it was possible to choose whether to let individual users post on the page, or only allow them to comment on the administrators' posts). Following this initial change, Facebook continued to constrain user intervention on its pages such that the administrator of the Italian CCSVI Facebook Page, on 19 October 2017 created an associated Facebook Group in order to reoffer visibility to MS patients and caregivers' posts.

On the positive side Kavada (2015:873) mentioned Bimber, Flanagin and Stohl's reports (2012) on activists' empowerment in organising dissent without conventional structures, which allowed people to organise without organisation (Earl et al. 2014), allowing new forms of membership with the click of a *like* button (Chadwick, 2013). An example was the *Groups* function on Facebook which allows for the building of communities of common interest whose membership is quantifiable, as well as allowing for costless collective action (Della Porta and Mosca, 2005), where "liking, sharing, and commenting have become audiences' dominant modes of productive engagement" (Picone et al., 2019:2012). Still on the positive side Kavada recalled Bennett and Segerberg's definition of connective action (2013) as a kind of protest made possible by platforms which emphasised individual interactions, thanks to which participants could personalise action frames "that allow for diverse understandings of common problems to be shared broadly through digital media networks" (Bennett, Segerberg, and Walker, 2014:233). This was possible even without the leading role of recognised organisations, thus transforming social media into "important organizational agents" (Bennett and Segerberg, 2012:755). Bennett, Segerberg, and Walker (2014) offered Twitter as an example of how "stitching technologies (…) can lend organization to the broader crowd", allowing a "set of elemental processes" of "peer-production mechanism" (239): the production and sharing, the curation with a set of norms and boundaries, the dynamic integration of contributions of different parts of the crowd.

Criticising Bennett and Segerberg’s connective action for treating all collective and individual accounts in the same way, and for not clarifying whether the activities observed were only on social media or not, Kavada (2015) preferred to use the traditional collective action organisation. She focused her argument on “the place of social media in communication processes that render an aggregation of individuals into a collective” (874), turning to a communication approach through Melucci’s theorisation of collective identity with insights from organisational communication. Melucci suggested the use of the term “identization” (1995:51) to describe how “collective identity is becoming the product of conscious action and the outcome of self-reflection more than a set of given or ‘structural’ characteristics” (50-51). Kavada sought to make clearer “how this interactive process takes place and how communication technologies affect the process of ‘identization’” (2015:875). In relation to her studies on the Occupy Wall Street movement, she recognised that “social media users were not provided with many opportunities to contribute to these internal processes of ‘identization’”, which was “accorded to the few who could attend the physical meetings” (2015:884). In this same vein, Coretti and Pica showed how social media protocols hindered “the circulation of personal narratives” (2015:961) in favour of centralised frames which “hampered the formation of a strong collective identity” (963).

Kavada and Coretti and Pica’s findings are to be compared with the movement analysed in this thesis, where the process of “identization” together with Castells’ timeless time (see Ch. 4) strongly decreased with the foundation of associations representing the patients’ advocacy and ended with the change of Facebook’s protocols which eroded the movement’s collective identity. Kavada in her chapter

‘Connective or Collective?’ (2018) noted that “what at first glance appears as a disagreement over the collective nature of online mobilizations, is instead a misunderstanding that arises from the diverging concepts and methods of two distinct but overlapping lines of enquiry” (108), distinguishing between social movements and crowds, more specifically online crowds which are those referenced by Bennet and Segerberg in their connective action. Kavada aimed at tracing not only the differences between crowds and social movements, but also the intersections, arguing that “it is not a matter of either/or, connective or collective” (115) and that social movements studies can improve their knowledge both distinguishing and understanding the confluences as a dynamic process between personal expression and framing of the movement. Kavada concluded that “questions of power and agency” are “the most crucial in evaluating the intersection between online crowds and social movements in the study of contemporary activism” (115).

Drawing on boyd’s definition of collective publics, which are “publics that are restructured by networked technologies” (2011:39), that is “publics that have been transformed by networked media” (42), Papacharissi built the definition of affective publics as “networked public formations that are mobilized and connected or disconnected through expressions of sentiment” (2014:125). She interpreted *affect* as providing “the intensity with which we experience emotions like pain, joy, and love, and more important, the urgency to act upon those feelings” (2016:311). Papacharissi clarified adding that networked technologies have transformed publics “to suggest both space for the interaction of people, technology, and practices and the imagined collective that evolves out of this interaction” (2016:125-126). She underlined that much of the disappointment and dystopian assumptions about social media’s alleged lack of political impact relies on the expectation, driven by the movement's story "unfolded and spread quickly through social media" (321), that the change advocated follows at the same speed. She suggested that "understanding social media as structures of feeling, as soft structure of storytelling, permits us to examine them as soft structures of meaning-making practices that may be revolutionary", that possibly "help publics collaboratively reimagine a shared future" which "may progressively lead to change" (321).

Papacharissi and Trevey underlined that the traditional view of collective action implied that the "action is only impactful when the cost to individuals is high and the goal is achieved" (2018:90). However, they said, this view can be problematic because in its first part it was an unverified assertion. A dangerous or time-consuming involvement of the individual was not indispensable to achieve an impactful action. Furthermore, they deemed it problematic because "in fact, everyday, non-goal-oriented actions could reasonably be considered politically impactful" (90). The experience of the CCSVI movement activists also those with physical impairments confirms that an impactful action can be achieved without a high cost to the individual, and when there is a time-consuming contentious activity, this can be moderated by the convenience of staying safely at home. This is why the CCSVI movement may be a better example of a social media movement than the Occupy Wall Street movement, for example, where Castells noted that the full-time activists who could manage the daily tasks of the movement on the street, were "without family responsibilities, jobless, and increasingly devoted almost exclusively to the movement" (2015:135). They did not have to work, think about their kids and make the Sunday chocolate cake (as one activist reported apologising for not being available for a planned online action one Sunday afternoon).

Papacharissi and Trevey were likely correct when they said that “it is important to highlight the different logics that underlie collective and connective action as both are relevant to the study of democratic power” (91). It is generally true that through the use of digital communication, the “collectivization of personally framed expression” (88) is not always possible. However, the logic of connective action can emphasise “the importance of personal expression, scalability and the organizational power of networks” (91) and helps to explain how actors come together in “organic, evanescent and non-collective formations” (94). Papacharissi and Trevey added that publics that emerge from connective action are not crowds and they are not leaderless, and furthermore, “it is the force of the affective refrains, produced and propagated through connective action, that open up windows of opportunity: unique moments in time when change can occur” (95). In fact, the CCSVI movement was not leaderless, there was a connective leader, and the affective refrains were present and shouted in capital letters, represented by words such as *LIBERATE US ALL* and *TIME IS BRAIN* among the others, which created exceptional moments in time that are described as timeless time in Chapter 4.

The role of leadership has tended to be diminished by the use of framing theory, but Morris and Staggenborg argued that successful framing is likely attributable in part to the movement’s leaders “who possess the education capital and necessary skills” to “meet the complex demands of framing work” (2004:184). They noted the importance of a strong intellectual component in leadership – including, for instance, the ability to frame grievances, formulate ideologies, interface with media, synthesize information gleaned from local, national and international venues, develop rationales for coalition building and channel emotions – and postulate that the critical significance of this educational capital may explain why so many leaders were from more privileged class backgrounds. They also offered some insight into the role of leaders who guide the early stages of a movement, typically characterised by participants that “share stories, socially construct meaning, and explore new ideas” and seek to mobilise participants by offering “frames, tactics and organizational vehicles that allow participants to construct a collective identity and participate in collective action at various levels” (180). More recently, leadership in the time of social media, has been characterised as a “form of ‘soft’ leadership conjured up by the notion of choreography” (Gerbaudo, 2012:14) and as connective leadership (Della Ratta and Valeriani, 2012; Poell et al., 2016).

Connective leadership in the time of social media is a way to lead a movement which does not imply the traditional top-to-bottom broadcasting of instructions to be followed. Connective leaders are typically protected by anonymity and represented by an impersonal name, such as that of the appropriate Facebook Page. Their activity is that of “inviting, connecting, steering, and stimulating” (Poell et al., 2016:1009). The main function of a connective leader is checking the content of the news and putting it in context, “framing information and managing the so called "information politics"” (Della Ratta and Valeriani, 2012), thereby simplifying the activist’s work of becoming informed and empowered. Ultimately, the connective leader aims to prompt individual engagement and transform it into group activism. As an activist put it in relation to the administrator of the Italian CCSVI Facebook Page:

> You didn't put yourself forward as a person, it's very important to me, because you didn't propose yourself as a person, it was like a group thing, a splendid thing (Beatrice).

Gerbaudo and Treré (2015) highlighted the problematic relation between connective action and collective identity and the diminution in scholars' attention to the latter. According to Gerbaudo and Treré the decrease of scholars' interest in collective identity is caused by the emphasis of "the material affordances and organizational structures of protest movements", by "the dominance in empirical accounts of digital societies of the notion of networks, and its application to the sub-field of social movements, as seen in the theory of 'connective action'", and by "the scholarly fashion of quantitative 'big data' analysis" (866). Gerbaudo and Treré said that focusing primarily on big data has brought about "a neglect of qualitative analyses, the only ones capable of getting at the symbolic and cultural processes involved in collective identity" (867). The ethnography involved in this thesis, represents an important point of contrast to the growing focus on the big data analysis affordance supplied by the technology used by online social movements. Words should be weighed up, put in a timely context, and not only counted (see Ch. 2.5).

Melucci's book published in 1989 reminded us that the tendency to focus on quantitative analysis is not just a consequence of a specific technology's affordance, but likely a renewed tendency given by every technology's improvement timely branded as new technology or new media, with its new visibility affordances, as at one time with the television. Melucci drew attention to the fact that the increase in data analysis is favoured by the "myopia of the visible" as Melucci called it, "which leads the analysis to focus all its attention on the measurable aspects of collective action", thus limiting the analysis of collective action "to the political system" (1989:44), that is to the visible confrontation with political authorities. Limiting attention to visible action "becomes an unhelpful form of reductionism when it neglects the processes of 'production' of collective action - and thus ignores the creation of cultural models and symbolic challenges" (45). Mellucci added that processes and not facts constitute collective action, therefore, as processes are less visible and "outside the political domain, their identification requires a different methodological approach" (45). This is also true with the explosion of the use of social media which was examined using the numbers of clicks and shares labelled by some researchers as clicktivism because it did not lead to one of the most classic measures of social movement analysis, that is, physical confrontation with political authorities, or other public activities.

It took ten years from its inception for academic studies to examine the CCSVI movement in Italy, only then determining that it had "succeeded in creating a collaborative network of patients", "which in some cases turned the traditional doctor-patient relationship upside down", "which is unprecedented at least in Italy" (Matteucci, 2021:175). In Canada, neurologists referring to the Canadian movement, have said it was "reminiscent perhaps only of few others such as the HIV movement in the 1980s" (Benjaminy et al, 2018:5). Perhaps it took so long for media researchers to take an interest in this movement because it was not political in the classic sense, and the researchers did not have at hand the traditional measures used by social movement scholars. The CCSVI movement did not disrupt road-traffic, it was not photographable nor quantifiable in terms of the number of people involved if not through clicks, shares and comments lost in Facebook's wall that in the hype of the movement were characterised by activists as similar to unrolling “toilet paper”. Despite only its clicks and shares being visible, the CCSVI social media movement has nonetheless been considered responsible by the international neurological community for diverting more than 3 million Euro in Italy, and $2.4 million in Canada thanks to the activities of its local CCSVI movement (see Ch. 5.5), into research on a vascular therapy deemed to be a hoax by that same international neurological community.

To clarify just what the traditional academic view of collective action might have lost and may lose in light of the burgeoning use of media by contentious action, it is important to highlight that all media devices are used not only to propose, share or render meanings publicly visible, but more and more also to publicly and privately discuss and create meanings that will eventually be proposed and enacted. Under this view, the connection between media and activism becomes fundamental, despite not yet being considered as such by social movement researchers. As Latour put it in his actor-network theory, the meanings of technical networks and organisation networks “merge since network becomes a privileged mode of organization thanks to the very extension of information technology” (2005:129). Earl and Garrett (2017) argued that in order to reach significant research contributions, political communication should be more broadly incorporated into social movement studies, focusing attention on social media opportunities “that are profoundly different than traditional news outlets” (485), because the digital networks embody the movement organisation and campaigning. Earl and Kimport (2011) stressed the importance of social movement scholars focusing on “existing work on technology and society” otherwise “they will almost inevitably build overly thin theories” (199), because social media are not only a matter of supersizing collective action: "technology can and do change social phenomena" (200). They suggested, for example, the conceptualisation of "costs and copresence as variables rather than constants" in a protest (199). This conceptualisation would highlight coordinated collective action as "the common characteristic that binds tactics" in the digital contention field, rather than emphasising "a separation between protest and more enduring social movements" as well as the use of different features which include the tactics of non-political protests that have emerged (201). The logic of connective action can indeed be a methodological approach to render visible those processes which are not recorded by photo reporters, journalists and passers-by in the streets, because digital media can be not only an organizational means but similarly a means of contention, that is, social media's digital streets are the place where the action happens.

Mass media are considered a very important resource for the growth of social movements, for attracting new activists and for raising the awareness of the public as to the existence, actions and aims of the movements. However, the internet also plays a role in social movements' contention, which includes, according to Tilly and Tarrow (2015):

> (1) to assemble people in demonstrations at one site [the 1999 Seattle demonstration] or (2) to coordinate demonstrations in many sites across a broad range of territory [the Peace movement against the invasion of Iraq in 2003]; and it may also be emerging (3) as a form of [Bennett and Segerberg's] 'connective action' itself (2015:16).

When digital communication is the primary resource of the structure of the organisation, Bennett and Segerberg (2012) made two clear distinctions in the logic of the organisational dynamics. The first distinction was "the familiar logic of collective action", when a high-level structured organisation is at play in the formation of collective identities and where the use of digital media does not influence the action's dynamics. The second was "the less familiar logic of connective action" (739), which referred to the sharing of personalised messages through media networks, where the use of digital media is pivotal to the action's dynamic. The boundary zone where connective action prompted collective action was the social movement that used personal communication for organising ways of contention (745). In the use of digital media by action networks with the logic of connective action, Bennet and Segerberg described two organisational patterns. The first saw well-known advocacy organisations preparing the campaign without branding it, instead appearing only to endorse an event while in fact facilitating the spread of the word through digital media. The second pattern was represented by the *indignados* and *occupy* protests which "entails technology platforms and applications taking the role of established political organisations" with the use of "very personalized accounts" including emails sharing personal stories and images on social media (2012:742).

Bennett and Segerberg underlined how these digitally-enabled action networks became in a shorter time larger than the conventional and structured anti-capitalist collective actions, with higher levels of WUNC, using only simple political communication through social media. In fact, they added, connective action networks were individualised, and they based the organisation on technology connectivity which did not require the emotional effort deriving from joining a collective identity frame and which did not need human and economic resources traditionally supplied by structured organisations (2012:750). So, the problem of getting the individual to participate was not at stake as it was for collective action, which required the examination of relations between activists and organised groups and between groups. Instead, for connective action the starting point was the facilitation of personalised engagement and self-motivation in sharing personal ideas and plans which were already internalised on social media, and digital technology networks involving loosely-tied participation which may then rapidly scale up action in the networks thanks to personal action frames. Connective actions were “flexible organizations in themselves (…) even crossing geographic and temporal boundaries in the process” (Bennett and Segerberg, 2012:753), where “in place of collective action frames, personal action frames become the transmission units across trusted social networks”, “inviting personalized interpretations of problems and self-organization of action” (755).

Connective actions as self-organised activities were implemented in collective action on and through the internet in the case of the Italian CCSVI Facebook Page. Earl and Kimport (2011) coined the term “e-tactics” to identify collective action with “varying degrees of off- and online components and varying degrees of affiliation” (9), tactics that had a long history in the activities of social movements also before the advent of the internet. Petitions, boycotts, and letter-writing (email) campaigns became very popular on-line, and they have been extensively used also in the case study of this research. Those “e-tactics” were predominantly promoted and spread by the Facebook Page. However, there were also activities that were undertaken solely at the behest of patients or caregivers, such as a boycott of drugs prescribed by neurologists, something that was never endorsed by the CCSVI Facebook Page itself.

To better frame the on-line implementation of the traditional tactics of petitioning, boycotting and letter writing by the CCSVI movement, it is helpful to refer to Van Laer and Van Aelst's (2010) distinction of two main types of repertoire of action: on the one side, internet-based actions (that "exist only because of the internet") versus internet-supported actions (traditional actions that are better organised and coordinated thanks to the internet) (1148), and on the other side "low versus high thresholds" in relation to the level of risk and commitment entailed by participation in an action (1150). E-tactics in the CCSVI movement were not mere internet-supported actions to complement hand-written petitions and letters, rather they were social media-based actions using e-mails and online signed petitions:

> With a fairly close-knit group of users who populated that Facebook Page, … that I absolutely did not know, let's say, we immediately took initiatives, we found ourselves writing the letter which was then sent to the President of the Republic, and then it was of great importance as the President of the Republic replied to all the signatories of that letter personally, through an official communication, and therefore, let's say that was what I remember the first job in synergy with some users of the Facebook Page. Then also the realization of small dossiers on multiple sclerosis and CCSVI, with other subjects, with ... then various contacts with other people, and from there then in January 2010, the idea was born to create a movement a little more, how to say, organized (Lorenzo).

By contrast, the individually-driven boycotting of drugs was an internet-supported action (though unsupported by the CCSVI movement as such). Though not in the form of a typical sit-in, occupation or destruction of property, the decision to stop taking drugs prescribed by the neurologist or threatening not to take them, or simply contesting the neurologist and risking to be abandoned as a patient, implied a high level of risk and commitment, which has always been a personal decision because the CCSVI movement as such as well as the scientists working on the discovery, never suggested abandoning therapies prescribed by neurologists. On the contrary, it was always advised to continue taking the drugs prescribed.

Another example of the use of e-tactics of boycott or sabotage in the CCSVI movement was the remixing of found material, strongly favoured by social media's making and doing culture (Gauntlett, 2011). One example of this emerged when it became clear that AISM (Associazione Italiana Sclerosi Multipla), Italy's traditional MS patient association, would not support research into CCSVI. In response to a campaign by AISM to sell apples to raise money, a group of CCSVI activists compiled a number of images combining AISM's publicity with the tale of Snow White where the witch offers her a poison apple (Fig. 2, 3 and 4).

Figure 2: Witch, poison apple: "Come on, buy my apple!" (CCSVI activists' image against AISM campaign to raise money selling apples).

Figure 3: Snow White-Witch, poison apple: "Take an interferon-flavored apple ... it will do you good!!! An apple for life? No thanks". (CCSVI activists' image against AISM campaign to raise money selling apples).

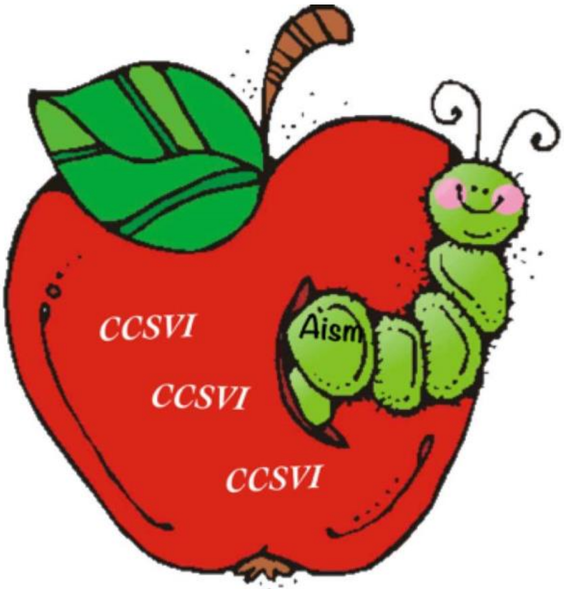


Figure 4: Apple with caterpillar: The caterpillar represents AISM eating the apple that represents CCSVI. (CCSVI activists' image against AISM campaign to raise money selling apples).

(iv) Social media movements

Cultural jammers rework media images to draw people's attention to the concerns they are advocating in the social movement, because following Melucci's remarks: "Collective action, by the sheer fact of its existence, represents in its very form and models of organization a message broadcast to the rest of society" (1996:9). Nevertheless, social movement research does not pay a lot of attention to the strong interrelation between media and movements' activism. As an example, Meikle reported that "Tilly and Wood's (2013) major textbook *Social Movements 1768–2012*, grants 'movements and media' a little under five pages" (2018:3). Already before the advent of social media, Downing et al. complained of the fact that social movement specialists think it is "feasible to analyze the dynamics of social movements without systematic attention to their media and communication" (2001:26). Furthermore, Mosca (2014) remarked that while scholars used traditional media "above all else as a source of information about the evolutionary dynamics of social movements" (222), social movements studies have subordinated the communicative dimension to three main frames: "organizational structure, interpretive frames and repertoires of action" (219). According to Mosca, social movements' communication has been historically framed through the repertoire of collective action and "rarely were they considered as targets and interlocutors of social movements, or as actors actively engaged in political processes with which movements must deal" (222). Only recently due to the low-cost of internet media used by movements, scholars have considered how political processes can be influenced by a medium which bypasses the gatekeeping of the mainstream media. This was also the case of the CCSVI movement here studied.

Mattoni and Treré (2014) explored the complexity of media and social movements' interaction, an analysis which has not been properly carried out yet because, they said, the "literature suffers from two main biases: the one-medium bias and the technological-fascination bias" (254), where there is the predilection to analyse only one medium or platform and the tendency to focus on the latest technological support. Ardizzoni (2015) contributed to the bypassing of the one-medium bias focusing attention on the different use of media by activists. The digital convergence of various media and the new ambivalent spaces of media practices, allow for example the production and selling of calendars, documentaries and films to support campaigns and obtain visibility, as for the Association *CCSVI nella Sclerosi Multipla* section of the Regione Calabria with its short movie *Presto* (*Quick*, https://www.youtube.com/watch?v=_20a1-aTWuU), and for the CCSVI movement in Canada with the documentary *Living proof* premiered at the Toronto International Film Festival in 2017 (Wissot, 2017). Ardizzoni proposed to frame the change using the definition of matrix activism, as an activism which "complicates the relationship between production and consumption" and "intersects private spaces and commercial platforms", "able to produce arguably new zones of protest and contestation in post-industrial societies of control" (2015:1080). The matrix activism suggested a tendency of activist resistance being "necessarily embedded in the neoliberal logic of contemporary society" (1086), using the codes of the mainstream media instead of rejecting them.

Recalling that the internet can be used as a broadcasting medium or a discussion facilitator favouring the organisation of a community, Kavada (2013) underlined that the new communication technologies are adapted by activists in different organising practices according to their cultural level resulting in different uses and strategies. These social movement media practices have been examined by Downing (2018) since social media broke into the field. He outlined a series of ruptures with the past, listing first the "sheer access to making media" (26), and then the feasible worldwide distribution at very high speed; the "meso-level of media communication, in between face-to-face and the 'one-to-many' mass audience" (27); the ubiquity of the portable 4G communication, and the rapid mobilization of traditional public protests. Among the new headaches of the use of social media and portable devices, Downing cited "phone surveillance technologies" (27).

Pavan, introducing the concept of multidimensional networks (MDNs) (2014) argued that the separation "between social and technological elements within collective action practices" (442) produced a false dichotomy "between on- and offline spaces of participation, which, in turn, created opposite standpoints on the relevance of online networks", a framing which "made it difficult to understand the hybridization of collective action practices" (444), creating an ontological separation between social networks and communication technologies. "The Internet has raised new questions around the outcomes of collective action and its interface with policymaking" (Calderaro and Kavada, 2013:2), furthermore, "an adequate understanding of social mobilizations (…) can only be obtained by looking at the dynamic interactions among a multitude of contenders, including allies and adversaries, elite and non-elite, institutional and non-institutional actors" (Padovani and Calabrese, 2014:8). Della Porta and Pavan also recognised the need "to comprehend how fluid and ever-evolving communication networks can become agents of democratization" (2018:35).

(4) Overview of research on patients' use of social media

Most of the general theory of social movements has been developed with reference to political and civil rights' movements and much has been written on how people and more specifically activists have used social media in the last decade, starting from the Arab Spring and the Occupy Wall Street movements. However, there is not much analysis in mainstream social media research as to how patients and caregivers have used social media, and there is even less research focused on patients' social media movements, most of which has been conducted by medical doctors.

A review of studies on the usage of the internet among patients and caregivers, conducted among others by the faculty of Medicine and Dentistry of the University of Alberta, Canada (Hamm et al., 2013), found that the majority of all the studies analysed (284) from 1997 to 2011, were descriptive, and in almost all the cases investigated, the usage of the internet "studied was intended to facilitate self-care". Mostly focused on discussion forums, only 16 out of the 284 studies analysed were on Facebook, and 10 on Twitter. Hamm et al. suggested that the use of social media can go beyond supportive internet communities and could be used to set the healthcare agenda, however the review found that questions remain as to how effective such communities might be in this context. This thesis may help to provide some insights on this issue.

A study on social media and rare-disease patients, which did not include MS patients, conducted by media and communication researchers (Vicari and Cappai, 2016), focused on the use of social media by health movements that were already formalised, and on how social media shaped and contributed to Embodied Health Movements (EHM) activism. These movements comprised solely patients advocating for research in general, as the small number of patients could not return profits to the pharmaceutical industries. The study analysed the practice of health discourse in the digital media which goes beyond social support and offers a larger variety of choices on how to engage.

To my knowledge, to date there have been no ongoing ethnographic studies of the formation and development of a social media counter power patients' movement, born and at the moment of writing still active on Facebook, even if with a lowered momentum. The research on social media movements at large has mainly focused on the use of social media as an instrument supporting the activists to coordinate their protests on the street, and the literature on patients' movements is focused mainly on the social media usage as an exchange of information or disinformation on research, and as self-help. At times social media were considered a loss of time or a game, or considered not to be real life and full of fake human relations, at best considered clicktivism or, worse, slacktivism (Morozov, 2011; Fuchs, 2014). This runs counter to the experience of CCSVI activists:

> I was alone at home, because my children often go to their grandparents and the other family as I am separated, I was alone at home, and I took it as a curiosity of that moment. For me, Facebook was a good discovery, because the choice to sign up was linked to contacts, to have a relationship on the

> computer with people, this was the triggering motivation. (…) I joined Facebook in 2008 and my children were against it, they joined 3 or 4 years later. It depends how we use it. However, you are active. It is a key feature. I am an adult, and I am sure it is not true that social media are cold. As long as you can walk it is true that you know people outside and you frequent them outside the home, but with a disorder of this type [MS] there are times when you are not so able to leave the house, and social media are still a social opening, at home. And this is very important (Elisa).

In a context where the hallmark of activism is deemed to be the visible and research-quantifiable traditional street protest (which it is arguable whether they achieve any tangible results or real change, see the 99% movement, Ch 4, and earlier the anti-war movement of 2003, Ch 5), I believe that the formation and development of a social media movement considered responsible on two continents for influencing medical research investments should become the object of social media movement research. Notwithstanding the current characterisation of social media as the locus of society's ills, they can also be a vehicle for fostering human relations and developing supportive communities. They should be studied to see how effective they can be in bringing about real change, despite the fact that some may have been deluded as to their once alleged democratising power (Morozov, 2011). I was never thus deluded, having concluded in my master's thesis in 1999 that the possibilities given by the internet could not breach the ideological *status quo* of the communication structure within an organisation, because it would affect the chain of command.

(i) Review of research and medical opinions on MS and CCSVI patients' use of social media

There are a number of studies and authored opinion pieces directly related to MS and CCSVI which analysed the patients' use of internet. The majority of them are focused on the danger of the internet in spreading uncontrolled and pseudoscientific discourse and diverting research funding, characterising social media as "pester power" (Mazanderani, O'Neill, and Powell, 2013:424). Whilst most of the studies are from medical institutions of different countries, those conducted by Canadian medical institutions constitute the larger proportion (see Ch. 3.1 for the reasons why there are more studies from Canada and from neurological researchers). The few studies which did not have a negative view of the use of social media by the CCSVI movement, were focused mainly on the patients' use of the internet and social media. They confirmed the CCSVI movement's influence on political research priorities, and praised the great advancements social media gave to patients' empowerment, to patients' interaction and to the exchange of information. Social media were also considered a positive opportunity for an improved patient-doctor interaction. This concise review begins with studies conducted by medical institutions focusing on the danger of social media spreading uncontrolled medical information.

Fragoso (2011) pointed out that medical information of questionable provenance on the internet ran faster than medical scientific methods. Her paper is the only non-Italian study that referenced the Italian CCSVI Facebook Page by its number of members, nearly 30,000 on November 3, 2010. The paper did not mention the name or the nationality of the Facebook Page, but at that time and to date, the Italian

Facebook Page is the only CCSVI group to have more than 25,000 members (see Table 1 in Driedger, Dassah and Marrie, 2018: 480-483, about English speaking CCSVI Facebook Pages and Group dimensions). The same information (30,000 members of the Italian CCSVI Facebook Page) was referenced in an article published in November 2010 in a famous Italian magazine (Mattalia, 2010).

The following two studies on CCSVI communities are to my knowledge the only ones that do not refer to either English or Italian speaking CCSVI communities. Sudau et al (2014), analysed the debate on new findings in the internet forum of the German traditional MS association, pointing out that most of the linked sources were to social media and that only a few people fuelled the discussion on CCSVI. Koschack et al. (2015), analysed the same forum and the users' interaction published in the same period as those analysed by Sudau et al. (2014), but with different criteria for selecting posts. They concluded that the different evidence criteria of the lay discourse with the expert discourse, could be an indication of cognitive dissonance to reduce the contradictory information available on CCSVI studies.

Other articles referring to the English-speaking CCSVI communities were more overt as to the use and danger of social media for advocating CCSVI in influencing the political medical debate and research funding. Chafe et al. (2011), examining the pressure exerted by the Canadian CCSVI social media patients' group, acknowledged that the public is no longer deferential to scientists, and called for the presence of medical experts in the social media discourse to give voice to science and avoid public resources being diverted to scientifically unsound research. Born and Sullivan (2011), reported that the aggressive campaigns about CCSVI on social media in Canada even prompted a political debate in the Canadian House of Commons. Fox (2011) said that the new theory gained momentum through social media, and that perhaps social media had never been so successful at promoting a new medical theory as with CCSVI, which might be "just another fad" (1825). Lau et al. (2012), used Chafe et al.'s article (2011), to contribute to their review on the risk of potential harm caused by poor quality health information on social media, which could influence the health policy agenda and research funding. Machan, Murphy and Traboulsee (2012) warned the Canadian medical community about the impact of social media and a society with increasing access to everything, including rumours, and that "Physicians, administrators, and politicians are being asked to respond to new developments, sometimes within hours of their first discussion" (S3). Machan and Traboulsee later, in 2014, published in *The Lancet* one of the most negative and contested studies on CCSVI (see Ch. 3.3). Gafson and Giovannoni (2014) launched a call "to clinicians and scientist to vocalise in an internet age", because the public interest in CCSVI was caused by the disconnection of the scientific community with social media. Tsivgoulis et al. (2015), suggested that physicians should replace the blogosphere as the "main source of "sensational" but inaccurate information" on CCSVI, educating and communicating to patients the scientific evidence refuting the new hypothesis. Benjaminy and Traboulsee asked to harness "the power of social media platforms to foster sustainable support for evidence-based science" (2017:270). The same researchers together with others in another paper underlined that the CCSVI movement expressed "a demand by the public rarely seen in the history of medicine" (Benjaminy, Schepmyer, Illes and Traboulsee, 2018:1), "reminiscent perhaps only of few others such as the HIV movement in the 1980s" (5). They added that social media-generated endorsements "led to significant political pressure that shaped science policy and mobilized funding for CCSVI clinical trials” (5), emphasising the risks and challenges of democratising science, while at the same time promoting stem cell research. This appeared to be a typical example of the blending of genres (Kress and Leeuwen, 2001:35), that is arguing the ineffectiveness of a therapy and the unjustness of funding its research, and at the same time offering an alternative research to be funded as if it were already effective (see Ch. 1.2.v), even if other researchers considered the same stem cell therapy a clinically unproven and potentially unsafe procedure (Peterson, MacGregor and Munsie, 2016). Three medical doctors from departments of neurology, in an editorial commenting on one of the main studies on CCSVI and MS (Brave Dreams, see Ch. 5.6), stated that the advances in medicine thanks to the information age “have come at a cost”, “an important danger that we need to address” and that “the creation of Facebook pages and patient interest groups” (Green, Kamel and Josephson, 2018:15), provoked the US National Multiple Sclerosis Society (NMSS) and the Canadian Institute for Health Research (CIHR) to dedicate millions of dollars to set up studies of CCSVI.

A number of medical longitudinal studies focused on the videos related to CCSVI uploaded on YouTube. Ghahari and Forwell (2016), analysed patients’ YouTube videos from 2009 to 2011 on the results from the CCSVI treatment. They stressed the influence of social media in patient decision making and asked for doctors to be engaged with the public to inform patients of possible complications from the treatment for CCSVI. Hynes, Ghahari and Forwell (2019), analysed YouTube videos on CCSVI uploaded subsequent to the previous study mentioned, but by different patients from 2011 to 2019 (“63% of the people have reported improvements in function in the current study, this is down from 86% found by Ghahari and Forwell", 9). Findings show the power of social media in influencing health policies and warn that in the future doctors may be pressured to allow treatments which are not evidence driven.

The few studies and commentaries from medical doctors with a background in vascular medicine (a small branch compared to neurologists, with about one tenth the number of doctors, and with much narrower profit margins for their few remunerable therapies), who mentioned the use of social media, follow the "neurology vs. vascular surgeons" scientific debate reported by Driedger, Dassah and Marrie in a review of Canadian newspaper articles (2018:488). This scientific debate was characterised as "a clash between doctors cruel to the sick" (D'Amico, 2013). As a doctor interviewed put it:

> The initial intuition at the basis of the studies on CCSVI came outside the neurological context, and therefore we were faced with a group of ... a category of doctors such as neurologists who normally managed the disease, MS, who however did not have the cultural tools to investigate aspects and issues relating to related vascular pathologies. And so, they probably found themselves completely displaced, disoriented, responding with distrust (…) We have seen it for example in the pathogenesis of gastric ulcers, where, let's say, that there was infectious etiopathology it had already been demonstrated many years before it was then accepted by the scientific community (MD Riccardo).

According to Lakatos' "two rival research programmes" theory, after years of debates it appears that the neurological approach to MS is "progressing" and the vascular approach is "degenerating" not attracting interest from the medical community (1980:6), but some vascular researchers worldwide are sticking to the CCSVI programme with further research trying to make it become progressive.

It follows relevant contributions by medical doctors with a background in vascular medicine who expressed a different view about MS patients' use of social media. Vera et al. (2012), in their review of internet resources on CCSVI, consider the use of social media pivotal to information sharing on new theories and therapies among patients. Though uncontrolled, they recognise social media's potential for improving interactions between physicians and patients interested in CCSVI. Zamboni (2011), the scientist who proposed the new theory of CCSVI, in contrast to Chafe et al. (2011) whose article was published in the same journal underlined that his initial research was funded by the Italian government and bank institutions with peer reviewed protocols, well ahead of the involvement of the public through media and social media, which were able to emphasise the pre-existing scientific research. Five scientists from different international institutions were not surprised that a neurologists' editorial "bemoaned the power of social media" (see Ch. 5.6), following the results of a "crippled" negative study on CCSVI, whose conclusions are deemed by the same vascular surgeons to be "misleading" (Juurlink, Bavera, Sclafani, Petrov and Reid, 2018:27). The vascular surgeon Bruno (2019), contesting the same study mentioned above on CCSVI with negative results, underlined that his research on CCSVI was not promoted through social media but in scientific international conferences and received international diffusion.

Outside of neurological or vascular medical institutions' researchers, but not yet in media studies, Rhodes (2011) found that social networking sites are a natural ally for advancing understanding of CCSVI among patients, noting that, notwithstanding the general acceptance for the past 170 years of a vascular element in multiple sclerosis, neurologists would always consider it not pertinent (27), and considering that some activists called for a boycott of the National MS Society of the United States (NMSS) for not supporting the discovery. Riise (2012) pointed out that further funding into CCSVI research might be due to the public engagement through Facebook and other social media. Pullman, Zarzeczny and Picard (2013) highlighted the success of the internet and social media in challenging the ivory tower of medical academia, advocating for a stronger presence of scientists in order to balance the messages shared. Snyder et al. (2014) affirmed that social media advocacy groups for CCSVI have influenced political debate, and that the loss of faith in the Canadian care system (which forbade any CCSVI treatment in Canada, probably the only case in the world), pushed several patients to travel abroad to access the procedure. Mazanderani, O'Neil and Powell (2013) examined YouTube videos uploaded by MS patients before and after the treatment for CCSVI. The study concluded that social media provided patients with new instruments for advocating different treatments, and that physicians should engage with what is significant for patients instead of disregarding what they consider not to be evidence-based. Ploughman et al. (2014) found that "Facebook groups became important sources of information to locate the best surgery hospitals, compare hotels, and to connect with taxi drivers and medical tourism companies" (1209), and patients used social media to stay connected while travelling abroad for the procedure. Mazanderani, Kelly and Ducey (2018), enrolled and interviewed on CCSVI forums and social media 48 MS patients from seven different countries. Many of them had undergone the liberation procedure and the researchers recognised that they were "far from being naïve" (28) and that they presented themselves “as empowered individuals who have taken an informed decision to pursue an experimental therapy” (3). They suggested that those patients should not be “dismissed as ‘irrational’ or psychologised as ‘desperate’” (5). Mazanderani et al. (2020) recognized that knowledge was in part generated “through embedding experiences within patients” (277), systematically aggregating evidence for advocates to convince policymakers and researchers on the validity of the CCSVI theory. This activity was carried on through “practices of cross-referencing, linking and liking, all of which serves to create agreed-upon, mutually reinforcing patterns within particular groups” which is in part due to community dynamics and platform architectures, and in part as “a result of the active policing and moderation of platforms” (276).

Almost all of the studies reported above refer to English speaking social media CCSVI communities, including the very small CCSVI-UK Facebook page (which peaked at 2,600 Facebook followers, compared to the over 30,000 followers of the Italian Page). The vast majority of the studies reported refer to the Canadian CCSVI social media communities which, however, fail to meet the “standard definitions of a social movement in terms of organization and structure” (Driedger, Dassah and Marrie, 2018:473). The reason is that the Canadian CCSVI social media communities mostly started up in response to a W5 national televised documentary aired on 21 November 2009. Indeed, most patients “cited the W5 national television program as their first introduction to CCSVI theory” (Ploughman et al, 2014:1212). In fact, Canadian MS patients did not have time and, mainly, a reason to unite within a social movement, because the acknowledgment of CCSVI theory by doctors and the population at large had already been accomplished through mainstream media.

This constitutes the main difference with the Italian CCSVI movement, which received primetime television coverage only in September 2010, one year after its inception. By that time the legally recognised CCSVI association which grew out of the Facebook movement had already been formalised and was legally active, organising meetings and scientific conferences. In fact, the mainstream media primetime coverage in Italy was a direct result of the social media CCSVI activists' efforts since August 2009. Furthermore, most of the studies on the English-speaking CCSVI communities analysed the medical tourism phenomenon, that is travelling abroad for the procedure because it was not available in their own country. This required a logistical organisation the information for which was shared on social media among patients which was analysed together with the results of the procedure shown on YouTube. In Italy the medical tourism phenomenon has had little resonance because the procedure was available, both privately and through the Italian NHS, in the national hospitals.

The only study specifically related to the Italian CCSVI social media movement is also the only paper here listed conducted by a researcher in media sociology. It is a phenomenological-interpretative-anthropological narrative-based medical approach research, on the posts published between 2010-2016 in the Italian Facebook page *CCSVI nella Sclerosi Multipla* (mistakenly identified as the page of the Association, see Ch 2.5). The study, conducted by a professor in sociology of health and welfare in the faculty of Science of Communication, underlined the successful creation in the Italian CCSVI Facebook Page of a "collaborative network of patients, associations and the doctors themselves" (Matteucci, 2021:175), "which may represent a sign of change in the field of health" (167). The paper put in evidence the importance of social media in empowering patients and giving them a sense of belonging, where they were able to actively participate in the decision-making on the activities of the movement, despite the geographical distance separating them.

(ii) An a priori assumption about the correct source of medical information

All but one of the studies, commentaries and brief thoughts on digital media, CCSVI and MS listed above, were conducted by medical doctors or researchers of medical and health institutions, rather than sociologists of communication, and were published in medical journals. They do not generally focus on the use of digital media, but on the patients' health-related behaviour. Particularly those papers written by researchers with a neurological background focus on an *a priori* assumption of the right source of medical information. The vehemence of some neurologists in denigrating whatever appeared on social media which was not backed by them, forced vascular doctors to declare that their research started and was published before it became publicly known in the media, and that it had been presented by them in scientific institutions, not on Facebook. Accordingly, most of the neurological community characterised social media and patient activism as "pester power" (Mazanderani, O'Neill, and Powell, 2013:424).

This research differentiates itself from the majority of studies listed above by not having an a priori assumption about the correct source of medical information and it does not take part in a dispute as to what can be defined as scientific medical information, which should be solely medical. This research, through autoethnography and interviews, applies Tilly's questions "how, when, where, and why" (2004:ix) collective claims are made on public authorities and other holders of power. It aims to examine the views of the activists without assuming they are right or wrong, solely to analyse their motivations in creating a counter-power social media movement, an aspect not analysed by previous research largely based on movements the existence of which was tied to the occupation of space of places (see Ch. 4). This thesis draws from the specificity of the embodied health movements (Brown et al., 2004), in relation to the dynamic, interactive sequences of the transgressive contentious politics (McAdam, Tarrow and Tilly, 2001), applied to the opportunities offered by the internet and, specifically, social media.

CHAPTER 2. Methodology

(1) Introduction

This thesis draws upon multiple data collection methods: the author’s direct experience as an activist and as creator and administrator of the social media patients’ movement Facebook Page here analysed; triangulation with 62 in-depth face-to-face semi-structured field interviews with activists; information gathered through key informant and informal conversations; documents of patient associations available online; videos, newspapers, conferences, scientific articles and commentaries of the medical community, all available online. Most of the published material selected and reported in this thesis was encountered by international CCSVI activists at the moment of its publication through the years. The journalistic or scientific publications were either experienced as medical communication aiming at denying or confirming the CCSVI theory, or were cited on Facebook by activists to uncover and react to what was considered by them the plot against the CCSVI theory (see Ch. 3). In relation to the CCSVI research, the internet search engines have been thoroughly used only to complete the ‘Review of research and medical opinions on MS and CCSVI patients use of social media’ (see Ch. 1.4).

All the material is collected and analysed only to describe the motivations which strengthened or weakened the activity of the CCSVI movement, without any intention to judge.

In regard to my direct involvement in the movement, one of the main criticisms of my research approach is that of the classic mainstream view (Whyte, 1991), according to which the researcher should “not get directly involved in linking social research to action” (8). However, there was no participation of the activists in the research process, nor were there any influences, corrections or improvements in the activists’ action or practice in the course of the PhD research, also because my research focuses on a period in which I was not yet a researcher, so that it cannot be considered a Participatory Action Research (PAR; Whyte, 1991; Melucci, 1996:387; Benjamin-Thomas et al., 2018).

Another critique of my direct involvement is that being too familiar with the object studied, the research would lack objectivity, implying that I would not be able to keep an academic distance. However, I had the benefit of a master’s degree in Communication, and it was also the case that since the start of my PhD the movement’s activity had weakened considerably making it easier for me to substantially reduce my involvement. Research on this topic, as well as the close mentoring of my supervisor helped me to take an academic distance from my activism. Furthermore, I was able to transform this perceived weakness into a distinctive feature of this research drawing from autoethnography’s theory (Miller, 2011), and from an insight into to a pure activist’s outrage and hope *modus operandi*. As ethnographers put it:

> Autoethnographers offer accounts of personal experience to complement, or fill gaps in, existing research”, they can tell “stories in novel ways when compared to how others may be able to tell them”, and they can “write against harmful ethnographic accounts made by others—especially cultural “outsiders”—who

> try to take advantage of, or irresponsibly regulate, other cultures (Adams, Ellis and Holman Jones, 2017:3,4).

(2) Background

My research draws upon my online personal participation as the only administrator and as an activist since the emergence in August 2009 of the Italian-language Facebook Page advocating CCSVI, and its subsequent growth (Stokes, 2013); when I went to interview the activists during the CCSVI associations conferences in 2014, I was for the first time an in-person observer of the associations' governance dynamics.

Following the University of Westminster policy (laid out during the Doctoral Researcher Development Programme, DRDP, of Autumn 2013), for privacy reasons in the research I do not report even any anonymous quotations from Facebook posts or comments which theoretically a research engine could tie to their authors. There was no need to make "extensive changes in detail and combined materials from different participants" (Miller, 2011:xi) to protect the activists' anonymity because personal information and references to personal life and behaviours are not the object of this research. Informants are not cited, not even anonymously, to ensure that certain unique information can not help in identifying them.

In addition to the ongoing observation of the activists' behaviours including mine (Bryman, 2012) since 2009, in 2014 I conducted 62 in-person, audio-recorded, semi-structured interviews within the qualitative research framework of my research questions. I have tried to be very pragmatic in the use of all techniques (Della Porta, 2014a), considering my range of first-person social media experience initially as an activist and, since starting the research in the form of active participant observation.

Having deployed a qualitative method, the procedure of the research design was flexible. The research strategy was unstructured, the format of the research was an emerging design, and there was not a confirmation relationship between theory/concepts and the research. Rather, I examined processes of interactions in the relations between cases. I did not consider statistical representation in the selection criteria as is otherwise common in quantitative research. Types of concepts were orientative, the data collection tool was adapted for each unit of analysis, and data were aggregated in cases. The fieldwork adopted a close relation to the subject: as a researcher I was an insider.

The type of data analysed, rich and deep, were words in the form of a dense narrative. The mutual internal understanding was informally explained, interpreted and classified. Theoretically relevant cases were identified based on the research problems constructed from my active participation, but new concepts were adopted as they emerged during the work, because as Della Porta and Keating put it: “Predictability is impossible since human beings change in time and space and, in the words of Bourdieu (1977: 109), ‘practice has a logic, which is not that of logic’” (2008:27). For this reason, I adopted grounded theory as a “family of methods” (Bryant and Charmaz, 2007:11), following Wittgenstein’s statement “don’t think but look” (cited in Bryant and Charmaz, 2007:11). As Charmaz puts it:

> Grounded theory involves taking comparisons from
> data and reaching up to construct abstractions and then

> down to tie these abstractions to data. It means learning about the specific and the general—and seeing what is new in them—then exploring their links to larger issues or creating larger unrecognized issues in entirety. An imaginative interpretation sparks new views and leads other scholars to new vistas. Grounded theory methods can provide a route to see beyond the obvious and a path to reach imaginative interpretations (cited in Bryant and Charmaz, 2007:13).

Grounded theory allowed me to examine what seems to have been seldom investigated by scholars, like "perceptions, identities, emotions and, more in general, cultural dimensions of protests" (Mattoni, 2014:22). Grounded theory's aim "is not to explain causal correlations between empirical evidences" (38). Rather, it seemed to be particularly effective when in the presence of "new phenomena and/or understudied areas in social movements (…) in which the researcher focuses on the meanings and interpretations linked to contentious collective actions" (38), which, in turn, could deepen the knowledge of specific causal mechanisms. Self-reflection due to direct experience with the movement "might help to put under critical scrutiny previous theoretical knowledge and its role in the interpretation of data", which comes from the social reality in which the researcher is situated, as pointed out by the "constructivist grounded theory" (25). In fact, abstractions are the "outcome of an intense analytical process in which researchers interpret the views and voices of social actors under investigation (…), coupling them with constant self-reflections on the very research process" (39).

(3) Activism and anonymity

My activist experience since the inception of the movement has been solely through interactions on social media. I had never revealed my real name or a photo of myself to movement participants, before becoming a PhD student in 2013. In January 2010 I participated as a listener in the first public conference in Vicenza, Italy (Pepe, 2010), where the scientists who had just published the new research theorising a correlation between CCSVI and MS made their first public appearance. The conference had more than 1000 participants, thanks also to the publicity circulated on the CCSVI Facebook Page (1000 members by the end of November 2009), and social media and web-forums at large. The 600-people capacity hall for the conference could not contain all the participants. The organisers had to prepare another hall where the conference was projected. Besides my personal interest in the conference, I wanted to see with my eyes the “CCSVI people” (see Fig.1), the way members of the CCSVI Facebook movement have been called since that conference. Indeed, I could recognise some of them, by their Facebook profile pictures with which they appeared when they left a comment, by their name or, when they used fake profile pictures and names, simply by what they were discussing when they were talking to each other, because they were saying the same things that could be read online.

The event pushed me towards presenting myself to join them and share the strong emotion which we had lived together online, but I privileged the responsibility of leading a fragile movement which was just starting to walk on its own legs, without the risk of being blackmailed (doctors involved denounced intimidations), or in other ways personally influenced in my independent decisions, as an interviewee puts it:

> You have first of all kept an important distance. That is, the fact of not saying who you were, of not establishing contact… you see, it's something a bit contradictory, but actually your role was important precisely because you managed to keep certain distances. Because the people with you had to be careful, they could not involve you or deceive you, or manipulate you, no way, because they had no tools to do it. (…) in human contacts it is not possible to maintain distance because fluids, sympathies are established. Maybe you buy the story of the handicapped daughter, the wife who cheats him, the husband who mistreats her… you get carried away, right? In short, this can also have a negative impact (Vittoria).

Among other reasons for refraining from becoming one of the recognised leaders of the associations that grew out of the movement, there is that, at that time, I was mostly living outside of Italy, and I would have not been able to attend the meetings.

I did not know that the social movement experience I was living as an activist would become a PhD project. In regard to the "special engagement with the ethical dimensions of research" (Milan, 2014:446) required by the field of social movement studies, the social movement under study in this thesis has not, since late 2012, been dependent on the Facebook Page I founded and still manage. At that time, the movement's discussion and activities were shifting from social media to the fully independent associations created in 2010/2011, and Facebook's role transitioned to providing information about on-the-ground developments in the movement as it had been for many other movements such as Occupy Wall Street. As the CCSVI movement was not a political movement, there was no risk of exposing "activists to surveillance as well as repression" (446). However, unless stated differently in writing and signed by those who would have liked to be named, all interviews were confidential and references and sensitive information that might have exposed the source, have been obscured.

Because I was the founder and an activist within the movement, the other activists and interviewees knew my views and that I would have had “some sort of political alignment with the principled ideas they embody” (446). I have always kept the members of the group informed about the development of my research, including the collection of the interviews and the presentation of the research project at the CCSVI associations assemblies when interviewing, and at conferences around Europe in the following years.

(4) Ethnography, native ethnography and autoethnography

Ethnography is a theory and a qualitative research method of investigation associated with many fields of study, that situates with awareness the researchers in place among actors’ social relations where routine life, discussions, decisions and actions are happening, “resulting in a practice perhaps better termed “observant participation” (Juris and Khasnabish, 2013:374). The systematic requirements for the ethnographic fieldwork were first described by Malinowski in his *Argonauts of the Western Pacific* of 1922. Malinowski insisted on the necessity to actively participate in everyday life, and he provided ethnography of “theoretical and comparative analyses, thereby transcending the division between armchair anthropology (big questions) and ethnography (small facts)” (Eriksen, 2015:21) which can help in unearthing unpredicted issues. Analysis must be grounded in observation (Castells, 2015:18) and “developing ethnographic understandings of relations and events remains essential” (Bennett and Segerberg, 2013:112).

With ethnography I have sought to answer these questions posed by Madison to interpret the CCSVI social movement actions: “Where do our systems of thinking and theories come from? To what end are we employing certain regimes of knowledge, and who or what is being heard or silenced?” (2005:93). Examples of this approach can be seen especially in Ch. 3 and Ch. 5. It can be interpreted as an ideological stance as well since “all research is ideologically tinged” (Palmer and Caldas, 2017), but the aim is not to seek for social change or implement results into practice (382). Instead, the purpose is to use theory to describe the activists’ motivations and use of social media which recalls an attempt of “semiological guerrilla warfare” (Eco, 1997), more than the typical self-help or advocate groups described in the academic literature when talking about patient activism. More precisely, as ethnographer and auto-ethnographer, I report the voices of the CCSVI activists that “carry forward indigenous meanings and experiences that are in opposition to dominant discourses and practices”, where “the position of the ethnographer is vaguely present but not addressed” (Fine, M. cited in Madison, 2005:6).

As I analyse the so called “CCSVI People”, and I am one of them, my work can be considered a native ethnography, that means “conducted by ethnographers about their own people” (Chang, 2008:44). Among the possible advantages of being a native ethnographer, in the interviews I might have experienced “lower levels of ‘performance’ from the subject informant and higher levels of natural or authentic discourse”, as well as “greater attunement to metacommunication (for example, there is more likely to be a mutual understanding of when comments are made ironically)” and a tendency to “mutual recognition when misunderstandings have occurred” (Webb and Carroll, 2017).

Autoethnography is an ethnographic research method “that uses personal experience (“auto”) to describe and interpret (“graphy”) cultural texts, experiences, beliefs, and practices (“ethno”)” (Adams, Ellis, Holman Jones, 2017:1). The first formal use of the word autoethnography was in the 1970s, but the importance of personal experience in research was not clearly acknowledged until the 1990s, when autoethnography “became a method of choice for using personal experience and reflexivity to examine cultural experiences, especially within communication” (2). My work is first of all autoethnographic especially but not only in retrospective or insight, collecting data and experience, because my research focuses on the period before becoming a researcher. I consider my work to lean both towards an objective and a subjective autoethnographic approach (Chang, 2008:46). In fact, as distinct from ethnographic research where “insiders and outsiders are different people”, in my autoethnographic work “the insider and the outsider converge” (127), and I have found myself excavating “meanings from two different contexts and wrestle with contradictions and similarities between them” (128).

Autoethnography is more important in a time where “data appear to be so self-evident and big data seem to hold such promise of truth” (Baym, 2013), because there is the risk of “decontextualizing a moment of clicking from a stream of activity and turning it into a stand–alone data point”. This is true not only for clicking *likes* and *shares*, but also for the analysis of words and sentences outside the temporal context in which they are produced. The most evident example is a study that to date offers the only objective view on the Italian CCSVI social media movement (Matteucci, 2021).

Matteucci analysed the posts from 2010 until 2016 from a selection of 40 users of the Italian CCSVI Facebook Page. Notwithstanding the qualitative textual analyses of the posts, the study mistakenly states that the Facebook Page analysed, is the Association's Page (2021:169). In fact, it has never been the Facebook Page of the Association. Rather it was the place where the activists first met and then organised to create the Association with the same name but with its own separate Facebook Page in April 2010. Members of the Association kept on being activists in the original Facebook Page where there was freedom of speech, because in the new association's Facebook Page there was a control (and self-censorship) towards an institutional communication and behaviour (which, I argue, progressively contributed to the weakening of the grassroots movement). The misunderstanding may come from the unclear information in the CCSVI association web page since its inception, where the distinction was never made clear (see Ch. 4.4.i).

Furthermore, in Matteucci's article it is stated that all the posts analysed were from users registered with the Association. I can speak for myself, as the administrator whose posts are analysed and quoted in Matteucci's study: I have never been a member of the Association which took the name of the Facebook Page I created. The misunderstanding probably came from the several statements from representatives of the CCSVI association, who presented themselves with the number of the original

Facebook Page, not with the number of the real associates. This example serves only to stress the importance of ethnography and the benefits of interviewing those directly involved and in charge of the object studied.

(5) Activism and active participant observation

> “Participant observation and ethnography are not the most common methods in social movement studies” (Balsiger and Lambelet, 2014:144).

Participant observation means: “to view and to understand events through the perspective of the people one studies” (146), that means through experiencing first-hand feelings coming from the context and from the activists. Thus, participant observation is different than being an activist: the context is shared but there are different purposes. To make a distinction, for the first four years of my participation in the movement, I was not a participant observer. Rather, I was only an activist. Since starting my PhD research in 2013, I remained an activist but in addition, I have been undertaking participant observation, effectively becoming an active participant observant studying ‘my own’ social media activity as an administrator in relation to the others’ activities in the movement.

The advantage of having become a researcher only 4 years after the inception of the movement, is that I was able to become also the unbiased object of my research, because my sole target in the first 4 years was the movement’s goal, with all the risks that such an activity involves on a personal level. I did not aim at professional achievements, which could have biased my genuine social movement activity. I only found out later that I behaved as a “connective leader” (Della Ratta and Valeriani, 2012; Poell et al., 2016), a concept which had not yet been described when I studied social science and new media at the University of Bologna in the mid ‘90s.

The distinction of the dual role of researcher and activist was not difficult to negotiate, because already in late 2012, when I decided to apply as a doctoral researcher, the movement at large was independent from the Facebook Page, which by then was more and more a mere informational reference for the on-going research and the activities of the movement’s associations. As Balsiger and Lambelet put it: “participation and observation conducted with reflexivity, combined with other methods for triangulation, produce data that are confident enough for extrapolation” (2014:146), and the other methods of triangulation included in my research are interviews, medical and social science published research, and newspaper and television news.

Biases are undoubtedly part of my research, but as the constructivist grounded theory recalls, all researchers are biased because they bring with them their previous knowledge “both empirical, related to the fieldwork, and theoretical, related to concepts and models” (Mattoni, 2014:25) of the social reality in which they are situated. I believe it would be quite difficult to become a real activist for research reasons, if not by pretending, following actors’ trainings like the Stanislavski's system (1938), or Chekhov’s Psychological Gesture (Dalton, 1986), not to mention ethical problems in cooperating in tasks and then suddenly saying: “I am sorry, I have to leave. I ran out of funding for my research”. I therefore rely on the fact of finding myself in the unique position of those who, before becoming movement scholars, were active participants (not observers), such as Doug McAdam (Balsiger and Lambelet, 2014:144).

Being an activist or an active participant is a different activity than the one of the participant observer (144), and it is also slightly different than the activity of the ‘active participant observer’ (Johnson, Avenarius and Weatherford, 2006:112), because the activist who has not yet become a researcher has experienced activism with outrage and hope, unbiased by academic frames and driven only by necessity, faith and ideology. On the other side, I literally was an observer during the CCSVI conferences of 2014 while recording the interviews, because it was the first time that I attended the CCSVI associations’ conferences. Nobody had met me before in person, I never was involved in governance decisions not even online, and I could not even participate in voting because I was not a member of those associations. Even if my first public appearance as a researcher and especially as the administrator of the original CCSVI page did not go unnoticed, I never expressed preferences in voting and governance decisions. Until the start of my PhD research, I had done research solely to advocate the movement’s goals, that is more research into CCSVI. At the beginning of my new role as a social media researcher, I was still partially embedded in advocating the movement’s goals in my research, not immediately being able to thoroughly distinguish between extolling and describing the social movement’s use of social media to oppose the obstacles put in place by the medical establishment regarding CCSVI research. It took some time and the guidance of my supervisor to transition into the detachment required for academic research.

(6) Coming out as a researcher

As the pseudonymous founder and manager of the Facebook CCSVI movement with the name Marco Fiore, I had always refused all invitations to public conferences organised by the MS associations which grew out of the CCSVI Facebook page movement. I was not interested in becoming *the star* of the movement, and I wanted to keep my decisions dependent only on the results of the scientific research, and to keep the movement untouched by possible *ad hominem* attacks. However, by the time my PhD research project was accepted, the movement was quite steady on its legs with independent decisional democratic processes within the patients' associations advocating CCSVI. Therefore, I felt I could immediately start weakening the anonymity protection there was around my person, and for the first time I accepted a public invitation which came from an independent and prestigious academic institution.

I was invited to join a round table on May 3, 2013 on 'Medicine 2.0. Research on CCSVI and social media' ('Medicina 2.0. La ricerca sulla ccsvi e i social media') organised by the master's in Journalism and Institutional Communication of Science (http://www.unife.it/master/comunicazione/medicina-2-0-la-ricerca-sulla-ccsvi-e-i-social-media-ferrara-3-maggio-2013), using the pseudonym Marco Fiore. I was living and working in Cairo at that time, and from there I flew to Italy to attend the round-table. Since I was added at the last moment (I was invited less than a week before the event, when they had known by informant that I had been accepted to become a PhD student), Marco Fiore was not listed as a speaker. An activist recorded a video of my intervention (https://www.youtube.com/watch?v=NGwEkPv6X6I Part 1 and https://www.youtube.com/watch?v=Px4r8zvdgkA Part 2).

It was the first time I had appeared in person, though without revealing my real name, in front of academics, journalists, students at the University of Ferrara as well as some activists I had been cooperating with for years uniquely through social media.

(7) Preparation for the fieldwork

In September 2013 I started my PhD, and at the end of that same year I started organising my fieldwork, because four of the biggest CCSVI Italian associations all of which grew out of the Facebook movement were planning to host national conferences in March and April 2014. The public conferences were held in Catania organised by the Association CCSVI Italia Onlus – AIC and the Association CCSVI e SM Lombardia Onlus, in Naples organised by CCSVI Campania Onlus, and in Rome (organised by the first and biggest association which grew out of the online movement, and which took the exact same name as the original Facebook Page: *CCSVI nella Sclerosi Multipla*). The reason I started to plan an early fieldwork was that I was well aware that in 2014, five years after the start of the Facebook Page, the social media movement and the activities of the associations were losing momentum. The activists' enthusiasm was trapped by the health care bureaucracy, the bureaucratic control of the CCSVI associations over their members' fervent outrage, the sceptical neurologists' community, the long enervating wait for positive scientific research results, and the traditional MS associations' co-optation of media and patients at large attracted by the movement's novelty (see Ch. 5). Those three national conferences were real events that fortunately coincided with the beginning of my PhD but, more importantly, I knew they may have been the last for many years to come, and maybe forever.

Those conferences were very important for my research because the movement's activities were mainly organised online and put into practice online. Members lived in all parts of Italy, so it would have been difficult to meet a sufficient number of activists in a short time travelling back and forth. I did not want to lose the chance to meet movement activists in person and in action during a noble expression of democracy: the election of their legal representatives within the associations, including the president. While the annual conferences of the associations between 2010 and 2014 had been crowded, since then and to date, there have not been any other conferences which could have attracted a similar number of activists. While in 2015 another conference was organised in Sicily by the association CCSVI Italia Onlus, it did not draw the same attention and participation and was a prelude to the dissolution of the same association in 2017.

There wasn't much time left to think, I had to be fast in preparing the interviews. My strongest advantages in starting my fieldwork at an early stage in my PhD programme, was a master's degree in 2000 from the University of Bologna in, among others, media, psychology and sociology (including authors like Giddens and Goffman), and the fact that I had been an activist in the movement since its inception. I already knew all the steps of the movement formation in relation to research publications, medical community reactions, mass media coverage and the like. I was able to fact-check in real time the statements of the interviewees and, if necessary, to help them in recalling pivotal events in order to collect their feelings on those experiences.

I prepared the questions based on the literature review and the research questions, which were refined after the pilot interviews and then updated with new concepts that emerged during the interviews (della Porta and Keating, 2008). I also added questions such as this one suggested by an interviewed doctor: “What do you consult first, your doctor or social media?” This process is what Corbin and Strauss (2008) call theoretical sampling: “…a method of data collection based on concepts/themes derived from data” (143). The difference with other conventional methods, is that it is “responsive to the data rather than established before the research begins”, and that instead of “sampling people and controlling variables”, the researcher is sampling concepts (144). Additional questions were asked during some interviews, depending on the on-going interview and on the personal characteristics and experiences of the interviewee.

(8) Pilot interviews

In early January 2014 I had announced through the CCSVI Facebook Page the start of my research, the location and the limited dates. My post was eventually shared in other Facebook groups and between 18 and 20 January 2014, I conducted pilot face-to-face audio-recorded interviews with three volunteers, all of whom were long-time, heavily engaged activists in the CCSVI social movement, one of them since the very beginning. They were strongly motivated to express their opinions and for the first time to meet me, the founder of the movement. Indeed, one of them travelled a considerable distance to attend the interview.

Whilst I had a set of questions ready to carry out semi-structured interviews, the friendly setting encouraged a longer engagement resulting in more unstructured interviews, rather than a Q and A session. The three interviews lasted a total of more than 6 hours. Questions were strictly related to the research questions, but the purpose of the pilot interviews was not only to test the questions which had come from the literature review and my direct experience of the movement. The intention was to ensure that I did not impose my interpretation of the experience through the question selection. I let the interviewees drive the discussion, leaving them to decide which areas to deepen, to avoid personal bias and to enlarge my knowledge of those private and public events the existence of which I probably did not even know. I did not interrupt them while talking. If needed, I would take note of any clarifications to be asked after the interviewee had stopped talking, and not before leaving a short time of silence in which the interviewee had the time to think and in case start talking again. For this situation and others, an in-person face to face interview is fundamental in order to better interpret the body language as well as the silences. For example, to understand the discontent in expressing some opinions, doubts, smiles which, if the interviewee is not talking, only in person observation can detect.

While recording I was taking notes for immediate further widening of the scope of questioning as well as for future suggestions. I then transcribed all three interviews in order to analyse which information I should solicit in the subsequent interviews (scheduled for one month later), either reformulating or adding questions. Furthermore, I used the transcription of the interviews to understand my behaviour as an interviewer, how bad or good I was in order to make improvements (Creswell, 2009). It was not just a process to collect the data to be analysed at the end of the interviews. Rather, analysis had already started after the first interview and was a work in progress during the following interviews. The new concepts coming from the analysis generated new questions which brought additional data collection so as to learn more about those concepts, aiming at reaching the point of “saturation” (Corbin and Strauss, 2008:145), where all possible concepts are defined and explained.

(9) Interviews

Whilst the pilot interviews were used primarily to develop ideas and methods, my knowledge as an activist as well as my active participant observation was pivotal in the study because it provided the necessary insight regarding developments inside the movement, the kind of interactions, non-verbal behaviour, patterns related to chronological events, which provided the background knowledge to help inform appropriate questions to interviewees (Gunter, 2000). The interviews were semi-structured (Berger, 2016), so as to allow for a more in-depth probing of unscheduled topics related to the participants’ answers and interactions. Contrary to Della Porta’s caution (2014b:237), I started with a set of questions to collect basic demographic information from the interviewees, and I did not notice that it limited in any way the conversations; on the contrary those questions appeared to me a way to break the ice. Because they were easy questions, with automatic and non-thoughtful answers, they actually gave the opportunity to warm up the situation and put the interviewer and the interviewee at ease. Surely the fact that they were not random people I had met on the street, that everybody knew who I was (even if they saw my persona for the first time), helped to make the situation friendly and open to discuss any subject.

For my fieldwork conducted in parallel to the interviews I carried out a participant observation, attending the assemblies where members of the advocacy groups undertook discussions to prepare for a unique event, the election of the President of the association, which happened to be for all three national and regional CCSVI Societies every three years, in 2014. As founder and manager of the social media movement, I was invited to attended informal lunches and dinners with presidents, top members of the societies and doctors presenting at the conferences, where I had the opportunity to refine my understanding of internal dynamics and the possibility of having off-the-record talks which were not used without the explicit consent of the informant. I learned about untold truths and information on events, decisions of the associations and scientific studies’ outcome, which combined with my personal insight helped me to refine and at times redefine the interpretation of facts and interviews. Some conferences offered educational credits for doctors, and the presentations of Italian and international researchers assured a high level of scientific debate and a good participation of public and activists.

I first announced my intention to attend the assemblies to take interviews to the associations, and after their acceptance, publicly on Facebook to all the activists and participants of those assemblies. The first conference was in Catania, Sicily, on March 2 organised by two societies: *Associazione Italiana CCSVI – AIC Onlus* and

CCSVI e SM Lombardia Onlus, where I conducted interviews from 28 February to 2 March; the second in Naples, on 23 March, organised by *Associazione CCSVI Campania Onlus*, where I conducted interviews on 22-23 March; the third in Rome, April 12, organised by *Associazione CCSVI nella Sclerosi Multipla Onlus,* where I conducted interviews on 11-12 April. The interviewees were requested to read the information sheet about the study and to sign the consent form, allowing the data to be used as part of present and future research activities. No personal medical history was requested or taken into account for this research. Unless explicit consent to do otherwise was given, the interviewees are not identifiable. For this purpose, also any direct reference to information that could lead back to the identity of the interviewee, has been removed from quotations or my analysis.

I was equipped with a professional portable digital voice recorder (with a number of extra batteries at hand), a professional traditional microphone (a type called 'Dynamic Mic'), given to me as a present by my brother (a professional singer), and earphones to make sure I could check instantaneously that the recording was functioning, i.e. clearly audible and without interference. Once the person was available to be interviewed, I would look for the quietest and most comfortable place where we could sit. The microphone was positioned between me and the interviewee on a table or on the arm of the sofa, so that there was no need to move the microphone back and forward with my hand; this would avoid the imposition of the microphone and the threat of pulling it away. The ability to hear the interview through earphones contemporaneously assured that the microphone was always correctly positioned for both the interviewer and the interviewee. I had the impression that the presence of the microphone did not impact negatively on the interviewees, on the contrary the apparent (but not substantial) formal setting gave me the impression that the interviewees became more focused on the interview, and more willing to talk, more aware that someone was really listening to what they were saying, something that very rarely happens for the matter of CCSVI in everyday life.

The interviewees were selected based on their long-time involvement in the movement, especially those active between 2009 and 2010, because I personally knew they had been very active on the Facebook Page since its inception, and because they also helped to create the CCSVI societies. Others were selected because of their well-known negative but constructive critique within the CCSVI movement or associations, or because they were critical of the CCSVI movement in general (a few). Some of the participants would show up voluntarily to be interviewed, and others were selected randomly when there was time, to take advantage of the presence of so many members of the movement. I also looked for doctors to interview because I was particularly interested in their opinion, as only a few of them were active on social media. My time was completely dedicated to conduct interviews and I exploited any chances given by someone available even if I was very tired. I avoided conducting interviews during the conference presentations, to make sure I did not disturb anybody. I always made the interviewees feel comfortable and I was an active interested listener, encouraging them to talk without pressure. I showed natural empathy being a native ethnographer (see above Ch. 2.4), but I also controlled my reactions that otherwise could have led the interviewees to satisfy my expectations or to feel disappointment. In the end I audio recorded 62 interviews for a total of 22 hours and 49 minutes, for an average length of 22 minutes per interview.

(10) Coding

After I completed the fieldwork, I started transcribing all the 62 interviews. It took a very long time but, I knew that If I did it in the best way I could, I would have gained plenty more time than I invested, when further analysis would come up. Besides clearly mis-pronounced words (which I had to correct, otherwise a word search would have not found them), I tried to be as literal as I could in the transcriptions, in order not to lose all the emotional data that came from the impetuous expressions, to allow for possible subsequent coding of words and phrases which may help in deepening the analysis, refining the interpretation and group meanings (‘In Vivo coding’, Saldana, 2012:91). I also added comments describing the tone of voice when relevant, and any other relevant non-verbal information. I made sure to write the questions in their original form above the given answers of all interviews, and again before additional insights which at times were given after different questions. This helped in quickly recollecting in nodes all the answers under the same question within the same interview first, and then of all the interviews, with a simple word search. During the transcription, I noted in a separate document some parts and themes which I thought could be relevant for future coding and analysis.

I then downloaded the NVivo 11 Plus software with the University of Westminster’s license, and participated in an introductory course through a University license, ‘Lynda.com’, and tutorials, videos, support and manuals accessible from the start screen of NVivo 11 Plus. I imported all the transcripts into the software and I started doing the Attribute Coding, i.e., the notation of fieldwork setting, and I coded all the answers to each main question for each node or container, in a process called ‘Structural coding’, a method particularly fit for a study with multiple participants and semi-structured transcribed interviews (Saldana, 2012:84). I did it manually, which gave me the opportunity to explore again the text and gather further related material in themes, topics and other concepts which were not asked directly (i.e. *timeless time*, and the like), and look for emerging patterns, trends and ideas to be coded, in a process which grounded theory defines as composed of three stages: “two cycles of coding organized around three coding methods” (Mattoni, 2014:34). A first-cycle coding method called *open coding* or *initial coding* (“is truly open-ended for a researcher’s first review of the corpus” Saldana 2012:84); then two second-cycle coding method called *axial* (“Axial Coding describes a category’s properties and dimensions and explores how the categories and subcategories relate to each other”, 209), and *focused coding* (“Focused Coding categorizes coded data based on thematic or conceptual similarity”, 209).

I ran a query for each new pattern, to see if it was mentioned in all interviews, and gathered and reviewed the query results in each related node. I repeated this process making more nodes in the coding step. Other methods were implemented, for example Simultaneous Coding as at times the same data required two or more different codes (Saldana, 2012:80), and Subcoding when within a code there was need for a more detailed coding (77). It was not possible to properly use some automated insight functionalities of NVivo 11 Plus, like the text analysis tool *Sentiment* for detecting a range of positive and negative opinions, because the interviews were in Italian, a language which is not implemented in the software.

I created a node for each main question which comprised also some questions added during the fieldwork (Corbin and Strauss, 2008). A special node was dedicated for my personal comments, which were considerations that emerged during the interviews. 8 nodes were dedicated to themes, which are work in progress. The interviews were semi-structured in the form of a talk, that means that many themes which were unintentionally covered and mentioned are awaiting coding. One example is the “Timeless time” theme, whose indirect mentions were coded when, studying the 2015 edition of the Castells book *Networks of Outrage and Hope. Social Movements in the Internet Age*, I recognised the timeless time experience described in the Occupy Wall Street movement being similar to the experience in the CCSVI patients’ movement, both directly as an activist, and from the interviewees. This is discussed further in Chapter 4 below.

CHAPTER 3. The reasons for the counter power activity of the CCSVI social media movement

(1) Introduction

Power can be defined as the capacity to impose decisions on others. It follows that *counter power* can be defined as the will to oppose decisions taken by those in power. In this chapter I report, from the subjective point of view of the activists, a comprehensive sourced description of the motives of rage and hope of the Italian MS patients advocating the CCSVI theory on social media, which led a number of them to lose the blind faith towards a part of the neurological community and towards the traditional association in relation to multiple sclerosis (MS). As "power is transmitted and practiced through discourse" (Machin and Mayr, 2012:4), the idea is to highlight the "socially constructed" discourses (Kress and Van Leeuwen, 2001:4) to better interpret and describe the use of social media by the MS patients' reaction and resistance.

In this chapter I analyse most of the main sourced public interviews, actions and publications (see the Methodology Chapter 2.1) of three of the main actors within the MS health care community, namely doctors, medical journals and traditional patient associations. Those expressions in response to the CCSVI medical research were collected, contested, organised and disseminated by activists on social media in a process called "information politics" (Keck and Sikkink, 1998). Medical statements or the absence of medical statements or answers (Fairclough, 1995:5) denounced by activists, provoked outrage among some MS patients and motivated their use of Facebook. The alleged misbehaviours of the power-force were well documented and accurately deployed in a transnational social media context by CCSVI activists, in order to generate consensus for their discontent also through memes. Furthermore, it represented also the "frame alignment process", as a "necessary condition for movement participation" organising "experience and guide action, whether individual or collective" (Snow, Rochford, Worden and Benford, 1986:464). The material here presented does not purport to be a scientific review of the medical quarrel on CCSVI. This chapter, as the whole thesis, does not seek to judge whether the movements requests were right or wrong, therefore, I deem it not necessary to report the point of view of the neurological community and traditional MS associations that discarded the CCSVI theory.

At the moment of writing, angioplasty for MS patients with CCSVI is available in Italy since 2010, executed by trained vascular surgeons in some public hospitals without any cost for the patients through the Italian NHS, or privately at a cost. None of the CCSVI researchers ever suggested MS patients to abandon the drug therapies prescribed by their neurologists before or after the vascular procedure. They always said to follow the neurologists' prescriptions. The CCSVI Facebook Page where the social media movement started, always recommended to follow the indications of the neurologists:

> First of all, you always said to the others on your CCSVI Facebook Page to keep taking medicines prescribed by neurologists (…) you have never proposed yourself as a doctor (…) your idea was not to wage war on drugs or AISM [which rebuts any correlation between CCSVI and MS] (Beatrice).

These communications arguably exhibited a consistent pattern that, according to the activists advocating for the CCSVI theory, deviated from the cautious and thoughtful approach at least of empathy and hope they expected to characterise any scientific discussion. This pattern catalysed the creation and the growing activity of what it was at the beginning only an advocating, and after also a counter-power social media movement.

I sought out further material to deepen and investigate the pattern of commodification strongly suggested by activists which has driven their resistance and advocacy. Commodification theory (Marx, 1976; Mosco 2009; Hardy 2014) may provide an explanation for these patterns of communication denounced by CCSVI activists, by positing that each of the three main actors within the health care community may in some way be commodified to the pharmaceutical companies that might have a significant vested economic interest in refuting a theory that challenges the supremacy of drug-based therapies for MS. I begin by introducing the background to the case study under consideration.

MS is one of the most common progressive diseases of the central nervous system which leads eventually to severe physical and mental impairment. Significantly there is no known cure. At the time of the highest peak of confrontation on the CCSVI theory when the traditional Italian MS association (Associazione Italiana Sclerosi Multipla, AISM) started refuting any correlation between CCSVI and MS, more than 2,300,000 people around the world had been diagnosed with MS (MSIF, 2014). In 2020 the people with MS around the world reached the number of 2.8 million

(NMSS, 2020). The majority of the people with MS were and are prescribed an extended course of drugs, as the currently preferred treatment. Table 1 shows the list of the ten best selling drugs for patients with MS, approved by the Food and Drug Administration (FDA) in the United States of America, ranked by their 2013 reported sales (Philippidis, 2014), at the peak of the confrontation between the CCSVI vascular research and the neurological community.

#1. Copaxone	**Teva**	$4.328 billion
#2. Avonex	**Biogen Idec**	$3 billion
#3. Gilenya	**Novartis**	$1.9 billion
#4. Tysabri	**Biogen Idec**	$1.67 billion
#5. Betaseron	**Bayer HealthCare**	$1.05 billion
#6. Tecfidera	**Biogen Idec**	$876 million
#7. Rebif	**EMD Serono**	$622 million
#8. Ampyra/Fampyra	**Acorda Therapeutics and Biogen Idec**	$302.301 million
#9. Aubagio	**Genzyme (Sanofi)**	$226 million
#10. Extavia	**Novartis**	$159 million

(genengnews.com February 2014)

Table 1: 10 FDA approved drugs for patients with MS ranked by their 2013 sales, as reported by the companies that market them (Philippidis, 2014).

Not only do sales of MS drugs represent a multi-billion-dollar industry, but the nominal costs of these drugs “have increased annually at rates 5 to 7 times higher than prescription drug inflation” (Hartung, Bourdette, Ahmed and Whitham, 2015:2185), which “has resulted in large profit margins and the creation of an industry ‘too big to fail’” (2191), at least in the U.S. The drug market size for MS worldwide was USD 10.9 billion in 2013 and it was expected to grow to USD 14.2 billion in 2018 (Zutshi, 2014). However, beyond researchers’ expectation, instead of 14.2 billion in 2018 the MS drug market reached USD 23.46 billion (Fortune

Business Insights, 2019), and it is expected to be worth USD 41.99 billion in 2028 (Fortune Business Insights, 2021a).

Table 2 shows how “prices for interferon (IFN) and glatiramer acetate-based platform therapies have accelerated dramatically over the past 15 years” (Hartung, 2017:1019).

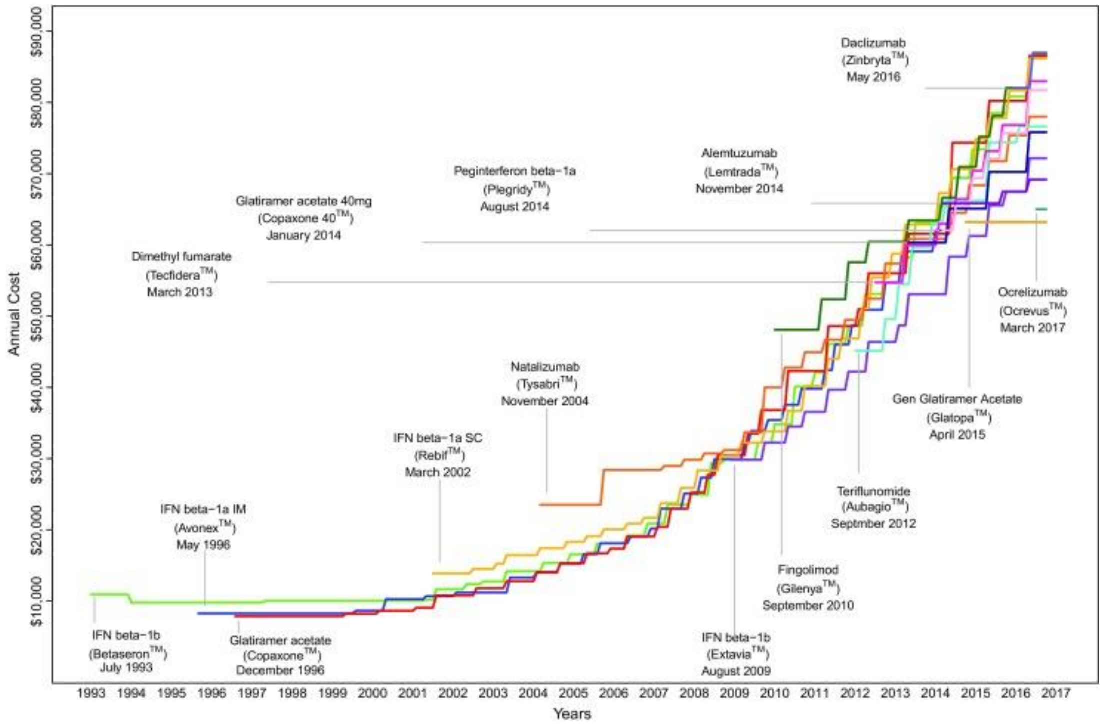


Table 2: Graph showing how prices for interferon (IFN) and glatiramer acetate-based platform therapies have accelerated dramatically over the past 15 years (Hartung, 2017:1019).

The new medical discovery publicly announced by the vascular surgeon Zamboni of Italy at an international scientific conference in Bologna in September 2009, posited an association between a venous malformation, [Chronic cerebrospinal venous insufficiency (CCSVI), a syndrome that results from a reduction or blockage of the drainage of blood from the brain and spine (Zamboni et al., 2009a)] often found in

MS patients, and the disease itself. This discovery challenged the medical orthodoxy within the MS community which for years has characterised MS as an auto-immune disease even if without a scientific proof, according to the American National MS Society (NMSS, http://web.archive.org/web/20140304073953/http://www.nationalmssociety.org/What-is-MS/Definition-of-MS/Immune-mediated-disease). The discovery also called into question, in the eyes of some MS patients, the utility of the traditional drug-based therapies, and offered the possibility of a non-drug-based therapy to alleviate the symptoms of MS, in addition to the more than 20 pharmaceuticals drugs already available.

Initially, the publication of the first studies of Zamboni's discovery (2006, Zamboni et al., 2007, 2009a, 2009b), elicited little or no response from the MS health care community. However, the studies were quickly picked up on social media and sparked the establishment of the first two patient-based social media movements related to CCSVI and MS in August 2009, the first in the U.S. (CCSVI in Multiple Sclerosis, 2009), and the second a week later in Italy (CCSVI nella Sclerosi Multipla, 2009), the aim of which was to inform patients and traditional MS associations about, as well as promote clinical research into the new theory. In November 2009, partly as a result of growing interest among these social media-based movements, and partly because of an on-going medical study on the new theory at the University of Buffalo (at the border with Canada), the new theory received its first mass-media coverage in Canada (Favaro and Philip, 2009), which in turn prompted the MS Society of Canada in late 2009 to announce "a special research competition for CCSVI related studies" (MSSC, 2010). From 2010 onwards (see Ch. 5.5), the social media movement in Italy gave rise to numerous off-line, legally recognised societies (see Ch. 4.5) advocating for research into the relationship between CCSVI and MS. The first was established in April 2010, and had as its Honorary President Nicoletta Mantovani, widow of the famous tenor Luciano Pavarotti (Associazione CCSVI-SM, 2020). These grassroots social media movements dedicated to exploring the potential of CCSVI for MS succeeded in raising the public profile of Zamboni's discovery, both on social media and in more traditional media channels and provoked a reaction from the MS health care community which had previously ignored the issue. It is to this reaction which was the inception of the CCSVI counter power movement that I now turn, beginning with an analysis of doctors' communications.

(2) Analysing doctors' communications

I review a range of oral and written communications by doctors in response to the growing public awareness and public response through social media and mass media to the discovery of CCSVI and its relationship to MS experienced by activists (see Ch. 2.1). Most if not all the communications were from neurologists, who are specialised in the treatment of MS, which provoked further reactions from the CCSVI activists. The backlash against the CCSVI theory started already in late 2009 (see Ch. 4.3.i), in the ambulatories by the neurologists whose patients asked for attention to be given to the new theory, as reported also publicly on social media by many enraged patients:

> We also told the neurologist about CCSVI so that she would be interested in saying something, but she didn't give the green light, she said they were things

> on the internet, she didn't give importance to medical publications (Emma).

I begin by examining the significance of both the content and the timing of a selection of official public comments by a number of eminent MS neurologists. I then turn to review a selection of scientific publications and editorials and I examine the conflict of interests of the neurologists whom I cite which were publicly available and then exposed on social media by CCSVI activists. I conclude introducing a selection of academic articles which facilitate in attempting to explain the nature of these communications denounced by CCSVI activists who blamed doctors' labour commodification to pharmaceutical companies.

In November 2009 the theory of CCSVI received its first mass-media coverage in Canada (Favaro and Philip, 2009). Leading Canadian neurologists reacted swiftly to the news. Among others, two statements released by a Canadian newspaper *National Post*, angered Canadian and American activists and, as a consequence, Italian activists. The first was from Dr. Mark Freedman, a neurologist at Ottawa Hospital and a leading MS researcher, who is reported on January 23, 2010, less than two months after the new theory became known to the public opinion in Canada, to have said: "I think there are going to be millions of dollars spent now to follow a hoax.... If I thought for one instant there was substance to this, I'd be all over it. But there really is very, very vague backing for the whole theory" (Blackwell, 2010a). The second statement is from Dr. Paul O'Connor, a neurologist at Toronto's St. Michael's Hospital, and National Scientific and Clinical Advisor to the MS Society of Canada, who is reported to have said in an article of February 11, that he would advise against patients even getting tested for CCSVI: "there is not a shred of real evidence anywhere that messing around with these veins does anything to help MS patients", and added: "if there is no treatment for this condition, there is no need to detect it" (Blackwell, 2010b). The foregoing statements were made immediately following the announcement on Canadian public television of the discovery of a possible link between CCSVI and MS, based on one clinical trial suggesting a correlation (Zamboni et al., 2009), and well in advance of any further clinical trials. These categorically dismissive statements were only the tip of the iceberg of neurologists' allergy to the vascular theory shown privately to MS patients while visiting them.

I turn now to a selection of publicly sourced statements identified by activists, which offered the views of one of the leading neurologists specialising in MS, Dr. Compston from the University of Cambridge, UK. The first statement is from December 2009, reported by the British MS Society, of which he was one of the six MS medical advisors, where he said: “people with MS are unlikely to benefit from treatments that dilate blood vessels” (MS Society UK, 2009). His following statements were taken from an article published in *Medscape Medical News* (Brooks, 2011), given at a press conference in August 2011 on his recently published study on genes (The International Multiple Sclerosis Genetics Consortium & The Wellcome Trust Case Control Consortium 2, 2011). Nonetheless the study object of the press conference was not related to CCSVI [see official press release which does not refer to CCSVI (University of Montreal, 2011)], Dr. Compston felt compelled to use the opportunity to belittle the theory of CCSVI, characterising it as a “completely rival theory”. He went on to say that: "the general point I'm making is that I think our work really puts some of these, what you might call maverick or eccentric, ideas [i.e., CCSVI] on one side, and it is not in the interests of patients to go on pursuing those ideas when we have such a clear narrative going across the nature of the disease" (Brooks, 2011). The “clear narrative” to which Dr Compston was referring is that of the medical orthodoxy which characterises MS as an autoimmune disease, a theory based on the nature of human autoimmunity which has not been yet fully understood, as he himself admitted (University of Cambridge, 2010), and it is not scientifically proven. Dr. Compston’s comments are reflective of a more general resistance among neurologists to any challenges to the dominant autoimmune narrative, which describes as rival, maverick or eccentric the new CCSVI narrative on MS pathogenesis. It did not go unnoticed by activists that Dr. Compston also used the press conference to mention the ways in which his research pointed to the utility of certain drugs in combatting MS, including natalizumab (Tysabri), rituximab (co-marketed in the U.S. by Biogen Idec.), alemtuzumab (produced by Genzyme Sanofi, commercialised as Lemtrada), and daclizumab (ZINBRYTA™ Biogen), (Brooks, 2011).

The autoimmune narrative, the CCSVI activists found out, had not yet been proved. See e.g., the medical science articles: ‘Is multiple sclerosis an autoimmune disease?’ (Gulcher, Vartanian and Stefansson, 1994); ‘Multiple Sclerosis Is Not an Autoimmune Disease’ (Chaudhuri and Behan, 2004); ‘Multiple Sclerosis is Not a Disease of the Immune System’, (Corthals, 2011); ‘Futility of the autoimmune orthodoxy in multiple sclerosis research’ (Behan, 2010): ‘Is Multiple Sclerosis an Autoimmune Disease?’ (Wootla, Eriguchi and Rodriguez, 2012). Also the American NMSS stated that “experts believe it to be an *autoimmune* disease, although no specific antigens (proteins that stimulate the immune system) have been identified in MS” (NMSS, 2021). A quick review of the MS associations whose neurological experts were cited in this chapter or directly involved in the research on CCSVI, has found that only the two MS associations which opposed the research on CCSVI, the Italian and the Canadian, mentioned the word autoimmune in their pages describing MS. The British MS Society defined MS as "a condition that affects your brain and spinal cord" and there's no mention of the word autoimmune in its webpage 'What is MS?' (https://web.archive.org/web/20210702022759/https://www.mssociety.org.uk/about-ms/what-is-ms). The MS Society of Canada (MSSC), in the only known country where angioplasty for MS patients is forbidden, is the only one that explicitly defined MS as autoimmune: "MS is a chronic autoimmune disease of the central nervous system" (https://web.archive.org/web/20210703115732/https://mssociety.ca/about-ms). The Italian MS association (AISM) defined MS as a "neurodegenerative disease affecting the central nervous system", mentioning a few paragraphs later in the same page that it is included among the autoimmune pathologies because of an irregular immune reaction against parts of the central nervous system (https://web.archive.org/web/20210310060735/https://www.aism.it/cosa_%C3%A8_la_sclerosi_multipla).

The next selection of statements I wish to examine are those of Dr. Comi, president of the Italian Society of Neurologists (SIN), member of the scientific committee of AISM, and former president of the European Neurological Society [See Dr. Comi's CV for additional information: (Comi, 2015)] which appeared to the CCSVI activists as expression of the bias of the Italian neurologists already experienced in ambulatories of MS centres. The first statement was referred to in Italy's leading investigative programme, *Report,* on CCSVI and MS broadcast by Italian Public

Television - RAI in 2011 (comparable to the BBC). The investigative journalist reported that Dr. Comi in his capacity as president of the Italian Society of Neurologists had said that any of the Society's members who choose to participate in a randomised multicentre study on CCSVI and MS, publicly funded by the Directorate General for Health and Welfare of the Italian region of Emilia Romagna (Assessorato Politiche per la salute, 2012), and led by Prof Zamboni and the neurologist Fabrizio Salvi, (ClinicalTrials.gov, 2011), "puts him/herself in open conflict with his/her own scientific society" ("chi partecipa alla sperimentazione si pone in contrasto aperto con la propria società scientifica") (Iovene, 2011). *Corriere della Sera* dossier's on CCSVI published in 2013, comments about Comi's statements: "the associates - is the gist of the message – should refrain from cooperating in any CCSVI study" (Corcella, Meli, Natali and D'Amico, 2013:38). Chapter 5 offers further explanations for this behaviour. In response, Nicoletta Mantovani, then honorary president of the Italian society, *CCSVI nella Sclerosi Multipla Onlus* (Associazione CCSVI-SM, 2010a), former patroness of AISM, in an open letter to Dr Comi commented that: "it is like saying if you collaborate in this research, you are out of the group. And the group manages committees, competitions, scholarships, visibility, prestige, appointments" [è un po' come dire se collabori a questa ricerca sei fuori dal gruppo. E il Gruppo gestisce commissioni, concorsi, borse di studio, visibilità, prestigio, incarichi] (Marozzi, 2011).

Further on in the same RAI television programme, the journalist mentioned the neurologist researching with Zamboni, Dr. Salvi to Dr. Comi and the latter immediately interjected: "But he [Dr. Salvi] is not a neurologist, he is corrupted by this idea [CCSVI], because he is not a neurologist. I mean Salvi is a good boy, 'that's all' [original English in the interview], scientifically insignificant" - [Ma Salvi non è un neurologo, è un pervertito a quest'idea, che non è neurologo. Cioè Salvi è un brav fiò, 'that's all' scientificamente inesistente] (Iovene, 2011). Despite objections expressed by a number of doctors, the deontological assessment of the Ordine dei medici (General Medical Council) of the city of Bergamo where Dr Comi was registered, decided that with an unfortunate choice of words the President of the Italian neurologists meant to say that the idea is "corrupted", not Dr Salvi, and absolved Dr Comi (Clemente, 2012). However, the Ministry of Education excluded Dr. Comi from the ministerial commission for the qualification to the functions of first and second level university professor, to which Dr Salvi was applying, because Dr Comi anticipated his judgment on Salvi, "scientifically non-existent", together with the dubious definitions above reported. Dr Salvi also filed a libel suit against Dr Comi. It is interesting to note that the two in the past had worked and published a number of research articles together (Mantovani, 2013).

Dr. Comi's second set of statements of interest relate to comments made in his role as lead author of a study named CoSMo, on the correlation between CCSVI and MS which was scientifically contested on its methodology before starting (see Ch. 3.4 below), and it was funded by AISM. In October 2011, Dr. Comi participated in one of the few world-leading conferences on MS, the European and Americas Committees for Treatment and Research in Multiple Sclerosis (ECTRIMS/ACTRIMS), funded by pharmaceuticals. While presenting a poster of the study's design, which itself, quite appropriately, did not report any results as the study was not yet complete (AISM, 2011b), he is reported by one of the mainstream Italian press agencies to have said that the partial findings to date "completely deflated the hypothesis that CCSVI is a cause or a significant contributing cause of multiple sclerosis" (Adnkronos Salute, 2011). The study whose anticipation of results were revealed before completion and two years before its publication, was a double blinded study, i.e., data should have been unidentified by the scientists involved, that means Dr Comi should have not been in possession of those results, or that as activists argued, the study was not completely blinded. Interestingly, Dr. Comi's remarks about CCSVI followed his presentation at the same conference of his study on drug-based treatments for MS, which was funded by Sanofi (Gever, 2011), one of the pharmaceutical companies listed in Table 1.

A recognition of the awkwardness of presenting to journalists partial results of a study supposed to be double blinded, is provided by AISM, the sponsors of the study, who chose not to report Dr. Comi's inconvenient comments, but rather reported the more cautious words of his colleague the neurologist Dr. Mancardi, President of the Scientific Committee of AISM who said that the interim analysis suggested that there was a good reason to continue with the study (AISM, 2011c), without mentioning the reasons by which otherwise the study should have not been continued. The following statement on the same study above is taken from an article in the magazine Medscape Medical News, October 26, 2012 (Jeffrey, 2012) in which it is reported that Dr Comi, once again in advance of the peer reviewed study published only the year after (Comi, Battaglia, Bertolotto, et al, 2013), said that: "the findings should end once and for all the controversy about whether venous insufficiency has any role in the MS disease process", and concluded that: "I think that I do really hope that this is the last time I have to talk about this topic" (Jeffrey, 2012).

The statement followed from the presentation of the results of CoSMo presented in 2012 one year ahead of the publication of the research, at the same ECTRIMS' congress of the year before. The news was quickly picked up also by Italian mainstream media as the *Corriere della Sera:* "Multiple sclerosis: new study rejects Zamboni's thesis" (Corriere della Sera, 2012). In the same article were reported the statements of Dr Battaglia, past president in 1996-1998 of the European Multiple Sclerosis Platform (EMSP), since 1994 member of International Medical Advisory Board, Multiple Sclerosis International Federation (MSIF), and president since 1998 of Multiple Sclerosis Italian Foundation (FISM - Fondazione Italiana Sclerosi Multipla) of AISM (updated to 2016 <https://web.archive.org/web/20210721175814/https://www.dsv.unisi.it/sites/st15/files/allegatiparagrafo/11-10-2016/cv_battaglia_mario_alberto_0.pdf>): the results, he declares, "eliminate the possibility of creating even bland connections between MS and CCSVI - To cure MS and defeat it, he stresses, «it is therefore necessary to take other paths»". In the same article, were reported also the statements of the neurologist Comi: "There is no reason that [research] might lead one to think that by treating this pathology [CCSVI], you treat multiple sclerosis ", and the statements of the neurologist Mancardi, president of the scientific committee of AISM: "the [CoSMo] result is reliable" (*Corriere della Sera,* 2012; *Pharmastar, 2*012).

All these statements from leading neurologists aimed at influencing public opinion and at the same time stirred the CCSVI activists' anger towards the MS medical establishment. It was not the CCSVI activists who went to search for those statements, but they were publicly reported by mainstream media and MS associations and privately by their own neurologists. The reason was to discredit as soon as possible the CCSVI theory to MS patients, as neurologists were having a hard time: their patients were having the vascular procedure done even without their (not required) consent as also reported by the public Italian TV: “And did you do it [the procedure to restore the blood flow] with the consent of your neurologist? - My neurologist? To one of my neurologists, I expressed a simple opinion of the fuck off series” (Iovene, 2011:3).

Activists did not need a scientific degree to understand that those declarations were against the rules of the scientific method which underpins scientific progress. The study CoSMo contested in its methodology (Darelli, 2010; Zamboni, 2010; Associazione CCSVI-SM, 2012; Rasman, 2012), in the end found only 3% of CCSVI in people with MS. Activists later discovered that the results of the few experienced vascular centres involved in the study, which found over 70% of CCSVI in MS patients, had been discarded because the value was too different from the average results of the 3% obtained by the neurological centres. It is not my intention to judge the science, rather I wish to highlight the patients’ viewpoint that leading neurologists, whose expertise informs the policy of the MS societies, showed no compassion for them, which contributed to the counter power activity of the CCSVI movement.

Doctors’ efforts to impose their considerations on the medical establishment, public opinion and directly on MS patients, can also be seen in the way they have sought to characterise this medical discovery in their publications, i.e., scientific research, editorials, invited commentaries (at times written by doctors with vascular background but without appropriate academic standards even in prestigious medical journals, said informants), etc. The brief review of a selection of publication titles that follows, was picked up and contested by CCSVI researchers and CCSVI activists:

- ‘The perfect crime? CCSVI not leaving a trace in MS’ (Mayer, Pfeilschifter, Lorenz, et al, 2011);
- ‘CCSVI and MS: A Never-Ending Story’ (Reekers, 2011)
- ‘The “Liberation Procedure” for Multiple Sclerosis: Sacrificing Science at the Altar of Consumer Demand’ (Brant-Zawadzki et al., 2012);
- ‘Goodbye to all that: a short history of CCSVI’ (Rasminsky and Terbrugge, 2013);
- ‘Multiple sclerosis: CCSVI deconstructed and discarded’ (Barkhof and Wattjes, 2013);
- ‘What went wrong? The flawed concept of cerebrospinal venous insufficiency’ (Valdueza, Doepp, (…) Wattjes, 2013);
- ‘Venous angioplasty for "CCSVI" in multiple sclerosis: ending a therapeutic misadventure’ (Bourdette and Cohen, 2014);
- ‘Chronic cerebrospinal venous insufficiency in multiple sclerosis: the final curtain’ (Paul and Wattjes, 2014)*;*
- ‘A swan song for ccsvi’ (Reekers, 2014);
- ‘Chronic cerebrospinal venous insufficiency: the end of “The Big Idea”?’ (Stolz, 2015).

In the eyes of MS patients and caregivers not accustomed to the harsh debate among scientists, these titles ridiculing scientists and research that had given hope to many patients, would better suit a tabloid medium than professional scientific discourse.

Instead of doctors showing compassion and regret for not being able to confirm the connection of CCSVI to MS, the CCSVI activists witnessed what in their eyes appeared to be an incomprehensible bitterness and resentment, relishing the failure of a scientific theory. They experienced a lack of professionality and a willingness by neurologists to impose their judgment on that of the vascular surgeons, which stirred the CCSVI movement’s anger and activities.

> Doctors are arrogant. I work with them, they are arrogant in character, I don't know if they become so… you know, because they have to save lives. They behave so arrogantly on all sides. Then there will be the exception (Beatrice).

While this is by no means a comprehensive review of doctors’ responses to CCSVI, which was acknowledged and contested by international activists, it does provide a compelling insight into the strength of resistance to this medical discovery among a number of leading MS doctors.

(i) Theorising doctors’ labour commodification

In seeking to find an explanation for the nature of the statements of these leading neurologists related to CCSVI and MS, activists theorised a possible relationship between the desire of these scientists to use their public communications to prematurely cast doubt on the theory of CCSVI and their self-declared conflicts of interest. Their disclosures set out below at the time they were collected by activists, revealed their close financial relationships with the very drug companies which profit the most from the currently orthodox drug-based therapies for MS, listed in Table 1. While it is not compulsory to report conflicts of interest within a particular medical study, authors general opt to voluntarily disclose any conflicts. It is important to underline that voluntarily disclosing financial relationships should be considered a way to prove the truthfulness of the scientific results found by researchers, as if they were military collage badges and ribbons proving their loyalty and abnegation:

- Mark Freedman has disclosed the following relevant financial relationships: Served as an advisor or consultant for: Actelion Pharmaceuticals, Ltd; Bayer HealthCare Pharmaceuticals; Biogen Idec Inc.; Celgene Corporation; EMD Serono, Inc.; F. Hoffmann-La Roche Ltd; Genzyme Corporation; Glycominds Ltd.; Merck Serono; Novartis Pharmaceuticals Corporation; Opexa Therapeutics, Inc.; Sanofi; Teva Neuroscience, Inc.
  Served as a speaker or a member of a speakers bureau for: Genzyme Corporation.
  Received grants for clinical research from: Bayer HealthCare Pharmaceuticals; Genzyme Corporation (Medscape, 2013).
- Paul O'Connor reports: Scientific Advisory Boards: Novartis Fingolimod. Steering Committee--member--2007-present Teriflunomide Steering Committee (Sanofi Aventis)--chairman--2006-present Bayer BEYOND study steering committee--chairman--2007-2009 BRAVO (Laquinimod) study DMC--chairman--2007-present Genentech advisory board--member Roche advisory board Receptos advisory board Actelion advisory board.
  Funding for Travel or Speaker Honoraria: 1 Biogen Idec-ECTRIMS meeting Dusseldorf--2009--presentations of data from two studies 2 Teva--Meeting in London--advise and present data on safety of MS drugs--2009 3 Advisory board meeting in Montreal 2010 4 Advisory board meeting in Toronto 2013.

Editorial Boards: 1 MS Journal. Editorial advisory board. July 2012--March 2013.

Consultancies: Biogen Idec consultant 2007-2012 Actelion consultant 2010 Bayer Consultant 2007-2009 EMD Serono Consultant 2009-11 Teva Consultant 2007-2013 Genentech Consultant 2007-2008 Sanofi Genzyme Consultant 2002-2013 Novartis Consultant 2005-2013 Warburg Pincus Consultant 2009.

Research Support, Commercial Entities: 1 Bayer--study grant support for BEYOND study--2006-8 2 Novartis--study grant support for FREEDOMS, TRANSFORMS and INFORMS study--2006-2012 3 BIOMS--study grant support 2006-9 4 Sanofi Aventis-grant supprot for TEMSO, phase 2 , CIS and nerispirdine studies 5 ROCHE; grant supprot for phase 2 OCRELIZUMAB study 6 Biogen Idec: grant support for ASCEND and JEMS study 7 Roche grant support for OPERA and ORATORIO studies 8 Novartis support for INFORMS study of PPMS.

Research Support, Foundations and Societies: National Scientific and Clinical Advisor to the MS Society of Canada. 2008-2013 ongoing (Bar-Or, Freedman, Kremenchutzky, et al., 2013).

- A. Compston reports: “receiving consulting fees, lecture fees, and grant support from Genzyme and lecture fees from Bayer Schering Pharma, and has consulted for Lundbeck, all on behalf of the University of Cambridge.” (McCarthy, Tuohy, Compston, et al., 2013).
- G. Comi has received consulting fees for participating on advisory boards from Novartis, TEVA, Sanofi-Aventis, Merck-Serono, and Bayer-Schering, lecture fees from Novartis, TEVA, Sanofi-Aventis, Merck-Serono, Biogen-

Dompè, Bayer-Schering, and Serono Symposia International Foundation, he is a member of the Board of the Italian MS Foundation (Comi, Battaglia, Bertolotto, et al., 2013).

- GL. Mancardi received honoraria for lecturing, travel expenses for attending meetings, and financial support for research from Bayer Schering, Biogen Idec, Sanofi-Aventis, Novartis and Merck Serono Pharmaceuticals. He is also a member of the Board of the Italian MS Foundation. (Comi, Battaglia, Bertolotto, et al., 2013).

I turn finally to review a number of studies which theoretically describe in terms of labour commodification of doctors, what it was supposed by CCSVI activists since the early reactions of the neurological community to the vascular theory.

There is a wide literature not only theorising but also analysing lawsuits on the controversial relationship between doctors and pharmaceutical companies. One study found a strong association between drug studies with positive results and the researchers' conflict of interests (Friedman and Richter, 2004). Another study reported the following interactions between doctors and pharmaceutical companies that could serve to diminish patients' best interests: "gifts, samples, industry-paid meals, funding for travel or lodging to attend educational symposia, CME sponsorship, honoraria, research funding, and employment" (Mandal, Yadav, Karn, Sah, 2012), as it is also denounced by the National Physicians Alliance in the U.S. (2018). The scale of the financial transfers has been estimated to be tens of billions of dollars a year. One known case demonstrated that pharmaceutical companies paid

$1.6 million in consulting and speaking fees to a single doctor over the course of seven years (Angell, 2009).

The reason pharmaceuticals spend so much money in this way is that, a study said, unlike most other businesses, “they must go through an intermediary in order to sell their product. This places physicians in a position of singular trust. They stand between corporations and the vulnerable, sometimes desperate patients that those corporations call customers” (Elliott, 2014). Furthermore, often patients who underwent a clinical trial for MS therapies were not informed of the presence of a conflict of interest, which might influence their decision to participate (Solomon, Klein, Corbov and Bernat, 2015).

Doctors’ labour commodification could also come into play in education, a study reported. In 2006, the Association of American Medical Colleges (AAMC) set up a Task Force to investigate this issue and published a report in 2008 entitled ‘Industry Funding of Medical Education’ (AAMC, 2008a), which came out with the following results: “Mounting scientific evidence indicates that gifts, favors, and other marketing activities, both explicit and implicit, prejudice independent judgment in unconscious ways” (AAMC, 2008b). The report’s conclusion urged “all academic medical centers to accelerate their adoption of policies that better manage, and when necessary, prohibit, academic-industry interactions that can inherently create conflicts of interest and undermine standards of professionalism.” The association also urged industry to “voluntarily discontinue those practices that compromise professionalism as well as public trust” (31). The consequences of the sponsorship of textbooks from the medical industry was that: “Medical students may be particularly vulnerable to commercial influences, as they have had little or no training in commercial biases and generally believe what they read in textbooks" (Lundh and Gøtzsche, 2010:14). Another example of the involvement of pharmaceutical companies in education was the direct funding of clinical academic posts like the one created by the pharmaceutical Genzyme at the University of Cambridge with $6 million (2010), coordinated by Dr. Compston whose controversial statements against CCSVI, while working together with Genzyme, are reported above. As an interviewee put it, neurologists defended their independence blaming patients for their bitter reactions:

> I went to a neurologist, and it is yet another neurologist who always tells me the same thing: "you started badly because you attacked us, (...) you ridiculed us, we had to clam up, because it was a catapult on us, on what we have always known, you have not given us the opportunity to…" (…) I regularly reply, yes ok, it was all wrong, but we certainly cannot pay for the mistakes of others. We are all capable to make mistakes, (...) [but] you continue to talk about a study, CoSMo, which has not yet been published and of which it is not clear how they reached such ridiculous figures [3% of CCSVI in MS patients]. As a lay person, I am not a doctor, I helped about 400 patients to have Doppler ultrasounds [diagnosis of CCSVI done on MS patients], only two of whom were without CCSVI (Vittoria).

CCSVI advocates findings on the pharmaceuticals connections to the doctors who ridiculed the new research, led the movement to the conclusion that those doctors "had a vested financial interest in dismissing CCSVI and liberation therapy as scientifically unsound so as to maintain the status quo" (Pullman, Zarzeczny and Picard, 2013:6).

(3) Analysing medical journals' communications

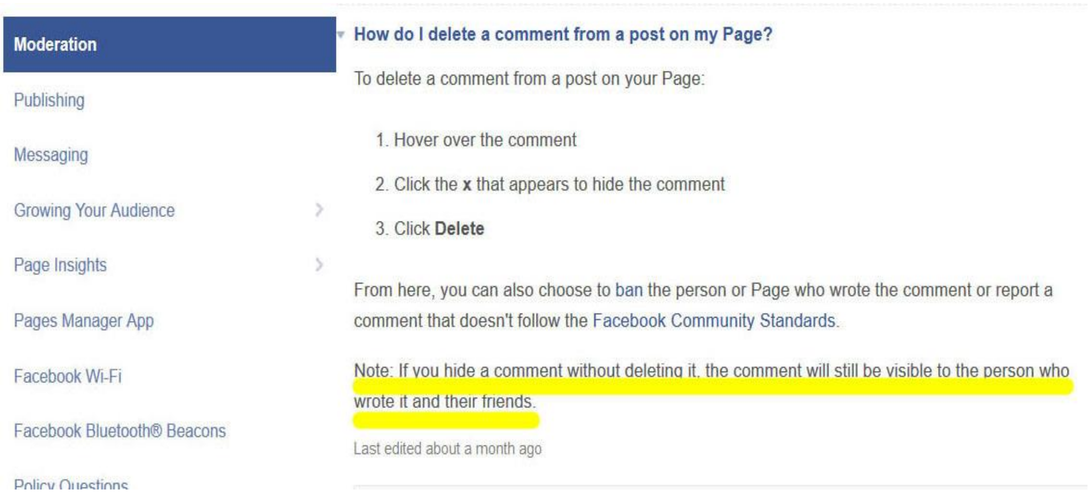
I turn now to review an example with a unique insight on a prestigious medical journal that exercised its editorial discretion to allegedly cast CCSVI in a negative light. It was contested for not giving an opportunity to the counterpart to contribute to the dispute, once again in a way that did not appear to befit rational scientific debate (Docherty and Smith, 1999). Thereafter, I organise the activists' allegations in seeking an explanation for this behaviour, by reviewing an editorial published in the same medical journal mentioned above, on why medical journals may not always act to further *good science*. I then review an article written by the then Editor of BMJ, Smith (2005), which goes some way to providing support for the relevance of commodification in this context.

On 9 October 2013, *The Lancet* published online an article ahead of print (Traboulsee, Knox, Machan, et al., 2014), which called into question data from clinical studies demonstrating the prevalence of CCSVI in MS patients. On October 16, 2013 Professor Zamboni, one of the leading doctors from the study challenged in *The Lancet* article, asked the editor to publish a comment in response, because there were "scientific inaccuracies that need to be clarified for the benefit of the scientific community" (Zamboni, 2014:75). In January 2014 the article came out in the printed version of *The Lancet* without Zamboni's comment, and two weeks later the senior Editor of *The Lancet* wrote to Zamboni telling him he had rejected his comment, while inviting the authors of the article to reply to Zamboni directly. Anyway, instead of publishing Zamboni's comment, who was cited personally in the article, *The Lancet* chose to publish a comment entitled: 'Chronic cerebrospinal venous insufficiency in multiple sclerosis: the final curtain' (Paul and Wattjes, 2014). In November 2014, after eleven months, as the authors of *The Lancet* article had still not responded as wished by the Editor, Professor Zamboni published his response to *The Lancet*'s article in another journal though with a lesser exposure, including an account of the conduct of *The Lancet* editor as described above (Zamboni, 2014). Activists made sure that *The Lancet* knew about the allegation, but it never responded nor denied the Editor's conduct.

When CCSVI activists knew what happened, they decided to go to *The Lancet* Facebook Page, and post comments below the most recent post then available at the end of 2014. In those comments they were politely asking why Zamboni's comment had not been accepted for publication, with the link to Zamboni's article describing the conduct. There weren't any harsh or unpresentable words. Over 70 comments all from different users, but all with the same text and link to the article. *The Lancet* never answered any of those comments, instead the administrator of *The Lancet* Facebook Page decided to hide all those comments from public view, but none of the activists realised what happened, because the activists could still see each other comments. The administrator of *The Lancet* Facebook Page used a function that kept unwanted comments only visible to the authors and their friends (see Fig. 5). Most of those who published the comments were CCSVI activists who knew each other for years and they were all Facebook friends among themselves, so for some time they did not realise the trick. In using this approach, *The Lancet* was able to keep those who commented in the dark, without ever denying Zamboni's public exposition of facts. It did not appear that any science journalists or web debunkers ever questioned the editor of *The Lancet*. As this thesis does not seek to find the balanced scientific truth but only to represent CCSVI activists’ motivation in their rage and hope within the social media movement, there was no need to ask the Editor’s opinion.

This was not an isolated case. Zamboni had already previously lamented the lack of opportunity to respond to editorials and opinions challenging the CCSVI theory, most of which had been written at the journal’s request as *Invited Commentary*, and that at times “may be more suited to an opinion-based section of the journal rather than a section requiring academic standards to be met when writing commentary about a peer-reviewed article”, as denounced by international neurologists (Zivadinov, Salvi and Weinstock-Guttman, 2012).

This insight highlights the way in which medical journals drove the debate through their editorial selections which, I will argue in the next section suggested by international CCSVI activists’, are likely to align with powerful economic interests, e.g., pharmaceutical companies.



How do I delete a comment from a post on my Page?

To delete a comment from a post on your Page:

1. Hover over the comment
2. Click the **x** that appears to hide the comment
3. Click **Delete**

From here, you can also choose to ban the person or Page who wrote the comment or report a comment that doesn't follow the Facebook Community Standards.

Note: If you hide a comment without deleting it, the comment will still be visible to the person who wrote it and their friends.

Last edited about a month ago

Figure 5: Facebook Page function that keeps unwanted comments only visible to the authors and their friends.

(i) Theorising medical journals' audience commodification

The activists' allegations that sought to find an explanation for this seemingly unbalanced medical journals' approach, which furthered stirred anger and resentment towards the neurological establishment, it can be framed again by commodification theory and, in this specific case, audience commodification.

The audience of medical journals can be very wide, depending on the involvement of public relation's firms. It comprises mainly researchers and physicians, but it can also reach patients' associations, national health services policy makers, and the wider public (Smith, 2005), through traditional mass media and digital media reporting on medical journal content. Unlike doctors, journals are not required to disclose conflicts of interests, so it was much more difficult to discern the exact nature and extent of their financial arrangements with industry (Garfield, 2006).

However, several former editors of leading medical journals, including *The Lancet* mentioned above, have written articles that helped to shed some light on this issue.

I begin with an editorial published in April 2015 by the Senior Editor of *The Lancet*, Richard Horton. The editorial reports on a two-day symposium hosted a week before in London by the Academy of Medical Sciences (AMS), on the reproducibility and reliability of biomedical research. Horton was not able to attribute any of the statements made under the Chatham House rules, but he summarised the discussion in the following way:

> Much of the scientific literature, perhaps half, may simply be untrue. (…) Afflicted by studies with small sample sizes, tiny effects, invalid exploratory analyses, and flagrant conflicts of interest, together with an obsession for pursuing fashionable trends of dubious importance, science has taken a turn towards darkness (Horton, 2015).

As he reported that one participant put it, “poor methods get results” and another is reported to have said “A lot of what is published is incorrect” (Horton, 2015:1380). Additional research revealed that the Chatham House rules appeared to apply only to London, because Professor Marcus Munafo of the University of Bristol was the Keynote Speaker at a Symposium in Sheffield, UK, and a record of what he is purported to have said, later published by the University of Sheffield, is worth recalling:

> There have been a number of high profile cases of academic fraud recently. However, a more insidious threat to the integrity of science is the extent to which distortions of scientific best practice increases the likelihood that published research findings are in fact false. I will provide evidence for a range of systemic problems within science, such as flexibility in the analysis of data, selective reporting of study results, publication bias against null results, influence of vested

> (e.g., financial) interests, and distorted incentive structures. I will show that under some plausible and quite conservative assumptions, it is likely that the majority of published findings are in fact false. A number of strategies for improving the situation will be discussed (University of Sheffield, 2015).

Horton added a “mea culpa” in his editorial, saying: “Journal editors deserve their fair share of criticism too. We aid and abet the worst behaviours. Our acquiescence to the impact factor fuels an unhealthy competition to win a place in a select few journals” (Horton, 2015:1380). The impact factor measures the frequency with which an article is subsequently cited, and the more are the citations of the articles of a journal, the higher is the impact factor of that journal. Horton appeared to be wanting to portray the influence of the impact factor as limited to journal editors acquiescing in selecting “bad science” which is likely to carry a high impact factor based on its results. However, there were a number of studies that show it was not always the bad-science-maker competition which decided which article would be published; instead, some articles brought as a dowry the certainty of improving the impact factor, which in turn drove the choice of the journals’ editors. For instance, it was found that industry-supported trials were more likely to be published because they were guaranteed a higher number of citations (Lundh, Barbateskovic, Hróbjartsson, and Gøtzsche, 2010:2). Industry-sponsored clinical trials were more likely to have positive results as compared to non-industry-supported clinical trials, and also were more likely to receive ghost-authored reviews, which were both positively associated with the impact factor (5).

Researchers at the Evidence-Based Medicine Data Lab of the University of Oxford reported that a sizeable number of pharmaceutical trials were not published or were not reported to the ClinicalTrials.gov database (Powell-Smith and Goldacre, 2016). Other findings stated that pharmaceutical studies with negative results were significantly less likely to be published than those with positive results, both to allegedly hide negative results to making treatments look better (Piller, 2015) and because they were rejected by journals. The latter happened because studies with negative results decreased the journals' impact factor (Song, Parekh, Hooper et al., 2010). CCSVI activists noted that the leading doctor of a contested study on CCSVI with negative results (Traboulsee, Knox, Machan, et al., 2014), was from the Canadian University of British Columbia that reportedly did not publish 72.4% of its registered pharmaceutical studies (Hol, 2016), whilst the other doctors mentioned were from the Canadian University of Saskatchewan that was reported not to have published 70.6% of the pharmaceutical studies registered.

For industry, it was important to publish in high impact factor journals otherwise called prestigious journals, to influence clinical decision-making which in turn may enhance the sale of drugs and devices (Lundh, Barbateskovic, Hróbjartsson, and Gøtzsche, 2010:2). A press release publicised by a "public-relations firm hired by the pharmaceutical company that sponsored the trial", said the former editor and chief executive of the BMJ publishing Group, Richard Smith, together with "a million dollars on reprints of the trial for worldwide distribution" (Smith, 2005:364), distributed to key doctors, might work to improve the impact factor through further citations (Lundh, Barbateskovic, Hróbjartsson, and Gøtzsche, 2010:2).

Another study found that randomised controlled trials of drugs published in journals were more likely to present favourable results, in the sense that they failed to disclose all the negative or adverse elements of their studies (Riveros and Dechartres, 2013). Smith also published an article in 2006 which focused in part on the conflicts of interest that plagued both authors of clinical trials published in journals, as well as the journals themselves. Specifically, he argued that medical journals should better manage the conflicts of interest of its authors, noting that many of them have financial relationships with the pharmaceutical industry: “These undeclared conflicts of interest can have profound effects on the studies undertaken and the conclusions they reach” (Smith, 2006:116). In respect of the journals themselves, he said that:

> Many, including some of the most prestigious journals, publish mostly trials that are funded by the industry. The results of these trials are rarely unfavourable to the companies. The journals depend on income from advertising and sales of reprints (a company might pay over $1m for reprints of one study, which it funded in the first place) (118).

For the general audience of doctors who were not specialised in research and who made up the majority of a medical journal’s audience, the prestige of the journal itself “will bless the quality of the drug” (Smith, 2005:364). Smith also noted that doctors rarely had the time or the expertise to read original journal articles. Most of their information about the results of clinical trials, according to Smith, came from synopses of medical journal articles published in free newspapers funded by the pharmaceutical companies (Smith, 2006). It is not only editors who bear responsibility for this situation. Sometimes, they simply follow the indications of their paymasters in deciding to publish research related to a trial with an expected high profit margin on reprints, the stark choice they face is either: publish a trial that will bring high profits or be forced to meet the end-of-year budget by losing an editor (365). Horton himself admitted in 2004 that “as editor of The Lancet I have attended medical conferences at which I have been urged to publish more favourable views of the pharmaceutical industry" (Horton, 2004). Another admission came from the former editor of the *New England Journal of Medicine*, Angell: "It is simply no longer possible to believe much of the clinical research that is published, or to rely on the judgment of trusted physicians or authoritative medical guidelines. I take no pleasure in this conclusion, which I reached slowly and reluctantly over my two decades as an editor of The New England Journal of Medicine" (Angell, 2009).

As described above, it seems that some journals had financial needs which compel them to select articles with a dowry of a high impact factor, namely industry-sponsored trials, the majority of which had positive findings which favoured a higher number of citations. At the same time, some pharmaceutical companies needed to publish their studies in prestigious journals with high impact factor in order to be convincing, with a dowry of buying a high number of reprints of the prestigious journals which have published the study, in order to be distributed to inform doctors, as well as public opinion through public relations' firms. The reprints ordered by pharmaceuticals were a fundamental income for the journals, and their distribution to key researchers increased the number of citations and so the impact factor, which in turn raised the prestige of the journal. This ensured the journal future income and *football career* (see paragraph below) through publishing future industrial trials which sought a prestigious journal. This financial relationship between pharmaceuticals and journals, could be one of the reasons why, as said the editor of *The Lancet:* "journals have devolved into information-laundering operations for the pharmaceutical industry" (Horton, 2004).

Commodification theory suggests that the main actors may be involved directly, or indirectly. The indirect involvement might be as it has been described for example with the big and richest football team. They might be favoured unintentionally and subconsciously by some socially influenced referees' decisions (Erikstad and Johansen, 2020; Boyko, Boyko and Boyko, 2007), or they might be favoured by referees that assumed that they could improve their own career only by refereeing big rich teams that, if unfortunately disappointed by unfavoured decisions, might put a veto on the referees' participation in international tournaments (Senaldi, 2017). As a Professor at Bristol University put in a paragraph titled 'Psychological slavery': "a referee is unlikely to have a long and glorious career if he gives a series of penalties against Juventus" (Foot, 2007). I am a Juventus fan and I personally don't agree with that.

(4) Analysing patient associations' communications

I turn finally to review four examples of communications by traditional MS associations, both national and international in reactions to the discovery of the potential relationship between CCSVI and MS.

Two examples are from two national, traditional, mainstream MS patient associations in Italy (AISM) and Canada (MSSC) that, as reported by the president of the Italian Society of Neurologists Dr. Comi, an "assessment by European experts in multiple sclerosis" (Colasanto, 2012) recorded they have faced the most active CCSVI patient groups worldwide. The third example is from the Multiple Sclerosis

International Federation (MSIF), which is the world's "only global network of MS organisations", 45 members, one for each nation including the above cited MSSC and AISM (MSIF, 2015). The fourth example is from the European Multiple Sclerosis Platform (EMSP), which has AISM among its 40 national member societies, and MSIF among its partners.

The last two, MSIF and EMSP, are supra-national societies which wield great influence among their membership and supra-national institutions, i.e., the EU. Thereafter, I turn to commodification theory to seek an academic framing to the CCSVI activists' complaints on the way in which these patient associations responded, which then sparked the creations of alternative MS-CCSVI associations.

At the outset, I want to introduce briefly the structure and mandate of patients' associations. Patients' associations are representative bodies for patients. Their leadership is generally elected by the association's members which may not be limited to patients and their caregivers. Their mandate generally includes disseminating information about the disease and its treatment, raising money and funding research. They also act as intermediaries between patients and various policy-makers/institutions, to represent patients' interests. National patient associations generally have a scientific committee, comprised of medical experts generally running the main drugs' scientific studies, which substantially guides the association's decisions. Informants say that AISM candidates for presidency are chosen among the most trustworthy members with MS by the leading neurologists, whose conflict of interests are listed above in paragraph 2.i.

The first example of communications from a patient association that I consider is that of the Canadian society, MSSC. My personal research has shown that until late 2009 MSSC had never informed their members about the new theory on MS pathogenesis and the possible correlation with CCSVI in spite of numerous published studies on the subject (Zamboni et al. 2006, 2007, 2009July), nor had they funded further research in this area. This was until November 2009, when a TV programme dedicated to exploring Zamboni's theory was aired on national television in Canada (Favaro and Philip, 2009) reporting the study's results just published and while another research on MS and CCSVI was undergoing in Buffalo, NY, in association with the researchers and MS patients of the Hospitals in Buffalo N.Y. and Bologna and Ferrara, Italy. This was the first television exposure the theory had received anywhere in the world

The TV programme provoked a lively Canadian debate on mainstream media, starting with the national newspaper *The Globe and the Mail* (Picard and Favaro, 2009) and galvanised a strong patient response, requesting MSSC to provide information, as well as inquiring about research. A few days later the Canadian Broadcasting Corporation (CBC) reported that MSSC had announced "it will be accepting research proposals on the topic from Canadian scientists", "spurred by the overwhelming interest in the new theory" (CBC News, 2009). It is interesting to note the Association's choice of language here. Their decision to fund the research was publicly attributed to outside influences, namely the massive scale of patient inquiries to their neurologists and association on the subject following the television programme (which then was recorded by CCSVI activists as a sign of co-optation, see Ch. 5), rather than the science behind the discovery. A leitmotif that will characterise most of the medical editorials and research on CCSVI and social media (see Ch. 1.4). The result was that over $2.4 million "was committed by the Multiple Sclerosis Society of Canada and the National MS Society of the United States (NMSS), to support seven new research projects focusing on chronic cerebrospinal venous insufficiency (CCSVI) and its relationship to MS" (MSSC, 2010).

The participation of the American MS Society in the funding of the studies prompted by MS patients and mass media outcry in Canada is notable. The American CCSVI social media movement even if it was very well scientifically prepared, was not numerous. The membership was more international than American. None of the completed studies funded by MSSC and NMSS found a correlation between CCSVI and MS (NMSS, 2017), although the methodology used in these studies has been called into question. In particular, in the Traboulsee study (mentioned above in Ch. 3.3), which was published in *The Lancet*, attempts to highlight the scientific irregularities in the study's methodology were quashed (Zamboni, 2014; Mandolesi, d'Alessandro, Niglio and Rossi, 2015).

I now turn to consider the reaction of the Italian MS society – AISM - the third biggest research funder among global MS associations in 2009 (AISM, 2009a). As set out above for the Canadian MS association, my personal research and ethnographic experience has shown that before the Italian social media CCSVI activists advocation since August 2009, the Italian national MS society had never informed their members about the new theory on MS and CCSVI nor had it funded further research in this area nevertheless studies were published since 2006. Zamboni reported that AISM was informed but refused to fund his first two research on patients (Corneo, 2012, Marozzi, 2011:98). The first research refused by AISM on CCSVI and MS was published in late 2009 but previously available in e-publication online in March of the same year. Convinced by the rationale of the research on CCSVI, in July 2008 the former Magnificent Rector of the University of Bologna created the Foundation Hilarescere, financed by a local Italian savings bank, CarisBo. The same Foundation Hilarescere funded the second study started in late 2008 carried on in Buffalo, N.Y. and Italy, with American and Italian patients.

There is further proof of the fact that the national president of AISM and FISM, Prof Mario Battaglia, was informed on CCSVI well before than any social media activism had started. Furthermore, AISM was informed by the president of the AISM local section of Bologna at least since 30 March 2009 and during the course of the same year (https://ccsvi-sm.org/la-nostra-storia/lettera-al-presidente-mario-battaglia/). As a result of advocating the CCSVI theory, the following year the president of the local section of AISM Bologna was not re-elected and the local AISM website, which mentioned the research on CCSVI, was then turned off (https://ccsvi-sm.org/la-nostra-storia/10-francesco-tabacco-non-piu-rieletto-aism/).

Following the patients' social media turmoil (see Ch. 4.3) and the unexpected just born CCSVI association (see Ch. 5.5), on April 16, 2010, the Italian MS society AISM announced its intention to fund two studies on CCSVI and MS together with Professor Zamboni. In its official press release, AISM announced it was "moving in the right direction" in deciding to fund this research, noting Professor Zamboni's recent appearance at the American Neurological Society's annual conference to present his discovery. AISM made no reference to the growing calls from patients to fund additional research, but the CCSVI activists noted its alleged quick reaction informing on its availability, right a few days after the formation of the CCSVI association on 9 April. AISM-branded banquets in shopping centres were already raising funds for Zamboni's research by young volunteers they did not know what it was for. CCSVI activists denoted the AISM's decision to suddenly change direction, as "poisoned meatballs", a sign of a start of co-optation (see Ch.5.5). In fact, when in June 2010 AISM refused to use the angioplasty for CCSVI in aggravated MS patients because it was an experimental therapy, the new born CCSVI association noticed in a public letter that AISM was allowing the experimental marrow transplant even without confirming studies, and with a mortality of 1-3% (https://allegati.aism.it/manager/UploadFile/2/lettera_mantovani_mancardi.2010611_12303.pdf). Furthermore, the CCSVI association noted that in the UK was revealed by a BMJ article that NHS spent £ 250 million in drugs for MS patients which did nothing against the disease (https://web.archive.org/web/20170221155512/http://www.telegraph.co.uk/news/health/news/7800543/NHS-has-wasted-millions-on-MS-drugs-which-did-nothing-to-help-patients.html).

Of the two studies announced by AISM, one, epidemiological (i.e. how many MS patients have CCSVI), double blinded randomised control study (CRT), was proposed by the society itself and was named CoSMo (an acronym for "CCSVI: Studio Osservazionale Sclerosi Multipla e OND -i.e. other neurodegenerative diseases-'' which translates to Observational Study of the prevalence of CCSVI in multiple sclerosis and OND); the other, interventional (i.e. if the therapy works), also double blinded CRT, was proposed by the Italian region Emilia Romagna, BRAVE

DREAMS (AISM, 2010), an acronym for “Brain Venous Drainage Exploited Against Multiple Sclerosis”. Zamboni was part of the steering committee of AISM’S study CoSMo, but decided to opt out in September 2010 saying that:

> (…) None of the scientific suggestions which I advanced in meetings and in correspondence has received a response; most of the time I have not even had the privilege of a discussion or a reply. In summary I am strongly convinced of the non-feasibility of the study based on the compromise protocol which is taught in a different way than mine by other centres, the timing required for the preparation of the investigators and the subsequent data collection (…) (Zamboni, 2010).

Zamboni’s public letter of resignation described how the outcome of a study could be influenced by the protocol. Dr. Comi’s premature declaration of the partial negative results of the incomplete double blinded CoSMo study (Adnkronos Salute, 2011), discussed above in the part on doctors’ communications (Ch. 3.2), likely prompted AISM in January 2012 to withdraw their intent to fund the Brave Dreams study, which was ready to start, citing “insufficient scientific reasons to finance an interventional study” (AISM, 2012). The choice was based on the analysis of the Scientific Committee of the Multiple Sclerosis Italian Foundation (FISM), whose president and board members are leading researchers of CoSMo, included Dr Comi. Among the “insufficient scientific reasons” AISM mentioned the lack of studies on smaller number of patients even if two of them were previously conducted and completed, that AISM was asked and refused to fund (Corneo, 2012). In spite of AISM and FISM’s purported concerns over the scientific value of the study, it was fully publicly funded by the Italian Region Emilia Romagna one month later (Assessorato Politiche per la salute, 2012). Also the *CCSVI nella Sclerosi Multipla* association tried to contribute to the study with an international fund raising (https://web.archive.org/web/20120305165711/http://bravedreams.ccsvi-sm.org/en), but it was refused, which raised concerns among activists:

> Financing it in that way it meant removing tools from the CCSVI association (...) the only way to get rid of us was to finance [without the contribute of the CCSVI association], finance and then remove tools from Brave Dreams, because excluding out MS centres from the study in the way they did... (Ginevra).

The AISM study, CoSMo, which was eventually published in October 2013, rather unusually for a scientific conclusion used the definitive tone that “CCSVI is not associated with MS” (Comi, Battaglia, Bertolotto, et al, 2013), in spite of further ongoing research on the issue. AISM’s position on CCSVI was later re-affirmed by the President of its Scientific Committee, Mancardi, also one of the leading researchers in the CoSMo study who said in 2015: "It is enough: on this issue there is nothing more to add" (Paganelli, 2015).

I now turn to consider MSIF, an international charity registered in the UK, which confederates 44 national MS societies. The Canadian and the Italian MS patients’ associations were full members of MSIF. My personal research has shown that until late 2009 MSIF had never mentioned CCSVI. Whilst it is still possible at the time of writing to read about CCSVI on the Canadian and Italian MS societies’ websites, about past news and their funded studies’ negative results, on the MSIF website there was not anymore mention of CCSVI already in 2013. In 2015 the only internal research engine of the MSIF website was available on the webpage “News & Events”, and seemed to give results of only last year’s news: there was no occurrence of the words “CCSVI”, “Chronic cerebrospinal venous insufficiency”, or “Zamboni”, whilst there were plenty of results for drug-related research and therapies. Nor was there any mention of ongoing CCSVI research in the MSIF *Atlas of MS 2013*, an yearly publication started in 2008 which informs about the worldwide MS epidemiology and the global availability of treatments (i.e., drugs). The publication was carried out in collaboration with the World Health Organization (WHO), and was funded by various pharmaceuticals: Biogen Idec, Genzyme, Novartis, Merck Serono, Synthon, and Teva (MSIF, 2015). Two historical hyperlinks found on other websites connecting MSIF to CCSVI, they were published on the MSIF websites in 2010 and 2011 and were no longer active. They can be found on the Internet Archive (https://web.archive.org/web/20110810211035/http://www.msif.org/en/research/ccsvi.html and https://web.archive.org/web/20100625231214/http://www.msif.org/en/news/msif_news/ccsvi.html).

The fourth example is the European Multiple Sclerosis Platform (EMSP), which had AISM as one of its 40 national MS member societies, and MSIF as a partner, and reflects a similar pattern above reported for MSIF. From the internal research engine of EMSP website in 2015 (https://emsp.org/) there was no occurrence of the words "CCSVI", "Chronic cerebrospinal venous insufficiency", or "Zamboni", whilst there were plenty of results for drugs-related research and therapies. One historical hyperlink connecting EMSP to CCSVI found on another website, published in the EMSP website in 2012 was no longer active but it can be found on the Internet Archive (https://web.archive.org/web/20141003121603/http://www.emsp.org/news/emsp-member-news/185-press-release-there-is-no-correlation-between-ccsvi-and-ms). It was a press release published on 12 October 2012 on the CoSMo study from AISM, titled: “There is no correlation between CCSVI and MS”. EMSP did not even wait for the publication of the CoSMo study an year later in October 2013, to put the word end on the CCSVI research, following AISM behaviour. On its website, in the section ‘MS fact’, there were links to MSIF’s Atlas of MS as a detailed worldwide MS database, which as seen above, did not mention CCSVI. The aforementioned Battaglia, president since 1998 of the Multiple Sclerosis Italian Foundation (FISM - Fondazione Italiana Sclerosi Multipla) of AISM, was president in 1996-1998 of EMSP, and since 1994 was a member of International Medical Advisory Board, of MSIF (updated up to 2016 https://web.archive.org/web/20210721175814/https://www.dsv.unisi.it/sites/st15/files/allegatiparagrafo/11-10-2016/cv_battaglia_mario_alberto_0.pdf).

These MS patient associations and MS international organisations had adopted the aforementioned denying approach to CCSVI already in 2012 in spite of scientific methods or the following:

- CCSVI and its non-drug-based treatment initially proposed, was officially recognised by the International Union of Phlebology (IUP) (Lee et al., 2009; Lee et al., 2015).
- A significant prevalence of CCSVI in MS patients suggesting a possible correlation, was confirmed by three independent meta-analyses (Laupacis et al., 2011; Tsivgoulis, Sergentanis, Chan, et al. 2013; Zwischenberger et al., 2013).
- A Cochrane Institute study (Zuuren et al., 2014) called for the need for a randomised-control trial to verify the efficacy or safety of the treatment

initially proposed for CCSVI in MS patients, as there was not enough evidence in favour or against the procedure.

- The International Society for Neurovascular Disease (ISNVD) published the “Recommendations for Multimodal Noninvasive and Invasive” diagnosis of CCSVI (Zivadinov et al. 2014).
- Thousands of MS patients with CCSVI had already undergone the treatment initially proposed for CCSVI, many of which have been reported by scientific publications.
- The AISM study, CoSMo, which refuted any correlation between CCSVI and SM and presented unilaterally in 2012 as motivation to abandon the CCSVI theory’s research, was published only in 2013.
- The double-blind interventional randomized trial requested also by the British NICE, Brave Dreams (see Ch. 5.6), was about to start in 2012 and it was then published in 2018.

(i) Theorising associations’ audience commodification

In seeking to find an explanation for the CCSVI activists’ complaints about the behaviour of the traditional MS associations, I turn once again to commodification theory, in this case audience commodification. Here, by audience I mean to encompass all the people who are exposed to the culturally dominant view of the patient associations. This includes association members, patients, caregivers, doctors, healthcare policy makers, public institutions, mass media and public opinion. Specifically, patient associations issued communications that influenced the decisions of health policy makers, constituted a referral for doctors vis a vis their patients and funded their conferences, advocated mostly for branded drugs being accessible without restrictions for patients, influenced the mass media agenda and sat on various advisory panels. For example, EMSP teamed up with the European Federation of Pharmaceutical Industries and Associations (EFPIA), and presented itself to its 40 national MS member societies as the only organisation that could influence European Union policies on MS, included the European Medicines Agency (EMA), which is the European regulatory body for drugs, equivalent to the FDA in the US. These activities made patient associations valuable to pharmaceutical companies. Indeed, researchers found that the advocacy of patient associations tended to overlap with the interests of pharmaceutical companies, and that the associations often did not disclose the funding they received from those companies (Rothman et al., 2011).

While information about the financial relationships between patient associations and pharmaceutical companies was fairly opaque, the following evidence was publicly available. Research from the independent Netherlands-based Health Action International Europe found that two-thirds of the patient and consumer organisations working with the EMA, received partial or significant funding from pharmaceutical manufacturers and/or industry associations, and many of them did not disclose the conflict of interest. The study reported also that patient associations' main funding source were pharmaceuticals because of insufficient non-corporate or public funding (Grogan, 2010). The research prompted EMA to identify actions to increase transparency (EMA, 2010).

A number of articles report on the normality of corporate pharmaceutical support and advertisements on patient associations' websites. Some of the most recent studies published on *The New England Journal of Medicine*, *BMJ* and *Plos One* confirmed that trend (McCoy et al., 2017; Parker et al., 2019; Mulinari et al., 2020). The industry support to patients' associations paired with a lack of transparency of their financial relations (Ball, Tisocki and Herxheimer, 2006; Colombo et al., 2012), with a patient associations pressure in overturn National Institute of Health rules (Jones, 2008), with the pharmaceutical activity of mobilising patient associations to lobbying policy makers (Sample, 2013), and with patient associations making profits from selling drugs (Fauber, 2013). Another study expressed concern that:

> Patient groups often shout loudly for access to drugs but are quieter about their links to industry. (…) There is also concern that federations of patient groups—both national and international—receive funding from industry that is not clearly labelled in individual groups' accounts because it is channelled through the umbrella group. Under regulations established by the Charity Commission, charities in the UK are not legally required to name all their donors (Arie and Mahony, 2014).

Turning now to consider the financial relationships of the aforementioned MS patient association I found the following. The Canadian MS society stated that the "total revenue from pharmaceutical companies is less than two per cent of the amount of money the organization receives annually" (MSSC, 2016). Among the pharmaceuticals that have a financial relationship with AISM were: Biogen Idec, Genzyme, Merck Serono, Novartis Farma and Teva (note, they all appear in Table 1 which lists the pharmaceutical companies that manufacture the top 10 best-selling drugs for patients with MS in 2013). Among the pharmaceuticals which had a financial relationship with MSIF were: Biogen, Sanofi Genzyme, EMD Serono, Teva, Novartis and Roche (MSIF, 2016), many of which also appear in Table 1 above in the introduction of this chapter. In contrast to the other three patient associations which only listed their donors without specifying the amount of money they received from each one, EMSP is a beacon of transparency. Its website revealed that 79,3% (€ 1,043,646), of the 2014 overall budget was funded by 11 different industry partners, most of them among the best-selling MS drug producers and distributors (table 1), with their logos shown: Bayer Pharma, TEVA, Roche, Novartis, Biogen, GW Pharmaceuticals, Genzyme, Merck Serono (ESMP, 2014).

The reason why pharmaceuticals relied upon patient' associations is that in most countries, there were clear regulations preventing them from advertising their drugs directly to the public if not in some countries under strict guidelines. Consequently, pharmaceutical companies sought to influence patients through their associations, which in turn exercised pressure on doctors, policy makers and regulators to render drugs available through national healthcare systems (Colombo, 2013). Studies have shown that patients associations were influenced by pharmaceuticals. For example: "Cancer United, a patient group funded by Roche, which markets trastuzumab (Herceptin) and bevacizumab (Avastin) is run by the public relations company Weber Shandwick. The group advocates full funding of cancer drugs in Europe" (Mintzes, 2007).

On the other side, Kent who was in favour of patient groups accepting money from drug companies, argued that patients would be indifferent to the source of the funding when there were changes for the better (2007). However, while this might be true for small groups or for single patients, it might be questionable when the associations were very big and required management and finance foundations whose choices were in control of a few scientists with declared conflict of interest with pharmaceuticals, and whose behaviour was tied to their own paradigm, without any opening to a possible shift (Kuhn, 1962), even when scientific meta-analysis might suggest it.

An analysis by the American Patients for Affordable Drugs found that all but one of 15 top entities representing patients, failed to clearly disclose the amount of funding received by pharmaceuticals. Some patient associations were defined Astroturf (see Ch.1.2.iv) because they were not authentically grassroots organisations, instead, they "serve the purposes of their drug industry funders and act on their behalf". Some patient assistance charities, as legal settlements and investigation from the US Congress revealed, were "tools of drug companies designed to ensure they can sell more drugs at ever-higher prices", and all 23 groups investigated are financially, structurally or in both ways linked to pharmaceutical industry (Patients for Affordable Drugs, 2021:3). This does not mean that all MS patients' associations are involved with pharmaceuticals. For example, the American NMSS in 2016 started a campaign over concerning on the rise of the average annual cost for MS drug therapies (see Table 2), a 400% rise from 2004 to 2016 (https://web.archive.org/web/20161003221024/https://www.nationalmssociety.org/About-the-Society/News/Make-MS-Medications-Accessible). The *New York Times* reported what Zagieboylo, the CEO of NMSS said when the campaign started: not only she said that some MS associations did not join the campaign, but also that some congress men said to tread carefully: "We were warned, you know, in a number of ways, just sort of to be careful about this", "A couple of pharmaceutical companies mentioned, ‘Boy, we support you, why are you doing this to us?’” (Thomas, 2016).

International MS patients advocating CCSVI felt betrayed by the bitter and angry reaction of their neurologists and MS association to the news of a theory whose research, argued the activists, could be carried on while continuing the drug therapies. It’s never been a fight against drugs, but a fight to feel better. Instead of compassion they experienced derision and unjustness, which turned them to seek a rational explanation which led to beware of some actors of the MS international healthcare, which however did not avoid the co-optation of the MS patients and the public opinion at large (see Ch. 5.7).

CHAPTER 4. Timeless Time Momentum of the CCSVI Social Media Activism

(1) Introduction

In 2015, Castells described the experience of timeless time as characteristic of certain social movements. The timeless time experience of the movements analysed by Castells, and particularly of the Occupy Wall Street movement, was experienced during their street occupation. This chapter aims to demonstrate that the experience of timeless time may not be limited to situations where people gather physically on the street over a period of time to call for social change. By analysing the experience of the CCSVI online patients’ movement, I aim to show that timeless time can also be experienced by activists who gather on social media to call for change. This example represents an extension of the timeless time concept not contemplated by Castells. To my knowledge, this is the first instance in which timeless time has been described in a social movement that originated and flourished on social media, i.e., it did not need the occupation of public space to organize its polity (Castells; 2015:134). This is in contrast to Castells’ example, where the physical space of occupation was fundamental to the existence of the movements that he analysed.

I begin by introducing Castells’ concept of timeless time and the different contexts in which it was defined. I then consider the common characteristics of the CCSVI patient-based movement with the movements in which Castells identified timeless time (2015). In the final section I describe the ways in which timeless time was experienced by the patients' movement.

(2) Timeless time

Castells' definition of timeless time has evolved over the years (Castells, 2010 and 2015). An appreciation of his most recent definition of temporality requires an understanding of the concepts of network society, space, space of places and space of flows. The internet is the device which together with technological, social, economic and cultural transformations, allows for the creation of a new social structure, which Castells called the network society (2010). The network society was a concept which implied both technological and social organization, "since network becomes a privileged mode of organization thanks to the very extension of information technology" (Latour, 2005:129). While it was not hierarchically organised, it did not necessarily lead to a democratisation of resources. Instead, the network society might "result in an unequal concentration of power resources in certain kinds of node within certain kinds of network" (Meikle and Young, 2012:18), and it was in the network society that the space of places encounters the space of flows.

According to social theory, space is the material support that brings together social practices of time-sharing that are simultaneous in time which, today, does not necessarily imply physical contiguity (Castells, 2010:441-442). Specifically, for Castells space was a concept created through experience which defined the boundaries of social relationships and was not a touchable reality (xxxi). From the more general concept of space, Castells defined the space of places as the space of contiguity, an “historically rooted spatial organization of our common experience” (2010:408), where form, function and meaning are physically restricted as in the Parisian quartier of Belleville (453). Significantly, the space of places is bounded by natural rhythms and the oppression of the clock time (497) of everyday life.

In contrast to the space of places Castells defined the space of flows as “the material support of simultaneous social practices communicated at a distance” (2010:xxxii). Communication in the space of flows, the “dominant spatial form of the network society” (448), could be simultaneous or at a chosen time, and was not based on contiguity but on connectedness (Van Dijck, 2013:12). According to Castells, the elites’ decision-making processes needed to take place in the space of places, in a micro-network made of face-to-face contact. Major strategic decisions were still “taken over business luncheons in exclusive restaurants, or in country house week-ends over golf playing” (2010:446), where relations were built and maintained in the space of flows, and where the implementation of those decisions happened.

(i) Timeless time in the space of flows: the global financial markets

Castells pointed out two different forms born from the transformation of time in our society: simultaneity and timelessness (2010:491). The first was the temporal immediacy to events from all over the world. The second was the mixing of temporal events in a collage with no sequential nature, but rather a social context timing or hypertext. Timeless time happened when there was a perturbation of chronological events in a given context of the network society, “which is tantamount to eternity”

(494). Timeless time was mainly the time of power of the network society, the time of the privileged global financial markets and powerful social actors of the network society. Castells considered timeless time as belonging to the space of flows as the prevailing temporality of the present times, while chronological control from the clock time of the industrial age and sequential socially structured events, portrayed places. Space shaped the timing of the present society: “flows induce timeless time, places are time-bounded” (2010:495). It was from the places that “the laments of time-chained creatures” could still be heard (497). Castells asserted that space and time are transformed and organized around the space of flows and timeless time, which appeared to the people as a “meta-social disorder” which subdued their social lives to the will of the “markets, technology, geopolitical order, or biological determination” (508), “through a selective inclusion and exclusion of functions and people in different temporal and spatial frames” (465).

(ii) Timeless time in the space of places: the Occupy Wall Street movement

In 2015, Castells gave a more detailed description of the timeless time concept as applied to grassroots social movements. There was a double shift in his understanding of the application of timeless time. Following the analysis of most of the famous first social movements (Morozov, 2013; Miller, 2017) at the time of social media, such as the Arab Spring uprisings in late 2010 in Tunis and early 2011 in Egypt, the Indignados in Spain and the Occupy Wall Street movement in 2011, the Gezi Park movement in Turkey in 2013, among others, Castells shifted from a definition of timeless time as belonging primarily to the privileged global financial markets, to a definition as experienced by grassroots movements that ultimately contested the financial and institutional social actors who once monopolized timeless time.

Castells drew on observations made by the activists in the Occupy movement's camps who described experiencing a *feeling of forever*. During the street occupation, their everyday routine was interrupted by a day-to-day living which fuelled the hope that another life was possible (2015:172). They believed the occupation would go on until their requests were met, they organized their new life in tents without time constraints, with only the duty of occupying and attending the movement's general assemblies. Their determination to achieve a positive outcome was fuelled by the confirmation that another life, the one of the camp with no restrictions, was real. Castells defined in detail two types of experience which generate the timeless time feeling of the movements he analysed during their occupation of the space of places. The first type is the camp life free of time constraints which characterized the activists' everyday life. A life lived on a day-to-day basis without any idea of when the police would dismantle the camp, with the feeling of having an unlimited time horizon in the practice of the actual moment. In addition to a limitless time horizon of activities described in the first type, in the second type of experience there is "an unlimited horizon of possibilities of new forms of life and community", a projection of their daily practice into the future society (2015:251). Everything could be changed and improved on an egalitarian basis and the organized camp life was a concrete example of the society of which they dreamed, because a request for new politics could be trustworthy only if experienced on the ground. With the rejection of the clock timing of existence, the second type of experience was an *extended now* which, together with the *now* of the first type, generates timeless time. I can personally recall the exact same emotions, the same feelings described above when in the second half of the ’80s I participated occupying the high school and, in the ’90s the university I was attending. For a few days we self-organised classes helping each other in small groups to catch up on textbooks.

As discussed above, Castells’ analysis of timeless time was latterly founded on grassroots movements in the network society. This chapter aims to extend that analysis to a case study of timeless time in a grassroots social movement during the period in which it operated exclusively on social media. Below the pertinent elements of the CCSVI social media movement are examined.

(3) The space of flows-based CCSVI social movement

The CCSVI social movement was initiated in August 2009 and grew out of a medical discovery (Chronic Cerebrospinal Venous Insufficiency, CCSVI), in contrast to accepted medical orthodoxy (Fox, 2011). Among the various international movements that emerged to address the new medical discovery, the Italian patients’ movement, CCSVI in MS, (CCSVI nella Sclerosi Multipla, 2009), was one of the most active (Colasanto, 2012) and the most numerous: within the first year its Facebook Page had attracted 30,000 members (Mattalia, 2010), and not only there’s no other English speaking CCSVI Facebook group or page that has ever reached that number of members (Driedger, Dassah and Marrie, 2018:480-483 Table 1), but also they didn’t reach “standard definitions of a social movement in terms of organization and structure” (473).

The nerve centre of the movement’s contentious politics (Tarrow, 2011) was its Facebook Page, where its members gathered to share information, discuss strategies and plan activities. The movement was characterized by its connective style of leadership which enabled its membership to initiate organizational growth as well as plan and execute activities. The movement’s primary activities planned on Facebook were as follows:

- Using social media to discuss, plan and inform other Facebook users about the new discovery.
- Sharing information on social media about developments related to CCSVI, i.e. doctors’ conferences, new medical research.
- Directly contesting misinformation about CCSVI as circulated both in the mass media and by institutional actors and members of the medical community online, using posts on Facebook to directly address the source of the misinformation.
- Drafting informative leaflets distributed through social media that could be printed by each patient and distributed in doctors’ waiting rooms.
- Drafting informative emails to institutional actors and emails calling for mass media to cover CCSVI.
- Meeting local and national political figures to discuss CCSVI.
- Patients discussing CCSVI with their neurologists during visits.

In addition, individual patients undertook on their own initiative, within the first year of the social media movement, a range of activities to spread the message about CCSVI. For instance, one patient conducted a CCSVI tour with a car painted with images from the movement (Fig. 6).

Figure 6: Activities undertaken by activists' initiative: car.

Another organized to talk about CCSVI during a presentation at a local theatre for a then SERIE A Italian national football team, and others who underwent the medical procedure talked about the experience at a local television, magazines and newspapers. One patient created a Wikipedia entry for CCSVI and for the Italian scientist who made the discovery, and asked for help on the Facebook Page when it was under attack:

> Now someone is attacking Wikipedia. This morning I realized that the CCSVI and Paolo Zamboni entries on Wikipedia are under attack. Look at what is said in the discussions of the related entries. Whoever wants to help me contact me by text message (Matteucci, 2021:174).

Others developed CD-ROMs containing PowerPoint presentations and research studies about CCSVI (Fig. 7):

> I saw that there was a particular ferment in that period, and I thought that my contribution could be useful to the cause honestly. I did, I had prepared a PowerPoint that could be conveyed through the Facebook Page, through other channels that could be a more usable tool by the public who came into contact with the CCSVI for the first time (Lisa).

Figure 7: Activities undertaken by activists' initiative: CD-ROM. On the left the logo of the original CCSVI Facebook Page where the movement started. On the right the logo of the first CCSVI association.

Thus, the movement's activities fit within Tilly and Tarrow's definition of "a sustained campaign of claim making, using repeated performances that advertise the claim, based on organizations, networks, traditions, and solidarities that sustain these activities" (2015:11). The foregoing examples of individual and collective action also represented "a message broadcast to the rest of society" (Melucci, 1996:9), as well as examples of WUNC (worthiness, unity, numbers and commitment), performances, noted by Tilly and Wood (2013) as characteristic of social movements (see Chapter 1.3). In lieu of the traditional square, the CCSVI Facebook Page was the space in which WUNC performances were staged, and membership became quantifiable:

> Facebook that until that moment I had used partly out of curiosity and partly for experimentation, I decided to use it as a tool, that's it. At that moment I decided that I was using it as a tool. The square was no longer the physical square, the square was virtual, and at that moment, however, the square was needed (Ginevra).

As discussed above, the CCSVI movement's organizational activities, information sharing and dissemination, and direct engagement of institutional and political actors, took place almost exclusively online for most of the first year of its existence (2009-2010):

> Surely, I joined before the Vicenza congress [the first public conference on CCSVI held on 23 January 2010], because all the preparatory part was done on Facebook… I only use Facebook. (…) Among other things, I opened the Facebook user only in CCSVI function (…) and I thought it immediately dedicated solely to this interest, so much so that my user has nothing personal, it has no photos, personal data or personal things, because it is a tool to talk about CCSVI fundamentally (Aurora).

This was made necessary due to the particular characteristics of the movement's members. Firstly, the number of MS patients in 2009 was small compared to the population at large (approximately one in 1000), and they were geographically dispersed, making it difficult to gather physically in any one place even to share their experience with the disease:

> The Facebook Page was very useful for many sick people, because it allowed for ... a dissemination of

> information, a comparison and knowledge between people who previously also had difficulty talking about their disease (Lorenzo).
>
> I found people who wanted help by word of mouth, in the period that we began to write in your Facebook Page, we were all asking for friendship anyone who came in there, or from private messages introducing themselves saying: I am a friend of Whatshisname... (Giorgia).
>
> Even before the association, the fact of interacting ... (...) So, let's say, we realized at a certain point that alone one is alone but, in a group, we were strengthened, so we could be more incisive. And therefore, even before the association, when we arrived at the Vicenza conference [January 2010], we already presented ourselves as 7000 subscribers to the Facebook Page of *CCSVI nella sclerosi multipla*, this fact of not being alone, but of being a group, and this in short clearly gave strength to action then (Aurora).

Secondly, MS patients had to face physical challenges: a proportion of them could not move without assistance, needing wheelchairs.

> When I fell, I walked down the street like everyone else and ended up on the ground. Walking, this leg was either stuck or gave way so you landed (…) embarrassment, you don't go out alone... once I seemed drunk in a pizzeria with a friend... sometimes I fell, my leg gave way, people looked at me as if I were drunk. (…) The husband of a colleague has had MS for 20 years. All he can do alone now is eat, for the rest he requires help (Arianna).

Other challenges included tiring easily and needing frequent access to a toilet. All these challenges made it difficult for many MS patients to participate in traditional forms of street activism. However, these problems were all overcome with online activities that could be undertaken from home:

> I have travelled all over Italy for information, from north to south, not physically, but on the internet [Facebook]. Asking questions… (Marta).
>
> There was the possibility by taking action, to be able to facilitate these new discoveries (Lisa).

Thus, social media were ideally suited as a platform for activism among this population (Dubois and Dutton, 2014), and we can talk about the CCSVI movement as being a networked social movement in the space of flows, and not in urban space in the traditional form of street occupations.

(i) Characteristics common to the space of places' movements in which timeless time was identified

Castells' book focused on the social movements emerging in the network society. In it, he discussed the background characteristics shared by the range of social movements he examined. These characteristics form the backdrop to the activists' timeless time experience, in that they served to motivate outrage and hope. This section analyses the patients' movement, particularly in its first year of activities, through the lens of some of the common background characteristics identified by Castells (2015:246-247), which I here identify in Italics: *distrust, intimidation, triggered by emotions, social change, injustice, global, leaderless, togetherness, community.*

Patients within the CCSVI movement *distrusted* institutions, namely those that managed MS, for two reasons. Firstly, because rather than being informed by their neurologists or MS associations about the radical shift in understanding MS suggested by the new medical discovery, they had to rely on social media to find out about it: "In the case of CCSVI in MS, MS patients continue to play a fundamental role in driving change, supplanting the lack of information of traditional channels" (Matteucci, 2021:176). As one interviewee described it:

> The fact that they weren't talking about it in, let's say, the appropriate places, so neurological departments, or also the answers given by neurologists on the matter were full of gaps, so there had to be a problem (Luisa).

Secondly, because it quickly became clear to the activists that the neurological establishment was keen to discount the validity and significance of the discovery:

> Immediately there was this obvious perception that we were facing something that was being obscured, obstructed, and boycotted, and hence the idea that something was needed to be done to support this research to avoid it being ditched (Aurora).
>
> The scientific world, the hospital world and the political world had done everything to block Zamboni, so his discovery could no longer continue to be researched in university clinics as scientific discoveries should, at that point, that is, it was good that the information reached the sick, the people who… who needed to know about this discovery (…) In the first time in the history of this disease there was the hope of beginning to understand a potential possible cause, and all this was blocked for reasons related perhaps to personal prestige.. thus. Well, that was the thing that outraged me (Ginevra).

These two factors propelled people towards contentious collective action (Bennett and Segerberg, 2013), outside the traditional institutional channels which were the medical centres of MS or the traditional MS patients' associations.

Patients experienced *intimidation*:

> I said - look professor, I'm tired I'm desperate I can't take it anymore. Let's try to stop the drug to see if that's what hurts me (…) I'm ending up in the wheelchair! And I remember that in a very arrogant way, he told me off in a really rude way, because I was daring to propose such a hypothesis. And he said no, if you want to stop the drug, at your own responsibility and without me. (...) He told me if I stop taking the drug, in three months I will go back to see him in a wheelchair… and I answered him, I then hope not to see you again. And I left (Vittoria).

Other patients reported that if they followed other therapies not prescribed by the neurologist, the neurologist would no longer see the patient. As the interviewee above reported:

> There are people with MS who go to the hospital to take the Interferon [one of the drug therapies prescribed by neurologists] and throw it in the dumpster, because they tried to say to the neurologists that they wanted to suspend the therapy (…) and the neurologists answered if you stop taking the drug you are no longer my patient. So, to keep the neurologist, patients throw 1700 euros [per month in 2014] in the bin, is that normal? (Vittoria).

Furthermore, informants reported that they would not tell their MS association AISM about their interest in the CCSVI theory, because they feared being excluded from its services including physiotherapy.

The patients' social movement was *triggered by emotions* brought about by the new medical discovery which for patients offered the visualisation of a tangible hope "as vital to [their] lives as the very oxygen that [they] breathe" (Groopman, 2004:208), the possibility of a simple intervention which could alleviate MS symptoms:

> It has led me the hope that there may be something more than pharmacological therapy. (…) A hope, a chance, I don't mean of healing, but above all to improve the quality of life (Camilla).

> The enthusiasm, the chance to feel better (Monica).
>
> My medications had been stopped. I have seen new hope in this research. (…) My hope that this is a discovery that will be successful (Edoardo).
>
> There was hope to begin to understand a possible potential cause (Ginevra).
>
> An opportunity for my wife, for the care of my wife, who for years with the Interferon treatment... I mean she suffered more the passive stages of the Interferon treatment, let's say, that the disease itself (Federico).
>
> There was a great hope for real personal salvation or for improving your health (Dario).

In addition, the information was easy for MS patients, even for a lay person, to understand:

> It seemed a thing so easy to understand for me, a great ignoramus, but so simple to understand (Adele).
>
> Because CCSVI is simple. To understand. And anyone who has tried to get close, has understood the very structure of the message, has understood exactly what was happening. It is a very simple thing. Because anyone would understand when you explain that the water hose in the garden if you bend it in one point the water no longer passes and therefore what happens ... (Dario)
>
> It is absolutely not clear what they do, what they inject, what they use to cure the problem. With the Zamboni method it was clear immediately, they use angioplasty. And since I know that there are, I had read that there were studies also in 1800 always referring to venous problems related to neuromuscular diseases, in his genius he did not invent anything new. He had the courage to go into this story and see if something could be done to solve the CCSVI problem. Here it is what convinced me (Eleonora).

> They had always made hypotheses, hypotheses, but they never went to investigate what the vascular effects in the disease could be. Instead, this was the next step, which is why it sees us as advocates of, not of a total resolution of the disease, for heaven's sake, but of a different interpretation and a possibility of improvement in the symptoms of the disease itself (Federico).

The patients sought to achieve *social change*, both individual and collective:

> That is, a series of actions on the internet forced the Emilia Romagna regional director of health to enter the office in the morning and open the CCSVI movement’s Facebook Page to see what was happening, and the CCSVI association did not exist yet [in 2009-2010] (Ginevra).

The patients perceived the medical establishment’s rejection of the new medical discovery as an *injustice*. As interviewees commented:

> I had trusted neurologists (Giorgia).
>
> Behind the stage there are power struggles. Let's imagine what this means for neurological science… you have thrown away billions of euros doing damage by administering terrible drugs ... they are chemotherapy drugs, blows to the body (Arianna).
>
> If anything, the criticism at this moment, I could address it to a part of the medical profession that closed itself in a form of prejudicial refusal, in facing certain issues, and did not open up, sharing what are the just rights of patients (MD Riccardo).

The fact that the patient movement developed in the *internet age* is another commonality. Technology is not the cause of social movements (Lyon, 1988), nor was it the cause of the patients’ movement. Rather, it offered a model of behaviour but ultimately did not decide its final usage, because social organization together with technology embodies the network (Meikle, 2016:6). Indeed, technology and explicitly the easy-to-use platform Facebook, helped the movement in facilitating "personalized interpretations of problems and self-organization of action", through the logic of connective action (Bennett and Segerberg, 2012:755; Vicari and Cappai, 2016):

> Without social media it would not have gone on. CCSVI research would have been lost, that is, someone in the sector would have known it and then it's over. We patients would not have reached it. This went on because we patients were interested. And this could only be done through social media (Caterina).

The relatively limited number of people in comparison with the potential of a political movement, and their physical condition, even though strongly self-motivated, would otherwise have hindered the development of this movement:

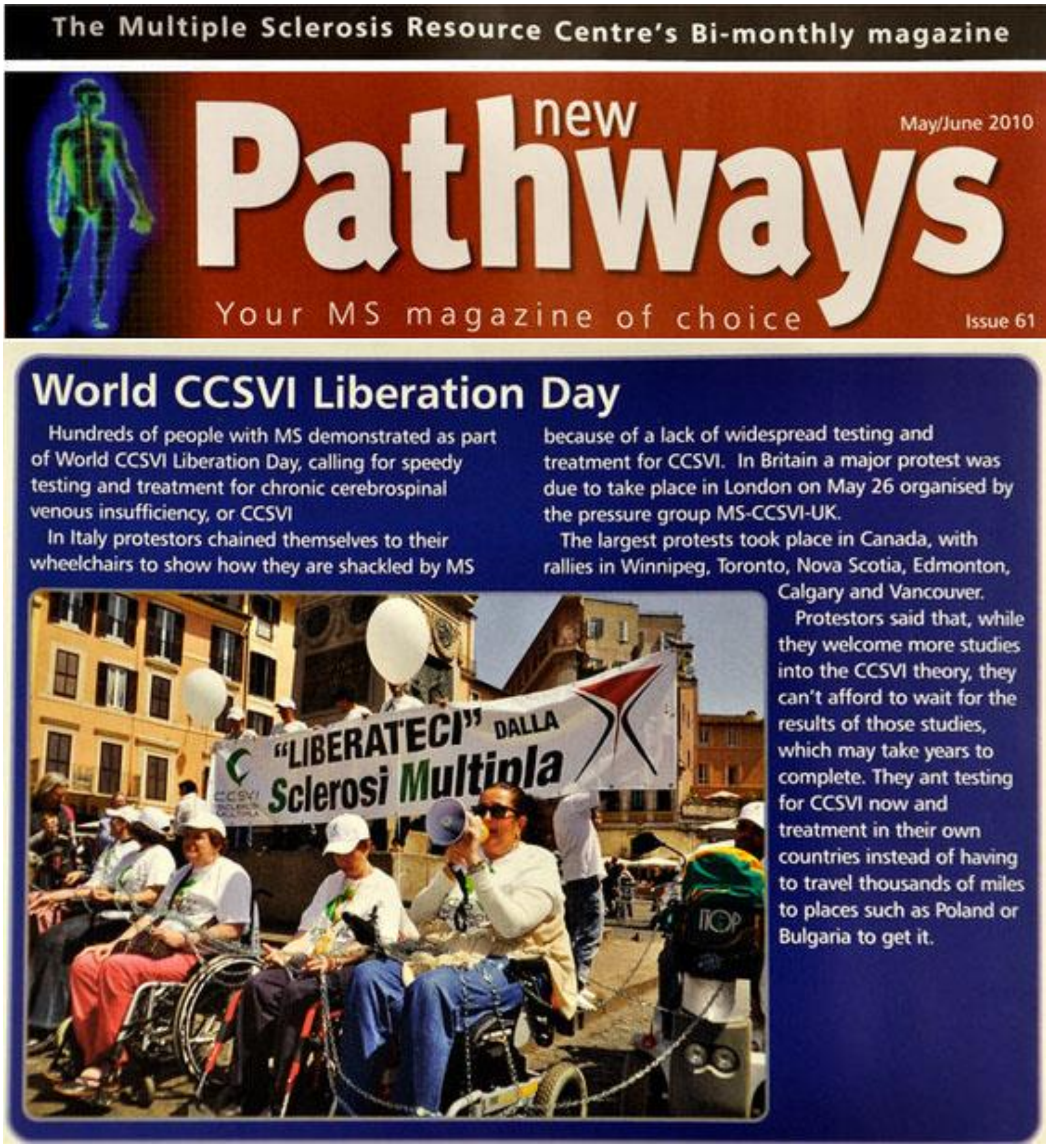
> People who could not leave home started living their relationships within Facebook, within the Page. That is, human relationships were built (Ginevra).
>
> Based on my life experience where I found myself alone, not without friends, but alone with my illness at a time when I no longer knew whom to talk to because I did not know anyone who was sick like me and social media did not exist... today there is this possibility, to receive more information than before, if you also want, I don't mean ... the consolation of having someone who lives your situation with whom you can compare yourself, however, to know that if you want to express your doubt, on the other side you will probably find someone who has already lived through it and they will answer you. This is important in my opinion (Eleonora).

Other commonalities are that the patients' movement was *global*, as there were other active Facebook pages and groups in USA, Canada, UK, Australia and New Zealand, among others (see Ch. 4.1):

> The sister of the husband of my cousin, in the US, she did not know about the CCSVI, so I informed

> her. I also gave her connections that she can contact in Italy, because through Facebook I contacted a person who has more information about MS and CCSVI in the USA, and I put them into contact. Soon I will also inform another friend who is in Madrid in Spain, who has recently learned that he has multiple sclerosis (Marta).

The research was international: only in the first year 2009/2010, medical studies were published by researchers in Italy, USA, Poland, Jordan, UK, Germany, Lebanon and Holland (Laupacis et al., 2011). Small accomplishments in other countries were taken as examples and a source of new hope. The Italian movement learned from other movements' experiences, and tried to mobilize in a global way, for example participating in the organization of the 'world CCSVI liberation day' in 2010 which took the form of the only two known street protest that ever occurred in Canada (CTV News, 2010a; CTV News, 2010b), and the only known street protest in Italy (on 25 April 2010), with activists from the CCSVI Facebook Page (New Pathways, 2010: see Fig. 8).



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World CCSVI Liberation Day

Hundreds of people with MS demonstrated as part of World CCSVI Liberation Day, calling for speedy testing and treatment for chronic cerebrospinal venous insufficiency, or CCSVI

In Italy protestors chained themselves to their wheelchairs to show how they are shackled by MS because of a lack of widespread testing and treatment for CCSVI. In Britain a major protest was due to take place in London on May 26 organised by the pressure group MS-CCSVI-UK.

The largest protests took place in Canada, with rallies in Winnipeg, Toronto, Nova Scotia, Edmonton, Calgary and Vancouver.

Protestors said that, while they welcome more studies into the CCSVI theory, they can't afford to wait for the results of those studies, which may take years to complete. They ant testing for CCSVI now and treatment in their own countries instead of having to travel thousands of miles to places such as Poland or Bulgaria to get it.

Figure 8: Photo of the only known CCSVI street protest in Italy (front page of a bimonthly British MS magazine).

The Italian patients' movement was a *leaderless* movement, that means there was not an identifiable person taking decisions and driving the movement in the form of traditional leadership. Rather there was a connective leader (Della Ratta and Valeriani, 2012; Poell et al., 2016), whose main function was to disseminate information grounded in scientific research to patients and people at large:

> I saw that the news was coming from all over the world, looking out on this page meant I could take

> advantage of this news researched by others, that then they would publish on this page (Caterina).
>
> Every day I kept reading, always on your Facebook Page, because every article that was posted I read it, I learned more about drugs, it helped me to understand everything that was published, all the opinions, one study said one thing, the other no, even I tried to compare them to understand whether there was an economic interest or not (Giorgia).
>
> In the first phase the Facebook Page was a fundamental tool, to have a space to talk and in my specific case to understand what was really there (Diego).

It was through *togetherness* brought about by having a common space in which to share their stories, knowing that they were not alone, belonging to a group in which each supported the other, that the patients overcame fear and discovered hope, as Matteucci described the Italian CCSVI Facebook movement: “despite the geographical distance separating them, they were empowered by the sense of belonging to a group and by making joint decisions” (2021:176), which eventually led to a *community* with a set of common values:

> …the enthusiasm that came out especially in the early years. I remember the Fan Page, it was very exciting, it was great to participate because a very cohesive group was created, so I had the curiosity to go and see what this group was saying, at the beginning at least the desire to let out, to let the whole Italy know about the new research of Prof Zamboni, so we started with enthusiasm (Monica).
>
> Back then, I remember the early days when every extra writing on that Page was celebrated, and every milestone was seen as a goal of the whole group (Lisa).
>
> Well, let's say that immediately enough trust was created among the people who were present on the Page, with almost daily exchanges between private chats or sharing of contents, posts on Facebook, the

> creation of personal accounts with the ... that also mentioned the pathology (Lorenzo).

(4) Timeless time in the CCSVI social media movement

As discussed above, timeless time was first described by Castells as experienced by global financial markets in the space of flows and latterly as experienced by the grassroots movement, Occupy Wall Street in the space of places. I present a case study of timeless time as experienced by the CCSVI movement's activists in the first year of the movement's existence, during which most of the activities and human interactions were conducted online. I aim to demonstrate the way in which the activists' experiences mirrored the experiences of Occupy Wall Street activists who gathered to occupy the streets almost two years later. In this section I examine the two types of experience which created in the CCSVI social media movement the overall timeless time sensation; the first type is characterized by a time-boundless, day-by-day life; the second type is characterized by an extended now of unlimited possibilities.

The CCSVI movement's Facebook Page, comparable to a physical location, was the space in which its activities were planned and coordinated, i.e., its headquarters. Some patients even signed up on Facebook only to join this particular community advocating the new discovery exactly like people joined the space of places (represented by Zuccotti Park), to join the protest. Facebook, by permitting simultaneity in social practices at a distance, allowed online activists to have an analogous experience to those occupying physical space:

> I didn't really like joining Facebook, I said I'll never waste time in this load of codswallop. Then after a few months of reading people's comments [in 2009-2010 unlike personal profiles, Facebook Pages were publicly visible], it was impossible not to be a user, that is, the need to interact was so strong that I overcame all the qualms, and I created the account (Aurora).
>
> The strength of the people pushed me, because I am convinced that when there are many people with the same goal, if you put your strength together and you move in the same direction, otherwise you become crazy balls (Eleonora).

The Facebook Page fostered a strong sense of community - those who signalled their entrance with a post had often never talked before about their disease to anybody, and they were warmly welcomed and made to feel at home:

> I remember with pleasure the initial phase in which in my opinion the Facebook Page played a very important role, a phase in which there was no information, and each person, the patients were actually left to fend for themselves. There was still no newspaper article, no broadcast that talked about this problem, and people desperately sought a source of information, and the information exchanged among peers on the CCSVI Facebook Page was fundamental (Mattia).

Informing other patients about the discovery served to empower individual activists as well as cultivating a feeling of belonging and harmony within the group. Newcomers to the Facebook Page were introduced to the movement's accomplishments and immediately invited to engage in the powerful momentum of its continuous activities, as this patient described the experience of coming together on Facebook to draft emails about CCSVI to authorities and mass media:

> The beautiful moments I remember were the period of the mail bombing, that is, in that period in which we all got together [on Facebook] to write an email and send it to those directly involved in the quarrel.

> And I remember with great emotion that period, because, apart from the fact that there was also a strong harmony, the group was at the beginning, so there was a strong solidarity. After, in the following months, in the following years the group broke up a bit, clearly, as the group was growing troublemakers also joined, isn’t it? But there was this solidarity of saying, let’s do the draft, then one would edit it, improve it, the other saying “you did a good job”, and then together we would send the email! They were disruptive, because we really placed in crisis the regional council or institutions even important ones. So, I think it was one of the first actions, let's say group actions, that left a mark even outside of Facebook, right? Even at the institutions. I remember that period very well (Aurora).

Facebook was the conduit through which activists could channel their emotions (Gerbaudo, 2012:14). The movement’s Facebook Page was the site of emotional condensation (50) where patients’ indignations and hopes took form, boosting the speed of mobilisation which in turn helped to foster a strong sense of collective enthusiasm. The strength of patients’ emotional engagement (Goodwin, Jasper, and Polletta, 2004), helped to drive their active involvement in the movement, and underpinned the first type of timeless time experience. Much like the activists who participated in the occupation of Zuccotti Park, the activists in the CCSVI movement over a period of months, poured on walking into the digital streets, in a 24/7, full-time occupation. As one interviewee said:

> Generally, patients are people often alone, who can’t anymore move from home. And they used social media to walk (MD Angelo).

To participate in a digital occupation, online activists had to make their presence in the various sites of occupation known either through leaving a comment about CCSVI, with some even altering their profile picture to reflect their commitment to CCSVI. During the height of the occupation, activists coordinated to collectively broadcast their messages on sites such as the Facebook Pages of the traditional MS associations, MS centres, the personal profiles of some doctors and non-CCSVI related MS groups. The CCSVI Facebook Page itself became like a ticker tape, with activists sharing information, jointly organizing activities, responding to comments left by visitors, in a constant buzz of 24/7 activity that helped to draw others in.

> It was nice because if one arrived on the CCSVI Facebook Page at 3 am, asking about a headache, there was immediately another who answered you. You went at 7 in the morning, at 9, there was always someone ready to answer on the page. This was beautiful, very beautiful (Giorgia).
>
> That is, then I spent evenings on Facebook, for example, and the sick people asked me many questions, and in short, this was not easy [emotionally] (Ginevra).

Another important driver of the movement's momentum was the fact that MS is a progressive disease. Thus, the patient activists had a strong motivation to pursue the movement's objectives, which for them represented the possibility of personal salvation from physical impairment and suffering, as an activist highlighted: "There was a great hope for real personal salvation or for improving your health" (Dario). The activists' timeless time experience was triggered and strengthened by emotions related to the time ticking of their progressive disease. MS can surprise its sufferers with unexpected and highly debilitating overnight aggravations. For instance, some patients suddenly stopped mobilising after finding out, as they woke up, they were no longer even able to use the computer keyboard. One family member described a relative's condition in this way: "relapses were more and more frequent, he wasn't well, he wasn't anymore the person he had been" (Giorgia). For activists with MS it was like living with the sword of Damocles, making it more likely for them to become deeply engaged when the prospect of reversing their inauspicious destiny seemed easy to achieve. An MS patients’ world could be reduced to the thought let’s try to delay ending up in a wheelchair for as long as possible. With the new discovery they all jumped on to social media because now they had to rush to do it:

> I mean, at the beginning when Zamboni’s novelty arrived, it shocked a world that had been stuck for years on trying to ride a wheelchair as late as possible. That is, the hope was born and everyone, and some perhaps in a reckless way, aimed at the goal of supporting Zamboni, let's do the therapy as quickly as possible, let's think about the sick (Diego).

Time is brain became the common motto referring to the progressive disabilities the disease inflicts on the brain. One activist suffering extreme disabilities emphasized this race against time:

> I am sure that if the disease is addressed in time the patients would not reach my level, they would get better (Eleonora)

And another did not lose time:

> Usually, people first sign up to the association, acquire information and then go and do it [the angioplasty], but I have acted in a way ... I read whole nights about what this angioplasty was, then I have to be honest … I only live once, I try to get better, so even going a little bit against my family, I did this thing, I tried, I did it, then I studied / observed myself for 3/4 months to see how my body reacted. Only then I joined the association to testify that it worked for me (Martina).

Social media’s ability to blur “the distinction between personal communication and the broadcast model of messages sent to nobody in particular” (Meikle and Young 2012:61), facilitated its use to immediately translate the private desperation at the unjustness of having the disease into a scream of outrage and hope to the world. A scream which could be endlessly mirrored and reiterated by the constant online connectivity, leading to a loss of the sense of time passing fostering the hope for the new discovery. The “temporalizing practice”, the reproduction of the immediacy of being constantly connected in an everyday social media practice (Barassi, 2015:79), contributed to the creation of the timeless time experience:

> The positive thing is that you had the information quickly. It’s all accelerated (Eleonora).
>
> I mean, I now use very little social media. That is, I used social media when I decided that I wanted Zamboni's discovery to be known. So let's say at this particular time I don't use them. When I decided to use them in 2009, I was aware that only through a mass dissemination of that information could anything be achieved, that's it. At that time, let's say I started using Facebook a lot, a lot (Ginevra).
>
> I who am absolutely ignorant in quotes, I go there, after two hours I already know a lot more. It is possible to learn a lot of news. It is also possible to learn breaking news because there will always be someone who has gone to get it in who knows which site or from which scientist or doctor, so a sure and safe source, and immediately brings it back there, because he has the pleasure of sharing it and making it reach everyone and it does reach everyone (Dario).
>
> I think that the benefits of social media is it disperses information more readily, so it’s a way of conveying information that is different and new, than any other prior experience, particularly in medicine. I think with CCSVI… - very different with social media than anything else before (MD Giacomo).

The sense of solidarity and connectedness, coupled with a strong sense of collective outrage at the medical establishment’s rejection of the new discovery, emboldened patients, with some even refusing to proceed with the recommended drug treatments (Blackwell, 2010a). As reported by an activist in a wheelchair who was taking one of the primary drugs prescribed for MS patients, interferon:

> I was too tired of drugs that didn't resolve anything, I took interferon for 7 years and it was killing me, I sent them all to hell and decided to go another way (Adele).

In the second type of experience of timeless time, patients had an unlimited horizon of possibilities through debates and projects as in Castells' description of the Occupy movement's general assemblies, with the difference that debates did not occur in the space of places but in the space of flows, i.e., online. For the patient activists, those unlimited horizons were the request for further research by the medical community and the request for recognition of the new theory by the Italian national health care institutions in order to render the new therapy widely available to MS patients. Contrary to the analysis by Barassi (2015:84-85) and Kaun (2015), the social media movement here analysed did have positive effects on MS political action. In 2010 the movement's Facebook Page was the location where it was planned the CCSVI national association (Associazione CCSVI-SM, 2010a), which took the same name as the Facebook Page, that is its fertile ground and roots were the space of flows:

> Another event to say that I remember, was clearly when the name of the association was chosen, where practically, on the CCSVI Facebook Page, a sort of survey was started to choose the name, until then it came, in short, to decide that the name of the association was the same name as the Facebook Page (Pietro).

Eventually was founded in the space of places in front of a notary who commented that: "This is the first time that I have assisted in the birth of a National Association with more than 30 founding members appearing in person", in what was recorded as the first Italian association born from a social media (Franchina, 2010a).

> They said you have to get out of Facebook and enter reality, and it was a deeply wrong thing because

> Facebook was reality too, in short, everything was born there (Ginevra).

The high participation was a projection of “their time in the future of history-making in terms of their anticipation” (Castells, 2015:251), where the “imminent forth-coming is present, immediately visible, as a present property of things, to the point of excluding the possibility that it will not come about” (Bourdieu, 2000:207). This was a practice of “prefigurative politics” where the “real and the ideal, become one in the present” (Maeckelbergh, 2011:4), simultaneously challenging online the existing MS political structures, and building alternative MS structures. The national CCSVI association was the answer to the need for something, as one interviewee stated:

> That could stipulate agreements, that could do things that a Facebook Page like a newspaper can’t do (Ginevra).
>
> To draw up minutes, sign concrete, juridical acts, where one cannot absolutely rely on virtual reality (Dario).

In the certainty of an unlimited horizon of possibilities for a new therapy for their disease, patients needed a qualitative leap to interact with institutions:

> Which was not just making things real, because we were already real [on Facebook] (Ginevra).

Patients did not use social media to represent their activity run in the space of places, as was done by the Occupy movement where camps set up Facebook groups to be used as a showcase (Castells, 2015:177). Nor was social media only a broadcasting channel through which to follow remotely the Occupy movement’s activities but without the possibility to participate: “Social media users could [….] follow remotely the meetings of the general assembly where the foundational documents were ratified, but their voices were not included in the process” (Kavada, 2015:872).

Rather, in the CCSVI movement social media were the places where the activity started and happened in a virtual contiguity, connectedness. Patients joined and advocated the medical discovery in the space of flows represented by Facebook, exactly as people joined the space of places represented by Zuccotti Park and other places around the US for the Occupy Wall Street movement, in order to participate in the protest.

I have examined the way in which activists within the patient movement experienced time during their active occupation of the digital streets. I found that what Castells defined as timeless time was indeed experienced despite the fact that no street occupation occurred. The timeless time dimension was achievable for the patients even as they remained within the physical space of their everyday lives, for a number of reasons. MS often strikes in the mid-late twenties, an age when people are busy planning and starting to build their own dreams and careers to fully realize their coming adult potentialities. The disease stopped them in their tracks and they could never really set their enthusiasm free but only fret under restraint. The wide range of choices were progressively limited with the advancement of the disabilities. They showed on Facebook their photos of the time they were able to ride a motorbike, to swim, to dive or, simply, to stand up. Thus, for these patients, the prospect of a tangible, easy-to-understand solution to the disease, albeit still unverified, gave them not just the hope, but the drive to speed up taking back what was unfairly taken away by the disease, the certainty that another life was possible. The fact that some patients who underwent the initial studies had already seen dramatic improvements in their symptoms boosted patients’ hope and the projection of a free, normal life in the present. This further fuelled their commitment to the occupation of the space of flows without interruption, awakening the supressed juvenile enthusiasm to spend entire nights actively engaged in the internet protest. They freed themselves from the bridle of an inauspicious destiny. For patients the fight was now, tomorrow might be too late: *time is brain*, referring to the progressive degeneration of brain functions imposed by the disease, was a motto of the online patients' movement.

The urgency of patients' commitment strengthened when they experienced first-hand the neurological community's rejection, as when some were belittled by their neurologists when they mentioned the new discovery, some of whom even threatened that they would refuse to continue seeing the patients if they abandoned their drug therapies. Patients were particularly frustrated by the stance taken by the traditional MS association, which appeared to activists to have a strong resistance to alternative therapies. These personal experiences further motivated patients' engagement, contributing to their experience of timeless time, as they increasingly abandoned their daily routine to further the cause. The patients' timeless time momentum was an unplanned, unexpected weapon, in which each activists' decisions and actions were taken independently as the need and opportunity arose because there was no chain of command, rather a connective leadership (Della Ratta and Valeriani, 2012; Poell et al., 2016). Each activist or small group of activists fed and were fed by the emotional condensation (Gerbaudo, 2012) of the Facebook community with a logic of contentious connective action (Bennett and Segerberg, 2013).

Being first only an active participant and a few years later also a researcher doing autoethnography (see Ch. 2.5), experiencing longitudinally for years since its inception the development of the patients' movement, made it possible to experience first-hand the conditions in which they fought and where the timeless time drive came from, and for a number of them, I could experience through Facebook the inauspicious results of the progression of the disease. The meaning of the fear and the urgency of living with the sword of Damocles. During the peak period of the protest and in the following years, some activists silently disappeared as dead soldiers. For some of them it was discovered that they were no longer able to type on their computer or communicate in other forms. One of the first and most vigorous and popular activist confined to a wheelchair, later also one of the founders of the CCSVI association, unexpectedly one morning died because of complications from the disease, leaving the movement mourning for years as he was one of their family even if many of them had never met him in person. In a very moving public message, a family member literally wrote that he died fighting for more research and for the recognition of the CCSVI theory. This to demonstrate how patients were driven to put aside their duties investing days and nights on Facebook together with the other patients taking away time from their families and from their not any more so important routines. I report here an article published on an information website on 29 January 2010, which intensively described what the timeless time of the CCSVI Facebook Page was during the first months of its existence:

> (...) Reading their page on Facebook, which sees them united with anger, grit and determination ... well, I do not hide that I almost wonder if you have to suffer through gritted teeth to be able to spread and share with education, dignity, determination and affection what they know, sharing their need for clarity that goes beyond a simple information pole, and also reaches the eyes and soul as a life lesson ... regardless of the discomfort that multiple sclerosis brings. Information, and specifically that of the correlation between CCSVI and multiple sclerosis travels and uses networks such as Twitter

> and Facebook, many groups, in many languages, but all turn to the competent institutions with a unanimous message that says: "Listen to us, we are many". The group is open to all, and cuts out loneliness, alas the life partner of many people who, either out of shyness, or out of nature, make the pain implode and do not come out easily. It’s a Facebook Page that I also recommend to those who do not have MS, but perhaps a relative or friend would need information they do not have. Visit the page and sign up. (...) (Franchina, 2010b).

The constant engagement and connection made real the immediacy of the solution, where their belief was reinforced by their timeless time experience in the occupation in the space of flows:

> With one click you can go to Milan while you stay at home. Before, however, no. Before you had to put up posters, playbills, go to door to door. (…) Now it is easier. Instead of covering a kilometre, you do a hundred kilometres of information (Marta).
>
> Facebook, in this it was of great use, we can practically reach the sick in all parts of Italy (Federico).

The patient movement’s decision-making process and occupation in the space of flows, characterized by a feeling of timeless time, provoked traditional MS Societies to react by setting up medical studies in the space of places to verify the theory (see Ch. 5.5), and launched a series of peer reviewed articles in medical journals blaming social media’s inopportune worldwide influence on the health care agenda (Chafe et al., 2011; Mazanderani, O’Neill, and Powell, 2013, Green, Kamel and Josephson, 2018; see Ch. 1.4 and 5.6).

(5) Disruption of timeless time in the CCSVI social media movement

Unlike the Occupy Wall Street movement whose “material form of existence was the occupation of public space” (Castells, 2015:171), the CCSVI movement’s timeless time dimension was not interrupted by the disciplinary order of the institutions. There were instances in which occupying websites and Facebook Pages of some traditional associations or Medical Journals, patients were banned or their comments were hidden to the view of the public (see Ch. 3.3), but they quickly moved to occupy another place in the space of flows. Rather, what interrupted the timeless time dimension, and the feeling of forever were other two developments.

Firstly, the sense of timeless time arguably started to dissipate when the first CCSVI association became fully operative in mid-2010, because the association cut off its roots with the Facebook Page where it was born, and tamed the disruptive social media action of some of the most important activists:

> When I took on a role in the association, I realized that, since I no longer spoke in a personal capacity but inevitably, I was speaking in the name of an association, I began to filter the things I said much more, precisely because one must have a role and be consistent with one's role, right? This is also a constraint, but it is a necessity at some point, if you have made that choice, you speak aloud about the association, and therefore not being able to speak in a personal capacity anymore, it has limited my use. In fact, now I really limit myself to a few things, a few considerations” (Aurora).
>
> I started to close the social media, at the moment in which ... and therefore now, I practically blocked all but the closest friends on Facebook, and therefore no one can see anything, from the moment I started having a direct role in the association, so to protect the association not to protect me (Luigi).

> It is okay to commit to the territory but then we dedicate some people to continue to engage on the Facebook Page, and not completely abandon that field there. Dedicated people who do not go to undermine the responsibility of the top management. We cannot…. Or at least it should not be experienced as a dichotomy. If you are born in a certain way you shouldn't betray your origins. A post of mine on the CCSVI Facebook Page [instead of in the association Facebook Page] in which I said: "this thing is being done in Bologna", I did it because for me that Page was the origin, right? (Ginevra).

The association did not only limited the participation of its members to the original Facebook Page, which was not even mentioned as the source of the name in the official web pages (https://web.archive.org/web/20110726203241/http://www.ccsvi-sm.org/?q=node/631), but also changed the way activists used Facebook with their own new born association Page, transforming it from the place where things happen, to at best a place where to getting to know new friends and attract associates (https://web.archive.org/web/20101023202910/http://www.ccsvi-sm.org/?q=node/2), without a real confrontation with old activists and newcomer seeking for information and social media participation:

> …and that they did not disavow what they have been, where they had originated, in short. Because does this make them lose also… that is, apart from the fact that ethically I don't like it, in short, no? But I think they also lose credibility if they don't have respect for their roots. It is that many think that you have to control everything, but sometimes you don't have to control, that is, sometimes you have to go out for what you are, and take responsibility for what you have done, explaining why, in short, you cannot jump from a wagon to the other because in one moment it is convenient, in the other not. You just have to be aware that some tools can help you and at other times they can, let's say create other problems, right? That is, it is not that Facebook is beautiful when you have a lot of contacts who then help you, and then it is bad when there are the bad

> and the ugly who contest you. That is ... If you have chosen the tool, I mean, you must be able to use the tool to the fullest (Ginevra).

This disconnection from Facebook started a process of disengagement of the social media activists, who could not anymore contribute with their time and proposals. The momentum of the movement was social media sourced and lived on the process of “the material production of social change not from programmatic goals but from the networked experiences of the actors in the movement” (Castells, 2015:147), whose timeless time counter power activity was neutered by the bureaucratic needs of a legally representative association. Nevertheless the association changed in 2020 the name into another MS association name, as to signify a cut with the past advocating for the CCSVI theory (see Ch 5.6), from its renewed website recounting on the origins of the association, at the moment of writing it is still impossible to clearly understand that the independent original Facebook Page’s activities were not those of the association, as a sign of an unresolved dichotomy (https://web.archive.org/web/20220129005036/https://ccsvi-sm.org/la-nostra-storia/05-si-costituisce-lassociazione/). This constant, since the association’s inception, inability to state the reality as something to be ashamed of, may be the cause of the misunderstanding of Matteucci’s study where it’s stated that the original Facebook Page is the CCSVI-SM association’s page and not two separate and independent realities (see Ch. 2.5).

Secondly, the sense of timeless time started being disrupted when suddenly the CCSVI angioplasty therapy was made available in Italian private clinics, even before its utility had been confirmed by scientific studies. This gave rise to the interruption of timeless time because chronological constraints strongly permeated the patients’ on-line timeless time dimension. When it became clear that the traditional MS association were opposing the theory nevertheless the promises, it seemed obvious to the MS patients that there was no hope for having the procedure done through the Italian National Health Service, as they were advocating, within a reasonable short time. Timeless time's broadening of patients' life expectation became the real present and many patients did not lose time in having the procedure done even if privately. The impetus of actualising the future in the now was such among patients that one of the most important and awaited publicly-funded studies in Italy (see Ch. 5.6), declared that one of the first limitations of the study was finding a sufficient number of patients who had not already performed the procedure in private centres (Zamboni et al, 2018:41). Many patients could not afford to forget the worsening limitations imposed by the chronometer of their disease, causing most of them to step down from their enthusiastic day-to-day activity in timeless time, and to undertake the procedure even if still experimental and uncertain in its results:

> Those who had positive results from angioplasty kept them for themselves and maybe forgot about Facebook (…) My fear for some time is that the interest is waning, even if everyone tells me it is not true, I get scared when we talk about something serious and concrete and you see three Likes, when once on such a thing we went on to discuss for four hours (Diego).

In addition to the above, what was left of the timeless time momentum was undercut by the many CCSVI associations created as alternatives to the first that brought different views into conflict, challenging the sense of unity and infinite possibilities which underpinned the notion of timeless time:

> I am very sorry that a different dialogue has not been created between the associations. (...) First there was only one, then CCSVI Campania, then AIC [Associazione Italiana CCSVI], then CCSVI e

> SM Lombardia, then SMuovilavita, then Abbraccio, and that and the other [Isola Attiva]... how many associations advocating CCSVI are there now? I have lost the count (Vittoria).
>
> Moreover, another thing that associations should do in my opinion is that they should not fragment, because what fragmentation does, is that everyone wants to manage their parish priest, as we generally say. It is the most wrong thing because by fragmenting one begins to lose even that spirit, and above all, people then no longer have credibility towards associations, because it seems as if everyone wants to manage their little power (Federico).
>
> There have been controversies, (…) we have had problems with the CCSVI national association, misunderstandings ... sometimes people have the same objectives, but they come from different paths ... I don't know who is right, I tend to try to do "like this", and this has put us in conflict (Martina).
>
> Territorial associations must exist because health care is regional, so it is certainly right that there is an association in the region, then that there is also the national one is fine because at a national level maybe you can have more grip on politics, on ... both are right that they exist in my opinion. Then, the fact of getting along is another matter entirely [laughs] (Eleonora).
>
> Unfortunately, likes and dislikes were born for which a thousand factions were created that even if in theory they all have the same final goal, they say, but in reality, each one follows its own path, each one follows its position, it looks for its enclosure, therefore we split up, then we tried to get back together but, with quite poor results (Diego).
>
> Not being able to have a common basis is a defeat for everyone, in my opinion. A basis of common struggle ... (Ginevra).

These additional associations included:

> CCSVI Campania Onlus (https://web.archive.org/web/20130327124432/http://www.ccsvicampaniaonlus.it/ccsvi%2Dcampania/);

Associazione Italiana CCSVI – AIC Onlus
(https://web.archive.org/web/20110626101234/http://www.ccsviitalia.org/);
Isola Attiva Onlus
(https://web.archive.org/web/20110525233832/http://www.isolattiva.org/);
CCSVI e SM Lombardia Onlus
(https://web.archive.org/web/20140228230738/http://www.ccsvi-lombardia.org/).

Ultimately, a contested study which strongly limited the credibility of CCSVI before public opinion (see Ch. 5.6) and which foreclosed the CCSVI discussion in some MS Facebook groups, put the movement into a sort of dormancy. At the moment of writing, whilst some associations have scaled down and some others have changed their name deleting the word CCSVI, or closed down, the original Facebook Page *CCSVI nella Sclerosi Multipla* is still active.

The end of timeless time and the shift to the chronological time experience for the activists happened when the “expectations and the world which is there to fulfil them, is broken” (Bourdieu, 2000:208). The detachment of the first CCSVI association from its Facebook source and the sudden availability of the therapy even if still experimental and privately, followed by the conflicts among the various CCSVI associations, were the main causes of the loss of the timeless time momentum of the CCSVI movement.

CHAPTER 5. The fantasies and the realities of the CCSVI social media movement.

(1) Introduction

With this chapter I seek to contribute to theorising the ways in which power operates in communicative capitalism and I give examples of possible resistance to co-optation in a context of a patient-based social media movement. The extent to which the social media movement supporting the new theory has mobilised MS patients and indirectly, as well as unwillingly challenged corporate power, has exposed to the activists some of the mechanisms of the strategy of co-optation essential in the interdependent relation between the base and the superstructure, and critical to the psychological supremacy of the dominant ideologies towards non-official and in-the-making ideologies.

I begin by presenting the battlefield, that is the MS global market which is expected to move $39 billion by the end of 2026. I then describe the *fantasies*, that is the delusion of the internet mobilisation described in Dean's paper 'Communicative capitalism: Circulation and the foreclosure of politics' (2005), and I apply those fantasies to the CCSVI social media movement. Dean acknowledges that there can be exceptions, and this chapter aims to propose the CCSVI social media movement as one of those exceptions at least in some instances. I highlight the realities produced out of the same social media activities and enthusiasm that were arguably negatively described as fantasies, and which eventually led to co-optation.

After, I analyse the conclusions of the study Brave Dreams and the Editorial which led to the definitive rejection of the CCSVI theory discussion in the neurological community and led to the ban of any mentions about CCSVI by the administrators of some of the most popular Italian MS Facebook Groups. This eventually took to the dormancy of the CCSVI societies with the definitive loss of the momentum of the international movement, though still active in Italy.

Then, I compare the CCSVI case study to the one of the 2003 anti-war movement put forward by Dean to emphasise the different moves through which communicative capitalism has co-opted a patients' social media movement that is not political or about social inequalities. The CCSVI movement did not occupy a physical space so it couldn't be interrupted by being physically removed, and the activists could not be coerced (yet) by law to swallow the pill of the dominant ideology.

I conclude by examining how a formalised network of legally recognised societies dedicated to CCSVI, that arose out of and backed up by the social media movement, may be characterised as a challenge to communicative capitalism, resisting co-optation.

(2) The battlefield: the MS global market.

There is currently no cure for MS, but the majority of MS patients are recommended an extended choice of drugs as treatment. Drug treatments are strongly backed up by worldwide traditional MS associations that are adherents to an umbrella association, the Multiple Sclerosis International Federation (MSIF, see Ch 3.4). At stake there is the global MS drug market, which reached $17 billion in 2014 (RnR Market Research, 2015), and it is projected to reach more than $39 billion in 2026 (Fortune Business Insights, 2019). The overall global market of the pharmaceutical industry reached $1,310.0 billion in 2020 (expected to arrive at $2,151.1 billion by 2027, Fortune Business Insights, 2021b). In comparison, the global defence/military market in 2020, reached $1,981 billion (SIPRI, 2021).

In 2010, when pharmaceutical companies in the USA became "the biggest defrauder of the federal government surpassing the defense industry", the drug industry had given FDA between $0.7 billion and 0.8 billion in cash, covering two thirds of the drugs review costs, in addition to $200 million for lobbying (Goodman, 2010). An FDA top lawyer said that drug industries are fined for a combination of civil and criminal violations, but compared with the profit the penalties are insignificant: two companies have paid around $7 billion in 20 years, but in one year they make about $15 billion profit (Goodman, 2010). However, the FDA does not only review drugs but also procedures like angioplasty for CCSVI in MS patients. In May 2012 FDA issued a safety communication, putting into question the existence of CCSVI and its correlation to MS, and the risk of related treatments (FDA, 2012).

The medical research which proposed in 2009 the CCSVI suggesting a different aetiology and a non-drug-based therapy, challenged the MS medical orthodoxy. In fact, the opposition was not coming from the natural capitalistic competition on the MS therapy market, but from the medical MS researchers and the neurologists-led MS societies. To the eyes of the activists, the vehemence of the neurologists' reaction seemed to be provoked not only by their different specialisations, but also by the fear of losing new funding for the research they were working on. An example of the prejudicial rubber wall that CCSVI researchers seemed to be facing, was given in another context by one of the main Covid_19 vaccine pioneer, Prof Katalin Karikó who created the basis for the Pfizer and Moderna vaccines. In 1995 she had to give up her prestigious faculty position and academic career and accept a substantial pay cut, in order to keep carrying on the research on mRNA. In 2021 she said: "If so many people who are in a certain field would come together in a room and forget their names, their egos, their titles, and just think, they would come up with so many solutions for so many things, but all these titles and whatever get in the way" (Sample, 2021). MS patients were expecting with candour of mind words of hope and collaboration among all scientists, and not what then appeared to their eyes to be a confrontation which recalls a Gramscian war of position, which "does not consist solely of a set of actual trenches; it comprises the entire organisational and industrial structure of the territory that lies behind the arrayed forces" (Gramsci, 2007:162).

(3) Communicative capitalism and its ‘fantasies’.

Communicative capitalism is a description of contemporary society focusing on the renovation of the productive forces that adapt communication and communicability. Dean (2005) enlisted a series of devices through which corporate power reinforces its dominant position. According to this description, the WWW in the age of communication produces messages with no response, which do not support a real democracy, instead they raise the volume of chatter and strengthen the basis of capitalist production. In detail, tied to the concept of *no response*, the *fantasy of abundance* is described as a shift in communication from the message, whose content loses importance without eliciting any response, to the mere contribution of circulating content. The exchange value of messages becomes more important than the value of their use, where the lack of understanding precludes real antagonism. What prevents people from being aware of this shift is the *fantasy of participation* through the *technological fetish*. Technology is presented as the solution to the complexity of politics, it transposes political energies on to the everyday use of the internet, and ultimately, it has become an ontologisation of political activity. The *fantasy of wholeness* draws from the celebration of the internet as representing freedom and absence of restrictions and fuels a sense of global belonging.

(4) The fantasies and exceptions within the CCSVI social media movement.

In the CCSVI case study the fantasy of abundance where the circulation of content is more important than the value of the content, was manifested by different aspects.

The CCSVI Facebook Page was created in August 2009, in the end of November had 1,000 active and lively members and by February 2010 had an online membership of 10,000, when the CCSVI association was already in the process to be founded. One of the aspects of the CCSVI fantasy of abundance was the difference between the big number of members of the Italian CCSVI in MS Facebook Page, which in 2011 was more than 34,000 members, and the smaller number of associates to the legally organised society for CCSVI (slightly more than 1,000), which required a minimal annual fee.

Another aspect supporting the fantasy of abundance emerged based on experiences from autoethnography. Many patients and caregivers relied on the novelty of the hope offered by the new theory, more than on the content of the message. The theory of the correlation between CCSVI and MS was supported by scientific research, but the therapy proposed was experimental and could not give relief to all patients. The study was made public by a number of scientists at an ad hoc international conference only to justify, defend and promote further research into the discovery because it was hindered by the MS medical establishment and traditional MS associations. That was always made clear by the CCSVI Facebook Page.

Nevertheless, the message was not fully understood by some MS patients and activists. Eventually, for some of them it was more important to contribute to the circulation of the message than understanding its content. In fact, CCSVI researchers were blamed to think only about their career and dreaming of Nobel prizes instead of applying themselves the therapy to all MS sufferers, which anyway would have been impossible. Therefore, when some Italian and international private hospitals suddenly offered the procedure without furthering scientific confirmations recommended by CCSVI researchers, many patients flocked to have the procedure done. As already stated in the 2009 study, about half of those patients did not have any improvement and those of them who did not understand the message, in the end blamed the message. They kept on blaming the message even when they were confronted with its original content and ultimately, some abandoned, and a few of them even actively opposed the movement: "Those who had negative results used them badly" (Diego).

On the other side, the negatives of the contribution to the circulation of the message that was not by all fully understood, produced substantial exceptions. The high circulation of the message through the sharing of Facebook posts, comparable to the People's Mic in the General Assembly of Occupy Wall Street, not only reinforced a sense of belonging, but also gave chances to reach and then elicit a response from those who were able to understand it, and who otherwise would have never had the chance to get to know it. For example, the circulation of the message could potentially meet the attention of some of those of the 3,400 people newly diagnosed with MS in Italy alone every year (AISM, 2016), who for the first time would look for information on-line about the disease:

> Before the illness I had never worried, that is, if you don't get sick, you don't think about it (Vittoria).
>
> Everything is accelerated, really, the world of information, but in my opinion, it also moves other situations, in the sense that Prof Zamboni, I mean, thanks to the internet, I mean social media, has had in a very short time a vast amount of people who supported him that, instead, with simple television and newspapers it would take much longer (Eleonora).

> My Facebook membership is due to MS, not directly for the CCSVI but to MS (…) social media and the internet have helped me to acquire more news, they have given me the opportunity to have access to information on CCSVI that otherwise I would never have, because no doctor, willy-nilly, unwillingly because we know how closed neurologists are on CCSVI, they never told me about it. I would never have had access to this mass of information (…) To me, I repeat, the social media with this problem [MS] has changed my life (Martina).

Others reached by the circulation of the message were not newly diagnosed:

> I mean, I think when I got sick there was still no internet and therefore, I also had difficulty in retrieving information on multiple sclerosis (Eleonora).

Some of the first most important social media activists who then actively helped creating and leading the CCSVI associations were reached by the initial abundance of contributions:

> I registered on Facebook a few months after the opening of the CCSVI Fan Page. Maybe late 2009, I think October. We were 300 registered [in December 2009 the Italian CCSVI Facebook page had 1000 members] (Aurora).
>
> So, social media were indispensable because they formed the basis, a bit of a virtual square for people with similar problems, they found themselves sharing experiences, sharing resolutions to bring together. So social media have been fundamental, both for the viral capacity that social media have in sharing content, and precisely for the possibility of being able to be equal in dealing with an issue. Obviously, the next step that we have decided to take is to set up an association (Lorenzo).
>
> No, I didn't know anyone. Basically let's say so, I had this report and I started ... at the time it's not that there were even so many publications around, so I started to understand what it was about by interacting with others (Pietro).

Some other main activists joined the movement one or two years after it started, because they were diagnosed with MS only in 2010 or 2011 and answered the message helping the associations in organising and participating in activities:

> So, on Facebook, it was because when I arrived there was already this CCSVI page with 25-30 thousand users and it was the simplest point of immediate discussion (Diego).
>
> I didn't know anyone. I met everyone through social media (Lisa).

One of those diagnosed after the start of the movement, thanks to the circulation of the message eventually even created alone one of the most active CCSVI associations, as recounted in one of the interviews:

> I searched for multiple sclerosis and came to these Facebook groups of patients talking about CCSVI and communicating with them (…) then I landed on the main CCSVI movements’ Facebook Page (…) and I immediately went to what was at the time the first conference of the association *CCSVI nella sclerosi multipla* [September 2010]. Let's say that my intervention at that conference was decisive in creating another CCSVI association, in the sense that at the time of the question time ... my comment was not appreciated by the board that was in charge of this conference ... but when I was leaving the conference, the people came to shake my hand and thank me for having said what I had actually said. And I remember that at the time a doctor complimented me and told me that they wanted people who have the courage to speak. But as a member, I did not feel protected by the associative management that existed ... So, the idea was born a bit from there. I knew nothing about associations, I had no idea at all. That is, I knew there were associations, yes, because I have always made donations and various stuff. But from there to build one (...) in the end I decided. I said to myself well, why can't I do it too, to create an alternative. And thus, a new CCSVI association was born” (the president of one of the main CCSVI associations).

The circulation of the message also reached those who had personal communication channel with one of the most popular investigative TV shows. This is how, in late September 2010 the CCSVI social media movement breached the mainstream media through a very popular prime time TV show targeting young people (Il Sussidiario, 2010), called *Le Iene* (The Hyenas, from the Italian title of the Quentin Tarantino's 1992 movie *Reservoir Dogs*. Presenters and reporters dress like the characters of the movie):

> Then when there was the first news that even *Le Iene* had prepared the TV show on CCSVI, the whole group involved itself to join in this enthusiasm (Monica).

The television dossier was aired in three episodes one every week (https://www.iene.mediaset.it/2010/news/ccsvi-e-sclerosi-multipla_72024.shtml) and boosted the membership of the Facebook Page and arguably increased also the number of patients who went to have the therapy privately done, outside of scientific research as requested by researchers. A study on Google Trends-based MS hit search volume over the years from 2004 to 2012 in Italy, recorded the highest peak when *Le Iene* TV show on CCSVI was aired in late 2010 (Bragazzi, 2013:3). However, the show did not spark a national mass media discussion nor influence the national health policy. By that time, the traditional association AISM had already taken control of the situation, presenting itself as the referee of the situation, reserving for itself the final word.

The first ever monothematic dossier on the renowned *Corriere della Sera*, published in February 2013, was dedicate to the contention between MS and CCSVI (Corcella, Meli, Natali and D'Amico, 2013). It was conceived thanks to the circulation of the message and pressure from social media activists, as stated by one of the authors, D'Amico, at a conference in Ferrara (see Ch. 2.7).

However, the increasing popularity of social media with its related fantasy of abundance, and the engagement of the traditional patients' associations and corporate interest in the social media arena producing messages, meant that already in 2014, five years after the inception of the movement, the CCSVI message was further lost in the massive stream of contrasting messages:

> It was easier to disentangle information about the CCSVI 4 or 5 years ago than now. Apart from the fact that everything is in progress, and we are here to testify it, however it is much more of a hitch now (Martina).
>
> Now you have to be able to skim, because unfortunately the bad thing is that you find everything, that is, you also find bullshit. You need to have this great ability to rationalize and skim (Eleonora).

The reach of the increasing abundance of contrasting messages can be given by the following numbers. The Facebook Page of the Italian MS Association (AISM), which initially was smaller than the one of the CCSVI activists (in February 2011 AISM had 4800 members while the CCSVI Facebook Page had almost 31,500 members, Cammarata, 2011), in 2016 it became more than double, and in January 2022 became almost four times bigger with patients who also became social media influencer for AISM: 128,000 Facebook members against the more than 33,000 of the CCSVI page.

About the fantasy of activity or participation, materialised through technology fetishism, MS patients and caregivers could not reach the number of protestors comparable to that of a political movement. For example, in Italy with a population of around 60 million, in 2009 there were about 60,000 patients diagnosed with MS. Furthermore, it should be considered that most MS patients had disabilities which not only limited their mobility, but also did not allow them to engage in public activities or protest on the street. Only to cite a few examples, they tired easily, required ready access to public facilities and they needed walking aids, and social media allowed to overcome all of that:

> I learned to walk, I learned to walk thinking that I am walking like babies do, if I am about to fall, I have learned to let go, it hurts less to fall than if you stiffen. If I stagger, I try to lean on someone, I don't care if I lean on a person I don't know (Arianna).
>
> As long as you can walk it is true that you know people outside and you frequent them outside the home, but with a disorder of this type [MS]… (Elisa).

For some MS patients it was even too difficult to use social media by themselves, because their use was too much a mental effort and for their lack of physical resistance, and eventually relied on caregivers:

> I certainly had the intention to use social media, but I realized that I had tiredness, also problems of time because having limited autonomy, so in some way I delegated my partner, fortunately we have the same goal, the same way of reasoning, and in the end what he did I would have done and vice versa. So, we moved in the same way in short (Eleonora).

The use of technology, in the case of this patients' movement is fundamental and instead of technology fetishism I propose to talk about technology as *social prosthesis*, allowing patients with disabilities to take an active part in society, where often the architectural barriers and the lack of proper infrastructures would be an impediment to their mobility, besides their physical and mental tiredness. Disabled patients used social media as streets and squares where to walk and socialise:

> I must say that there has been diversification [on physically meeting Facebook contacts]. I think I have not met people who, let's say whose pathology anyway ... was very disabling, let's say… because people who have a certain quality of life, for better or worse, immediately tried to build a relationship, to see each other, to... (…) There are people that I continue to hear today, with whom we write through Facebook that I have never met personally, I don't know their faces, eh .. but I know some very intimate thoughts for absurdity, right? Sometimes it is easier to confide some things to a stranger, a stranger in the sense that … a person you do not physically know (Ginevra).
>
> I did not actively participate for physical reasons, but I participated from the beginning [on the CCSVI Facebook page] (Monica).
>
> I also asked, because, then I go to the bottom of these things. I also asked and: some have physical impediments and prefer to have this virtual life where they can... (Federico).

Later in the history of the movement's activity symptoms of technology fetishism were recognisable. This happened especially from 2016 when the hoped and expected positive results of clinical trials were slow to arrive and the medical establishment raised the volume of contributions without responding to the activity and requests of those advocating the new theory. Participation became the same as rooting for your local football team, where it does not matter who deserves to win. What matters is only to win, where the enemy becomes "a threat to be destroyed" (Dean, 2005:52).

The mantra of internet openness and its lack of boundaries fostered the fantasy of wholeness and global belonging in the formation of the CCSVI social media movement, facilitating its growth. The increasing volume of contributions also from the traditional MS associations which caught up with the involvement in social media's activity, shifted the sense of belonging to a larger context which brought to the lack of confrontation, where the new theory is not any more in the debate, instead it is a threat which has to disappear in the wholeness of a higher volume of chatter, and eventually banned from some Facebook groups' administrators.

(5) The realities of the CCSVI social media movement which led to co-optation.

As described in the previous paragraph, the fantasies in the case of the CCSVI patients' social media movement produced some realities. The activity of the social movement created awareness and hope in the activists themselves and patients at large. The tepid or sarcastic response to the new theory prompted some MS patients to rage against their traditional MS associations and their neurologists, with some of them also refusing to take the usual drug therapies (Amadeo, 2010). As reported by some activists:

> I have taken interferon [MS drug]... for 16 years. 4 relapses [worsening that at the beginning of the disease can be recovered with high doses of cortisone] a year for 16 years, and new lesions [in the brain]... 16 years of 39.5 of fever every other day, I couldn't take it anymore. I have to go to work in the morning ... I took Tachipirina [paracetamol] for the fever but it wasn't enough, going to work was hard. But also with Fingolimod [MS drug], in the morning I can't get out of bed, 50 of low blood pressure (...) ok, it doesn't give me high fever… but I saw that it's not good. For three weeks I tried it and I already had a relapse (…) When I read about CCSVI (...) it seemed to me that it coincided with what I have (Beatrice).
>
> While I do the interferon I get a worsening, and they tell me "you know how much worse it would have been without taking the drug?" If the crisis comes when I don't take the interferon, they tell me "see lady

> what happens if you don't take the interferon?
> (Arianna).

It is important to stress that researchers and the CCSVI Facebook Page always said to keep following the recommendations of the neurologists. The materialization of patients' discontent, which brought to abandon the usual silently-acceptance of the neurologists' prescriptions, it appeared to have prompted the international traditional associations to quickly organise and fund studies on the new theory (Chafe e al., 2011). Interestingly, the studies were set and carried on exactly where the traditional MS associations had to face the most active counter power CCSVI patient groups, as evaluated by an "assessment by European experts in multiple sclerosis" cited by the international MS neurologist expert Dr Comi (Colasanto, 2012), that is in Italy and Canada. It was not the new theory that was taken into consideration by worldwide multiple sclerosis experts as to be scientifically verified, but the threat from the social media movement and enraged patients backing up the new theory.

As a matter of fact, the CCSVI movement and the social media chatter motivated also small independent medical research group to set up studies:

> This wide dissemination of information has also been a stimulus for some research groups to start some research (MD Riccardo).

A few days after the success of the first public conference dedicated to the research on CCSVI and MS held in Vicenza with a thousand participants, mostly social media activists (Pepe, 2010), on 29 January AISM issued a press release with the promise to fund research on CCSVI (https://web.archive.org/web/20201201142711/https://allegati.aism.it/manager/UploadFile/2/aism_hilarescere.2010127_124358.pdf). However, the tepid and controversial response by neurologists and AISM beyond the announcement, strengthened the process to unite. Meanwhile, on 2 March 2010, one of Italy's leading public television health-based news programme dedicated an episode to the relationship between CCSVI and MS (RAI2, 2010), which was again covered the day after in another national public news programme (RAI3, 2010). In order to resist the attempt at co-optation which was evident already since the inception of the studies announced by AISM, the Italian CCSVI Facebook Page activists who started considering formalising the movement already since the conference in Vicenza, quickly organised its first constitutive meeting on 5 March (Associazione CCSVI-SM, 2010b). They created a legally recognised national association the following month, on 9 April 2010, which took the name of the Facebook Page where it all started in August 2009:

> The association that existed at the time, which was AISM, and which still exists, it had not approached the problem as I thought it was right, so I said OK, we will make an independent association, free from constraints (Diego).
>
> In the past I worked in the field of continuing education in medicine, I organized medical conferences. So, I knew that ... strong interests. I, first-hand, have seen knocked-off studies, I've seen fake studies, so anyway I knew that I wasn't going anywhere by myself (Daniele).
>
> You can help and help yourself to achieve goals, and therefore the reason for the association was this, supporting together Professor Zamboni and his discovery in which we believed and still believe today [2014], despite a massacre [from AISM] (Eleonora).

Former patroness of AISM, Nicoletta Mantovani, Pavarotti's widow, was the honorary president of the newborn CCSVI association. As an interviewee recalled:

> The truth is that I entered your Facebook Page in 2009 and I began to meet people, the people who

> were frequenting the most, I was contacted privately … that Mantovani would become the honorary president of the association gave everyone a large store of enthusiasm. We had already formed a group … in short, with the ones that were more active, then many have disappeared but with many we are still in contact [in 2014] … this group was created well before the idea of the association (Giorgia).

Eventually, the movement provoked the allocation of millions of euros for studies about the new theory. In Italy one study, called CoSMo, was privately funded (to the tune of 1.5 million Euros) and run by the traditional Italian MS association, AISM (d'Ercole, 2011). A second study in Italy, Brave Dreams, was publicly funded (2.742 million Euros) by the region of Emilia Romagna (Assessorato Politiche per la salute, 2012). In Canada, the Multiple Sclerosis Society of Canada (MSSC, 2010), lobbied the government for $10 million of public funding into the research, which then was reduced to $2.4 million privately funded by MSSC with the contribution of the National MS Society of the United States (NMSS, 2010). All the studies financed privately or jointly set up by the MS national associations as the public funded study Brave Dreams (see following paragraph), gave contested negative results regarding any correlation between MS and CCSVI.

According to Italian CCSVI social media activists, since the beginning there were signs that a process of co-optation of the general public, of the medical community and of MS patients, was being setting up. These signs were that the traditional international MS associations involved (AISM, MSCC, NMSS), which were all members of MSIF, they knew of the existence of the research since more than a couple of years. But only after the patients' social media turmoil of the end of 2009 they had a sudden urgency to find scientific confirmations into CCSVI (see Ch 3.4), setting up their own studies. Furthermore, while studies were set up with contested methodology in collecting data, the harsh negative comments of world leading neurologists were widely distributed to and published by mainstream media and medical journals (see Ch. 3.3). Some of those neurologists were directly or indirectly involved with the scientific committee of the same traditional associations that were supposed to genuinely investigate on the alleged correlation and figured among the leading researchers of industry funded drug studies which further fuelled the resentment of the activists (see Ch. 3.2).

The negative results of AISM's double-blinded study, CoSMo, were publicly anticipated even before completion two times in the previous two years before publication, against the rules of the double-blinded scientific method which underpins scientific progress (see Ch 3.2). The reasons behind the urgent anticipations were that Brave Dreams, which AISM had previously fundraised (https://web.archive.org/web/20210724170750/https://www.aism.it/dona_2_euro_un_mondo_libero_dalla_sclerosi_multipla?codpage=2011_02_gardenia_sms) was ready to start before the publication of the study CoSMo. The anticipations of the negative results of an uncompleted double blinded study, which found only 3% of CCSVI venous malformations in MS patients, was the way to opt out from its involvement in Brave Dreams. Since then, AISM did not want to talk anymore about CCSVI. What came out to light is that while the president of the Italian Neurologist Society and of the scientific board of AISM threatened the neurologists who were thinking to participate to Brave Dreams (see Ch.3.2), AISM participated in writing the Brave Dreams protocol (AISM, 2017a:34).

Following Kress and Van Leeuwen suggestions, the protocol could be seen as a design, which is the “conceptual side of expression, and the expression side of conception” (2001:5). The protocol of a study is the design that impose a particular kind of interaction. The protocol is as important as the design of a house made by architects who do not execute the building themselves (6), which means AISM was an architect of the study which was supposed to verify a theory which AISM had already with animosity and grudge discarded since its inception.

The birth of the CCSVI association was labelled as “a bit surprising” by one of the leading MS scientists of the Italian MS association AISM, Dr Comi (Colasanto, 2012). It probably became the further and decisive reality which accelerated and reinforced the reach of the co-optation. Rumours on social media said that AISM filed a complaint against the first (which became the last) national SMS fundraising of the CCSVI Association in February 2011, for alleged irregularities. Other social media rumours mentioned that a private settlement was agreed, which implied a sort of self-censorship accepted by the CCSVI association which could not financially afford a possibly endless legal battle.

The vicissitudes behind the Brave Dream study and the definitive negative results (see above and following paragraph), only served to strengthen the activists’ evidence on the reach of the co-optation. Activists on social media argued that industry funded evidence-based medicine criteria, that of the randomised double-blinded controlled trials (Krauss, 2018; Every-Palmer and Howick, 2014), eventually influenced the results. Criteria that suit an industrially produced one-pill-type for-all-patients treatment study, were applied to the protocol of a not-industry-funded study of subjective non-invasive surgical operations. For example, it was noticed that there were no highlights in the study of the 18 out of 20 patients from one of the participant MS centres whose neurologist stated they “showed improvements in symptoms and fewer lesions on MRI scans" (CTV News, 2017).

Notwithstanding the enigmatic though negative conclusions of the long-awaited Brave Dreams study, scientific research on CCSVI is ongoing even if some international researchers have informally said that if they want to be published in a medical journal, they do not have to reference CCSVI or Zamboni. Since 2011 Institutions such as the Italian Foundation *Il Bene* (https://www.fondazioneilbene.org/) and the International Society for Neurovascular Disease (ISNVD, https://isnvd.org), have organised annual conferences promoting CCSVI and vascular research in MS.

Among the many others, the most important is a study nicknamed Brave Dreams 2, that further analysed the data of Brave Dreams as it was requested in the conclusions. It remarked that thanks to studies published after the protocol was set for Brave Dreams, it was possible to recognise and select in advance the patients who were more likely to receive positive results from the Venous PTA/angioplasty (Zamboni, Galeotti, Salvi et al, 2020), excluding for example those with external bones or muscles that limit the blood outflow, for whom are to be considered different therapies than angioplasty. Unfortunately, Brave Dreams 2 did not have the same publicity and consideration as the previous most famous study, because published in a minor journal. Informants clarify that there are two kinds of MS research, for profit with industrial funding and non-profit, with public funding. Consequently, there are journals that live on for profit studies (see Ch. 3.3) and do not even consider access for peer reviewing the non-profit studies submitted which are straight away refused as not interesting. The journals that publish non-profit studies are not supported by marketing as for-profit journals are and have a lower impact factor (see Ch. 3.3.i). For a vascular surgeon to achieve the same profit that a neurologist's drug therapy for one patient makes in one year (repeated for many years), a vascular surgeon should operate on 10 to 20 patients in one year (with most if not all of them not needing new operations in the following years).

In early 2020 was set to start the first worldwide implant study of a novel stent (called *Petalo*) specifically created to keep the jugular veins open after an angioplasty (Russo, 2019). The existing stents are only for arteries, which have a different structure then that of the jugulars (arteries generally hold the stent without letting it move dangerously). The study was approved by a medical ethics committee and it's co-funded by the Italian Ministry of Health. The study makes no reference to CCSVI or MS, stating only that the novel stent is for reducing cephalea, which happens to be one of the most common and debilitating symptoms of MS. Because of the Covid-19 pandemic, the start of the study has been delayed and at the moment of writing has not started yet. In 2021 a group of Australian researchers noted that the research on the vascular connection to MS has been discredited because of non-objective diagnosis criteria and because of premature interventional studies. They recognise that angioplasty may be beneficial to a subgroup of MS patients encouraging other scientists to further the research which they are also carrying on (Bateman, Lechner-Schott, Carey et al 2021).

The same research on cerebral venous return without mentioning CCSVI is ongoing on the International Space Station (ISS), because astronauts report neurological symptoms similar to those of MS patients, limiting their space travel autonomy. Gravity is one of the recognised factors helping the blood flow down from the head towards the heart, and very little is known about how the downward flow works in microgravity. After the first study called Drain Brain carried on in early 2015 on one astronaut (https://www.nasa.gov/mission_pages/station/research/news/drain-brain), in Spring 2022 the continuation of the project, Drain Brain 2.0, tests the cerebral flow of all astronauts on board of the ISS, in view of more challenging journeys such as those to Mars and other planets of the Milky Way. Drain Brain 2.0 came first in the ranking of all the Italian scientific projects that aspired to experiment on the ISS (https://www.unife.it/it/notizie/2022/scienza-cultura-e-ricerca/drain-brain, in English: https://www.youtube.com/watch?v=y0d5nxeNfwY) and was funded by the Italian Space Agency (ASI).

(6) Conclusions of the Brave Dreams study and the lambasting of social media

The conclusions of the Brave Dreams study had been long-awaited by the CCSVI people (since 2010, see Ch. 3.4). It was expected to give the final positive word on the effectiveness of venous angioplasty to help MS patients, and to start a revival of activists' enthusiasm. Instead, it resulted in the broken dreams of the activists whose engagement, already exhausted by years of fighting and waiting, thereafter fell into a sort of dormancy. The Brave Dreams study was published seven years from its initial public planning in 2010. Already in 2014, an activist expressed the despair circulating in the movement:

> I don't know if Brave Dreams will ever see the end (…) because Brave Dreams is continually boycotted, because financing a project doesn't mean making it go on right? And many were deluded… (Ginevra).

The Brave Dreams study was conducted by 13 main researchers (plus dozens of other technicians), comprising neurologists and vascular surgeons, the two medical categories in conflict regarding a correlation between CCSVI and MS (see Ch. 1.4). The results of the Brave Dreams study were published first online in the November 2017 edition of the renowned neurological journal, *JAMA Neurology*. Informants reported that it had taken more than one year for vascular surgeons, neurologists and editors of *JAMA Neurology* to agree on the final text of the study, especially on the conclusions, which read as follows:

> Conclusions
> A number of neurologists and scientists expressed the opinion that the decision to conduct a trial on CCSVI in the absence of valid scientific evidence was unethical and a waste of resources. However, we believe that the best way to provide useful information to patients (and regulatory authorities) on the benefit and safety of venous PTA [angioplasty] was to conduct a randomized trial—as also recommended by NICE—that assessed outcomes directly relevant to patients. Venous PTA has proven to be a safe but ineffective technique in treating CCSVI in about half of patients. The procedure cannot be recommended for treatment of patients with MS; no further double-blinded clinical studies are needed. The delayed effect of venous PTA 6 months after the procedure on the magnetic resonance biomarker suggests a possibility that PTA may produce benefit for a subgroup of patients with MS. This should be further analyzed and investigated (Zamboni, Tesio, Galimberti, Salvi et al., 2018:42 https://jamanetwork.com/journals/jamaneurology/fullarticle/2664001).

The activists responded to the apparent contradiction within the conclusions, which on the one hand stated that: “The procedure cannot be recommended for treatment of patients with MS” and on the other hand stated there was: “a possibility that PTA may produce benefit for a subgroup of patients with MS” which “should be further analyzed and investigated”.

Activists also noted that in the conclusions of the abstract of the study, most likely to be the only part read by the general medical community, lay persons and health journalists, the utility of CCSVI was completely negated and no mention was made of the need for further investigations:

> CONCLUSION AND RELEVANCE. Venous PTA has proven to be a safe but largely ineffective technique; the treatment cannot be recommended in patients with MS (2018:35).

The conclusions of the Brave Dreams study were interpreted by the activists as demonstrating a difference between the way CCSVI (a medical procedure) was treated as opposed to the way drugs were treated. Indeed, a renowned CCSVI American blog (https://ccsviinms.blogspot.com/2017/11/exciting-ms-treatment.html) commented that if the results had come out from a drug study, neurologists would have reacted differently because each drug they proposed as a therapy for MS patients was not a cure and could only be useful for a subgroup of MS patients, as CCSVI activists also reported:

> They had stopped giving me all the drugs because of side effects in a very famous Italian hospital. So, I was looking for other treatments other ways, I saw that there was this experimentation on CCSVI. (…) I have seen new hope in this research (Edoardo).
>
> We inquired about CCSVI because a neurologist gave him a drug, while a neurologist from another centre

> gave him a different drug, but relapses were more and more frequent, he was not well, he was no longer what he was before (Giorgia).
>
> Basically, when I was diagnosed, I had a doctor who was not a neurologist, who told me look, all the drugs they propose is nonsense, there is no cure, you have to keep this disease with patience (…) and in the end I came across this CCSVI thing and, at first it seemed a bit like another hoax, right? Of this type ... but then I also met people in person, that is, in the sense I went beyond the use of the computer... (Daniele).

In the same edition of the journal, *JAMA Neurology*'s editorial was entirely dedicated to the Brave Dreams study. Despite the fact that the final words of the conclusions of the study were a clear request for further scientific investigation into the potential benefits of venous angioplasty for at least a subgroup of MS patients, the Editorial was entitled: 'Combating the Spread of Ineffective Medical Procedures. A Lesson Learned From Multiple Sclerosis' (Green, Kamel and Josephson, 2018), characterising venous angioplasty as ineffective and highlighting the dangers of social media as a purveyor of false medical hope.

The Editorial praised the democratization of knowledge thanks to the "Information Age" but underlined that "these advances have come at a cost". The Editorial noted that the "value of expertise has at times been degraded, and the careful judicious review of data has sometimes been compromised in the effort to quickly circulate new findings to the largest possible audience" characterising this as "an important danger that we need to address" (15). Specifically, the Editorial argued that the neurological community had been endangered by "the creation of Facebook pages and patient interest Groups" (15) advocating the CCSVI theory. Language and cultural barriers were influential here, as the only reference to social media-based patient interest groups in the Editorial was the English-speaking Canadian reality (see Ch. 1.4), even if the Brave Dreams study was conceived, planned, funded and run in Italy, solely with Italian scientists and strongly advocated since 2010 by Italian social media activists.

The conclusions of the Brave Dreams study coupled with the Editorial served as a gravestone for CCSVI in MS. Henceforth, the neurological community and the worldwide traditional MS associations would dismiss the scientific validity of CCSVI while blaming social media for propagating an unsound therapy. This message was spread to the mainstream media and the world medical community at large. In Italy, AISM published a dossier entitled 'CCSVI and MS, the last word' (AISM, 2017a:33), immediately after the online publication of the Brave Dreams study, introduced by an illustration showing a happy doctor freeing a happy patient in a wheelchair from a bandage covering their eyes from the truth. The strength of consensus was such that even some administrators of Facebook groups where MS patients could discuss any aspect of MS, felt empowered to ban anyone who mentioned anything related to CCSVI and Zamboni. The activists framed this moment as the successful completion of a co-optation process that had begun in 2010.

(7) The 'no response tactic' in the CCSVI and in the 2003 anti-war movements.

I compare the case study CCSVI and MS to the one put forward by Dean, about the anti-war movement and the Bush administration before the invasion of Iraq in 2003

(2005:52), on the basis of the *no response* tactic. Alternative media covered the anti-war critiques supported by the United Nations' reports (Nichols, 2004), against the evidence of weapons of mass destruction in Iraq set forth by the Bush administration. Alternative media also covered anti-war street protests around the world, but circulated within the medium, they were not reported by mainstream mass media. In the CCSVI Italian case, only social media i.e., Facebook, relaunched by a few MS internet forums, provided through activists information on the scientific paper published about the discovery and news about CCSVI, providing also international news' videos with subtitles translated into Italian on YouTube. The circulation reached more and more MS patients through social media, and the message was relaunched by the mainstream media only later, when in Italy the process of co-optation theorised by activists had already started.

In the anti-war case it was ultimately a political/governmental decision to declare war backed up by the "smoking gun" which the Administration vowed would not be allowed to become a "mushroom cloud" (Gellman and Pincus, 2003). The decision could be implemented notwithstanding the fact that part of the public opinion, and hundreds of thousands of people peacefully marching around the world, were against. The Bush administration acknowledged the message of the anti-war movement as a different opinion, but they had a no-response behaviour in order to avoid confrontations which could have undermined the evidence which justified the military invasion of Iraq. As the Bush administration had already started co-opting the American public opinion recalling the deadly 9/11 Al-Qaeda attack on the American soil of 2001 (MSNBC Documentaries, 2013), when it was presented the evidence of weapons of mass destruction in Iraq, that is the smoking gun, a no-response behaviour was implemented as soon as the anti-war movement started, and the *fantasies* of communicative capitalism made the rest. In February 2003 a small vial which was deemed to contain anthrax, was theatrically held by the US Secretary of State before the United Nations Security Council and presented as the final proof which a month later led to the invasion of Iraq by an international coalition (Roberts, 2021).

The situation in the CCSVI case required a more articulated process to reach the definitive phase of no-response. At first there had been a complete non-acknowledgment and denial from the neurological community and the traditional MS associations. Ongoing studies on the CCSVI theory had been available to the medical community through conferences and publications in international medical journals. This was true since the first conference at the Royal Society of Medicine in London (Zamboni, 2006) whose publication was subsequently relaunched by a press conference lead by the Chancellor of the University of Ferrara (Maggi, 2007) and by a renowned national newspaper, il *Corriere della Sera* (Jacomella, 2007). However, it had never been taken into account by the neurological establishment and by the traditional MS patients' associations worldwide, and the news was never highlighted to the general public or MS patients.

The traditional Italian MS patients' Association AISM, between 2006-2008 even refused to fund the real first two interventional studies on CCSVI and MS patients led by Zamboni (Corneo, 2012), the latter of which was eventually funded by a provincial bank-sponsored Foundation Hilarescere which was founded in 2008, one year before the inception of the CCSVI movement. Furthermore, AISM also silenced internal attempt at advocating CCSVI during the year 2009 by a provincial section of the association before the movement started (see Ch. 3.4). AISM pretended nothing ever happened, a complete denial of the realities of the new-born CCSVI research. AISM publicly acknowledged for the first time the news on the new theory only on 18 September 2009, three years after the first scientific news was published followed by other publications and requests to participate into studies, one months after the CCSVI Italian Facebook Page was created, and 10 days after the first international scientific conference on CCSVI was held on September 8 in Bologna, Italy (Cori, 2009). AISM's communication was welcomed by the activists, but the press release referred to the conference held in Bologna in an understated fashion not considering any further action to be undertaken on the subject but, already on the defensive, urging patients not to abandon the usual drugs (AISM, 2009b). Furthermore, it did not offer any information to the patients:

> From traditional associations, you could not find an answer, indication, listening, consideration, and you even had the feeling of annoying them or that, anyway, that from them you would not have found a support (Emma).

(i) The smoking gun

It was only when patients' social media movements raged against the association and against their doctors since late 2009 that the association fully acknowledged the CCSVI research. Activists were in possession of scientific studies allegedly proving the efficacy of the new theory: they had first the smoking gun, the 2009 study which was printed and handed to their neurologists. For the traditional association it was not anymore enough to pretend nothing existed in order to keep the status quo over the choice of therapies, also because patients in the presence of the smoking gun started to challenge their neurologists with some refusing to take any more drugs:

> I was driven by the lack of responses from doctors at the hospital's neurology departments (Lorenzo).
>
> About the CCSVI, if you go to the neurologist, it is difficult for him to come and tell you "look actually there is another study, it is having these and these results". When you ask, not everyone actually gives information on the subject (Luisa).
>
> Neurologists took it as a field invasion ... there was the absolute curse they treated you as charlatan healers (…) Clinical trials are often oriented, funded by pharmaceutical companies. Then it becomes doubtful. They will never tell you all the damage a drug does (Arianna).
>
> From there my journey began (…) I stopped the drug (Vittoria).

Some of the patients who did not want to take drugs even if the CCSVI Facebook Page always advised to follow the prescriptions of the doctors, have reported that they were labelled by their doctors as “bad patients” also in medical reports, or that they were refused further visits. Patients could not be coerced to take medicine. At that point AISM, as confirmed by its president Amadeo in July 2010 before the Italian Health Governing Body - Consiglio Superiore della Sanità, CSS (Amadeo, 2010), avoided confrontation and calmed enraged patients refusing drugs, by promising to set up studies on the new theory, appearing to be on the side of the patients and making sure they would not abandon their drug therapies.

(ii) No response

In order to adopt a no response tactic, AISM needed a bigger smoking gun than the one of the activists. AISM quickly set up an epidemiological study on 1,867 people in 2010, CoSMo (see above Ch. 5.5), to verify how many MS patients had CCSVI. The study was contested since its inception by Zamboni who opted out of the Steering Committee in September, before the start because he had proof the study was not going to run a genuine protocol (see Ch 3.4), among others, too many people to be tested in a very short time without a sufficient number of well trained operators. The patients' turmoil on social media and with their neurologists advocating CCSVI was such that partial results revealing negative outcomes were released twice (Adnkronos Salute, 2011; Jeffrey, 2012), before the completion and before being peer reviewed, in the two years before the publication of the double blinded study (Comi et al. 2013).

The negative results were characterised as early as possible as the final word on the matter, which allowed AISM to foreclose further scientific discussion on the new theory, with a tactic of no-response. In fact, instead of responding to activists or engaging in rebutting further studies on the new theory, they produced and sent status quo messages with new studies on drugs and dedicating more attentions to non-drug-competitors alternatives, as diet and mindfulness, also with the help of MS patients as social media influencer.

The impressive control over the mass media discourse which improved the volume of contributions (fantasy of abundance), reached stickiness and dominance of the circularity among health policy makers, medical community, patients, and the society at large. It rendered almost useless in Italy the completion of the publicly funded study Brave Dreams most awaited by activists, as a doctor reported:

> There are doctors who absolutely do not believe in this thing and who cling to anything to say that this technique that we use, angioplasty, is something negative, that it's useless, that it does not work, that it doesn't do anything. Also via social media, often it is patients themselves, since behind them there is always a neurologist or someone who denigrates us with all his might, in an absurd way and without any scientific basis, and then they enter into certain discussions where there are people who talk about absolutely positive experiences and in a calm way and other people arrive with those ideas instilled by doctors and do a whole series of counter propaganda that has nothing of scientific or ethical value... (MD Simone).

In addition to the no response tactics, which progressively separated and isolated the CCSVI debate from medical and public MS discourse, the fantasies of communicative capitalism would slowly complete the work in the following years:

> From year to year the new members of the CCSVI association have gradually decreased, so it means that this great wave with which we started has gradually waned (Aurora).

Every pro-CCSVI engagement became a technological fetish in the more and more dispiriting contribution in distributing the message, in a game of global chatter which obfuscates any real counter-power position. The Italian CCSVI associations remained active in the space of places through 2017 until when, with the publication of the study Brave Dreams which according to activists completed the co-optation process, they drastically reduced their activities and media pressure.

The broken dreams and disappointment of those who had spent 8 years advocating every day the CCSVI research and the study Brave Dreams itself, provoked some major repercussions. The American *CCSVI in Multiple Sclerosis* Facebook Page on 30 November 2017, right after the publication online of Brave Dreams on 18 November, changed its name to *The Vascular Connection to Multiple Sclerosis*, removing the word CCSVI, and greatly reduced its activity. A couple of years later on 9 April 2020 (exactly 10 years after its creation), the first Italian association *CCSVI nella Sclerosi Multipla* officially changed its name to *Associazione Sclerosi Multipla Albero di KOS ONLUS*, also removing the word CCSVI. The original Italian Facebook Page *CCSVI nella Sclerosi Multipla* did not change its name and to date it is the most active CCSVI social media advocate, disseminating news about ongoing research on CCSVI and MS. It also created with the same name on 19 October 2017 a Facebook Group whose algorithm allowed users' posts to be more visible so that patients could better interact and exchange information on CCSVI diagnosis and therapies where available. However, as a movement the Facebook Page and Group reached a form of "latency" (Diani, 1992:16) since 2018.

(8) Resisting co-optation as a challenge to communicative capitalism

The fantasies of the communicative capitalism theorised by Dean have been experienced in the activities of the social media movement advocating the correlation between the new theory and MS. However, the fantasies' features have also been positive for the activities of the social media movement. In the fantasy of abundance, the circulation of a message by those who were unfamiliar with its content gave it the possibility to reach and to be understood by those who otherwise did not have the chance to know it, as, for example, the thousands of new MS patients that every year searched for information about the disease. In the case of the fantasy of participation what appeared as technology fetishism for the CCSVI movement was in the first period a social prosthesis (see CH. 5.4), especially for those users with physical impairment.

The fantasy of wholeness is modular, i.e., it can start within a context related to a subject, and only when the volume of media chatter rises around the subject, the fantasy moves to a more global context where the debate loses strength and meaning. The no-response tactic can be implemented when decisions can be taken without any obstacle, otherwise a more articulated process of co-optation is necessary towards the production of the smoking gun, that is the revealed truth as it happened for the CCSVI movement. Whether or not to take the drugs prescribed by the neurologists was a patient's decision – it could not be imposed (as the war was imposed on Iraq in Dean's case study). For this reason, a more articulated persuasion was required not only directly towards MS patients, but also to their surrounding society and ultimately to the patients' family, in order to motivate MS patients to voluntarily accept the scientific truth.

When among the Italian activists after a few months it was clear that the traditional Italian MS patient association was not crystal clear in its intention, the social media movement decided to assume an official vest. The associations became the legal representative of the new scientific theory and its on-going research before the media, the medical community and health policy, putting a stake in the real world, attempting at resisting mass media control by the traditional MS association. This was possible also with the help of public figures like the widow of Luciano Pavarotti, Nicoletta Mantovani, who were invited in popular tv shows and interviewed by national newspapers.

Resistance to co-optation is arguably possible with activities on the ground, with the formation of an independent legally organised democratic structure which keeps alive the social media discourse with the one based on physical contiguity to allow an interaction with health care officials. The first MS association born from the Facebook Page exercised its counterpower among others in the following ways: it met with national health policy makers, regional health institutions, and national political representatives; organised conferences and public events such as concerts also in the presence of the higher state representatives (https://www.ilfattoquotidiano.it/2015/05/06/ccsvi-la-settimana-della-consapevolezza-dal-3-al-10-maggio-ci-ascoltino/1621090/); drew photographic and literature contests; collected donations to fund research into the new theory; delivered scientific reviewed press releases to press agencies which were then relaunched by tv and newspapers; commissioned calendars, tv and newspapers ads (https://www.youtube.com/watch?v=cvpee__7yEs), and short movies.

CONCLUSIONS

As one of the first case studies of a social movement in which all the core activities of the movement occurred on social media it was important to examine the extent to which this movement was similar to on-the-street social movements and the ways in which it differed. I have found that the experience of offline activists vs social media activists, from organizing through decision-making and protest, overlaps to a significant extent. While it could seem that social media, by virtue of offering only a finite number of modalities, would limit the ways in which people may interact, these limitations are arguably no less than they would be in the real world. Online activism also allows for interaction with no geographical or time restrictions (if someone leaves a comment, you may still read it and react the following day), whereas in the physical world, activists must coordinate in both space and time to organise effectively. The case study demonstrates how a group of geographically dispersed patients, several of them with physical limitations, was nonetheless able to converge on social media and build a social media movement able to transform realities in the real world.

I review here the answers to the three central research questions posed by this thesis, which provided the foundation for the chapters 3, 4 and 5, and the conclusions.

The answers to the first research question, that is, how social media interactions empowered patients and caregivers, revealed that social media were an easy-to-use instrument that gave patients a unique opportunity to virtually come together on an equal footing to share experiences and resolutions. For many patients it was the first time they had the chance to emotionally know the stories of pain and impairments directly from other people with MS. Social media allowed patients to receive information on the discovery that were not given or discussed by mass media or by their neurologists and allowed them to know directly from other patients the positive results of the new therapy. They understood it was not a cure but a new hope that would redeem them from their broken lives imposed by the disease. They learned how the traditional MS associations and neurologists refused and ridiculed other scientists and considered it an injustice which further motivated them in advocating for additional research.

Regarding the second question, that is what motivated them to become a movement, the research revealed that social media were the squares in which the people spontaneously developed networks through mere interaction and where they had the opportunity to help by taking action without any illegal occupation or activity. Amid the ferment of the multitudes, they did not any longer feel alone and abandoned, and this gave strength to their action with a burst of enthusiasm which was contagious in its feeling of togetherness and empowerment. They knew that alone they would not have any influence, and social media allowed them to unite from their own homes.

The answers to the last research question, that is, what are the elements that propelled the movement to create formal associations, revealed that having experienced the reality of joy and success working and reaching results together on social media, the evolution from the Facebook Page to the creation of an association was a question of a few months. It was a spontaneous, natural path for the activists also those, the majority of whom in the past never had or wanted to have any kind of associative involvement. The association grew out of a social media movement that wanted to go a step forward because the existing MS associations failed in representing them. A statute, a deed of incorporation to be accredited to the institutions and all the bodies that govern public health care in Italy, enabled them to stipulate agreements and have a greater capacity of persuasion in favour of further research.

Castells based his timeless time analysis, discussed in Chapter 4, on observations of the Occupy Wall Street movement, born and based in the space of places, which required physical contiguity. I would suggest that the CCSVI movement is an example of an actor born and based in the space of flows, which required connectedness and the communion of social practices. Unlike the Occupy Wall Street movement, the CCSVI social media movement did not need to occupy physical space to become and continue to exist as a movement. The movement was counter power in the space of flows and operated at the same time as counter power in the space of places but without occupying streets and parks.

Social media were not instruments where instructions were communicated, but they were the space, as in the squares, wherein decisions were discussed and taken. Such decisions were then implemented both in the space of flows and in the space of places, publicly and privately. The CCSVI social media movement enacted a counter power activity in the space of places when for example patients confronted vis-à-vis their neurologists, when they tried to encourage favourable institutions' choices interacting with officials and when privately or in public meetings, they challenged their traditional MS association. Shortly after, the movement became counter power also through formal CCSVI associations, as legal representatives acting in the space of places trying to wedge not just into the mainstream media and public opinion, but more importantly into the control room of Italy's nationalised health service. Notably, social media did not serve as the instrument of the first CCSVI association born from the Facebook Page. Rather, it was the association which emerged to support the patients' social media movement, as an instrument to allow the activists to deal with institutional authority, something a newspaper or a Facebook Page can not do.

The interviews and autoethnography showed that many of the CCSVI activists in 2009-2010 turned to social media, many for the first time, for information about the new discovery and interaction with fellow MS patients which would have been impossible without social media's ability to bring people together despite their geographical distance. Social media also allowed them to engage according to their own schedule, while continue to meet their responsibilities at work and in the family. Other activists turned to social media because of physical and mental impairments which per se penalise the free will of movement in the public-space architecture.

Many activists described how social media offered them a more functional social life without having to move from their own private architectural spaces, because they had no time to socialise and meet outside of their work or family life, if not when the friendship had already been built on social media. The digital architecture allowed people to live real emotional connections and foster deep friendships which arguably were the humus of the counter power timeless time experience itself, and that eventually can be expressed also with physical contiguity. This went well beyond the traditional self-help function, typically expected by patients in online communities.

It would follow from this, that in the network society drawing a dichotomy in the human experience of connection between the space of flows and the space of places might not always be the best frame for analysis. Both urban space and social media space are shaped by an architecture, whether it is made of real bricks or digital bricks within which people act. Programmers create the protocols that allow people to be able to choose alternatives within social media, and drive their choices starting from the default settings of apps and browsers, while in the physical world it is the architects who define the universe of options through the designs of their rooms, buildings and streets. Laws, social norms and the markets also constrain and shape human behaviour in both the space of places and the space of flows, though perhaps not always in the same way. The space where human interactions can foster social life and deepen personal emotional relations could be named the *space of humanity.* This is the space where timeless time and the realities of the counter power experience can happen, independent of whether that space is surrounded by real or digital bricks.

The experience of people with physical impairments can help to further elucidate the nature of the space of humanity as it exists online. For such people, forging connections in the space of places presents challenges that may be overcome by operating in the space of flows. Firstly, notwithstanding architectural impediments, at times they cannot fulfil the social needs of people that for example want to engage in open air activities. The second challenge is the involuntary behaviour of people who seek to help them. That is, when in the presence of such a person, people usually and rightly seek to enact a higher level of fair play in sharing the same space of places, for example not taking unconscious advantage of different moving abilities, or when helping excessively, almost forcing the reality of limited possibilities. This creates a barrier in the interaction, embedded in the feeling of not being treated for who one is, but for what one is not able to do. This is when impairments become the frontrunner of any relations and hinders the personality. On social media, however, one can live one’s persona without the cumbersomeness of the body whose impairments at times constrain the building of human relations. On social media physical impairments do not limit the extent of the emotional interaction which puts everybody at the same starting point. This seems to be possible on one side, when one does not feel compelled to enact fair play, and on the other side, when one is not being treated as a category in need of help. When both sides move away from the protocols of behaviour, that is when both sides enter the space of humanity.

When the movement was created in 2009, Facebook was a space of humanity, occupied by real people transmitting real emotions. It was not that the activists sought to stand against the institutions, rather they sought to involve and work together with institutional actors. However, at that time, institutional actors did not perceive social media as spaces of humanity where meanings are built. Instead of joining MS patients on social media and pursuing research into the new discovery together, their strategy was to stonewall, deny and attack the credibility of social media, thereby strengthening the counterpower movement. As a consequence, the research they ultimately undertook became an instrument of co-optation instead of a gesture of solidarity.

Builders of social movements may find utility in mapping emerging social media platforms to evaluate the extent to which they can become a space of humanity where things can happen for real and not merely as a showcase. Further research could include elucidating the elements required for a social media platform to become a space of humanity.

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