
Original Article

From embodied risk to embodying hope: Therapeutic experimentation and experiential information sharing in a contested intervention for Multiple Sclerosis

Fadhila Mazanderani^{a,*}, Jenny Kelly^b and Ariel Ducey^c

^aDepartment of Science, Technology & Innovation Studies, University of Edinburgh, Old Surgeons' Hall, High School Yards, Edinburgh EH1 1LZ, UK.

E-mail: f.mazanderani@ed.ac.uk

^bW21C Research and Innovation Centre, Cumming School of Medicine, University of Calgary, GD-01 TRW Building, 3280 Hospital Drive NW, Calgary, AB T2N 4Z6, Canada.

E-mail: jekelly@ucalgary.ca

^cDepartment of Sociology, University of Calgary, 2500 University Drive NW, Calgary, AB T2N1N4, Canada.

E-mail: aducey@ucalgary.ca

*Corresponding author.

Abstract People who pursue unproven therapies are often portrayed as 'desperate' individuals duped by medical racketeers peddling 'false hope'. These patients, in contrast, present themselves as empowered citizens who have taken an informed decision to pursue an experimental therapy. This paper explores the latter perspective through the case of the so-called 'liberation procedure': a controversial endovascular intervention proposed as a treatment for Multiple Sclerosis (MS). Drawing on interviews with 48 people affected by MS, we analyse the decision-making processes and justifications thereof of those who had the procedure ($n = 31$). While the decision to have the intervention might not have been justified according to the standards of evidence-based medicine, it was nonetheless premised on a shared 'experiential logic' – conceptualised as a logic of embodied risk/hope – that extends beyond the specific condition and therapy in question. The paper explicates this logic, concentrating on patients' negotiations of (a) risk and uncertainty; (b) expertise and evidence; and (c) hope and experiment. In particular, we foreground how, through a combination of therapeutic experimentation and experiential information sharing, patients turn their own bodies into (contested) sources of hope for themselves and others, which, in turn, shapes their embodied experiences of living with MS in the present.

BioSocieties (2017). doi:10.1057/s41292-017-0066-z

Keywords: multiple sclerosis; hope; risk; experiment; evidence; experience



Introduction

People with incurable health conditions who pursue unproven therapies are often portrayed by the media, policy-makers and expert scientific commentators as ‘desperate’ individuals duped by medical racketeers peddling ‘false hope’ (as opposed to the ‘realistic’ hope offered by evidenced-based medicine) (Petersen *et al*, 2015; Prasad, 2015). This is especially the case for those who travel abroad for controversial treatments not provided or sanctioned by their own country’s national healthcare system.¹ In contrast, these patients present themselves as empowered individuals who have taken an informed decision to pursue an experimental therapy. With a few exceptions, focused mostly on stem cell therapies (Song, 2010; Petersen, *et al*, 2014; Prasad, 2015), there has been little in-depth empirical research into patients’ perceptions and experiences of such treatments.

This paper contributes to social science research on people’s experiences of controversial therapies for conditions that conventional Western biomedicine has insufficient treatment options for. More specifically, it focuses on the case of people with Multiple Sclerosis (MS) who chose to undergo the so-called ‘liberation procedure’: an endovascular intervention, which was controversially proposed as a treatment for MS in 2009 (Zamboni *et al*, 2009a), prompting a wave of international patient activism and associated medical travel. Patients who resolved to have the liberation procedure were regularly framed, even by those sympathetic to their situation, as being led astray by dubious research, misguided activists and unscrupulous practitioners motivated by financial gain.² This framing was challenged by a countervailing narrative in which, in newspaper and magazine articles, on television and the internet, and in interviews with us, the very same patients presented themselves as informed citizens who, let down by mainstream biomedical research and their national healthcare systems, were *choosing* to have an experimental therapy, fully cognisant of the risks involved and the uncertain nature of treatment outcomes.

Drawing on interviews with 48 people affected by MS, living in seven different countries (Canada, America, the UK, Australia, Israel, Ukraine and Vietnam), we analyse how patients who had the liberation procedure described their decision-making processes ($n = 31$). While the accounts we collected were personal and highly individual, there were striking commonalities in how interviewees explained the decision(s) they had taken. Our findings, furthermore, correspond closely with research on the experiences of patients with various other health conditions who similarly chose to have unproven therapies (Song, 2010; Petersen *et al*, 2014; Prasad, 2015).

Through the analysis presented below, we show how, in the context of controversial therapies for unpredictable progressive diseases such as MS, decision-making involves uneasy negotiations around different forms of uncertainty. Patients and those close to them navigate these uncertainties through ‘weighing up’ competing claims about therapeutic risk, treatment efficacy and potential health outcomes. For those who choose to pursue unproven therapies, this weighing up is premised on a therapeutic rationality very different to that

1 On the rise of medical travel (or ‘transnational healthcare’ as some, like Botterill *et al* (2013) and Bell *et al* (2015), prefer to call it) as well as the widespread attention, it has received from the media, academics, medical practitioners and policy-makers see Turner (2007), Murdoch and Scott (2010), Whittaker *et al* (2010).

2 See, for example, the Grady (2010), the BBC (2011), Ubelacker (2012) and Fayerman (2013), for such coverage of patients’ responses to the theory and intervention.

found in mainstream biomedicine – one in which the shared *experiential*, and above all *embodied*, predicament of living with a particular condition is foregrounded. Thus, we argue that while the decision to have an unproven therapy, such as the liberation procedure, might not be justified by the standards of evidence-based medicine, it is nonetheless premised on a particular ‘experiential logic’ that is not only shared by those undergoing the same treatment, but extends beyond any one specific therapy and condition.³

In this paper, we explicate some of the key terms of this logic, concentrating on how the people we interviewed: (a) negotiated various risks and uncertainties associated with life with MS and the liberation procedure specifically; (b) weighed up different forms of evidence and expertise to legitimise or delegitimise the treatment; and (c) understood the meanings and implications of hope in relation to the therapeutic experimentation they saw themselves as engaging in. We conceptualise this logic as one of ‘embodied risk/hope’, in which, through a combination of therapeutic experimentation and experiential information sharing, patients come to ‘embody’ hope for themselves and others, counterbalancing the sense of embodied risk they live with on a daily basis.

The interviews we draw on are primarily with patients who have had the liberation procedure ($n = 31$), although we do occasionally compare their accounts with those who were either unable or chose not to undergo it ($n = 17$). A substantial majority of our interviewees adopted a positive attitude towards the procedure and the research that supports it, while being openly critical of mainstream MS research, treatment and care. This represents only one partial side of an acrimonious public debate. It is not our aim here to analyse the debate around the liberation procedure; nor is it to assess evidence and endorse or condemn either position. Rather, we seek to explore the distinctive rationality underpinning decision-making in cases where people pay considerable sums of money to have unproven therapies, often travelling long distances, in contravention of the prevailing healthcare advice.⁴ This is a rationality which, we suggest, needs to be understood for what it is and taken seriously, rather than dismissed as ‘irrational’ or psychologised as ‘desperate’.

Given the emphasis placed on patient choice in contemporary healthcare, as well as the rise in people choosing experimental therapies, it is essential that, as Alan Petersen and colleagues have argued, we explore not only how and why patients make such ‘choices’, but also how they

3 Our use of ‘logic’ is not meant to imply that the patients’ decisions were ‘logical’ or ‘rational’ in the sense that we have judged them to be ‘justified’ or ‘sound’. Rather we use the terms to signify that the practices we analyse have an internal coherence, albeit one that differs from the dominant logics of biomedicine. There are a number of alternative social scientific terms and concepts that we could have drawn on here, such as discourse, mode of ordering, regime or style. Taking inspiration from Annemarie Mol’s use of the term (Mol, 2008, p. 8), we use logic to indicate that the practices we explore have an underlying, if contingent and fragile, rationality that holds them together, linking words, practices and materialities in particular situated ways. In addition, we chose to use logic over other possible alternatives because it chimes with how our interviewees described their decision-making practices and would be recognisable to them.

4 A number of private medical ‘tourist’ clinics in countries such as Poland, Bulgaria, India and Cost Rica offered the intervention. It was available privately in the US and UK (in some cases as part of research studies, although patients still had to pay). Initially, if the patient could find an interventional radiologist willing to perform the procedure it was available in Australia, but finding someone willing to do so was not easy. As the intervention gained increased media attention and become more controversial, many of the radiologists and clinics that offered it stopped doing so. Costs varied greatly depending on country, radiologist, number of angioplasties and/or stents and could be anywhere between \$10,000 and \$15,000 per procedure, excluding travel and accommodation.



experience and rationalise them (Petersen *et al*, 2014, p. 681). In other words, what kinds of logics or rationalities underpin patients' decision-making processes. Cases such as the one analysed in this paper provide opportunities for enhancing our understanding of the collective 'risk epistemologies' patients develop alongside, within and, at times, in conflict with the wider anticipatory regimes that permeate contemporary biomedicine (Lupton and Tulloch, 2002; Adams *et al*, 2009). At the same time, they have the potential to provide insights of practical relevance to biomedical researchers, practitioners and policy-makers who are increasingly required to respond to controversial therapies such as the one described below.

Multiple Sclerosis and the Liberation Procedure: Background and Context

MS is the most common neurological condition to affect young adults and, although extremely unpredictable in terms of both symptoms and prognosis, for most people it is a progressive disease that results in some level of permanent, often severe, disability (Trojano *et al*, 2003; Compston and Coles, 2008). At present, there is no cure and although treatment options are available they are not suitable for all patients and are often accompanied by severe side effects. Disease modifying drugs (DMD) have been shown to reduce relapses, but are less successful at altering the long-term progress of the disease and cannot reverse neurological damage (Compston and Coles, 2008). As a consequence, people with MS not only cope with changeable, extremely disruptive, symptoms and drug side effects; they face an uncertain future with the prospect of declining health and mobility (for research on people's experiences of MS see Stewart and Sullivan (1982), Robinson (1990), Hakim *et al* (2000) and Lexell *et al* (2009)). Unsurprisingly, there is a long history of MS patients turning to alternative and complementary medicine as well as heterodox and experimental therapies originating from within the (bio)medical sciences (Robinson, 1990; Bowling, 2011). The liberation procedure is one of the latest to emerge in the latter category.

In 2009, Italian physician and former vascular surgeon Paolo Zamboni and colleagues published an article in the well-respected *Journal of Neurology, Neurosurgery and Psychiatry* which suggested that specific abnormalities in the jugular and azygous veins – what they termed chronic cerebrospinal venous insufficiency (CCSVI) – were strongly associated with MS (Zamboni *et al*, 2009b).⁵ Towards the end of the same year, the results of a prospective open-label study that used venous angioplasty – a relatively minor endovascular intervention involving the insertion of a balloon catheter to widen stenosis (blockages) in veins – to open the jugular and azygous veins of MS patients diagnosed with CCSVI was published in the *Journal of Vascular Surgery* (Zamboni *et al*, 2009a). Based on research with 65 people with MS, the authors argued it was safe to perform angioplasty on people with MS and, moreover, that doing so was positively associated with better clinical and quality of life outcomes, especially in patients with the most common, relapsing–remitting, version of the disease (Zamboni *et al*, 2009a). Thus, in addition to challenging the contested, but nonetheless predominant, theory that MS is an auto-immune disease,

⁵ Zamboni initially proposed the idea that vascular abnormalities might play a role in MS in 2006 (Zamboni, 2006). However, it was with the publication of the research studies in 2009 that his work started to receive widespread international attention from patient groups, the media and MS researchers.



Zamboni proposed venous angioplasty – quickly dubbed the ‘liberation procedure’ by supporters – as a new treatment modality, arguing that it had the potential to relieve MS symptoms and alter disease progression (Zamboni *et al*, 2009a, b).

People affected by MS across the world responded to Zamboni’s research with considerable interest. Greatly aided by the use of social media, such as forums, Facebook and YouTube, within a very short space of time patients and their family members were searching for medical practitioners (primarily interventional radiologists) willing to perform the relevant tests and, if deemed necessary, treat them for CCSVI (Rhodes, 2011; p. 15). Some patients were successful and soon they and their family members were sharing the names of sympathetic practitioners (Rhodes, 2011, pp. 28–30). Patients who had the procedure were quick to communicate their experiences, and while not all of these were straightforwardly positive, many people reported dramatic improvements (Mazanderani *et al*, 2013; Gafson and Giovannoni, 2014; Koschack *et al*, 2015), with the widespread circulation of positive accounts further encouraging patients to have the procedure (Ploughman *et al*, 2014; Snyder *et al*, 2014; Sudau *et al*, 2014).

Despite the enthusiasm of patients and the support of a small, but in some cases high-profile, group of biomedical scientists, radiologists and vascular surgeons, the majority of neurologists were vocally sceptical about CCSVI and its putative association with MS (Doepf *et al*, 2010; Mayer *et al*, 2011; Baracchini *et al*, 2012; Reekers, 2012). Furthermore, they raised serious concerns about the risks of performing angioplasty on the neck veins of MS patients. For, although angioplasty is a well-established, almost routine, intervention in other parts of the body, it is not typically done in the veins of the neck, and, prior to Zamboni’s research, it had certainly not been considered a therapy for MS. Concerns about the safety of the procedure were bolstered by reports of complications experienced by some patients and by the fact that a few people died after having stents inserted in their veins. Consequently, national MS Societies, MS researchers and health regulators (such as the National Institute of Clinical Excellence (NICE) in the UK, the Food and Drug Administration (FDA) in the USA and the Canadian Institute of Health Research (CIHR)) stated that CCSVI and the liberation procedure was not supported by scientific evidence, and venous angioplasty should only be performed on MS patients as part of appropriately designed research studies.⁶ As a result, interventional radiologists who had initially been willing to provide the procedure in countries such as Canada, the USA and Australia were deterred from doing so, making it increasingly difficult for patients to access either testing or treatment in their own countries.

This prompted an angry response from patient groups, triggering a groundswell of international CCSVI patient activism, with people affected by MS petitioning their healthcare providers, national MS Societies and politicians for the liberation procedure to be made available in clinical studies or on compassionate grounds (Laupacis and Slutsky, 2010; Chafe *et al*, 2011). However, as the procedure was (and remains) not available through the national healthcare systems of most countries – including Canada, which emerged as a fulcrum for patient activism – thousands of people travelled to private clinics

6 For the FDA’s warning about CCSVI and the liberation procedure see FDA (2012); for NICE’s guidance see NICE (2012); for the systematic review and advice of the CIHR see CIHR (2011).



(e.g. in Poland, Bulgaria, India, Costa Rica) or, where possible, took part in research studies (e.g. in the USA and Italy) in order to have venous angioplasty.

To date, numerous studies, spurred on and even funded by patient activism, have been conducted on the association between CCSVI and MS. Zamboni's initial findings have not been replicated and the consensus within mainstream medicine is that if CCSVI does exist as a distinct syndrome it is not causally related to MS. This would make the liberation procedure, at best, a placebo, and, at worst, dangerous for patients (Doepf *et al*, 2010; Mayer *et al*, 2011; Traboulsee *et al*, 2014; Tsiygoulis *et al*, 2015). Yet despite the biomedical establishment repeatedly announcing CCSVI's 'death knell' (Stolz, 2015), a cohort of scientists continues to pursue research on the vascular dimensions of neurological diseases, including MS, and have created a society devoted to this endeavour (<https://isnvd.org>). Moreover, many people with MS who have undergone the procedure feel that they benefited from it and an international contingent of patient activists are still advocating for further research into the role of the vascular system in the disease.⁷

Methods

Recruitment, sampling and data collection

This paper is based on an analysis of qualitative interviews with 48 people affected by MS (see Table 1). These interviews were conducted as part of two separate projects. The first project, which took place in Canada (July–November 2011), explored how people with MS used online resources to learn about CCSVI and how these practices informed their decision to pursue the liberation procedure. The second project, which took place in the UK (November 2011–August 2012), explored how people affected by MS used internet technologies, with a specific emphasis on the seeking and sharing of experiences. While the liberation procedure and CCSVI were not the key focus of the study, it was being widely discussed online at the time and interviewees were explicitly asked about their opinions on and experiences of it.

Participants for both studies were recruited online. For the Canadian study, the research was advertised on the CCSVI discussion board on a patient-led forum for people affected by MS, www.thisisms.com (TIMS); the Facebook page of the Alberta Chapter of the Multiple Sclerosis Society of Canada; and the website and Facebook page of Direct MS, a non-profit organisation that was supportive of CCSVI. The UK study was advertised on the research webpages of four UK-based MS charities – the MS Society, the MS Trust, the MS Resource

⁷ At the time of writing, the most recent update on CCSVI-related research was a presentation given by Anthony Traboulsee (Associate Professor of Neurology at the University of British Columbia) at the Society for Interventional Radiology's annual scientific meeting on the 8th of March 2017. Based on an unpublished double-blinded trial of 104 people with MS, the study found no association between venous angioplasty and improvement in MS symptoms 48 weeks post the intervention (Mulholland, 2017). Zamboni's much awaited BRAVE DREAMS (BRAIn VENous DRainage Exploited Against Multiple Sclerosis) trial has yet to be completed (<http://bravedreams.ccsvi-sm.org/>). While support for the liberation procedure has dwindled, many people believe the intervention had a positive effect on their health and activists continue to support further research, for example, the CCSVI Alliance (<http://ccsvi.org/>), the Canadian Neurovascular Health Society (<http://www.cnhs.ca/>) and CCSVI Australia (<http://ccsviaustralia.com.au/>).

**Table 1:** Overview of interviewees

Total number of participants	48
Canadian study	36
British study	12
Female	33
Male	15
Nationality	
Canadian	28
British	10
American	6
Israeli	1
Ukrainian	1
Australian	1
Vietnamese	1
CCSVI testing and treatment status	
Not been tested for CCSVI	13
Tested for CCSVI but not had treatment	4
Had one endovascular intervention for CCSVI	24
Had two endovascular interventions for CCSVI	5
Had three endovascular interventions for CCSVI	1
Had four endovascular interventions for CCSVI	1

Centre (now MS-UK) and Shift.MS; the blog of the Berkshire MS Therapy Centre; and the mailing lists of regional branches of the MS Society. One interviewee was contacted directly via an e-mail address provided on her YouTube channel.

All participants were given written information about the projects, and informed consent was obtained via e-mail. The interviews for the UK project were conducted over the telephone and lasted for approximately one hour; they were audio recorded and transcribed verbatim. In order to afford participants an added layer of anonymity, the Canadian study used online asynchronous interviews (Berg, 2009, p. 126). Due to the perceived anonymity of the medium and the fact that participants can take their time to think through their responses, asynchronous interviews can generate very open and forthright answers (Hamilton and Bowers, 2006; McCoyd and Kerson, 2006). They can also facilitate access to hard-to-reach and geographically dispersed populations that may not traditionally participate in research (Wilkerson *et al*, 2014), something that was particularly appropriate for a controversial topic such as CCSVI.

For the asynchronous interviews, interviewees were emailed the interview protocol by the primary researcher (JK), which they then filled out and returned at their convenience. Once the interview was returned, participants were asked if the researcher could contact them within three months for any further questions or clarifications. Follow-up questions based on key emergent themes were then emailed to participants during the data analysis phase. These questions were used to build a richer understanding of participants' experiences of MS, being tested for CCSVI and, if relevant, having the liberation procedure. Nine participants responded to the follow-up questions via e-mail. Asynchronous interviews can offer a rich or even richer detail than face-to-face or telephone interviews through follow-ups with the participant that may not be possible with more traditional qualitative data collection methods (Hamilton and Bowers, 2006; McCoyd and Kerson, 2006; Ratislavová and Ratislav, 2014). This was the case in the interviews collected in the Canadian study where



participants provided very detailed descriptions of their experiences, often reflecting in-depth on the questions posed to them.

Ethical approval for the Canadian study was received from the University of Calgary Conjoint Faculty Research Ethics Boards. Ethical approval for the UK study was received through the University of Warwick's Biomedical Research Ethics Committee.

Combined analysis

Between March and August 2015, the primary researchers on the two studies (JK for the Canadian study and FM for the UK study) re-analysed the entire interview corpus. As the liberation procedure and CCSVI were a topic of interest in both sets of interviews, this was not strictly speaking a secondary analysis, which is usually understood as analysing qualitative data for a purpose other than what it was originally collected (Heaton, 2004). Instead, our aim was to combine, compare and contrast the findings from the two projects in order to develop empirically grounded insights on the decision-making processes and practices relating to the liberation procedure from the perspective of people with MS.

As neither study had ethical approval to share entire interviews outside the initial project team, JK and FM revisited their respective transcripts independently. First, we organised the contents of our interviews into six descriptive categories that roughly mapped on to what we conceptualised, both literally and figuratively, as interviewees' treatment 'journeys': initial exposure and response to CCSVI as a theory and the liberation procedure as a potential therapy; perceptions of the CCSVI debate and the key stakeholders involved (e.g. neurologists, MS Societies, interventional radiologists, etc.); deciding whether to be tested for CCSVI and/or to have the liberation procedure; actual experiences of being tested and/or having the intervention; reflections on treatment outcomes, including whether they perceived it as being successful or not; and thoughts on the future of CCSVI research and treatment. These categories were then shared and discussed by all authors. Next, we performed a detailed thematic analysis within and across the categories. Here, we focused on how interviewees who had had the liberation procedure described and justified their decision(s). Each researcher took primary responsibility for analysing their own interviews, comparing notes and sharing codes. All notes and codes were reviewed by AD, who is very familiar with the interviews from the Canadian study. The findings and themes were extremely consistent across both datasets.

Three core factors emerged as particularly significant in terms of influencing the decision to have the liberation procedure: the first was how interviewees' interpreted and assessed the various risks and uncertainties they have to navigate in relation to the procedure and life with MS more generally; the second, how different forms of expertise and evidence were evaluated and prioritised in their decision-making processes; three, how both of the above were mediated by a specific orientation towards hope, which was bolstered through patients' experiential information sharing practices and online community dynamics. While these factors did not operate in isolation and were closely interrelated, we have separated them out for analytical purpose, both here and in the discussion below.



“Waiting for a Bomb to go off in Your Brain”: Existential Uncertainty, Embodied Risk and the Liberation Procedure

The majority of people we spoke to who had had the liberation procedure suffered from an aggressive form of MS, with frequent and/or severe relapses. They felt the disease was progressing rapidly and were already experiencing disabling symptoms and deteriorating health. Loss of mobility was one of the most frequently mentioned and, arguably, most feared symptom, with one participant describing himself as “chased by a monster called wheelchair bound”. Our interviewees were also very concerned about what, from a clinical perspective, are not typically considered the disease’s most disabling symptoms, such as fatigue, cognitive impairment and emotional changes (Rothwell *et al*, 1997). Alongside more overt manifestations of the disease, these subtle, pervasive and hard to define symptoms limited their ability to live what they considered a normal life – for example, altering their capacity to work, be a parent and engage in activities they not only enjoyed, but defined them as a person.

A core theme that emerged from our analysis was what, in research on other chronic illnesses, has been conceptualised as ‘existential uncertainty’: the feeling that one’s body, life and sense of self are persistently under threat (Adamson, 1997, p. 134). What is more, rather than being external to them, emerging from the environment or a consequence of their lifestyle, this threat was ‘embodied’ (Kavanagh and Broom, 1998, p. 438), with patients’ own bodies perceived as posing a constant, if at times latent, risk to their quality of life. In the words of one interviewee, a young mother with two children, living with MS was like “waiting for a bomb to go off in your brain all the time”.

This risk was not something they felt able to mitigate with mainstream medicine. Quite the opposite – those on medication spoke of struggling with side effects and expressed considerable concern about future ones. Tysabri,⁸ a DMD used in cases of aggressive MS, was referenced particularly frequently because its side effects can be fatal. More generally, many interviewees said they had exhausted all available mainstream biomedical options:

None of the current meds worked for me – I took Copaxone injections for years, followed by Rebif injections... my last MS med was chemotherapy in 2009, but as I mentioned earlier I had already experienced a decline in heart function, so I stopped. Nothing more was available. [Interviewee #8: A Canadian man who had venous angioplasty in Poland. He felt that the intervention improved his mobility and overall wellbeing].

Many of these patients had pursued alternative or complementary therapies, such as hyperbaric oxygen therapy, dietary restrictions, vitamins and supplements, or low-dose naltrexone (LDN).⁹ These therapies are mostly palliative and make no claims about MS as a disease. They are consequently usually accepted as relatively harmless, i.e. low risk, ways for patients to, at least potentially, relieve some of their symptoms and improve their sense of well-being. They are all, nonetheless, unproven and as such indicative of a wider context in which patients with MS experiment therapeutically, and in many cases are not averse to pursuing more radical treatment options, such as the liberation procedure.¹⁰

8 Natalizumab, a DMD for highly active MS.

9 An opioid believed to have a positive effect on the immune system.

10 Compare with Petersen *et al* (2014, p. 675) and Prasad (2015, p. 141).



For, while neurologists and other medical specialists queried the science underpinning CCSVI, foregrounding both the risks associated with the procedure and uncertainties about its therapeutic outcomes, our interviewees emphasised the profound existential uncertainty of living with MS and the embodied risks, both psychological and physical, they associated with ‘doing nothing’ and letting the disease progress unchecked. Given the progressive and unpredictable nature of MS, they believed that they simply could not afford to wait for biomedical science to follow through on large-scale double-blind randomised control trials (for similar arguments in relation to other conditions see Epstein (1995), Callon and Rabeharisoa (2003), Novas (2006) and Prasad (2015)). Instead, they felt they had to take action and do everything in their power to halt, prevent or minimise future deterioration now with the, albeit imperfect, knowledge available to them. From this perspective, the liberation procedure was seen as simultaneously a risk and a strategy of risk mitigation.

In addition to contrasting the risks of the liberation procedure with the embodied risks of MS, interviewees compared, usually favourably, the riskiness of balloon angioplasty with that of mainstream MS drugs. For example: “Three people have passed away since having CCSVI treatment, but there are literally hundreds of people who have passed away because of MS drugs” [Interviewee #38: An Australian woman treated in Australia. Her MS was very aggressive and she felt a major improvement in her symptoms and overall well-being]. This was further bolstered by the argument that angioplasty is hardly experimental in and of itself, as it is carried out regularly for conditions other than MS: “This is NOT a new procedure. It is performed daily in our hospitals just not on MS patients” [Interviewee #27: A Canadian woman who had the procedure in the US. She felt that she had considerable improvement in her mobility and a number of other symptoms such as fatigue, pain and balance]. Stenting was considered more dangerous and patients were aware of the increased risks associated with it. However, even here, some people, such as the woman quoted below, thought the benefits of keeping the veins open outweighed the risks:

I feel I am still doing very well because of that [having a stent]. Many refused a stent and have subsequently re-stenosed and their symptoms have returned. [Interviewee #13: A Canadian woman who was treated in Poland. She felt that her symptoms and overall wellbeing had improved].

Here, the increase in risk associated with a more invasive intervention was, to a degree, correlated with greater efficaciousness and ultimately better outcomes. The relative routineness and hence ‘safety’ of the procedure itself was, furthermore, not the only factor patients considered when assessing risk. *Who* performed it was vitally important:

What was most clear was that the risks of treatment were minimal and the potential benefit if it did stop MS progression and/or eliminate some of its side effects were such that there was no question that treatment made sense, IF the right IR [interventional radiologist] could be found to do the treatment. [Interviewee #4: An Israeli woman who was treated first in Poland and then the USA. She felt that her symptoms improved after the first intervention, but that they worsened after the second. Emphasis her own].

Patients who had undergone the procedure shared experiences of being treated by *particular* radiologists and surgeons, a number of whom were rated especially highly. Their reputation



was only in part due to their qualifications and experience as surgeons or radiologists. Arguably as important was their prominence online, publications on CCSVI, endorsements by patients, their own direct participation in online discussions (e.g. on TIMS or YouTube), and how promptly and thoroughly they responded to e-mail queries. Interviewees repeatedly emphasised that these were highly trained medical experts in whose qualified opinion venous angioplasty was a reasonable intervention for someone diagnosed with a blockage in their veins. They thereby shifted the locus of their risk assessment from the intervention itself to the expertise of the practitioner performing it (discussed in more depth in the next section).

Where the procedure would be performed was a related consideration, with treatment closer to home considered less risky. Those who were treated in their home countries thought that not having to travel abroad minimised physical strain and ensured continuity of care, while those who did travel internationally relied most of all on the recommendations of fellow patients who had undergone the procedure.

Like patients travelling for stem cell therapies (Petersen *et al*, 2014, p. 678), the *financial* risks of the procedure were as much, if not more, of a concern than the medical ones. Depending on location, practitioner and the number of angioplasties or stents required, the cost of the procedure ranged from US \$10,000 to US \$15,000, excluding transport and accommodation. This is not a negligible sum and cost was unquestionably a barrier. Nine interviewees who had not had the intervention said that this was because they could not afford it, rather than because they were sceptical about its scientific validity or worried about its safety. Those who did have it, often with the financial support of family and friends, recognised that it was expensive and took various factors into consideration when deciding whether it represented value for money. They compared the cost with that of other therapeutic options, pointing out that it was considerably cheaper than some alternatives, such as stem cell therapies. They also stressed that MS was an expensive condition to live with, rationalising the cost of the procedure against expenses they already faced or were likely to face in the future, such as converting their bathroom or buying a mobility scooter.

However, our interviewees' willingness to part with a substantial sum of money for an unproven therapy was less an indication of their faith in the procedure's potential to improve their health, or of their readiness to subject themselves to a certain level of risk, and more the outcome of a complex process of weighing up of, on the one hand, the *embodied risks* they already lived with and, on the other, their ability to carry the financial risk of paying for an intervention with extremely uncertain outcomes.

Which Expert? What Evidence? Perceptions of Professional Jurisdiction, Evidentiary Regimes and Empathetic Care

Although the liberation procedure was not endorsed by the vast majority of biomedical experts, patients who chose to have it did not reject the authority of biomedical expertise *as such* (as can sometimes be the case with those opting for 'alternative' therapies). Reputable journals had initially published encouraging research about CCSVI (for a review see Laupacis *et al*, 2011). The theory built on pre-existing vascular theories of MS (Nicolson and McLaughlin, 1988; Wong *et al*, 2012) and was supported by, at least some, biomedical



scientists. Thus, patients needed to negotiate disagreements about this therapy *within biomedicine* and, more specifically, between (most) neurologists – the primary medical discipline that deals with MS – and a small, but vocal, contingent of interventional radiologists, surgeons, (a few) neurologists and other biomedical scientists who were supportive of, or at least interested in, the theory. When justifying their decision(s) to have the procedure, our interviewees emphasised jurisdictional divisions between medical specialisations, arguing that they were simply prioritising the expertise of one set of experts over another. For example: “This is a vascular issue and neurologists have no right in expressing their biased views as to whether I get my veins treated or not” [Interviewee #27].

This prioritisation of the expertise of radiologists and other vascular specialists over that of neurologists when it came to knowledge about the vascular system was situated within a more extensive critique of neurology.¹¹ Most of the patients we spoke to who had had the procedure expressed profound dissatisfaction with mainstream MS medicine, and with neurologists in particular. Their frustration, and in some cases anger, was based both on negative experiences with specific neurologists and on their disappointment with MS research, treatment and care more generally, especially with what they perceived as the neurologists’ domination of it. Interviewees were unhappy with the choice of treatments that their neurologists were able to offer them and they also complained of not being treated either empathetically or holistically. They said they felt patronised, disempowered, and not listened to. They were especially frustrated by the constraints imposed on the types of research being pursued, by the slowness of therapeutic innovation and by the relative narrowness of approach, which they saw as prioritising the auto-immune theory of MS. They often blamed this on the influence of the pharmaceutical industry.

I dealt with the MS Clinic for 8 years. I found them to be condescending and depressing. In my opinion they had their own agenda and it was not always in my best interests. I no longer see a neurologist – I found they were more interested in pushing drugs than listening or trying to find solutions. [Interviewee #13].

Many patients discussed CCSVI with their neurologist. A small number received a neutral or, rarely, positive response. For the most part, though, their neurologist was critical of the research and strongly recommended they not pursue venous angioplasty as a therapy for their MS:

When I brought up the subject of CCSVI with the neurologist I was seeing, he had three stacks of photocopied ‘articles’ (negatively written, to ‘disprove’ CCSVI) on his desk, that he had ready to hand out to any of his patients who dared to show any interest whatsoever in the CCSVI angioplasty procedure. [Interviewee #32: A Canadian woman who had the intervention in Mexico. She did not feel that any of her symptoms improved, but she still recommends it to others in case it helps them].

For many people, responses such as the one described above reinforced a perception that their neurologist did not have their best interests at heart, and was enforcing the status quo without being able to offer effective alternatives. Some interviewees, especially if they were

11 The question of what medical specialism and expertise is best suited to researching and treating MS is a long-standing one and has been the cause of divisions in the field in the past. For more on the wider historical context of such debates, see Nicolson and McLaughlin (1988) and Nicolson and Lowis (2002).



already critical of mainstream MS medicine or had a troubled relationship with their neurologist, felt anger at such responses. While others, pre-empting a negative response, chose not to tell their neurologist that they were considering having the procedure and, in some cases, never informed them after they had it.

It is important to note that patients who chose *not* to have the procedure typically expressed rather different sentiments about mainstream MS research, treatment and care, and reported more positively about their interactions with neurologists. This was especially the case with patients who were sceptical of CCSVI and who voiced criticism of the ‘hijacking’ of the MS research agenda by a ‘pro-CCSVI lobby’. For them, the fact that their neurologist was not convinced by CCSVI was one of the key reasons they chose not to pursue the liberation procedure (for a review of how doctor–patient relationships can influence patient decision-making and outcomes see Ong *et al* (1995)).

What was at stake here, however, was not simply patients deciding to privilege one set of experts over another (essentially because they felt disappointed by one, older, established therapeutic promise, while being encouraged by another, newer, untested one). What was being weighed up and decided between were *different types of evidence* for what counted as a legitimate and efficacious therapy – what, drawing on the work of Tiago Moreira and Paolo Palladino (2005), can be thought of as related, yet distinct, ‘*regimes of truth*’.¹² For, whereas the neurologists who critiqued the liberation procedure rejected findings that were not based on double-blind randomised control trials (the ‘gold-standard’ when assessing biomedical interventions), the surgeons and radiologists who defended the procedure put forward observational studies of individual outcomes (conforming with the standard of evidence often used in surgical disciplines (Meakins, 2002)). The relative merits of these different evidentiary regimes and their appropriateness for assessing the liberation procedure were frequently discussed in interviews. For example:

And the thing is, in radiology, procedures aren’t developed through double-blind trials. The problem is neurologists are in the drugs mind-set [...] I know enough about clinical trials and how you blind them to know you can’t blind this procedure to an awake patient. You can feel the balloon blowing up. I’ve done it twice, I know. [Interviewee #5: A British man who had venous angioplasty twice, once in Greece, once in the USA. He felt improvement in some of his symptoms, but not his mobility].

The kinds of evidence generated from observational studies supported by the defenders of the liberation procedure was, moreover, better aligned with the *experiential logic of embodied evidence* (discussed in more detail in the next section), which patients continually emphasised in their own understanding of therapeutic efficacy (emblematised, for instance, by their posting before-and-after-treatment self-monitoring videos on YouTube). The regime of truth privileged by the neurologists (which enjoys greater currency in biomedical science more generally) was, by contrast, perceived by patients as alienating, disempowering and ‘depressing’. This regime of truth and associated care practices, from their perspective at least, appeared to serve the interests of ‘big science’ rather than those of the living, highly individual, patient.

12 We use ‘regime of truth’ here to indicate particular logics and associated forms of evidence, rather than the full Foucauldian sense of the term (Foucault, 1991).



Even though our interviewees were well aware of the large body of research that refuted the association between MS and CCSVI, they downplayed its significance by (a) raising doubts about the integrity of the researchers conducting such studies (e.g. highlighting their assumed close relationships with pharmaceutical companies); b) claiming they had a pre-existing bias (e.g. arguing that the researchers' original training prevented them from making the radical move of questioning the auto-immune theory of MS); and (c) challenging the design and management of these studies (e.g. querying the methods and equipment used, or questioning how closely the researchers had adhered to Zamboni's protocol). Our interviewees (especially, but not exclusively, those who had not had the procedure) did question the integrity of interventional radiologists offering the intervention. Here, a distinction was made between interventional radiologists motivated by financial gain versus those perceived as genuinely wanting to help patients. The latter was ascertained through assessing whether they were conducting and publishing research on CCSVI (even when patients paid to take part in the research); interacting with and recognised as legitimate by prominent figures, such as Zamboni; engaging directly and actively with patients (e.g. by contributing to online forums and discussions); and rated as supportive providers of high-quality care (by receiving positive feedback from other patients).

In debating and weighing up different forms of expertise, evidence and care, patients (or their family members) became avid researchers, compiling and analysing the wide range of sources and types of information available on the internet. This contributed to the creation of knowledgeable and highly influential people affected by MS, either patients or their family members, with 'lay expertise' similar to that which has been documented in relation to other conditions (Epstein, 1995; Caron-Flinterman *et al*, 2005; Sosnowy, 2014). These expert patients were often also treatment pioneers and, therefore, not only disseminated research articles and ideas, but shared their experiences of the procedure. This powerful combination of, on the one hand, 'interactional expertise', the ability to intelligently discuss a domain of knowledge, without necessarily being a practitioner in it (Collins and Evans, 2002) and, on the other, a personal (indeed embodied) experience of both the disease and the intervention played a highly significant role, often influencing other patients' decisions, as discussed in more depth below.

"Spreading Hope Around": Therapeutic Experimentation, Social Media and Experiential Information Sharing

The CCSVI theory and associated liberation procedure generated considerable hope amongst MS patients and their families, with our interviewees frequently stating that it had been a long time since they had felt as hopeful about a new therapy. Nonetheless, none of them thought the procedure would be a miracle cure. Rather, they hoped for more modest improvements, such as the restoration of a lost function, the minimisation of existing symptoms, and especially the prevention of future deterioration (this echoes related studies, such as Petersen *et al* (2014, p. 675) and Prasad (2015, p. 143)). What is more, our interviewees recognised that venous angioplasty was *unproven* as a treatment for MS, but, crucially, were willing to *experiment* with it:



My rationale was that even if it did not help me...I tried! And if it did, I could help move the research forward ...for my kids and grandkids to hopefully never have to deal with this thing called MS. [Interviewee #24: An American woman who was treated in the USA. She felt that after the intervention she had improvement in her sensory perceptions and less pain].

Their hope, in other words, resided not in some encouraging evidence of *provable* positive outcomes, but in the unpredictable ranges of possibilities that ‘experimentation’ *as such* entailed. Put differently, experimentation *with their own bodies* became a mechanism for, quite literally, ‘embodying’ hope. As illustrated in the quotation above, in a few cases, this experimental openness was linked to a more wide-ranging desire to contribute to scientific research on MS and to help future generations of people with the condition, including, potentially, their own children.¹³

By the time we spoke to them, our interviewees had already had a certain amount of time (from three months to two and a half years) to assess whether they felt the intervention had been successful for them. The vast majority reported positive outcomes – most frequently improved balance, vision, cognitive function and/or bladder control, reduced fatigue, pain, heat sensitivity and/or stiffness. Many of these changes appeared, on the face of it, to be relatively minor, but for the people experiencing them even small improvements were deemed life-enhancing. When patients shared their experiences with their neurologist they felt that their improvements were downplayed or dismissed as a placebo effect, which they found upsetting and which further contributed to the breakdown in patient–doctor relations. This is very consistent, again, with patients’ experiences of stem cell therapies (Petersen *et al*, 2014, p. 679).

Of course, numerous factors, including the relationship with and trust in the administering physician or surgeon, influence both patient perceptions of treatment success and more objective health outcomes (Di Blasi *et al*, 2001). This is further complicated by the fact that the most common version of MS is characterised by naturally occurring cycles of active (relapsing) and inactive (remissive) disease, while surgical interventions are particularly prone to placebo effects (Johnson, 1994; Shapiro and Shapiro, 1997, p. 22). What is significant here is not that patients made claims about the treatment’s efficacy expressed in terms of both identifiable outcomes and improvements in their overall sense of well-being, but that these claims were supported by a swathe of experiential reports shared online (on TIMS, Facebook, blogs, YouTube, etc.). These personal accounts went into considerable detail about the effect that having the procedure had on patients’ everyday life and struggle with MS, and resonated strongly with other patients (Vera *et al*, 2012; Mazanderani *et al*, 2013; Sudau *et al*, 2014; Koschack *et al*, 2015). Often dismissed by medical commentators as ‘anecdotal’, ‘biased’ and ‘subjective’, such experiential accounts are, nonetheless, a major reason patients choose to pursue experimental therapies (Whelan, 2007; Song, 2010; Prasad, 2015):

But to me you know watching people like Denise Manley [Canadian CCSVI activist with a YouTube channel] doing her videos and stuff like that it was like, do you know

13 Although MS is not strictly speaking a genetic disease, it has long been believed that there is a genetic component. For more on genetics in MS see Hoppenbrouwers and Hintzen (2011).

what that's good enough for me, that shows me that this is worth looking at. [Interviewee #37: A British woman who had the intervention in the UK. She felt that if anything she only had some very minor improvements].

As illustrated above, videos where patients not only discussed, but visually displayed improvements in their symptoms, such as mobility, balance and cognitive function, were particularly powerful (Mazanderani *et al*, 2013). The use of patient testimonials was quickly taken up by private clinics as part of their advertising campaigns. They also featured in media reports, including a Canadian documentary about Zamboni's research, which was widely circulated online, with subtitles in a variety of languages.¹⁴ Alongside video 'evidence' of this nature, patients shared venographic images, detailed, occasionally also videoed, descriptions of having the intervention, and information about their wider medical history. The most prolific sharers of experiential information of this nature kept textual or video diaries that spanned years, with an audience of regular viewers numbering in the thousands. This often inspired others to emulate the practice and share their own videos and other information, thereby turning their own bodies and experiences into a source of hope for other patients.

Patients who did not have such good experiences with the liberation procedure were far less likely to share them (something not specific to this therapeutic intervention), and a bias towards positive reporting was openly acknowledged:

In forums such as This Is MS and Facebook, the information presented is generally skewed toward positive reports without representative negative reporting. That's natural. Those who benefit are happy to take the time to tell others about the success of the procedure while those who don't benefit, mostly move on since this is yet another treatment that failed to improve their MS. [Interviewee #4].

Many reasons were given for this, but an important one was the reluctance of patients to dampen another's hope, something that was presented by some as a betrayal of fellow MS patients. CCSVI community organisers and patient activists did attempt to mitigate the bias towards the reporting of positive outcomes through collecting patient experiences more systematically. They worked hard at aggregating and (re)distributing experiential findings in a manner that showed an understanding of, but did not necessarily adhere to, standard biomedical methods for generating scientifically valid knowledge about therapeutic risk and effectiveness. This was done, for example, through a structured thread on TIMS where users were asked to document negative experiences. Another example is the CCSVI tracking website (<http://ccsvi-tracking.com>), which was designed to record and visualise patient-reported outcomes. Despite such attempts at providing a more balanced perspective, the sheer number of positive accounts circulating online undoubtedly influenced patients' decision-making: "The optimistic, encouraging outcomes helped me make my decision to go have it done. I figured THAT many positives couldn't possibly be the placebo effect" [Interviewee #20: A Canadian woman who was tested in the USA and treated in Costa Rica. She felt that she had some minor improvements in her symptoms, is happy she had the procedure and recommends it to others. Emphasis her own].

14 Titled "The Liberation Treatment: A whole new approach to MS"; this documentary was aired in November 2009 on CTV news' current affairs programme W5 (<http://www.ctvnews.ca/the-liberation-treatment-a-whole-new-approach-to-ms-1.456617>).



Hope was not generated, however, solely through the visibility of positive stories. Equally important were the practices of researching different treatment options and sharing experiences about their effectiveness, even when these were potentially in doubt. Indeed, hope here was not an individual affective state or attitude but a *practice* requiring (if it was to be maintained) continuous affective labour (Miyazaki, 2006) or, in the words of Cheryl Mattingly, a “strenuous moral project” (Mattingly, 2010, p. 3). This orientation towards hope was eloquently articulated in a YouTube video titled “About Hope” posted by a Australian woman whose YouTube channel contained some of the most widely viewed CCSVI videos:

I guess what CCSVI did for me was just give me a little spark to believe that my future could be different and even if it is just a belief and it changes our concept of our future, even that helps our health [...] Our state of mind if we have no hope is very different from if we do and to have that hope taken away or suppressed or to be told that there is nothing in this takes away something fairly significant for us as people with MS. So I don't apologise for spreading hope around even if this hope [...] gets proven to be an absolute placebo effect and this is just a coincident that so many people are feeling better. [YouTube video transcribed by researcher].¹⁵

Thus, in the case of the liberation procedure, the moral project of cultivating hope took the form of *therapeutic experimentation* combined with in-depth *experiential information sharing*, skewed towards the reporting of positive results. Through a complex array of practices, technologies and discourses (from undergoing the procedure itself to posting videos of themselves online after treatment), patients turned their bodies and their experiences into ‘experimental data’ and (at the very same time and by that very fact) came to *embody hope* for themselves and others (for very similar practices in relation to foetal-cell transplant treatment for Spinal Cord Injury (SCI) see Song (2010, p. 390)).

This embodiment of hope was multi-faceted. First, as described above, it was premised on the widespread, digitally mediated, textual and visual, performance of hope through undergoing and sharing individual therapeutic experiments and outcomes. Second, as positive accounts of the liberation procedure amassed online, a wider corpus of experiential ‘evidence’, collected and linked through forum threads, Facebook postings, and YouTube channels, came to embody hope for people affected by MS across the world. This, in turn, encouraged patients to share *their* experiences, thereby contributing to a recursive (re)articulation of hope as a means of challenging the pervasive sense of embodied risk and despair felt by many people with MS. Third, hope was embodied in that, as with other anticipatory modes of being, it was lived and felt in the present and, as such, had a tangible effect on people's sense of self and well-being, regardless of any measurable clinical improvements (Adams *et al.*, 2009, p. 248).

From Embodied Risk to Embodying Hope: Discussion and Conclusion

Fear about how MS might affect them in the future, the degenerative nature of the condition, a lack of viable treatment options, and ambivalence about the state of mainstream MS

15 Video available at: <https://www.youtube.com/watch?v=pjOvd4PBnoo>, accessed 12 November 2016.



research, treatment and care, all contributed to patients' decision to pursue the liberation procedure. Far from being naïve about the lack of scientific evidence supporting CCSVI, the majority of our interviewees readily acknowledged that CCSVI as a theory and the liberation procedure as a treatment were still unproven and that therapeutic outcomes remained uncertain.

It is widely recognised that many people at risk of or diagnosed with a serious illness, especially an unpredictable one such as MS, live with a sense of 'embodied risk', in which their own bodies are seen as posing a latent threat to their health and well-being (Kavanagh and Broom, 1998). People respond to such embodied risk in multiple ways: changing their lifestyle (e.g. eating healthily, exercising, reducing stress); engaging in self-assessment and surveillance (e.g. going for regular medical tests, engaging in informal self-monitoring practices); taking pharmaceutical, surgical or prophylactic measures; turning to complementary or alternative medicine; or indeed, by actively resisting (e.g. deliberately ignoring) their status as someone 'at risk'.

In this paper we outlined how 'embodied risk' coupled with a) a profound sense of 'existential uncertainty', b) the perceived 'failure' of mainstream biomedicine to provide viable therapeutic options, and c) the emergence of an alternative theory and associated experimental procedure rooted in an explanatory model and therapeutic logic (an endovascular intervention) that explicitly contrasted with the currently available options – all contributed towards encouraging some patients with MS to have the liberation procedure. For the most part these patients were well informed and carefully weighed up various medical, personal and financial factors before deciding to have it. We have discussed how they negotiated and rationalised this decision around different kinds of risks associated with the intervention and conflicting forms of evidence for its efficacy. Furthermore, we described how hope was (a) seen as a value in its own right in the experiential rationality of patients; (b) deployed as an important factor in the decision-making processes that led them to pursue an unproven therapy; and (c) actively cultivated and embodied through therapeutic experimentation and online experiential information sharing.

The critical (hope-generating) 'benefits' of the liberation procedure lay in the very process of learning about it and researching it online, in exchanging information and experiences pre- and post-procedure, in becoming an activist or online debater on the issue, in being inspired to take part in formal studies or informal self-monitoring campaigns. Critical was also the performative turning of 'the neurologists', 'the pharmaceutical industry' and 'mainstream MS medicine' into external obstacles that needed to be overcome or sidestepped. What is more, the very unpredictability of the experimental procedure in which the patients decided to become actively involved inspired more hope than the tentative results of evidence-based clinical trials about new drugs or other therapies, the latter being what biomedical experts might typically perceive as being more appropriately hope-generating.

Key to 'embodying hope' here was the extensive and widespread sharing and aggregation of experiential accounts. Such practices are certainly not unique to the liberation procedure. They have long been recognised as being a core part of how patient activists engage with, both supporting and challenging, biomedical knowledge, expertise and evidence (Epstein, 1996; Rabeharisoa *et al*, 2014). The distinctive contribution of this paper has been to



(a) explicitly link these practices to the question of patient decision-making and (b) to reveal how they contribute to the generation of a logic of ‘embodied risk/hope’.

We have analysed patients’ therapeutic experimentation and experiential information sharing as practices of ‘embodying hope’, which forms part of a much wider set of practices for cultivating hope that patients valued as a key part of their life with MS. For those who underwent the liberation procedure, engaging in an *experimental therapy* was never confined to simply choosing an intervention that would lead to specific physical improvements. Engaging in such a therapy became part of a much wider set of actions (especially those of sharing experiential evidence) through which patients with MS could wrest control of their life back from an incurable and, in their words, ‘devastating’ disease.

Hope, along with risk, forms a crucial part of the wider anticipatory regimes of contemporary biomedicine and healthcare (Novas, 2006; Rhodes *et al*, 2009; Adams *et al*, 2009; Mattingly, 2010; Petersen and Wilkinson, 2015). And while hope in such a context can be interpreted as ‘cruel’ (Berlant, 2011), or even exploitative (Cooper and Waldby, 2014), it is generally framed as a ‘good’ that is obtained through appropriate contact with biomedicine and healthcare. *Appropriate* is the critical word here. For when, as in the case of the liberation procedure, patients choose to deviate from biomedical orthodoxy and are hopeful about heterodox therapies, this hope is at best accepted as a ‘placebo’ and at worst dismissed as ‘false’ (but in both cases opposed to the realistic and beneficent hope recognised and endorsed by biomedical experts).

If ‘patient choice’ is not simply a rhetorical device, but is actually to be supported and valued within healthcare and biomedicine, biomedical and healthcare experts of all kinds, be they scientists, physicians, nurses or policy-makers (to mention but a few categories), have to accept that patients will, at times, make decisions that are not supported by what they as experts consider the best available evidence. This undoubtedly raises numerous ethical and professional challenges, which is a topic that deserves its own paper. However, we believe that a critical first step in dealing with situations where this happens, such as in the case of the liberation procedure, is to try to understand the logic(s) underpinning patients’ decision-making processes.

While critics and sceptics might automatically dismiss MS patients’ experiments with balloon angioplasty and stenting as rooted in an irrational form of magical thinking, and while some patients might genuinely believe themselves to be contributing (if only as patients) to innovative scientific advancement, what we argue here is that the logic that governs the rationality of patients’ actions and beliefs in this context is rooted in the *experiential* dimension of life with MS and needs to be analysed, understood and accepted *in and on these terms*. This is not the same as saying that one needs to respect the patient perspective or listen to the patient’s voice. What is necessary, and this is what we have sought to do in this paper, is to *make intelligible* the distinctive experiential logic underpinning this perspective.

Acknowledgements The authors would like to thank all our interviewees; without your generosity this research would not have been possible. We would also like to thank Kerri Cassidy for giving us permission to cite her YouTube video and for providing feedback on the final draft of the paper. Fadila Mazanderani would like to thank the NIHR who provided funding for her work as part of the iPEX programme. She would also like to thank members of the iPEX programme for discussions that contributed to the ideas put forward in the paper, especially John Powell. The iPEX programme presents independent research funded by the NIHR



under its Programme Grants for Applied Research funding scheme (RP-PG-0608-10147). The views expressed in this article are those of the authors, representing iPEX, and not necessarily those of the NHS, the NIHR or the Department of Health. Jenny Kelly would like to thank the Canadian Institutes of Health Research who provided funding through their Master's Award: Frederick Banting and Charles Best Canada Graduate Scholarships (#218607). Andy Byford provided invaluable feedback on an early draft of the paper for which the authors are very grateful.

About the Authors

Fadhila Mazanderani is a Chancellor's Fellow at the University of Edinburgh's Science, Technology and Innovation Studies group. Her research interests are in the production and mediation of alternative forms of knowledge and ways of knowing in biomedicine and healthcare, most especially those linked to digital technologies.

Jenny Kelly is a Research Associate at the Ward of the 21st Century, a research and innovation centre in the Cummings School of Medicine at the University of Calgary. Her research interests include examining patient experiences with chronic and degenerative diseases and improving patient access to health care services.

Ariel Ducey is Associate Professor of Sociology at the University of Calgary. Her research focuses on work in health care; policies and governance in health care; and the use of science and technology in medicine.

References

- Adams, V., Murphy, M. and Clarke, A.E. (2009) Anticipation: Technoscience, life, affect, temporality. *Subjectivity* 28: 246–265.
- Adamson, C. (1997) Existential and clinical uncertainty in the medical encounter: An idiographic account of an illness trajectory defined by Inflammatory Bowel Disease and Avascular Necrosis. *Sociology of Health and Illness* 19(2): 133–159.
- Baracchini, C., Valdeza, J.M., Del Sette, M., Baltgaile, G., Bartels, E., Bornstein, N.M. and Klingelhofer, J. (2012) CCSVI and MS: A statement from the European Society of Neurosonology and Cerebral Hemodynamics. *Journal of Neurology* 259(12): 2585–2589.
- BBC (2011) Concerns about controversial MS treatment. 7 March, <http://www.bbc.co.uk/news/health-12637191>, accessed 12 November 2016.
- Bell, D., Holliday, R. Ormond, M. and Mainil, T. (2015) Transnational healthcare, cross-border perspectives. *Social Science and Medicine* 124: 284–289.
- Berg, B.L. (2009) *Qualitative Research Methods for the Social Sciences*. 7th edition. Boston, MA: Pearson.
- Berlant, L. (2011) *Cruel Optimism*. Durham, NC: Duke University Press Books.
- Botterill, D., Pennings, G. and Mainil, T. (eds.) (2013) *Medical Tourism and Transnational Health Care*. Basingstoke: Palgrave Macmillan.
- Bowling, A.C. (2011) Complementary and alternative medicine and multiple sclerosis. *Neurologic Clinics* 29(2): 465–480.
- Callon, M. and Rabeharisoa, V. (2003) Research 'in the wild' and the shaping of new social identities. *Technology in Society* 25(2): 193–204.
- Caron-Flinterman, J.F., Broerse, J.E.W. and Bunders, J.F.G. (2005) The experiential knowledge of patients: A new resource for biomedical research? *Social Science and Medicine* 60(11): 2575–2584.
- Chafe, R., Born, K.B., Slutsky, A.S. and Laupacis, A. (2011) The rise of people power. *Nature* 472(7344): 410–411.



- CIHR (2011) Systematic reviews of the evidence regarding chronic cerebral spinal venous insufficiency (CCSVI) and multiple sclerosis – Summary of second report for CIHR expert panel, November 21, <http://www.cihr-irsc.gc.ca/e/445559.html?=&wbdisable=false>, accessed 12 November 2016.
- Collins, H. and Evans, R. (2002) The third wave of science studies: Studies of expertise and experience. *Social Studies of Science* 32(2): 235–296.
- Compston, A. and Coles, A. (2008) Multiple Sclerosis. *Lancet* 372(9648): 1502–1517.
- Cooper, M. and Waldby, C. (2014) *Clinical Labor: Tissue Donors and Research Subjects in the Global Bioeconomy*. Durham, NC: Duke University Press.
- Di Blasi, Z., Harkness, E., Ernst, E., Georgiou, A. and Kleijnen, J. (2001) Influence of context effects on health outcomes: A systematic review. *Lancet* 357(9258): 757–762.
- Doepf, F., Paul, F., Valdueza, J.M., Schmierer, K. and Schreiber, S.J. (2010) No cerebrocervical venous congestion in patients with multiple sclerosis. *Annals of Neurology* 68(2): 173–183.
- Epstein, S. (1995) The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology and Human Values* 20(4): 408–437.
- Epstein, S. (1996) *Impure Science: AIDS, Activism and the Politics of Knowledge*. Berkeley: University of California Press.
- Fayerman, P. (2013) The final curtain on CCSVI and liberation therapy for multiple sclerosis. Vancouver Sun (2013), 10 October, <http://vancouversun.com/news/staff-blogs/the-final-curtain-on-ccsvi-and-liberation-therapy-for-multiple-sclerosis>, accessed 12 November 2016.
- FDA (2012) News alert: FDA issues alert on potential dangers of unproven treatment for multiple sclerosis, 10 May, <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm303538.htm>, accessed 12 November 2016.
- Foucault, M. (1991) Politics and the study of discourse. In G. Burchell et al. (eds.) *The Foucault Effect: Studies in Governmentality*. London: Harvester Wheatsheaf, pp. 53–72.
- Gafson, A.R. and Giovannoni, G. (2014) CCSVI: A call to clinicians and scientists to vocalise in an internet age. *Multiple Sclerosis and Related Disorders* 3(2): 143–146.
- Grady, D. (2010) From MS patients, outcry for unproved treatment. *New York Times*, 28 June.
- Hakim E.A., Bakheit A.M.O., Bryant T.N., Roberts M.W.H., McIntosh-Michaelis S.A., Spackman A.J., Martin J.P. and McLellan D.L. (2000) The social impact of multiple sclerosis: A study of 305 patients and their relatives. *Disability and Rehabilitation* 22(April): 288–293.
- Hamilton, R.J. and Bowers, B.J. (2006) Internet recruitment and e-mail interviews in qualitative studies. *Qualitative Health Research* 16(6): 821–835.
- Heaton, J. (2004) *Reworking Qualitative Data*. London: Sage.
- Hoppenbrouwers, I.A. and Hintzen, R.Q. (2011) Genetics of multiple sclerosis. *Biochimica et Biophysica Acta (BBA) - Molecular Basis of Disease, Molecular Basis of Multiple Sclerosis*, 1812(2): 194–201.
- Johnson, A.G. (1994) Surgery as a Placebo. *Lancet* 344(8930): 1140–1142.
- Kavanagh, A.M. and Broom, D. H. (1998) Embodied risk: My body, myself? *Social Science and Medicine* 46(3): 437–444.
- Koschack, J., Weibezahl, L., Friede, T., Himmel, W., Makedonski, P. and Grabowski, J. (2015) Scientific versus experiential evidence: Discourse analysis of the chronic cerebrospinal venous insufficiency debate in a multiple sclerosis forum. *Journal of Medical Internet Research* 17(7): e159.
- Laupacis, A. and Slutsky, A.S. (2010) Endovascular treatment for multiple sclerosis: The intersection of science, policy and the public. *Open Medicine* 4: e197–199.
- Laupacis, A., Lillie, E., Dueck, A., Straus, S., Perrier, L., Burton, J.M., Aviv, R., Thorpe, K., Feasby, T. and Spears, J. (2011) Association between chronic cerebrospinal venous insufficiency and multiple sclerosis: A meta-analysis. *Canadian Medical Association Journal* 183(16): E1203–E1212.
- Lexell, E.M., Larsson Lund, M. and Iwarsson, S. (2009) Constantly changing lives: Experiences of people with multiple sclerosis. *The American Journal of Occupational Therapy* 63(6): 772–781.
- Lupton, D. and Tulloch, J. (2002) ‘Risk is part of your life’: Risk epistemologies among a group of Australians. *Sociology* 36(2): 317–334.
- Mattingly, C. (2010) *The Paradox of Hope: Journeys Through a Clinical Borderland*. Berkeley: University of California Press.
- Mayer, C. A., Pfeilschifter, W., Lorenz, M.W., Nedelmann, M., Bechmann, I., Steinmetz, H. and Ziemann, U. (2011) The perfect crime? CCSVI not leaving a trace in MS. *Journal of Neurology, Neurosurgery and Psychiatry* 82(4): 436–440.
- Mazanderani, F., O’Neill, B. and Powell, J. (2013) ‘People power’ or ‘pester power’? YouTube as a forum for the generation of evidence and patient advocacy. *Patient Education and Counseling* 93(3): 420–425.



- McCoy, J.L.M. and Schwaber Kerson, T. (2006) Conducting intensive interviews using email a Serendipitous comparative opportunity. *Qualitative Social Work* 5(3): 389–406.
- Meakins, J.L. (2002) Innovation in surgery: The rules of evidence. *The American Journal of Surgery* 183(4): 399–405.
- Miyazaki, H. (2006) *The Method of Hope: Anthropology, Philosophy, and Fijian Knowledge*. Stanford: Stanford University Press.
- Mol, A. (2008) *The Logic of Care: Health and the Problem of Patient Choice*. Abingdon: Routledge.
- Moreira, T. and Palladino, P. (2005) Between truth and hope: On Parkinson's disease, neurotransplantation and the production of the 'self'. *History of the Human Sciences* 18(3): 55–82.
- Mulholland, A. (2017) Study finds MS vein therapy ineffective, questions remain. CTV News, 8 March, <http://www.ctvnews.ca/health/study-finds-ms-vein-therapy-ineffective-questions-remain-1.3315927>, accessed 18 March 2017.
- Murdoch, C.E. and Scott, C.T. (2010) Stem cell tourism and the power of hope. *The American Journal of Bioethics* 10(5): 16–23.
- NICE (2012) Percutaneous venoplasty for chronic cerebrospinal venous insufficiency for multiple sclerosis: Interventional procedures guidance [IPG420]. March, <https://www.nice.org.uk/guidance/ipg420>, accessed 12 November 2016.
- Nicolson, M. and McLaughlin, C. (1988) Social constructionism and medical sociology: A study of the vascular theory of multiple sclerosis. *Sociology of Health and Illness* 10(3): 234–261.
- Nicolson, M. and Lewis, G.W. (2002) The early history of the Multiple Sclerosis Society of Great Britain and Northern Ireland: A socio-historical study of lay/practitioner interaction in the context of a medical charity. *Medical History* 46(2): 141–174.
- Novas, C. (2006) The political economy of hope: Patients' organizations, science and biovalue. *BioSocieties* 1(03): 289–305.
- Ong, L.M.L., de Haes, J.C., Hoos, A.M. and Lammes, F.B. (1995) Doctor-patient communication: A review of the literature. *Social Science and Medicine* 40(7): 903–918.
- Petersen, A., Seear, K. and Munsie, M. (2014) Therapeutic journeys: The hopeful travails of stem cell tourists. *Sociology of Health and Illness* 36(5): 670–685.
- Petersen, A., Tanner, C. and Munsie, M. (2015) Between hope and evidence: How community advisors demarcate the boundary between legitimate and illegitimate stem cell treatments." *Health* 19(2): 188–206.
- Petersen, A. and Wilkinson, I. (2015) Editorial introduction: The sociology of hope in contexts of health, medicine, and healthcare. *Health* 19(2): 11318.
- Ploughman, M., Harris, C., Hogan, S.H., Murray, C., Murdoch, M., Austin, M.W. and Stefanelli, M. (2014) Navigating the 'liberation procedure': A qualitative study of motivating and hesitating factors among people with multiple sclerosis. *Patient Preference and Adherence* 8: 1205–1213.
- Prasad, A. (2015) Ambivalent journeys of hope: Embryonic stem cell therapy in a clinic in India. *Health* 19(2): 137–153.
- Rabeharisoa, V., Moreira, T. and Akrich, M. (2014) Evidence-based activism: Patients', users' and activists' groups in knowledge society. *BioSocieties* 9(2): 111–128.
- Ratislavová, K. and Ratislav, J. (2014) Asynchronous email interview as a qualitative research method in the humanities. *Human Affairs* 24(4): 452–460.
- Reekers, J.A. (2012) CCSVI and MS: A neverending story. *European Journal of Vascular and Endovascular Surgery* 43: 127–128.
- Rhodes, M.A. (2011) *CCSVI as the Cause of Multiple Sclerosis: The Science Behind the Controversial Theory*. Jefferson: McFarland & Co Inc.
- Rhodes, T., Bernays, S. and Janković Terzić, K. (2009) Medical promise and the recalibration of expectation: Hope and HIV treatment engagement in a transitional setting. *Social Science and Medicine* 68(6): 1050–1059.
- Robinson, I. (1990) Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis. *Social Science and Medicine* 30(11): 1173–1186.
- Rothwell, P.M., McDowell, Z., Wong, C.K. and Dorman, P.J. (1997) Doctors and patients don't agree: Cross sectional study of patients' and doctors' perceptions and assessments of disability in multiple sclerosis. *British Medical Journal* 314: 1580–1580.
- Shapiro, A.K. and Shapiro, E. (1997) The Placebo: Is it Much Ado about Nothing? In A. Harrington (ed.) *The Placebo Effect*. Cambridge MA: Harvard University Press, pp. 12–36.
- Snyder, J., Adams, K., Crooks, V.A., Whitehurst, D. and Vallee, J. (2014) 'I knew what was going to happen if I did nothing and so I was going to do something': Faith, hope, and trust in the decisions of Canadians with multiple sclerosis to seek unproven interventions abroad. *BMC Health Services Research* 14: 445.



- Song, P. (2010) Biotech pilgrims and the transnational quest for stem cell cures. *Medical Anthropology* 29(4): 384–402.
- Sosnowy, C. (2014) Practicing patienthood online: Social media, chronic illness, and lay expertise. *Societies* 4(2): 316–329.
- Stewart, D.C., and Sullivan, T.J. (1982) Illness behavior and the sick role in chronic disease: The case of multiple sclerosis. *Social Science and Medicine* 16(15): 1397–1404.
- Stolz, E. (2015) Chronic cerebrospinal venous insufficiency: The end of ‘the big idea’? *Brain and Behavior* 5(1): 1–2.
- Sudau, F., Friede, T., Grabowski, J., Koschack, J., Makedonski, P. and Himmel, W. (2014) Sources of information and behavioral patterns in online health forums: Observational study. *Journal of Medical Internet Research* 16(1): e10.
- Trabousee, A.L., Knox, K.B. Machan, L., Zhao, Y., Yee, I., Rauscher, A. and Klass, D. (2014) Prevalence of extracranial venous narrowing on catheter venography in people with multiple sclerosis, their siblings, and unrelated healthy controls: A blinded, case-control study. *Lancet* 383(9912): 138–145.
- Trojano, M., Paolicelli, D., Bellacosa, A. and Cataldo, S. (2003) The transition from relapsing-remitting MS to irreversible disability: Clinical evaluation. *Neurological Sciences* 24(5): s268–s270.
- Tsigoulis, G., Faissner, S. Voumvourakis, K., Katsanos, A.H., Triantafyllou, N., Grigoriadis, N., Gold, R. and Krogias, C. (2015) ‘Liberation treatment’ for chronic cerebrospinal venous insufficiency in multiple sclerosis: The truth will set you free. *Brain and Behavior* 5(1): 3–12.
- Turner, L. (2007) ‘First world health care at third world prices’: Globalization, bioethics and medical tourism. *BioSocieties* 2(3): 303–325.
- Ubelacker, S. (2012) US FDA warns against controversial liberation therapy for MS. *National Post*, 10 May, <http://news.nationalpost.com/news/u-s-fda-warns-against-controversial-liberation-therapy-for-ms>, accessed 12 November 2016.
- Vera, C., Herr, A., Mandato, K., Englander, M., Ginsburg, L. and Siskin, G.P. (2012) Internet-based social networking and its role in the evolution of chronic cerebrospinal venous insufficiency. *Techniques in Vascular and Interventional Radiology* 15(2): 153–157.
- Whelan, E. (2007) ‘No one agrees except for those of us who have it’: endometriosis patients as an epistemological community. *Sociology of Health and Illness* 29(7): 957–982.
- Whittaker, A., Manderson, L. and Cartwright, E. (2010) Patients without borders: Understanding medical travel. *Medical Anthropology* 29(4): 336–343.
- Wilkerson, J.M., Iantaffi, A., Grey, J.A., Bockting, W.O. and Rosser, B.R.S. (2014) Recommendations for internet-based qualitative health research with hard-to-reach populations.” *Qualitative Health Research* 24(4): 561–574.
- Wong, C., Fox, R. and Rae-Grant, A. (2012) The history of the vascular theories of multiple sclerosis (S59.006). *Neurology* 78 (Meeting Abstracts 1): S59.006.
- Zamboni, P. (2006) The big idea: Iron-dependent inflammation in venous disease and proposed parallels in multiple sclerosis. *Journal of the Royal Society of Medicine* 99(11): 589–593.
- Zamboni, P., Galeotti, R. Menegatti, E., Malagoni, A.M., Giancesini, S. Bartolomei, I., Mascoli, F. and Salvi, F. (2009a) A prospective open-label study of endovascular treatment of chronic cerebrospinal venous insufficiency. *Journal of Vascular Surgery* 50(6): 1348–1358.
- Zamboni, P., Galeotti, R., Menegatti, E., Malagoni, A.M., Tacconi, G., Dall’Ara, S., Bartolomei, I. and Salvi, F. (2009b) Chronic cerebrospinal venous insufficiency in patients with multiple sclerosis. *Journal of Neurology, Neurosurgery, and Psychiatry* 80(4): 392–399.