

UNIVERSITY OF CALGARY

A 'Controversial' Decision: Multiple Sclerosis Patients, Online Medical Knowledge and
the CCSVI Procedure

by

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A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN PARTIAL
FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF
ARTS

DEPARTMENT OF SOCIOLOGY

CALGARY, ALBERTA

APRIL, 2012

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Your file Votre référence

ISBN: 978-0-494-87898-9

Our file Notre référence

ISBN: 978-0-494-87898-9

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Abstract

This thesis examines how people with multiple sclerosis (MS) used internet resources, including personal narratives on patient-based websites and medical information, to learn about a new and ‘controversial’ treatment based on the theory that MS is caused by chronic cerebrospinal venous insufficiency (CCSVI). In-depth asynchronous or telephone interviews were conducted with 49 people with MS. Findings are that people with MS have used internet resources to develop reflexive communities and sometimes challenge the authority and knowledge of medical practitioners. Also examined is how study participants view the use of the internet to make the theory of CCSVI indispensable. Finally, the thesis shows that while MS patients use internet resources to become informed, the decision to undergo the CCSVI procedure was subjective and based on how each participant viewed the progression of their disease and the chances that CCSVI could reconnect them with their sense of self.

Acknowledgements

This thesis would have never been completed with the support I received from my family friends and fellow students. I would, first of all, like to thank Dr. Ariel Ducey for her support, constructive comments and insightful remarks on my thesis. I have learned a lot from working with her and hope to take that with me wherever I go. I'd like to thank Dr. Jean Wallace for creating an open and informative environment for all the graduate students and a good ear to vent to when needed. Further, I would like to extend my thanks to committee, Dr. John Manzo and Dr. Chloe Atkins, for their thoughtful questions and comments about this thesis.

To my fellow graduate students, if it were not for the support and bright spirits of my cohort the challenges, pitfalls and tribulations of graduate school would have been difficult to overcome. I want to thank my cohort all for the support, kind thoughts and entertaining comments. Special thanks go out to Kristen Desjarlais-deKlerk and Alicia Polachek for the support I received, this thesis would have been a daunting task for one person to complete on their own. Without the support from my peers this would not have been possible. Thanks to the old and new friends that arrived in this year's cohort.

I'd like to thank my family for supporting me during my research, data collection and writing process on a document that I am very proud of. I don't think I could have made it through developing, researching and ultimately writing this document without the support of my parents support and inspiration from my brother to research this topic.

Finally, I would like to acknowledge CIHR for providing funds to conduct this research.

Dedications

This thesis is dedicated to my family, friends, and all of the amazing participants that agreed to partake in this study and share their inspirational stories with me.

Table of Contents

Abstract.....	ii
Acknowledgements.....	iii
Dedications.....	iv
Table of Contents.....	v
List of Tables.....	vii
 CHAPTER ONE: Introduction to MS, CCSVI and the CCSVI Procedure.....	 1
What is MS?.....	3
Autoimmune Theory of MS.....	5
Treatment Course – Disease Modifying Drugs.....	7
Vascular Theory of MS.....	8
The Vascular Theory of MS and CCSVI.....	8
CCSVI in the Literature.....	9
The CCSVI Controversy.....	12
CCSVI Online.....	16
An Overview of this Thesis.....	18
 CHAPTER TWO: Theoretical Overview.....	 20
The Sick Role.....	20
The Physician Role.....	23
Narrative Analysis.....	27
Narratives as Presentations of Self.....	31
Actor Network Theory (ANT).....	32
Networks of Medical Knowledge.....	33
ANT and the Context of Citation.....	35
The Translation of Scientific Facts.....	37
Reflexive Communities.....	39
Late Modernity and Reflexive Modernization.....	40
 CHAPTER THREE: Literature Review.....	 44
The Internet and Health Information.....	44
Lay Expertise and Knowledge Creation.....	44
Medical Knowledge, Experiential Knowledge and Narratives Online.....	46
Creating Non-Medical Narratives.....	47
Advice.....	48
Limitations and Problems of Knowledge Creation the Internet.....	50
Patient Agency in Medical Decisions.....	51
Patient Advocacy.....	52
Conclusion.....	55
 CHAPTER FOUR: Methods.....	 56
Sampling and Recruitment.....	59
Data Analysis.....	61
Sample Demographics.....	62
Types of MS.....	63

CCSVI Procedure.....	63
Participants' Internet Usage.....	65
Ethical Considerations.....	66
CHAPTER FIVE: Constructing and Contesting MS Knowledge Online.....	68
The Shape of MS Online.....	69
Support.....	69
The Internet and Knowledge.....	73
Online Knowledge of MS and MS Medications.....	73
The Internet and the CCSVI Phenomenon.....	75
Perceptions of CCSVI.....	81
The Politics of the Internet.....	84
Patient-Based Websites.....	86
Treatment Facilities in Online Forums.....	96
The MS Society.....	97
CHAPTER SIX: Medical Knowledge and the Doctor-Patient Relationship.....	102
The Changing Doctor-Patient Dynamic.....	102
The Attitudes of Neurologists.....	103
Generalists.....	114
Trust in the Doctor-Patient Relationship.....	119
Conclusion.....	121
CHAPTER SEVEN: The 'Controversial' Decision.....	123
The Internet and the Decisions to have CCSVI.....	123
The Decision.....	127
The Decision Against the CCSVI Procedure.....	137
CHAPTER EIGHT: Discussion and Conclusion.....	142
Summary of Project.....	143
Contributions.....	149
Future Research.....	150
Concluding Remarks.....	152
REFERENCES.....	154
APPENDIX ONE: Interview Guide.....	173

List of Tables

Table One: Participants and the CCSVI Procedure.....	64
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Chapter #1: Introduction to MS, CCSVI and the CCSVI Procedure

On November 21, 2009 the CTV program *W5* aired a special entitled “The Liberation Treatment: A Whole new Approach to MS,” in which the traditional view of multiple sclerosis (MS) as an autoimmune disease was challenged by a vascular surgeon from Italy, Paolo Zamboni (2009). He proposed that MS may be caused by blocked or malformed veins in the neck that are meant to drain blood from the brain, resulting in improper drainage along the blood brain barrier (BBB), a condition he refers to as chronic cerebrospinal venous insufficiency (CCSVI). In conjunction with his discovery of blocked or malformed veins, he devised a supposedly simple treatment option that involves the use of balloon angioplasty to widen the veins in MS patients to return proper blood flow and, in turn, reduce MS symptoms -- a treatment that has been dubbed the ‘liberation’ procedure by the media and many ardent activists.

After the *W5* episode countless MS patients contacted their local MS clinics seeking information or access to the CCSVI procedure. However, the medical community in Canada has approached CCSVI with caution and originally stated that there was no scientifically valid evidence to demonstrate a link between CCSVI in MS patients and warned against patients seeking the procedure. Health Canada and the Canadian Institutes of Health Research (CIHR) withheld approval for a phase I/II clinical trial of the CCSVI procedure until June, 2011. Many neurologists have questioned the effectiveness of the treatment and whether it can help MS patients. They do not openly discuss CCSVI or the CCSVI procedure with their patients and encourage a wait-and-see attitude towards the procedure. In fact, there are no hospitals or facilities in Canada that are authorized to perform venous angioplasty on MS patients at this time, although venous angioplasty is being performed on similar veins in kidney dialysis patients and angioplasty of the arteries

in the heart are routine. MS patients have turned to other sources to access information on CCSVI and the CCSVI procedure.

CCSVI has received a significant amount of media attention in Canada and a massive following online through a variety of websites – Facebook, patient blogs, and discussion boards like the one found on *This is MS* (TIMS) – where patients share their illness narratives of MS and the CCSVI procedure for others to read. Patients desired as much information as possible about the CCSVI procedure, so if they were not going to find it through the traditional sources of MS care, they branched out to online sources. Many medical professionals are concerned about how the internet is fuelling patients' decisions to have the 'controversial' new procedure. This has caused a rift between these medical professionals, who do not see the benefits of CCSVI, and patients, who have to live day-to-day with a chronic, disabling disease which traditional medical practices have not been able to cure, prevent, or even slow.

This thesis examines how the internet may be factoring into MS patients' decision to travel abroad and access the CCSVI procedure as well as provides an in-depth analysis of how people with MS are using the internet. The thesis will address three central questions, the topics of the substantive chapters – five, six and seven. Chapter five examines how the personal narratives posted online impact MS patients' perception of the CCSVI procedure, describing how people with MS use the internet to become more informed, as well as construct and contest medical knowledge about their disease and treatment options. The chapter argues that many people with MS have become reflexive consumers of online information, which they use to act against the influences of the social structure that has traditionally influenced their behaviour. The sixth chapter discusses how patient narratives and information posted online impact patients' perceptions of their

disease and its care, showing how the internet has become the ground for contesting the authority of medical knowledge established by medical professionals that treat MS and the traditional doctor-patient relationship. Chapter seven will explore the role of MS patients' use of the internet in making a difficult decision about whether to travel abroad to access the 'controversial' CCSVI procedure and shows the central importance to these patients of the uncertainty of living with a chronic illness.

To address these research questions, asynchronous in-depth online interviews and telephone interviews were conducted with individuals afflicted with MS who had looked into the CCSVI procedure. Participants were recruited through three websites – the Multiple Sclerosis Society of Canada Alberta Chapter, a discussion board on a popular patient-run MS website, and a local not-for-profit MS organization, Direct MS.

The overall theme of this thesis is patients' desire to enact control over their disease when the dominant medical narrative -- to cure patients and return them to a normal healthy state -- could not provide a ready solution for MS. In fact, some observers (Hardey, 1999; Hardey, 2001) of the internet have proposed that online resources are creating informed patients who can challenge the traditional authority of medical knowledge and decrease their dependence on medical professionals. Thus, the explicit aim of this thesis will be to determine how online information impacted MS patients' decision to have a 'controversial' medical treatment, but the implicit aim will be to examine how online information may be altering medical knowledge and the traditional sources of medical authority.

What is MS?

MS has traditionally been viewed as “an inflammatory demyelinating disorder of the central nervous system” (McNulty, Livneh & Wilson, 2004: 91) in which the immune

system attacks the myelin tissue surrounding the nerve endings along a patient's brain and spinal column or the central nervous system (CNS). MS stands for the involvement of multiple areas of a patient's CNS that are scarred by the myelin damage (Spencer & Karceski, 2008). The deterioration of the myelin tissue may result in vision loss, numbness, paralysis, and incontinence (Spencer & Karceski, 2008), in addition to irreversible damage to a patient's quality of life and social relations leading to, for example, early retirement (De Judicibus & McCabe, 2005; Green, Todd & Pevalin, 2007), dependency on loved ones (Boeiji & Van Doorne-Huiskes, 2003), strain on the family (Harrison et al., 2004; Power, 1979) and difficulty maintaining personal and sexual relationships (McCabe, 2002; McCabe, McKern, McDonald & Vowels, 2003). It is estimated that between 50,000 and 75,000 Canadians have MS.

MS is normally diagnosed between the ages of twenty and forty (D'haeseleer et al., 2011; Spencer & Karceski, 2008), and twice as many women as men are afflicted with the disease (Spencer & Karceski, 2008; Waxman, 1999). There is no cure for MS and the disease has an unknown aetiology. MS can be cumbersome to diagnose as its early symptoms – numbness, blurred vision, pain and mobility issues – are similar to numerous other diseases such as Lyme disease (Karussis, Weiner & Abramsky, 1999). In fact, it can take upwards of five years to receive an MS diagnosis since a patient needs to have injury in two separate locations of the CNS, occurring at different times in the life course, for there to be a definitive diagnosis (Spencer & Karceski, 2008). Many patients are either misdiagnosed at first, or given probable diagnosis in which the individual is told they may have MS but that they will need to have another MS attack (normally within a two year time frame) before the doctor can confirm the diagnosis.

There are four different types of MS that a patient may be diagnosed with: relapsing remitting (RRMS), secondary progressive (SPMS), primary progressive (PPMS) and progressive relapsing, however the last type of MS is uncommon (no participant in this study was diagnosed with progressive relapsing). RRMS is traditionally diagnosed in patients in their mid-twenties and involves the MS patient experiencing attacks or flare-ups of their MS that then remit as they return to a state in which there are few, if any, visible signs of the disease. During the RRMS phase of the disease, treatment regimes, or disease modifying drugs (DMDs), are available to help control attacks. Once a patient enters SPMS there are no more remissions and such patients are now on a slow, downward slide to disablement. When a patient is diagnosed with PPMS the progression and outcomes are similar to SPMS; PPMS and SPMS have a similar course, but SPMS patients are usually previously diagnosed with RRMS and slowly progress into the secondary phase over the course of ten to twenty years, whereas PPMS is an initial diagnosis typically made at a later stage in life, around the age of 40 (MS Society of Canada website).

Autoimmune theory of MS

MS is believed to have an autoimmune aetiology in which the immune system attacks the healthy myelin sheath, a fatty substance that surrounds the nerve endings in an MS patient's CNS (McNulty, Livneh & Wilson, 2004; Spencer & Karceski, 2008). The immune system turns on the body and the T-cells that are meant to attack foreign cells start instead to attack the healthy fatty proteins of the myelin sheath along the nerves in a patient's brain and spinal column resulting in demyelination (Dhib-Jalbut, 1997; Schwartz & Kipnis, 2002). When myelin tissue is damaged, the ability for the brain to send

messages to the rest of the body is degraded and results include compromised mobility, vision and cognitive problems (Spencer & Karceski, 2008).

However, the cause of the immune systems actions is unknown. It is commonly believed that a foreign substance enters the CNS of an MS patient and the body cannot distinguish between the foreign substances and healthy cells (Kasper & Shoemaker, 2010). Many have speculated that the origins of MS may be in the form of a virus such as Epstein-Barr virus (EBV) (Gilden, 2005; Lossius, Vartdal & Holmay, 2011; Sundstrom et al., 2004), a genetic predisposition (Chastain & Miller, 2012; Ramagolpalan et al., 2011) or environmental causes that relate to the course and outcomes of the disease and trigger the immune system response (Berlanga-Taylor, et al., 2011; Cannon & Greenamyre, 2011; Correale, Ysraelit & Gaitan, 2011; Cross & Parks, 2010; Handal & Ramagolopalan, 2012; Mowry, 2011).

Lending credence to the viral hypothesis of MS, Gilden (2005) found that MS patients have a higher than normal levels of antibodies that are important in fighting viruses in their brain and cerebrospinal fluid (CSF), as well as in many MS plaques. In addition Sundstrom and colleagues (2004) found that there were elevated levels of EBV infection in MS patients, in conjunction with high levels of the same virus fighting antibodies five years prior to the onset of MS.

A link between a viral cause and genetics has also been found by researchers. Ramagolpalan and colleagues (2011) found that there is a link between the genetic make-up of MS patients and the interaction with environmental triggers such as Vitamin D. Lower levels of Vitamin D in MS patients correlate with genetic factors that can impact the interaction of T-cells in a patient's body (Correale, Ysraelit & Gaitan, 2011; Handal & Ramagolpalan, 2012).

Moreover, studies (Cannon & Greenamyre, 2011; Spencer & Karceski, 2008; Cross & Parks, 2010) have found that MS has a geographical significance; there are higher rates of MS further away from the equator. Northern European countries and Canada have some of the highest incidence rates of MS in the world. That being said, many of the treatment regimes MS patients are prescribed address the immune systems reaction to foreign bodies in the CNS.

Treatment Course – Disease Modifying Drugs

The treatment options provided for MS patients are aimed at reducing the incidence of MS relapses by suppressing the immune system and are referred to as disease modifying drugs (DMDs). In addition, during severe attacks MS patients may be prescribed a high dosage of steroids like prednisone to further suppress the immune system. DMDs are administered as intramuscular or subcutaneous injections that the patient must administer themselves either daily, three times a week or once a week depending on the drug. These drugs are intended to reduce the number of MS attacks a patient may experience and, in turn, reduce the number of MS lesions in the CNS; studies (e.g., Goodin et al., 2002) have found that they are between thirty and forty percent effective at reducing the number of MS attacks. There are also side effects that may occur from taking these medications such as skin reactions at the point of injection and abnormalities in white blood cell counts. These treatments are only effective for RRMS. Once the disease has entered the progressive stage – SPMS or PPMS – there are few options available, outside of chemotherapy to try and suppress the immune system, for treatment.

Vascular Theory of MS

The vascular theory of MS is not new and has, in fact, been resurfacing for over 150 years. In 1863, Rindfliesh, a pathologist, discovered that there were inflamed vessels in the white matter of MS patients' brains (Yamout et al., 2010). Putnam (1935), an assistant professor of neurosurgery at Harvard Medical School, found that lesions were produced by a venous obstruction and were confined to the white matter of the brain. Moreover, Schelling (1986), an Austrian physician, found that reflux, or blood flowing back along the skull and spine, may play a role in neurodegenerative diseases such as MS. However, none of these theories raised a serious threat to the autoimmune theory until Dr. Paolo Zamboni, a vascular surgeon, proposed that CCSVI may have a causative role in MS.

The Vascular Theory of MS and CCSVI

The vascular theory of MS proposes that improper blood flow due to blocked, stenosed, or malformed veins along the extracranial venous drainage system, the internal jugular (IJV) and azygous veins (AZY), can lead to reflux along the blood brain barrier (BBB) of MS patients leading to a build up of iron deposits in an MS patients CNS (Singh & Zamboni, 2009; Zamboni, 2006; Zamboni et al., 2009, Zamboni et al., 2009). A stenosis, or abnormal narrowing in the vein, is considered significant if there is fifty percent or more reduction in the width of the vein (Zamboni et al., 2009). The list of what is considered a malformed vein, according to Zamboni et al. (2009), includes: the twisting or severe stenoses in the vein, a stenosis of the whole wall of the vessel, or a membrane almost completely occluding the vein. These blockages, stenoses or malformations result in increased pressure in the veins, referred to as hypertension, which causes strain on the vein forcing it to expand which results in a breakdown between the tight junction of the BBB of a patient (Simka, 2009; Talbert, 2008; Wuerfel, Paul & Zipp, 2007; Zamboni et al.,

2011). When the tight junction between the veins and BBB breaks down, T-cells are able to enter the CNS and degrade the myelin sheath (Singh & Zamboni, 2009). The vascular theory of MS therefore agrees that the immune system does become involved in the course of the disease but it is a secondary response, an attempt to clean up the mess created by the increased iron deposits in the CNS which can lead to neurodegeneration (Zamboni et al., 2009).

Zamboni and colleagues (2009) proposed performing venous angioplasty on MS patients to widen the strictures in the veins and return normal blood flow. This treatment has been dubbed the ‘liberation’ procedure since widening the vessels helps to liberate blood flow in the extracranial venous system. A catheter is inserted into the patient’s groin area and threaded through the venous system to the stenosed veins in which a balloon is inflated for thirty to sixty seconds to ensure the malformation is widened. Other vascular surgeons and interventional radiologists are inserting a permanent stent, a cylindrical mesh of medical that can be used to prop veins open when performing the CCSVI procedure on MS patients. Zamboni has openly questioned the use of stents in the media and warns MS patients against receiving the CCSVI procedure when a stent is used. In addition, not all supporters of the CCSVI theory see the need for surgical intervention. Simka (2009) and Simka and Rybak (2008) address the possibility of pharmacological drugs being produced to address the increased pressure in MS patients’ vessels. Many studies have been conducted that have examined the presence of CCSVI in MS patients, as well as the perceived efficacy of the procedure.

CCSVI in the Literature

Zamboni and colleagues’ (2009) original study tested sixty-five MS patients and two hundred and thirty-five healthy controls using the transcranial and extracranial colour-

Doppler to determine if they had any venous anomalies. They found that MS patients had 100% specificity and sensitivity, meaning that all MS patients tested positive for blocked or malformed veins whereas none of the healthy controls did. Zamboni and colleagues subsequently performed venous angioplasty on the sixty-five MS patients and followed the patients for six, twelve and eighteen months checking the patients' cognitive function, motor function and quality of life. The results were a slight quality of life improvement for patients in the progressive stage of MS at six months with negligible benefits after eighteen months. RRMS patients showed a significant improvement in the quality of life and disease severity eighteen months post procedure. However, only twenty-seven percent of RRMS patients did not experience a relapse in their disease after twelve months.

Several other studies (Auriel et al., 2011; Sundstrom et al., 2010; Yamout et al., 2010; Zivadinov et al., 2011) have been conducted to test the specificity and sensitivity of CCSVI in MS patients with a mixture of results. Zivadinov et al. (2011) has conducted the largest study of CCSVI to date with four hundred and ninety-nine subjects – two hundred and eighty-nine MS patients, one hundred and sixty-three healthy controls, twenty-six subjects with other neurological diseases and twenty-one subjects with clinically isolated syndrome (the subjects have experienced one neurological episode such as optic neuritis but may never develop MS). The authors found that 56.1% of MS patients, 22.7% of healthy controls and 42.3% of patients with other neurological diseases tested positive for CCSVI, nowhere near the results Zamboni achieved.

Still others (Auriel, et al., 2011; Sundstrom, et al, 2010) have found no connection between CCSVI and MS. In fact, Sundstrom and colleagues (2010) found that only three of twenty-one MS patients they studied had venous blockages. Auriel and colleagues (2011) found that only one MS patient in their study had reflux of the IJV and feels that it

is, in fact, dangerous for MS patients to seek the CCSVI procedure. Furthermore, Yamout et al.'s (2010) study demonstrated that extracranial venous stenosis is not present in recently diagnosed MS patients whereas patients that have been diagnosed with MS for ten years or more had extracranial venous stenoses, suggesting that CCSVI may be a secondary result of the disease, not causative as Zamboni had originally speculated.

In addition to not being able to replicate Zamboni's original findings, other researchers (Ghezzi, Comi & Federico, 2011; D'haeseleer, et al., 2011) have conducted extensive literature reviews of CCSVI in MS and come to similar conclusions. Ghezzi, Comi and Federico (2011), as well as Filippi and Rocca (2011) feel that CCSVI should not be explored by MS patients outside of a study that has received ethical approval through an institutional review board. In fact, D'haeseleer and colleagues (2011) concluded that at this moment in time there is little evidence to support the causative theory proposed by Zamboni. Nino, Tampieri and Melancon (2010) addressed the fact that patients that have had neck surgery do not develop MS like symptoms. In fact, they feel that the vertebral venous system is able to compensate for any flow changes that may result due to blocked, malformed or stenosed veins.

Nino, Tampieri and Melancon (2010) raised concerns about stenting the AZV due to the possibility of the stent migrating to the heart. A study conducted by neurologists from Calgary found that MS patients that have received CCSVI are experiencing stent migration, complete occlusion of stents which can lead to stroke-like symptoms, hyperplasing – over-sized stretching of veins – leading to extreme pain, the formation of blood clots in a vessel, and nerve damage (Burton, et al., 2011). Medical professionals have questioned the safety of the CCSVI procedure by addressing the that the walls of veins are thinner and more elastic than arteries, which can cause them to spring back into

shape after the vein has been inflated (Nino, Tampieri & Melancon, 2010). However, these concerns have not stopped MS patients in Canada from travelling abroad to access the CCSVI procedure, nor prevented them from telling their stories online.

The CCSVI Controversy

The neurological community and Health Canada are sceptical of the CCSVI procedure. The majority of Canadian medical professionals support a wait-and-see attitude towards CCSVI. They have urged patients to be cautious, wait for studies to be conducted into the association of CCSVI in MS and to only access the CCSVI procedure if it is in an ethically approved clinical trial (Ghezzi, Comi & Federico, 2011; Filippi & Rocca, 2011). This point of view is supported by the MS Society of Canada. Nevertheless, the MS Society did offer an unlimited number of \$200,000 grants to study the connection between CCSVI in MS on Monday, November 23, 2009, a move unprecedented in the history of the organization. And additional funds were granted in June of 2010 by the MS Society of Canada and the National MS Society in America in which they donated a combined \$2.4 million dollars to research CCSVI in MS. Nonetheless, Health Canada and the MS Society of Canada developed an advisory committee of medical specialists and patients to provide advice and review the studies conducted into CCSVI which concluded in August of 2010 that:

[T]here is currently no scientific evidence in support of the existence of CCSVI in MS patients and there is currently no scientifically valid evidence to support the use of venous angioplasty in the treatment of patients with MS (CIHR, 2010).

As a result, the Canadian Government decided, at that moment in time, not to fund a clinical trial and to wait for the results of the studies being funded by the MS Societies of

Canada and America, as well as studies all over the world, to be completed before they would reconsider funding a pan-Canadian clinical trial. The majority of Canadian medical professionals supported the wait-and-see attitude towards CCSVI. Most physicians are therefore unwilling to discuss the CCSVI procedure with their patients.

As a result of the attitudes of Health Canada and the neurological community, MS patients have been so far unable to receive the CCSVI procedure in Canada. One facility in Barrie, Ontario was performing the procedure in early 2010 but was soon shut down by the Ontario College of Physicians and Surgeons, due to the lack of evidence of a connection between CCSVI in MS. Canada was not the only country that had problems providing the CCSVI procedure to MS patients. In the United States, in early 2010 many treating interventional radiologists were ordered by the legal departments of their hospitals to cancel all appointments with MS patients until either more research was conducted or they received institutional review board (IRB) approval (*The Globe and Mail*, April 29, 2010, A1). MS Patients, however, were informing each other of doctors who were still treating MS patients with venous angioplasty through online communities. The climate has changed in the United States so that now, in 2012, there are several IRB approved studies into CCSVI being conducted at treatment facilities in cities such as Seattle, New York and San Diego. Canadian MS patients have not been dissuaded by the actions of hospital legal departments, the Canadian government, or the advice they received from their specialists and have accessed the treatment in other locations around the world such as Poland, Costa Rica, the United States and Egypt.

The cost for Canadian patients to travel abroad and receive the CCSVI procedure is significant. Many patients end up paying between \$10,000 and \$20,000 for the procedure including travel expenses. Some family members have paid for their children, siblings or

spouse to have the CCSVI procedure, while other MS patients held fundraisers or refinanced their home to be able to afford the cost. Even with the death of two Canadians due to complications from venous angioplasty – a completely clotted stent and a brain haemorrhage – patients still fundraised or accessed loans to have the CCSVI procedure in locations all over the world. Unsurprisingly, patients would prefer not to have the procedure abroad knowing that it would be less expensive and possibly safer when undertaken in Canada. According to the minister of health in Ontario, patients could receive the procedure for \$6,300 in Ontario if the government permitted venous angioplasty on MS patients (*The Globe and Mail*, May 9, 2011). In fact, throughout 2010 and 2011, MS patients advocated and rallied for the provincial and federal governments to fund a clinical trial for the CCSVI procedure and eventually governments have been forced to respond. Saskatchewan was the first province in Canada to state that they would fund a clinical trial of the CCSVI procedure, earmarking \$5 million for it and in December 2010 releasing a call for proposals. However, they received only one application, which did not meet the strict guidelines established by the expert panel reviewing the applications since it was submitted by a neurologist with no vascular training, and therefore, unable to perform the procedure. Therefore, in January 2012, the Saskatchewan government decided to send eighty-six MS patients to New York where half of them will receive venous angioplasty at a treatment facility in Albany and the other half will be the control group. In October 2010 the government of Manitoba committed \$500,000 to fund a pan-Canadian clinical trial, which was increased to \$5 million in April of 2011 to match Saskatchewan. The New Brunswick government agreed to subsidize MS patients \$2500 to travel abroad for the CCSVI procedure if it was matched through fundraising or a third party. Other provinces – Newfoundland, British Columbia and Alberta – are conducting observational studies to

determine if the CCSVI procedure is safe. The Alberta government, in December 2010, provided \$1 million dollars to MS researchers at the University of Calgary and the University of Alberta to conduct an online observational study of Albertan MS patients who have already travelled abroad for the CCSVI procedure who are being asked to fill out a survey at six, twelve, eighteen and twenty-four months post procedure. The study, entitled The Alberta Multiple Sclerosis Initiative (TAMSI), began in July 2011 and if it finds that the CCSVI procedure is safe, the Alberta Government will fund a \$7 million clinical trial.

Within a year, on June 29, 2011, Health Canada reversed their decision on CCSVI and decided to fund a clinical trial of the CCSVI procedure. The same advisory committee that was established with the MS Society conducted a meta-analysis of eight studies published on the CCSVI procedure which used the same ultrasound techniques that Zamboni and colleagues' used in their original study, as well as having a healthy control group to compare the instances of CCSVI. They found that there was a statistically significant association between CCSVI and MS although they could not make any conclusions about the causative role of CCSVI in MS (Laupacis, et al., 2011). Upon the advice of the advisory committee Health Canada and CIHR approved a phase I/II clinical trial of CCSVI. On November 30, 2011 they released a call for proposals to test the CCSVI procedure in approximately 100 MS patients. Funding is slated to begin in May 2012. Critics of the CCSVI procedure feel Health Canada and CIHR caved to the pressure from patient advocacy organizations that have dominated online discussion boards and Facebook pages.

Ultimately, many medical professionals blamed the media for fuelling the hype of CCSVI (Fox, 2011). Healthcare professionals felt that the *W5* special was pro-CCSVI

since it provided evidence that supported the procedure and did not interview anyone that was sceptical of the CCSVI procedure. Most physicians, especially neurologists, are therefore unwilling to discuss the CCSVI procedure with their patients. News outlets have reported that neurologists have thrown out information that patients have brought to their appointments regarding the CCSVI procedure. Neurologists are, in turn, facing backlash from their patients. Many MS patients have fired their specialists, and are arguing that doctors and pharmaceutical companies want to keep them sick since there are large profits to be made with the current treatment regimes. (The pharmaceutical giant Merck Serono recently paid \$44.3 million dollars to settle charges that they made false claims about their medication (rebif) to healthcare programs, by paying doctors to prescribe the drug (Bloomberg.com May 4, 2011)). Patients have turned to the internet instead.

CCSVI Online

Patient narratives about CCSVI quickly began to populate Facebook pages, discussion boards on popular patient-run MS websites like TIMS, and various patient run blogs. This alarmed healthcare professionals and in an August 6, 2010 press release, Alberta Health Services (AHS) warned patients against using the internet or patient-based websites to find information on the CCSVI procedure:

People with MS should be wary about getting information solely from media stories and reports or from patient's "blogs." They should seek out expert advice from knowledgeable MS caregivers and experts, and should carefully determine the credentials of any centre offering "liberation" treatment. (6)

Some medical professionals have argued that if it were not for the media and the internet, the CCSVI hypothesis would not have survived the traditional peer-review process.

Now there are now countless websites that are dedicated to MS and CCSVI. The most popular is the aforementioned discussion board on TIMS, a patient-run website which has been online for over ten years and strives to provide an unbiased forum to discuss a variety of MS treatments and news. The website has no affiliations with major organizations such as MS research clinics or pharmaceutical companies. The TIMS discussion board is cited by major CCSVI advocates like Marie Rhodes as being the first place online that discussed CCSVI, with threads dating back to 2008. There is now a separate thread dedicated solely to CCSVI in which patients can discuss their experience with the treatment and the benefits they have or have not received, post academic papers relating to the vascular theory of MS, and ask questions about the procedure to become more informed. To be able to post and comment on the TIMS discussion board, an individual needs to start an account in which they provide an email address and develop a username to sign-in with. Each thread on the discussion board has upwards of three moderators that oversee the posts, handle complaints from fellow users and can delete posts if they are deemed offensive, hurtful or unrelated to the topic.

Facebook has also emerged as a frontrunner for information on the CCSVI procedure. Advocates like Joan Beal created *CCSVI in MS* on Facebook to disseminate information on the procedure and other pages include *CCSVI Toronto*, *Newport Beach/Costa Mesa CCSVI*, and those of numerous local CCSVI organizations which use them to keep local patients up-to-date on events and general meetings. Some of these pages are open to the public while others require patients to contact the administrator of the page to gain access. It is through these types of sources that MS patients were able to learn about the CCSVI procedure and what to expect after having the procedure. Patient stories

have been encouraged on all of the pages as a way to communicate experiences to other patients and may change how patients experience their illness.

An Overview of the Thesis

This thesis is guided by four theoretical perspectives – reflexive modernity, actor network theory (ANT), Parsons’ functionalist account of the sick role, and narrative analysis – to provide insight into MS patients’ use of online resources. Narrative analysis provides a common thread between all three substantive chapters. Traditionally, the stories that patients tell are confined to the information that medical professionals need to treat the illness and cure the patient; the story of the patient’s suffering and illness is lost within the dominant structure of medicine (Frank, 2001). Online, MS patients have been able to come together to speak for themselves and with others, in discussion boards, forums and Facebook pages.

Chapter five provides an overview of the actions of MS patients online and considers how MS patients’ perceptions of their disease and CCSVI are changing due to online resources. People with MS are able to access support and advice based on personal experiences online, to increase their autonomy and develop their own knowledge in a way they could not have before. However, the information online can, in certain instances, be overly positive and predominantly reflect the views of certain individuals, or authority figures, strongly in favour of the CCSVI procedure. For this reason, the second section of chapter five addresses the way the information is being taken up, both for and against the CCSVI procedure, in online forums, websites and discussion boards frequented by people with MS. The participants’ perceptions and attitudes towards the CCSVI procedure influenced how they viewed and read these sites.

In chapter six, the discussion of who deserves to be authority figures in MS treatment is continued as I seek to answer my second research question about how the internet is impacting MS patients' perceptions of their disease and its care. This is done by examining how online information may challenge the authority of medical professionals. People with MS began to challenge the traditional sources of MS care – neurologists – due to the belief that they had a vested interest in maintaining control over the treatment of MS, while turning to their general practitioners (GP) for advice on the CCSVI procedure and an explanation of complex medical terminology.

Chapter seven addresses my final research question about how online resources have impacted MS patients' decision to have the CCSVI procedure. Before making a decision to travel abroad people with MS became as informed as possible about the CCSVI procedure through a variety of means, the most common of which are medical articles and personal stories. There are no definitive scientific or medical criteria to help MS patients decide whether to have the CCSVI procedure. Participants discussed the uncertainty of both the disease and the treatment, and the desire to enact control over their disease as the most important factor impacting their decision about the procedure. The more emotional or personal the aspects of the online narratives, stories, or videos were as, or more, important than the "information" or "facts" they might contain. MS can be considered a threat to the continuity and order, or ontological security, in an individual's life (Giddens, 1991). The CCSVI procedure for most participants presented a chance to mend a break in their ontological security, reconnect the body with the self and ensure they may be able to function ably and fully in their life. Still, the threat that MS poses to an individual's ontological security is subjective and varies for each person afflicted with the disease.

Chapter #2: Theoretical Overview

Parts of four theoretical perspectives guided the analysis of this thesis – Parsons' notion of the sick role, narrative analysis, actor network theory (ANT) and the idea of reflexive modernity. The work of each theory will help to build the story of MS patients, their use of the internet, and the CCSVI procedure in a way that could not be done with just one theory. Narrative analysis, reflexive modernity and ANT will frame the discussion in chapter five of how MS patients are using the internet. Chapter six will borrow aspects of ANT and the notion of the sick role to analyze how medical authority and the doctor-patient dynamic may be changing due to patients' use of the internet. In chapter seven, the work of narrative analysis and theories of self in late modern society will provide a framework to analyze how MS patients came to the decision to have the CCSVI procedure.

The Sick Role

From a functionalist perspective, each individual has roles they are to enact in society. When a person is struck with an illness, it can hinder their ability to perform their roles. For Talcott Parsons (1951), illness is a deviant, negative role in society since the individual is unable to perform normal day-to-day functions to the best of their ability. Thus, a person should want and desire to return to a normal healthy state. However, they are unfit and unqualified to do so themselves and, in turn, are required to seek technically competent help in the form of a medical practitioner to treat the illness from a scientific and objective perspective.

The sick role, proposed by Parsons, dictates that both the patient and the physician have set roles that they must enact in order for the patient to return to a healthy and productive state. The goal of these institutional roles is to return the sick patient to health,

and minimize illness in society. Parsons proposed that for a sick person to be exempt from their normal social responsibilities they must follow three expectations, which protect against malingering. First, the ill individual cannot help being sick and is in a state where he or she needs to be taken care of by others, namely medical professionals. Second, the sick individual has an obligation to try to get well by seeking technically competent help from a physician and, third, the patient must cooperate with the physician's orders as best as he or she can to return to a healthy state.

When a patient is ill they can become worried about their future for fear that the illness will continue to worsen and encroach on their day-to-day life. The ill person may suffer from emotional strain from the shock and anxiety that can accompany an illness which can cloud their judgement as has been shown in previous studies (McKneally et al., 2004; Elit et al., 1996; Step et al., 2010). Physicians and the knowledge they possess is touted and respected among individuals in society, so much so that patients turn to them when they are in their most vulnerable state to provide answers to their illness (Turner, 1987; Wynne, 1988). Patients see medical professionals as a way to feel they are actively doing something to rectify the uncertainty that is presented by an illness. Parsons (1951: 440) believed the patient is helpless and "in need of help" since they are not qualified to treat themselves. For this reason, the patient must seek technically competent help to diagnose and provide a remedy for the illness. The individual and their family are incompetent to provide aid due to their lack of scientific and medical knowledge. Parsons believed that most patients have some knowledge about treating an illness, but the patient tends to believe they know more than they actually do. Only a medical professional can help a sick individual return to a healthy state. Even when patients who are afflicted with a disease like MS seek alternative treatments, previous research (Wynne, 1988: 107) has

found that they provide a justification which needs to be grounded in “proper medical knowledge.” In addition studies have found that when MS patients try alternative treatments, it is in conjunction with conventional medical treatments (Marrie, Hadjimichael & Vollmer, 2003; Schwarz et al, 2008).

Previous studies (McKneally et al., 2004; Mendick et al., 2010; Pinguart et al., 2004; Sinding et al., 2010; Step et al., 2009) have found that many patients trust the advice they receive from their doctor due to physicians’ expertise. In fact, McKneally et al (2004) found, in their study of how patients develop trust in their medical professional’s decision to operate for cholecystectomy, that many patients deferred trust to competent caregivers or medical professionals. Mendick and colleagues’ (2010) found that participants in their study either deferred to their doctors for advice, or asked strategic questions to determine what their doctor’s preferred treatment option was since they trusted the advice and expertise of their treating medical professional. The participants in these studies trusted the knowledge and information their medical professional provided regarding their illness and appropriate treatment option. Even when patients felt the need to become informed through internet searches (McKneally et al., 2004), or accessing medical articles (Sinding et al., 2010) about a treatment their physician was recommending, they still trusted the advice they received. The option of, and access to, further information did not sway the participants in these studies away from their doctor’s advice.

For Parsons (1951) this trust and confidence in physicians and cooperation with the recommendations made by the treating medical practitioner was necessary, given the particular nature of what medical professionals do, and functional to society as a whole. Anne Wynne (1988) concluded in her study of the diagnosis of MS that patients not only turned to medical professionals to provide a diagnosis and legitimate their suffering, but did

not question them in the process; these patients were upholding their role by respecting the status of their medical professional. Other studies (Robertson, Dixon & Le Grand, 2008; Safran et al., 2001) have found that the quality of the relationship a patient has with a physician and the communication between the two parties led to patient loyalty. Moreover, previous studies (Calnan & Rowe, 2008) have found that a patient has a high level of trust in their physician or specialist based on the competency the medical professional displays within their field of study, a point that Parsons discusses at length.

The Physician Role

Medical knowledge that physicians and medical professionals possess has a privileged status in our society due in large part to the belief that it is based on objective scientific facts (Turner, 1987; Wynne, 1988). The role of the physician, in Parsons' (1951) view, involves treating the patient to the best of their abilities, as well as acquiring a high level of competency in scientific and medical knowledge. It is the physician's responsibility to do everything in his/her power to ensure the patient's health and day-to-day functions return to normal. The technical competence of a medical practitioner is based on his/her medical knowledge, which helps the physician maintain an objective stance in the treatment process. A high specificity of competence involves the physician determining the limits of their field to ensure that they will not be "spread too thin" (Parsons, 1951: 456) and that they will use the often very private, personal information they acquire from patients, for specific medical purposes. The physician becomes specialized within a set of treatment regimes through the use of their scientific knowledge, not personal opinion, and is thus able to aid a patient. Parsons (1951) stipulates as well that the physician is required to be affectively neutral to their patients, both emotionally and physically. Parsons recognized that a relationship between the doctor and the patient can

emerge over an extended period of time which can lead to transference in the doctor-patient relationship. He argued the patient inscribes more emotional meaning in the relationship than is appropriate, which can interfere with the physician's ability to objectively treat the illness. The physician must not reciprocate the emotional expectations of the patient; it is the physician's responsibility to remain affectively neutral in their relationship with patients. The overall wellbeing of the patient should be of central importance to the treating medical doctor and the doctor should remove all personal opinions, judgements, and prejudices about both the patient and the illness while treating a patient.

However, recent studies have questioned physicians' using only their own knowledge to treat their patients and have called for shared decision-making, in which the patient and the physician discuss and assess all the information to come to an informed decision about treatment. Karnieli-Mille & Eisikovits (2009) questioned the motives and actions of medical professionals when presenting treatment options as they presented only the information they deem relevant without any other treatment options. Karnieli-Miller and Eisikovits found that at a paediatric hospital in Northern Israel that the physicians exercised several different forms of power over their patients including expert, predictive and emotional power through tactics such as stressing the seriousness of the illness and need for intervention to explicitly avoiding alternative treatments, to ensure patients complied with the doctor's preferred treatment. Moreover, Allen et al. (2011) found that when patients suffering from haemodialysis presented their own experiential knowledge about their disease, their medical professionals did not take it into account and, in turn, an adversarial relationship emerged between the physician and the patient. The patients felt they had their own knowledge that could add to the discussion on medical treatments. Recent research (Bryan et al., 2006) about attempts to create a shared decision-making

model shows it is not upheld. Patients would provide information to the medical professional and the medical professional would subsequently decide which treatment option was best, reaffirming the medical narrative.

Patients afflicted with chronic and contested illnesses in particular pose challenges to the traditional doctor-patient relationship described by Parsons. Patients' have developed their own understanding of their disease based on their own experiences in the form of patient narratives (to be discussed later in this chapter), however not all treating physicians and specialists acknowledge the validity of patient-based knowledge. Zavestoski et al. (2004) demonstrated that patient narratives are not an accepted diagnostic tool due to the perceived lack of scientific evidence. Even when physicians do accept a diagnosis of a contested illness, Asbring and Narvanen (2003) found that many physicians have difficulty treating a disease that has little basis in what they regard as objective medical knowledge. Asbring and Narvanen (2003) provided a list of tactics that physicians used to deal with patients with contested illnesses, such as keeping an emotional distance from patients, referring to other specialists, or expressing scepticism because of the ostensible lack of scientific evidence on the disease.

As Parsons' (1951) stated, due to a patient's helpless state, lack of knowledge in the medical field, and the emotional impact of an illness in a patient's life, the patient may become vulnerable to exploitation. To keep the patient's wellbeing at the forefront of treatment, Parsons proposed that physicians need to be collectively oriented, in that they work for the betterment of the whole society more than their own self-interest. The physician cannot advertise, barter over wages with his patients, refuse service based on the economic situation of the patient; moreover the physician "is given the privilege of charging according to a 'sliding scale,' that is in proportion to the income of his patient or

his family” (Parsons, 1951: 464). Collectivity-orientation is needed to ensure that a patient can trust the medical practitioner, and know that they are not being exploited.

Nevertheless, studies (Conrad & Barker, 2010) have questioned the motives of doctors with respect to prescribing habits by addressing the connection of physicians and medical researchers to pharmaceutical companies in which they believe that the pharmaceutical industry may be shaping how medical knowledge is created. Fisher (2008) found that private sector physicians are ethically oriented towards the pharmaceutical companies that hire them to conduct clinical trials rather than their patients due to the financial relationship that is developed with the pharmaceutical company. Many researchers (Palmlund, 2006; Moynihan, 2003; Vallance, 2005; Vaithianathan, 2004) have scrutinized the link between how medical professionals prescribe medications and their association with pharmaceutical companies. Pharmaceutical companies have been known to provide ‘gifts’ and all-expense-paid trips to information sessions for physicians to ensure brand loyalty for their medications after the patent has expired. In fact, Palmlund (2006: 549) found in her study of clinical research into hormone replacement therapy (HRT) that “a gift relationship is a relationship of mutual obligation.” The economic power of pharmaceutical companies to influence physician prescribing habits has undermined the Hippocratic Oath and led to a decrease in patient trust.

Still further questions are raised about the economic incentive of pharmaceutical companies. In fact, studies that are funded by major pharmaceutical companies have a greater chance of finding significance than not-for-profit trials (Epstein, 2007; Moynihan, 2003; Palmlund, 2006). Epstein (2007) discussed how pharmaceutical companies mine their data using different variables such as race and gender, in addition to increasing the dosage of medications during trials, to ensure statistically significant results. Patients are

beginning to distrust medical professionals, their prescribing habits and the sources that fund their research.

Parsons would almost certainly regard these developments as dysfunctional, undermining trust and doctors' objectivity. As a response, MS patients are accessing information from other sources, firing and "quitting" their treating specialists, not following the treatment regimes dictated by their medical professionals and openly questioning medical professionals' association with pharmaceutical companies. In turn, specialists are not offering advice on the CCSVI procedure, and in some instances, refusing to treat patients that have had the procedure. The sick role will be used to examine healthcare in the twenty-first century in which care and knowledge can be gained through personal narratives of patients living day-to-day with a similar plight.

Narrative Analysis

In contrast, narrative analysis describes and valorizes how patients speak of their illness and suffering outside of the strict medical narrative discussed by Parsons. For this thesis, narrative analysis will provide the overarching framework as it addresses patients' unique illness stories and how they may impact others, in addition to providing specific areas to address in the study of how patients may read, interpret and subsequently tell their narratives.

In the nineteenth and the first half of the twentieth century, the medical narrative dominated due to the increased sophistication of the medical industry and a desire to cure the patient. During this time, as assumed by Parsons, there was a distinction between normal and abnormal; disease and illness were viewed as abnormal and in need of rectification, and required returning the ill individual to a normal, healthy state (Bury,

2001). In addition, the patient's voice was silenced and in its place emerged the technical expertise of the medical professional, who heard the patient's story of suffering and, in turn, described the suffering in medical terms, reducing the patient to a body and the illness narrative to the medical chart (Frank, 1995: 5).

The medical narrative seemed natural when medicine was (or is) able to cure ill patients, using surgical procedures or new drugs to treat illnesses and infections (Bury, 2001). However, in the second half of the twentieth century patients found their narratives did not fit into the medical narrative, especially those among the growing proportion of patients diagnosed with chronic or degenerative diseases (Bury, 2001; Frank, 1995). The medical professional was sometimes able to provide advice about how to live with a chronic condition, but provided no direct cure (Bury, 2001).

Narrative researchers have described that when a patient is diagnosed with a chronic or degenerative disease, it can be viewed as losing one's destination on life's map, since the person's life is now fraught with uncertainty (Frank, 1995: 1). In his work on patients' suffering from rheumatoid arthritis, Bury (1982) found that when an individual experiences an illness, and especially a chronic illness, he/she is encompassed with uncertainty: uncertainty about what is going on with their body, uncertainty about the course the disease will take, and uncertainty about their future. This uncertainty can interfere with an individual's self-conception, as well as familial and social relations (Bury, 1982; Bury, 2001; Williams, 1984). The medical narrative could not readily provide the knowledge that would return the ill body to its normal healthy state.

What subsequently transpired was what Arthur Frank (1995) refers to as a shift from the modern medical perspectives dominated by the medical chart, to postmodern experiences in which patients feel "a need for a voice they can recognize as their own"

(15). Patients began to reclaim their voices from doctors. Although patients may have limited control over their disease, they have been able to develop their own stories about their experiences to share with others. Throughout this transition, patients became more knowledgeable and informed about their conditions and began to question the generalisable nature of the medical narrative into a dichotomy of ill or cured (Frank, 1995: 9).

The voices that emerge through patient narratives provide the opportunity to discuss illnesses devoid of medical jargon (Frank, 1995; Hyden, 1997), and have been used to understand how individuals adjust to the disruption that illness causes in their life. In fact, postmodern experiences are in opposition to the modern medical perspective because of how rarely the medical industry is brought into a patient's story (Frank, 1995: 13). Narratives allow an individual to reassess and develop a new vantage point to view life (Frank, 1993) and determine what the illness means in their day-to-day lives (Frank, 1995).

According to Williams (1984: 177), narrative reconstruction is "how and why people come to see their illness as originating in a certain way, and how people account for the disruption disablement has wrought in their lives." Further, like Bury (1982), two out of three of Williams' (1984) participants, who had rheumatoid arthritis, said that there was a break in their social and personal relationships. Bill, Williams' first participant, situated his illness "as the product of malevolent social forces" (1984: 186). The origins of his illness were rooted in the political struggle between classes since he felt as though he was an exploited worker. This is similar to Williams' second participant, Gill, who felt that her illness was rooted in stress associated with womanhood and motherhood which caused her to suppress herself in order to be a good wife and mother. Her personal identity came in conflict with the social processes of motherhood. Both Bill and Gill located the cause of their illness in the social processes occurring around them (William, 2000). In contrast, for

Williams' (1984) final participant – Betty – this did not occur. For Betty, the concept of narrative reconstruction did not apply. She has strong religious beliefs, which provided her with an understanding that everything that happens in this life is part of God's plan. She did not need to reconstruct her narrative because she was not the author of said narrative. Narratives can provide patients with the opportunity to understand what their disease means in their lives and interactions with dominant social structures.

Other narrative researchers (Frank, 1995) have examined how narratives can be used to represent the path a patient can travel as they come to terms with their illness. Frank provided a typology of three types of narratives patients may tell with an illness; restitution narratives, which present the illness as short lived and assume the patient will return to a healthy state soon; quest narratives, in which the individual comes to terms with their new ill self; and chaos narratives (Frank, 1995: pp. 97-114), which will be addressed in this thesis.

There is no sequence to the events told in chaos narratives. They are considered incoherent speech and are an endless stream of words that are placed together to try and comprehend what has occurred normally connected by a series of "and then[s]" (Frank, 1995: 100). A chaos narrative centres on the emotional pain that can be caused by the disease. When chaos narratives are told, the individual feels they have no control in their life and believe the medical industry has limited control over their disease. But, because there is little coherence to the words that are being said, the chaos narrative is ultimately silent since the individual speaks a story that they do not comprehend. Frank (1995: 110) describes that "chaos is the pit of narrative wreckage", or the break in an individual's life story due to an illness.

There is a way out of the chaos narrative but it is through accepting the chaos before new stories can be told, stories which may be of acceptance and that are for the other – a quest narrative. Quest narratives acknowledge that the ill patient has gone to the edge and returned with a new acceptance of their life and body in which the individual “realizes the ethical ideal of existing for the other” (Frank, 1995: 49). Quest narratives are meant to help others with their own contingencies, as they move through the phases of their disease in an attempt to come to terms with their new ill body.

Narratives as Presentation of Self

Up until now I have discussed how patients’ narratives came to be and the different types of narratives that can be told. But, the creation and type of narratives differ for each individual, and thus an examination of the differing ways an individual interprets and creates their narratives needs to be undertaken. Once a narrative is told it enters the public realm and becomes a collective experience that others can hear, read, and interpret in their own way (Frank, 1993; 1995). Each individual will experience and interpret these stories differently depending on their own social, emotional, and personal experiences.

Frank (2010) developed the concept of narrative habitus, or a group of stories that an individual hears and experiences that help to inform their life and the direction it takes. The narrative habitus is a repertoire of stories that a person knows and shares with others and is organized by an individual’s inner library that catalogues all the stories they have heard. The inner library helps to shape how an individual interprets a new story.

A narrative habitus provides an individual with the opportunity to draw on prior knowledge about a topic to comprehend the events and stories told. The original stories become stored away in relevant sections of an individual’s inner library and can shape subsequent stories. Frank feels that some stories can have a particularly strong impact on a

patient's life and developed the concept of narrative ambush in which a story can have such an impact on an individual's life that it creates a new section in their inner library that may displace previous views held on the subject.

For these reasons, narrative analysis researchers like Frank (1995; 2010), Hyden (1997) and Riessman (1990) have stated that an individual's narrative can be viewed as a representation of the narrator. In fact, Riessman (1990) found in her methodological paper on narrative analysis that her participant, a man suffering from MS, strategically used his narrative to convey the fact that he still maintained a masculine identity although his mobility and social relations with his wife and son had been compromised. The shape of any story is dependent on who is telling it and their own personal views on the matter at hand. Thus, patient narratives can be considered edited versions of an individual's reality that represent their reasons and motives for acting as they do (Frank, 2010). Each individual is an expert in their own lives and can use their narratives to represent their hopes, desires or fears.

Actor Network Theory (ANT)

Similar arguments are made in actor network theory (ANT), however there are notable differences. Latour (1987; 2005) discussed the multiple interpretations that different individuals can take from an argument, and the different paths that can be traced surrounding a controversy. ANT typically studies scientific and technical facts. An ANT study begins before a fact becomes black boxed or when a new controversy emerges. A black box can broadly be defined as the general acceptance of a technical or scientific fact as universal (Latour, 1987). To study the creation of a black box, Latour (1987; 2005) suggests tracing backwards to the point when the controversial topic was first introduced.

To understand the associations and assemblages that occur, the researcher needs to follow the actors and mediators – objects that transform the meaning of events or help create social facts (Latour, 2005). The network that is established is what connects actors together; thus there are no groups, only group assembly (Latour, 2005: 27). To follow how a group is assembled, the researcher needs to trace all the human and non-human objects that connect to develop a network.

The knowledge that is created about any topic exists in its own separate network, the knowledge created in this network may not merge with other networks even if they are studying the same subject (Latour, 1988), much like the debate that is occurring between the immune and vascular theories of MS. For one form of knowledge to take precedence over another, the network for that group needs to be stronger than the other networks. Thus, Latour (1988: 232) feels that there are no forms of superior or inferior knowledge, just forms of knowledge with a stronger network.

Networks of Medical Knowledge

The medical industry has countless different networks and factions that study disease and illness from differing perspectives. In fact, Turner (1987) states that there has been a fragmentation of medicine in which certain specialised fields may have more power than subordinate medical domains and generalists. There is segregation among different fields of medical knowledge, services and expertise that patients must negotiate as they seek treatment for an illness. The different networks of medical knowledge may examine a similar problem within an individual's body, but they approach it from a different perspective in which they use their tools and knowledge to determine what has caused and, in turn, what will be a solution, to the problem (Mol, 2002; Nicolson & McLaughlin, 1988; Wynne, 1988). Thus, there are multiple ways of knowing and treating one disease.

Nicolson and McLaughlin (1988) studied the construction of both the autoimmune and the vascular theories of MS and found that power is present in the way different treatment options are given precedence in medical science. Nicolson and McLaughlin argued that both departments, neurology and vascular specialists, were able to reach conclusions about the aetiology and cause of MS via their scientific knowledge, as well as counter studies conducted by the other department, based on their expertise. Nevertheless, the authors state, “for medical knowledge about multiple sclerosis to be assessed as valid knowledge it has to accord with the protocols of immunology” (1988: 247), based on their discussions with major MS researchers who asserted that MS studies with an immunological basis received more funding than studies from other disciplines. They found that embedded within the medical system is a hierarchy of specialities and treatments, and an explicit power structure at work within MS research that privileges the immunological theory.

Annemarie Mol (2002) used ANT to study the way different actors enact the object of atherosclerosis in a Denmark hospital. She found, much like Nicolson and McLaughlin (1988), that each department had their own source of knowledge and tools to discover the problem of occluded veins in a patient’s leg. However for Mol (2002), the different forms of knowledge co-exist at the same time, in the same hospital, and rarely overlap in diagnosis or treatment. The object, the occluded vein, is more than one since there is more than one way to reach the conclusion of atherosclerosis, but less than many since it all equates back to the same object (Mol, 2002: 55). Mol (47) found, however, that when different forms of knowledge do come in conflict “the clinical way of way of working wins,” rather than the pathologists’ way of working or understanding, for instance.

Likewise, Barbot and Dodier (2002) found in their study of how AIDS patients negotiate scientific knowledge that the medical industry provides multiple interpretations of both the disease and preferred treatment depending on the specialist. More specifically, certain patients relied on specific actors – doctors – for information while others relied on a variety of sources for knowledge such as their own experiential knowledge, activist publications and new and unique studies into AIDS treatment. From the studies discussed above, ANT lends itself to the study and analysis of the development of and challenges to, medical knowledge.

ANT and the Context of Citation

Although Latour (1987; 2005) and ANT researchers study a controversy from the moment the black box is open until the black box is closed, that is not possible with this study. At this moment in time, the CCSVI controversy has yet to be concluded, there are still arguments and interpretations of the information being made by all parties involved in the debate. Nonetheless, ANT provides useful tools to understand the ways in which people are using resources such as the internet to further their claims, or detract from other forms of medical knowledge, by examining how the individuals in each group read, interpret and translate the information they find online. Several ANT concepts will be used in this thesis such as a spokesperson and authority figure, in addition to analyzing the different modalities each group uses, the number of allies they recruit, what claims the groups are making, and how the interested parties translate the controversy.

Latour (1987) describes two different figures that can represent a group and their cause. First, Latour (1987: 71) discusses the concept of a spokesperson – an individual “who speaks for others who, or which, do not speak.” The spokesperson does not stand alone in their arguments but is the loud mouth for a group that has appointed this person as

their representative and, in turn, justifies the group's existence. Second, an authority figure can be enlisted to lend support to the group. Latour refers to this as an argument from a higher and more prestigious member of a community, normally a scholar or recognized figure. By affiliating an argument with an authority figure, the number of allies increases to include the organization for which the authority figures works and all of their backers. A spokesperson speaks on behalf of the group and authority figures helps to further the argument by garnering new and more prestigious allies.

The researchers, selected spokesperson and acquired authority figures can use what Latour refers to as modalities, which can be used to modify or qualify a claim, to help further their argument as they try to make it a fact. Through the use of positive modalities, which strengthen an argument by taking the argument further away from its conditions of production, and negative modalities, used to question an argument and return it to its conditions of production, the spokespersons and authority figures are able to take the reader along the path they had originally intended. This is a concept that Latour (1987: 35) refers to as context of citation, in which the researchers uses or modifies other people's arguments to help turn their argument into a fact. The more support an argument can appear to have through the use of modalities and referring to the researcher's work, the greater the likelihood the argument will become a fact. By increasing the number of allies the more the social ties connecting different positions of a controversy together become visible (Latour, 2005).

An example of this was shown by Steven Epstein (1996) in his study of the AIDS controversy in the late 1980s and early 1990s. He used the concept context of citation to the study of the development of an obligatory point of passage in the science behind AIDS. He traced scientific articles published on AIDS between 1984 and 1986 in major scientific

journals to determine how Gallo's concept of a retrovirus hypothesis was taken up in the literature. Epstein found that Gallo and his supporters were able to cite themselves to create a large body of work to further the idea of the AIDS virus. Moreover, the idea of the retrovirus was solidify in 1986 when notable publications were released on AIDS from major medical establishments like the *American Medical Association* and *National Academy of Sciences' Institute of Medicine* that did not address any alternative theories of AIDS causation. Thus, due to the lack of challenge to a researcher as prominent as Gallo, the medical knowledge espoused in the virus aetiology of AIDS became the obligatory point of passage to studying the disease.

The Translation of Scientific Facts

ANT, like narrative analysis, holds that anyone can read and interpret an argument differently. Depending on the path that each individual in the group follows, they may end up at a completely different end point (Latour, 2005). Those building a network need to ensure that the allies that are acquired maintain the original goals and outcomes that they had imagined. For this reason, Latour (1987: 108) proposes the concept of translation, or "the interpretation given by the fact-builders of their interests and that of the people they enrol," to make their idea indispensable. This involves shifting and translating an idea and the goals of an argument to ensure that it gets taken up by others.

Latour (2005) describes important steps in the translation process; patients in the CCSVI movement are taking a slight detour to ensure their intended goals are eventually reached (Latour, 1987). This may mean taking a detour down another path to acquire supporters or funders for the fact or controversy being argued, but three conditions need to be present for a detour to succeed. First, the road must be blocked; second, the detour must

be well posted so that all parties involved know what is going on; and third, the detour must appear short to ensure that the intended goals are not lost.

Latour's (1988) study of how hygienists who studied health, sanitation and illness at the grand scale of society used Pasteur's idea of the microbe provides an example. In France hygienists faced a hurdle when trying to implement sanitation change due to the public's fear of change and the government's unease with the cost of undertaking the work. The hygienists were able to take a slight detour by finding a common denominator of illness through Pasteur's idea of a microbe and the use of standardized statistics to show that illness can affect anyone regardless of class. The detour through germs and microbes allowed the hygienists to gain support at the national level for their policies of sanitation. By developing an order – the microbe came before the infection – hygienists were able to provide legitimacy for their work. By taking a detour through another path, the hygienists, with the help of Pasteur's microbe, were able to make their views indispensable (Latour, 1987). Each individual that studies this phenomenon must pass through the same point to further their own interests; the idea has become an obligatory point of passage. Through the work of Pasteur and hygienists, the microbe was able to become the obligatory point of passage for illness – anyone wanting to talk about illness had to start at the microbe. This led to the creation of health and sanitation branches in governmental organizations in all major centers (Latour, 1988). Pasteur's laboratory, in turn, became the obligatory point of passage for understanding and combating the microorganism that causes anthrax, as well as illnesses and epidemics (Latour, 1999). An obligatory point of passage means facing the challenges that others present and proving that the idea “would become a routine black box in everyone's hands” (Latour, 1987; 120). The idea has acquired hegemony over the field and is an accepted method to follow to further subsequent ideas.

Reflexive Communities

In conjunction with translation, Scott Lash's (1994) concept of reflexive communities helps to provide an understanding of how MS patients may come together in online forums to discuss their illness. A reflexive community is a group of individuals that come together based on a shared meaning among its members. They are "reflexive" communities because individuals join by choice based on aspects and orientations that have been established in their lives, unlike in traditional society in which a person is born into a community. There are numerous different sites in which reflexive communities develop since they depend on the shared meaning of the individuals in the community and focus on the similar background factors that brought these individuals together. For this reason, Lash feels that the analysis of communities and the individuals that populate them needs to start with the already developed habits, predispositions and orientations of an individual's background factors. These are routine unthought, activities for individuals and are only evident through the shared practices of the community. The meaning associated with a reflexive community is inscribed in the practices that individuals undertake within the group. The self is integrated in all aspects of the reflexive community from the shared meanings that are created to the ideological challenges that are presented and the ways in which the community develops and grows. Lash feels that within reflexive communities there is care that comes from concern and, in turn, leads to care and concern for other human beings in the community.

Online communities can be considered a reflexive community as well since Lash allows that there can be a separation of space and place among members of a community. In online forums MS patients from all over the world are able to come together based on the common background factor of their disease and develop a shared meaning and

understanding of their disease which may aid in the development of knowledge, as well as understanding and treatment of their disease.

Late Modernity and Reflexive Modernization

The theory of reflexive modernization will be used to discuss how MS patients use the information and narratives found through online networks. Reflexive modernization is a concept developed by Anthony Giddens, Scott Lash and others which addresses the increased independence of individuals in modern society and takes place when full modernization has occurred. There is a complete break from traditional society in which set rules and obligations are now no longer present leading to a dissociation of set structures, such as the family, in modern society (Giddens, 1991; Lash, 1994). In reflexive modernity, individuals are more empowered and enact their agency in the face of social structures, which traditionally governed their behaviour, increasing their own autonomy (Lash, 1994). However, the break with traditional society can lead to an increase in uncertainty in an individual's life. The individuals must find a way to maintain a constant narrative of the self that represents who they are and their future roles as they attempt to mitigate risk in their lives (Giddens, 1991). Giddens refers to this uncertainty as a threat to an individual's ontological security since it can displace the continuity and order in life events. Aspects of both Giddens' late modern society and Lash's reflexive modernity will be used to assess the actions of MS patients with respect to their internet use and the CCSVI procedure.

In developing his theory, Giddens (1991) discusses a separation of time and space. In modern society, individuals are able to communicate with other people in various locales, dissolving the need to be together in one place and time to interact with others.

The separation of time and space can play an integral role in the trajectory of the self and impact the lives and choices an individual makes. Giddens' concept of mediated experiences in an individual's life will be of importance for this thesis. Individuals are able to hear about a variety of different events and news through mediated sources. The globalization of media has enabled individuals to access news, stories and events from around the world which can impact their day-to-day lives, even if they never come to experience these stories or events personally. Giddens provides an example of the impact that mediated sources like the internet may have on an individual's relationship as it can put them in contact with people they may never have met in any other social setting. By being able to access information on a global level, mediated communication may impact an individual's life planning which allows an individual to plan for future outcomes they hope to achieve such as allowing patients to contact and interact with medical professionals that perform a medical procedure like CCSVI.

No matter how much planning an individual does in their lives, they can still be confronted with risk, especially in reflexive modernity with the increased number of choices an individual is faced with and decrease in set rules and obligations. An individual wants to mitigate risk as much as possible to ensure that they are able to colonize the future in which the individual creates territories of future possibilities that they would like to inhabit. Giddens (1991: 113) discussed fateful moments as source of risk, in which the individual is presented with an event that is both "highly consequential and problematic." A fateful moment, such as the diagnosis of an illness, places the individual at a crossroads and is similar to a break in life's map discussed by Frank (1995). The event can be "phases at which things are wrenched out of joint, where a given affair is suddenly altered by a few key events" (Giddens, 1991: 113).

When the body does not cooperate, a threat to an individual's ontological security can emerge since "routine control of the body is integral to the very nature of agency and of being accepted by others as competent" (Giddens, 1991: 57). The discrepancy between what an individual's body can do and what the person wants the body to do leads to a disassociation with the body and the self. It is only when the body does not cooperate that a person may notice that something is wrong, that the invisible day-to-day actions of maintaining self-identity through the body become visible. A similar finding was discovered by Clark (2001) in her study of heart attack patients; these patients only sought help and medical aid when they felt that their self was threatened.

Giddens proposes that to mitigate the risk associated with a fateful event, an individual places their trust in expert systems that they believe are there to help them stabilize their life. Similarly, Deborah Lupton (1997) found that even when patients became active agents in the search for information on their illness or medical treatment, they still respected the knowledge that can be found within the expert system of medicine. However, in the case of CCSVI and MS patients, the expert system – neurologists – are providing little information, thus patients are turning elsewhere for information. In his discussion of reflexive modernity, Lash challenges Giddens' assumption of individuals turning to expert systems to mitigate risk and regain their ontological security. Lash argued that the expansion of the information and communication structure in reflexive modernity decreases an individual's reliance on expert systems. The information and communication structure has grown to the point where he feels that expert systems do not dominate the masses due to the ever increasing number of individuals employed within the structure making it difficult to enact control. In fact, Coburn (2006) found in his study of medical dominance that due to the increased number of voices which include patient experiences

and different areas of medical expertise, the power and dominance of the medical industry has decreased. The expansion of the information and communication structure came to be rooted in the increasing importance of knowledge acquisition in society since Lash states that the accumulation of capital is at the same time the accumulation of knowledge. By acquiring more knowledge, individuals are able to develop more autonomy and set their agency free from social structures that governed their lives. Knowledge plays an important role in reflexive modernity; it allows individuals to be able to become active members of society. The more knowledge an individual has, the greater their autonomy and freedom in their actions.

In the time of reflexive modernization, some individuals can access knowledge systems, develop autonomy and make decisions based on the knowledge that they have accumulated. The accumulation of knowledge enables individuals' to enact their agency in decision-making in ways those who lack the resources to access this information cannot. According to Lash (1994), in reflexive modernity, agency is set free from the structures of society since individuals, through the accumulation of knowledge are able to think reflexively and make their own decisions.

Chapter #3: Literature Review

The Internet and Health Information

According to Statistics Canada (2008; Middleton, Veenhof & Leith, 2010), accessing health information is among the top three activities commonly performed online. The internet can provide individuals with the option of being selective about which sources they access (Kivits, 2009) and allow anyone to have their voices heard (Kozinets, 2010). Online resources are fields of global information exchange since individuals and patients can access and send information all over the world. Through her study of women discussing breast cancer online, Shani Orgad (2006) found that women were able to communicate and share information with other patients around the world in an open and inclusive environment. Moreover, the internet not only allows individuals to access health information, but can provide health information and care to secluded locales. Lisa Cartwright (2000) found when she traced the development of telemedicine that mediums such as the internet have enabled healthcare to reach secluded areas and provide tailor made healthcare to individuals, a result that has been discussed by others (Breen & Matusitz, 2010). The internet can make it easier to expand and maintain a network of individuals and information at a distance, as well as foster stronger relationships due to its ease of use (Wellman, 1997). Due to the ease of use and accessibility of a vast assortment of people online, more people can interact together, share stories and, in turn, create knowledge.

Lay Expertise and Knowledge Creation

Lindsay Prior (2003) used the term experiential knowledge to describe knowledge creation that is based on a person's lay experiences with their own body. In some instances the knowledge that is created based on lay experiences can be used to challenge medical

knowledge, as was seen in Easton and Atkin's (2011) study, which examined the use of patient narratives in the treatment of neurological brain injuries. The authors found that the use of illness narratives can be an empowering experience for patients since they feel they are an active part of their own intervention. Moreover, patients' are able to develop their own forms of knowledge based on personal experiences that can legitimate their suffering (Barker, 2002; Barker, 2008; Bulow, 2004) and provide them a better understanding of their illness (Prodinger & Stamm, 2010). Bulow (2004) and Barker (2002; 2008) studied contested illnesses, and found that through the personal narratives that are discussed in support group meetings, self-help books, or online forums dedicated to the personal discussion of their illness, patients' were able to develop their own knowledge of their disease and symptoms based on personal experience. Prodinger and Stamm (2010) found, in their study of six women's life stories with rheumatoid arthritis that these women created their own knowledge based on their experiences with a chronic illness. This provided them with a better understanding of themselves and their illness, as well as helped them make informed decisions with respect to their health.

However, Mary Horton-Salway's (2004) study of lay knowledge creation in contrast to the expert knowledge of a psychologist in a support group for people with the contested illness chronic fatigue syndrome (CFS) challenges lay knowledge. She found that patient knowledge is still undermined in reference to medical knowledge since the latter carries more weight. Although patients are able to discuss the nature of their illness with medical professionals, due to the nature of the debate, it becomes difficult for patients to undermine the knowledge of medical professional.

Medical Knowledge, Experiential Knowledge and Narratives Online

Studies (Hardey, 1999; Kivits, 2004) have found that patients turn to online resources to verify information on a medical diagnosis or prescription. Hardey (2001) provides three conjectures as to why patients are turning online: first, the medical office can be an intimidating setting for patients. Second, a consultation with a physician is approximately eight minutes, which may be insufficient time to obtain the needed information (Hardey, 2001: 393). Finally, when a patient is diagnosed with a disease, it can be overwhelming and the patient may be unsure of what questions to ask. Therefore, patients are now turning online to acquire information about their disease and treatment regimes. The internet has provided patients with access to “the previously closed and exclusive domain of Western medical information” (Hardey, 2001: 400). Thus, the internet may be displacing healthcare professionals as the gatekeepers of medical knowledge (Lewis, 2006).

However, the internet provides access to not just medical information but also personal narratives posted by fellow patients. Hardey (2002) discussed the emergence of novice and expert narratives relating to health and illness on patient-based websites. The narratives that patients provide on their websites may either be in the form of novice narratives in which the patient informs the reader of their experience without providing direct advice on how to treat or handle their disease, or expert narratives, in which the patient provides what they feel is expert advice on how to live with, or treat, the illness. Much of the previous literature (Colineau & Paris, 2010; Mickelson, 1997; Kim et al., 2011; Seckin, 2009) on health information online has focused on the former – novice narratives. However, some studies (Schaffer, Kuczynski & Skinner, 2007) have found that the information acquired online can provide expert advice on treatment options.

Creating Non-Medical Narratives

Patients develop websites and blogs, or post in discussion boards to chronicle their illness, thereby allowing their illness stories to be told separately from the medical profession. The use of the internet to search for medical conditions can be beneficial for many patients since it provides an avenue to connect with others going through the same situation. Colineau and Paris (2010) state:

Every year, thousands of groups of people are created and organized in virtual communities to not only access information about their medical condition, but more importantly, to talk about being sick and share with others the daily emotional aspects of patient's life (142).

Patients come together in online forums to provide comfort, emotional support, and understanding of their condition through stories. These stories provide support that family and friends may not be able to (Colineau & Paris, 2010; Mickelson, 1997). In these online communities patients come together to foster, learn, and share knowledge about their condition and find out about treatments. In turn, studies (Kim et al, 2011) have found that patients that use online forums have fewer illness-related concerns. Patients access knowledge to become more informed and know what questions to ask their treating medical professional (Seckin, 2009) which allows them to feel competent when facing a life threatening illness (Ziebland et al, 2004). They, in turn, trust other patients online and consider them friends (Colineau & Paris, 2010; Orgad, 2006; Wright & Bell, 2003).

Although there are countless individuals that participate in online discussions regarding their illness, this is not always the case; some individuals only use the internet as a source to find information. For these individuals, forums are a venue to learn about their condition in a safe and anonymous environment (Colineau & Paris, 2010; Hardey, 2001; Josefsson, 2005; Lewis, 2006; Mickelson, 1997). In fact, individuals that use online

forums may never actually post in them but “lurk” to find information about their illness or treatments (Barker, 2008; Kozinets, 2010; Orgad, 2009) and whether others have gone through similar experiences (Josefsson, 2005).

Advice

Knowledge creation on websites can take the form of patients offering other patients advice embedded in personal experience (Hardey, 2001: 396). Offering advice to fellow patients is important and can provide the patient with the opportunity to frame their illness experience in a new encouraging light that can promote positive coping strategies (Josefsson, 2005; Kim et al, 2011). During online interactions, patients are believed to have knowledge about both their disease and medications which can be passed on to others to help inform decisions (Josefsson, 2005; Wright & Bell, 2003), or provide access to information on day-to-day aspects of medical treatments that may not be discussed by medical professionals (Ziebland, et al., 2004). Furthermore, patients’ develop a “shared condition” (Barker, 2008: 27) by informing each other of their symptoms and developing a unified understanding of their disease.

The advice that patients offer in online forums is not limited to personal experiences but also includes how to handle the medical industry. Patients use the internet to voice their opinions about unfair treatment that they have received from medical professionals (Hardey, 2001; Josefsson, 2005; Schaffer, Kuczynski & Skinner, 2007), discuss doctors that will treat contested illnesses (Barker, 2008), and provide information on medical professionals that may provide an appropriate diagnosis of an illness (Shaffer, Kuczynski & Skinner, 2007). Schaffer, Kuczynski and Skinner (2007) found that the information that mothers accessed online about genetic conditions enabled them to become consumers and producers of medical knowledge. They negotiated in medical terms with their doctor based

on the knowledge and advice they received from online sources to access new and experimental medications. The authors concluded that these mothers became active agents in the creation of medical knowledge with medical professionals.

Kristin Barker (2008) studied online support groups for the contested illness fibromyalgia (FMS) and found that online patients can draw on “their embodied experience to challenge medical expertise” (32). FMS patients sought to challenge medical expertise in order to have their illness medicalized, to legitimate their disease and receive medical treatment. For the FMS sufferers in Barker’s study as well as the mothers in Schaffer, Kuczynski and Skinner’s (2007) study, there is still a reliance on medical professionals to treat an illness, which reinforces the dominance of the medical profession.

Thus, researchers (Lewis, 2006) have found that the internet is often a complementary source of knowledge rather than the only source of medical knowledge. Numerous studies (Hardey, 1999; Hardey, 2001; Josefsson, 2005; Kivits, 2004; Nettleton, Burrows & O’Mally, 2005; Schaffer, Kuczynski & Skinner, 2007) have concluded that patients bring the results of their searches to their doctors for further verification or to challenge the diagnosis, creating a dialogue of negotiation with their doctors about their condition and its treatment. Patients may be able to access, learn and become versed in medical language but they still need to see a doctor to receive the treatment.

Several studies (Colineau & Paris, 2010; Hardey, 1999; Hardey, 2001; Kivits, 2004; Kivits, 2009; Lewis, 2006; Seckin, 2009) have shown that the internet enables patients to become more informed and reflexive consumers of medical knowledge and treatments prescribed by medical professionals. The doctor still prescribes the treatment but patients’ have become active agents in their health choices. Participants in Kivits’ (2004: 519) study considered themselves “near expert” because of how much information they found about

their disease. Thus, using the internet can be an empowering experience for many patients, but it does have drawbacks that need to be addressed.

Limitations and Problems of Knowledge Creation on the Internet

There have been several interesting studies that examine how patients use the internet to find health information (Nettleton, Burrows & O'Mally, 2005; Sillence et al., 2007) and address the difficulties lay individuals face when using the internet to access health information: the sheer volume of information (Hardey, 1999; Henwood, et al., 2003; Kivits, 2009), the variable quality of the material since information online does not discriminate between lay, expert and astral information (Hardey, 1999; Lewis, 2006), misinformation (Lewis, 2006) and, trouble discerning between the different perspectives found online (Hardey, 1999). The internet provides patients with access to many forms of knowledge, not just expert knowledge which may cause some patients to become confused and unsure of what information to trust. When faced with these difficulties, it is not surprising that patients tend to choose websites based on the aesthetics of the site rather than its content (Josefsson, 2005; Sillence et al., 2007), or to prefer sites endorsed by medical professionals or associations from within their own country (Kivits, 2004; Nettleton, Burrows & O'Mally, 2005; Sillence et al., 2007).

Many patients believe there is a plethora of false information online, but they feel that if they are diligent, they will not be duped by false information. Studies (Hardey, 1999; Colineau & Paris, 2010) have found that patients determine the 'accuracy' of information through constant verification of results with several other online sources – the more the concept, treatment or medication appear, the more accurate the patient feels it is. However, this tactic has its drawbacks since multiple sources may cite a treatment that is not accurate. A comment addressed by Prior (2003) in her study of lay knowledge creation,

she argues that lay individuals' do not possess the same level of skills in assessing and gathering data about an illness as medical professionals.

A common message on the internet is for patients "to become 'their own expert'" (Josefsson, 2005: 148) through both accessing information on medical treatments and developing awareness about their disease. Pitts (2004) demonstrated that by accessing and learning medical knowledge and terminologies, women suffering from breast cancer felt they were levelling the hierarchy of the medical industry. But Pitts also expressed concern that becoming an expert in the terminology and language used by the medical industry, in addition to the treatments offered, is now seen as a way to beat the disease. Pitts (2004: 45) found that the internet can be "a beacon of hope" in which the medical knowledge patients' gained about their disease and treatments were seen as "key to surviving breast cancer." By framing medical treatments as products that can be researched and discovered in online forums, the use of the internet to search for medical treatments can place the onus on the patient to search for a cure. Thus, the internet turns a social problem of finding and researching a disease, into an individual problem (Pitts, 2004: 54). Orgad (2006: 892), like Pitts, argues information on the internet does not provide an accurate picture of living with breast cancer since the internet is dominated by survival stories and advice on finding a cure, not the realities of the disease.

Patient Agency in Medical Decisions

The medical and experiential knowledge patients can access online provides patients with not only information, but the confidence to feel that they may be able to make critical decisions regarding their treatment options. Patients' can enact their agency through negotiations with medical professionals (Koenig, 2011), through copious amounts

of research to learn as much as they can about a treatment or procedure (Davis, 1995), by acknowledging that their sense of self is threatened due to a health condition and seeking out appropriate care (Clark, 2001), or in opposition to the dominant medical narrative.

When the medical narrative fails to cure a patient, they can be confronted with the choice to stay on a treatment which can be debilitating and intrusive or to stop taking it and experience some quality to their life instead of receiving the treatment (Radley & Payne, 2009; Sinding & Wiernkowski, 2009). Radley and Payne (2009) found that refusing cancer treatment once the disease had entered the terminal stage was a way to enact control over their disease and ensure that they had the quality of life they desired. Other studies have been conducted that show when patients do not comply with the medical narrative and either modify or refuse treatment, it is a way to enact control over their disease (Conrad, 1985; Radley & Payne, 2009). Conrad (1985) found in his study of epileptic patients that when they modified, changed or stop taking their medication it can be a way of exercising control over their disease as they negotiated their personal experiences with their illness to determine the appropriate dosage. Other studies (van Kleffens, van Baarsen & van Leeuwen, 2004; Sinding & Wiernkowski, 2009) have found that patients may refuse treatment based on their own past experience or that of a family members or friends that had a similar condition.

Patient Advocacy

The information produced by patients can also be used by patient advocacy organizations to further support for research and treatment of their disease. Advocacy groups are made up of individuals' with similar interests and experiences that come together because of a common bond. They play an important part in many controversial

diseases, treatments, or contested illnesses. Patient advocacy groups are usually non-profit grassroots organizations, which work in local communities to advocate and raise awareness about issues (Watney, 1996). They advocate at several levels, most notably towards scientists and political figures to gain recognition or funding research or treatment (Kolker, 2004; Nahuis & Boon, 2011; Zavestoski, et al, 2004).

Patient advocacy organizations advocate research in several ways, such as fostering good relationships with scientific researchers (Panosky, 2011). They may try to make the organization and its patients the obligatory point of passage for research (Nahuis & Boon, 2011) by developing a bank of tissue samples, a registry of patients afflicted with an illness that may want to partake in trials (Panosky, 2011), or by lobbying governmental organizations and pharmaceutical researchers to acquire a seat on the advisory committees for clinical trials (Epstein, 1996; Anglin, 1997). Many of these accomplishments require the use of the media.

The media offers a venue for advocates to disseminate their arguments and frames to cultivate supporters, as well as inform patients about their rights and options (Kolker, 2004; Watney, 1996). Advocacy groups have been known to borrow cultural frames that have been successful for other organizations. AIDS activists affiliated themselves with gay rights organizations to help further their own cause due to the high incidence of AIDS among the gay community (Epstein, 1996; Petchey et al, 1998; Watney, 1996). Whereas, breast cancer advocates used frames such as gender inequality in health research that were successful for the women's health movement (Kolker, 2004; Anglin, 1997). By latching onto previously successful movements patient advocacy groups are using the ideas and arguments of others to help further their claims.

The use of the media was elegantly demonstrated by Kolker (2004) in her study of cultural frames used by breast cancer advocates who used three cultural frames to garner support: breast cancer as an epidemic, gender inequity in research, and the damage that breast cancer causes not only to a woman's life but her family's as well. Through the media, breast cancer advocates were able to take what was believed to be a personal problem and make it a social problem for which they received government funding to research the disease.

Epstein (1996) and Watney (1996) examined the use of grassroots news publications as a way to inform AIDS patients in the late 1980s and early 1990s in which they disseminated research reports, drug trials and treatment options to AIDS patients. The publications became central to the controversy of AIDS not only because of the information they provided about drugs being tested all over the world, but also provided information on patient-based trials as many patients had lost confidence in the medical system (Epstein, 1996; Watney, 1996). AIDS patients and activists were frustrated with the paternalistic attitudes of research companies that tried to prevent them from making critical decisions about their own health and treatment options. The information that grassroots newspapers provided offered patients options for treatment and information on how to access it.

The above studies describe activism through traditional sources of media – print and television – however, the internet is becoming a source to cultivate support for causes at a far faster rate than traditional media. Henry Jenkins (2004) demonstrated that the internet can disseminate information and increase access to supporters for a movement faster than sources like newspapers and radio used in the Vietnam War. During the Gulf War, the internet provided protestors with a medium to gain supporters faster than during the Vietnam War and challenged the patriotic nature of American newscasts (Jenkins, 2004).

The internet is no longer merely a site used to find information but is becoming a site that often challenges the dominant discourses of the time. In a similar vein, Chamak (2008) found that parents of autistic children in France were able to access information from American activists to help pressure their local government to view autism as a disability instead of a mental illness. Moreover, Joseph Dumit (2006) found in his study of online advocates for chronic fatigue syndrome (CFS) provided information to patients about how to dress and act in court hearings to ensure they can get access to disability pay for their contested illness. The internet can allow patients to question and challenge the information that is provided by traditional medical sources as they become more informed about their condition.

Conclusion

The previous literature summarizes how the internet has become a source that individuals and patients turn to as they learn, discuss and advocate for diseases, treatments or causes. Through the internet patients are able to connect with other patients, access information that they would not have had access to before the internet and create knowledge based on their own personal experiences with their disease. Through the information that patients can access in the personal experiences posted in online discussion boards, this can help aid in their decisions regarding medical treatment that they may never have had access to before the internet. Furthermore, the internet is a forum that can disseminate information faster than traditional media sources and is reaching more people than ever before. The internet has, in fact, been a source that many MS patients are turning to as they access information, both medical and patient-based, on the CCSVI procedure.

Chapter #4: Methods

This thesis is based on thirty-eight asynchronous in-depth online interviews and eleven qualitative telephone interviews conducted with people with MS to gain an understanding of how their use of the internet may have impacted their views of the CCSVI procedure. The interview was semi-structured and used a set of open-ended questions (see Appendix). When verbatim quotes are used in the data analysis the pseudonym will be accompanied with either an OI, to refer to an online interview, or a PI to refer to a telephone interview. For the asynchronous interviews, the questions were sent to the participants' personal email accounts containing the interview guide to be filled out at their convenience and returned to me via email, fax or mail.

Asynchronous interviews may seem cumbersome for the participants, but there are several benefits to this method of research. The participant is able to fill out the interview guide anytime, eliminating the need to find a mutually convenient time to conduct the interview (Berg, 2009; Kozinets, 2010). Asynchronous interviews provide anonymity to the participant since there is no face-to-face contact with a researcher (Beck, 2005; Berg, 2009; Mann & Stewart, 2000; McCoyd & Kerson, 2006). In fact, several studies (Beck, 2005; Hamilton & Bowers, 2006; McCoyd & Kerson, 2006) have found that asynchronous email based interviews have lead to more forthright answers since respondents can think through their responses and have an added layer of anonymity. There is no face-to-face exchange between the participant and the researcher, removing any stigmatizing or marginalizing aspects of the participant such as race or sexual orientation, thereby potentially creating a more open environment (Giese, 1998).

The lack of face-to-face contact may nonetheless present problems. There is no way of knowing if the questions asked in the interview guide offended a participant as there

are no visual cues such as body language or facial expressions (Berg, 2009; Giese, 1998). Furthermore, the use of the internet can increase misunderstandings; Mann and Stewart (2000) state that participants may feel uncomfortable asking for clarification on the wording of certain questions, a problem that can be easily rectified in face-to-face interviews by noticing visual cues from the respondent. The internet provides the opportunity for an individual to be anyone they want, due to the lack of physical presence; there is no way to know that a person is who they say they are. (Acts of deception can occur in real life situations.) Nevertheless, the credibility of an individual's responses can be measured through clarification and elaboration of responses. Several methods texts (Berg, 2009; Mann & Stewart, 2000) state that the best way to ensure a participant's account is accurate is to ask follow-up questions to check the reliability of the response. Although the nature of asynchronous interviews does not allow for follow-up questions on the spot, the researcher can email any follow-up questions they may have at a later date. Problems can still arise due to the time delay, as it can increase the chances of memory attrition. However, through clarification of responses, the researcher has the opportunity to determine the credibility, or candour, of participants' responses and determine which respondents may be trying to dupe the researcher (Mann & Stewart, 2000). In this study, I followed up with nine respondents.

The telephone interviews followed the same interview guide and were conducted with participants that were unable to fill out the online interview guide. Unlike with asynchronous online interviews, probes that arose from specific responses were asked on the spot. The length of interviews ranged from half an hour to an hour and a half, and all phone interviews were audio recorded and transcribed verbatim.

The benefits of telephone interviews are similar to those of asynchronous interviews in that a geographically dispersed population is able to partake in the study (Berg, 2009; Jackson & Verberg, 2007). Phone interviews are also able to provide participants with a level of anonymity since the researcher and participant are not in direct face-to-face contact with each other and can lead to more open answers on controversial topics and perhaps protect the participant from prejudice or feelings of being judged. But once again, the performance of the interview is compromised as the interviewer cannot see the nonverbal cues that may be used to symbolize a participant's discomfort with a certain question (Berg, 2009; Jackson & Verberg, 2007). In fact, respondents may be less at ease in a telephone interview than in a face-to-face setting since they are unable to read the actions of the interviewer to determine the reaction they have to a response, or the nature of the questions asked (Jackson & Verberg, 2007).

I took several steps to put the participants at ease and provide an open and informed environment during both the asynchronous and telephone interviews. I emailed each participant a copy of the informed consent so they were aware of the objectives of my study. I informed the participants of the intent of my research to "break the ice" before the interview, by providing the participant with background information about myself and how I came to study this project (Frey & Fontaya, 1994: 371). Several researchers (Berg, 2009; Jackson & Verberg, 2007) have referred to this as an important step in the research process as it helps to build rapport with the participants and put their minds at ease about how the data may be handled and ensure quality data collection.

Sampling and Recruitment

The use of the internet to recruit participants for this sample was a strategic choice. The ‘liberation’ procedure has just been approved for a phase I/II clinical trial in Canada with funding slated to begin May 2012, thus many people with MS have been forced to find information regarding CCSVI from sources outside of traditional medical care. Moreover, many observers of this controversy believe the internet is one of the main sources patients are using to find information on CCSVI (Fox, 2011; AHS, 2010). The use of the internet provided access to a wide array of potential participants from all over the world (Beck, 2005; Mann & Stewart, 2000; McCoyd & Kerson, 2006). In fact, the internet can be a good source to recruit participants for a study of a controversial topic such as the CCSVI procedure. Members of online communities, blogs and discussion boards have already signalled a willingness to discuss their illness with others. McCoyd and Kerson (2006) found that they were able to recruit 26 of their 30 participants for their study of women that terminated a desired pregnancy via websites rather than traditional recruitment via posters in a medical clinic.

For this study, participants were found through three websites dedicated solely to MS patients and MS research. Each website was purposively chosen to access the widest audience of people with MS and involves the researcher using their “special knowledge or expertise about some group to select subjects” (Berg, 2009: 50). On each website information was posted that contained the goals of my study, the details of participation and an email address to contact me to participate or get more information on my study.

The first website I posted information on was a thread on the discussion board on a popular patient-run MS website in the section dedicated to CCSVI. This site was chosen because it is a patient-run discussion board without affiliations to any major drug

companies and it provides the opportunity for MS patients to post in an unbiased forum. A similar tactic was used by Victoria Pitts (2004) in her study of breast cancer websites online. This website contains a large membership and readership rate in comparison to other websites and discussion boards on MS and provided a large sample of possible participants.

Second, I contacted a local not-for-profit organization – Direct MS – that posted information on their Facebook page and website. This organization promotes alternative treatments for MS such as maintaining a healthy diet and using supplements such as Vitamin D to control MS attacks. Direct MS has recently become a vocal supporter of CCSVI and provided funding to the University of Buffalo to study the association between CCSVI in MS patients.

Not all MS patients are supporters of the CCSVI procedure. For this reason, the Multiple Sclerosis Society of Canada was contacted and they agreed to post information about my study on their Alberta Chapter Facebook page. The MS Society of Canada is a national not-for-profit organization that seeks to provide information and support to patients afflicted with MS, in addition to fundraising for MS research through local events such as the Super Cities Walk or Rona Bike tour. The MS Society of Canada has advocated waiting for more research to be conducted into the relationship between MS and CCSVI before undergoing the procedure.

These websites provided access to a broad sample of MS patients who might be ardent supporters of CCSVI or more leery of it. By selecting these three websites to post information for my study, all attempts were made to ensure that there was an ample cross section of opinions on the topic, but there is no guarantee that all opinions on the use of the internet and CCSVI were elicited by this research. Thus, this is an exploratory study of how MS patients used the internet to access information on the CCSVI procedure.

The sample is isolated to a specific group of individuals who use the internet, raising questions about generalizability of the data to all MS patients. Several studies (Hamilton and Bowers, 2006; Mann & Stewart, 2000; Middleton, Veenhof & Leigh, 2010; Statistics Canada, 2008) have found that internet users tend to be wealthier and more educated than the general population, although this tendency may be receding. Of course my project is to study the way the internet may be influencing patients' perceptions of MS and the CCSVI procedure, not opinions on CCSVI in general.

A second restriction that needs to be addressed is the nature of the interview material. Several narrative researchers (Frank, 2010; Riessman, 1990; Hyden, 1997) have stated that interviews can be presentations of self in which the information that a respondent provides may be used to further their own claim. However, given the nature of the debate surrounding CCSVI, the way that MS patients present themselves and their views of the CCSVI procedure may provide insight into how advocates and detractors of the procedure are arguing their point of view on the CCSVI procedure.

Data Analysis

All digital copies of the asynchronous interviews and verbatim transcripts from the telephone interviews were saved in a Microsoft Word document. The data was later imported into NVivo, a computer-assisted data analysis program. NVivo can be described as a code-and-retrieve analysis program since it “assists the researcher in dividing text into segments or chunks, attach codes, [as well as] find and display the coded sections” (Berg, 2009: 368-7). NVivo allows for easy retrieval of coded data to analyze, in addition to linking codes through memos. In NVivo, the data was analyzed and subsequently

examined for specific themes that presented themselves throughout the interviews and were developed from the previous literature already discussed.

The process of coding for themes presented in the data began by reading through all the interview guides and making notes regarding common themes addressed by the participants. I looked for both similarities and deviations from the norm in the interviews during the first round of coding (Berg, 2009). Lofland and Lofland (1995) refer to this as initial coding in which emergent themes are inductively analyzed. Following the original round of coding, a more focused coding was done that honed in on themes that were presented more often than others. During the focused analysis, memos were made connecting themes which were used as the basis for structuring subsequent analysis (Berg, 2009; Lofland & Lofland, 1995). In the data analysis that follows typical cases will be used to develop the theoretical argument of the thesis (Riessman, 2008).

Sample Demographics

In total, forty-nine individuals took part in this study, of which thirty-seven were female and twelve were male. It is not surprising the overwhelming majority of participants are female since twice as many women than men are diagnosed with MS (Spencer & Karceski, 2008; Waxman, 1999). The age of participants ranged from 32 to 76 years old and averaged approximately 50 years. Some participants in this study were diagnosed as young as 18 years old, while others were diagnosed as late as their forties and early fifties. The sample consists largely of North American participants, with thirty-eight respondents from Canada and six American participants (all from Northern states). In addition there were two participants from the United Kingdom and one each from Taiwan, Israel and the Ukraine.

Types of MS

For the purpose of preliminary analysis, respondents were broken into groups based on the length of time since their diagnosis: five years or less, between six and ten years, between eleven and fifteen years, sixteen to twenty years and twenty-one years or more. However, it can be difficult to determine the length of time an individual has “had” MS, which was demonstrated by Madilyn (61, OI) a woman from Portsmouth, USA who was diagnosed with RRMS eight years ago but believes she has had the disease for over thirty years. Madilyn said, when asked what year she was diagnosed with MS, “I always hate this question because diagnosis date means so little when it rarely coincides with onset of symptoms.”

In addition to the length of time an individual has had MS, the type of MS needs to be considered – RRMS, and the progressive stages SPMS and PPMS, having differing patterns of progression. The type of MS may be more indicative of the deterioration and impact of the disease on an individual’s life than time since diagnosis. The most common form of MS among participants in this study was relapsing remitting (RRMS) – thirty-nine of the forty-nine participants stated that was their original diagnosis. Of these participants, eleven stated they now have a progressive form of MS. Ten of the remaining participants stated they were first diagnosed with a progressive type of MS. Twenty-eight participants in this study still have or are believed to have RRMS and twenty-one participants are in the progressive stage of the disease.

CCSVI Procedure

The majority of the participants, thirty-seven of forty-nine, have undergone the CCSVI procedure, travelling to locales all over the world to do so. Twenty-seven female and ten male participants have had the CCSVI procedure. Of the twenty-one participants in

the progressive stages of the disease, seventeen had the CCSVI procedure. The four who have not had the procedure include Suzanne (59, OI), who is deciding which location she will travel to, and Lin (49, OI), who has decided to wait for the treatment to be available in his country. The remaining two participants in the progressive stage, Erin (49, PI) and Tamara (53, OI), are sceptical of the treatment and will not entertain the idea of having the procedure. The remaining twenty participants who have had the treatment have RRMS while only eight participants with RRMS have not had the procedure. Shown in Table one.

Table One: Participants and the CCSVI Procedure		
Had the CCSVI Procedure	Type of Multiple Sclerosis	
	Relapsing Remitting	Progressive
Yes	Ayala (39, OI) Christina (32, OI) Trina (49, PI) Janelle (41, OI) Julie (46, OI) Rawnie (47, OI) Carrie (44, OI) Kiara (41, OI) Gwen (48, OI) Sierra (49, PI) Brandi (52, OI) Brian (52, PI) Carla (52, OI) Mellie (57, PI) Elle (52, OI) Lori (56, OI) Kyla (55, OI) Andrew (61, OI) Diane (60, OI) Vincent (60, OI) Roslyn (OI)	Angela (39, PI) Callie (38, PI) Christie (46, OI) Paul (44, OI) Matthew (40, OI) Victor (44, OI) Todd (43, OI) Melissa (48, PI) George (58, OI) Adele (56, OI) Sandra (59, OI) Kurt (50, OI) Emily (51, OI) Adam (59, OI) Jill (62, OI) Anne (64, OI) Gillian (76, OI)
No	Bryce (38, OI) Haley (36, OI) Ashley (52, OI) Janetta (51, PI) Allison (54, PI) Caroline (51, OI) Madilyn (61, OI)	Lin (49, OI) Erin (49, PI) Tamara (53, OI) Suzanne (59, OI)

Participants' Internet Usage

In this study, the participants most active online were in their thirties (although with a few exceptions). In fact, four of the six participants in this age bracket have either developed Facebook pages or sites to provide information on the CCSVI procedure themselves or have spouses that have created web pages. One participant, Callie, (38, PI), originally diagnosed with RRMS twenty years ago which has now progressed into SPMS, developed a Facebook page dedicated to providing information on both CCSVI and MS; additionally, Angela (39, PI) is a moderator of several different Facebook pages. Christina (32, OI), and her mother are active online; her mother has been advocating for CCSVI through various means most notably on the Facebook pages she has developed. Finally, Ayala (39, OI), recently diagnosed with RRMS, has a husband that is very active in online resources and has become her source of information. However, older participants, such as Janelle (41, OI) and George (58, OI), have an active online presence as well, as they both write and maintain blogs about their experience with MS.

Among participants in their forties, there is still an active online presence, but it is more muted. Instead of developing pages to disseminate information, their online presence is typically limited to posting on discussion boards. This group includes Erin (49, PI), who ultimately stopped posting due to negative responses she received from others (a topic that will be discussed at length later in the thesis); and Sierra (49, PI) who engaged in the common activity of reposting on Facebook information found by others. Moreover, as the sample ages the proportion of respondents who only used the internet to “lurk” – search websites or discussion board for information without actually posting – increased. Participants such as Victor (44, OI), Matthew (40, OI) and Melissa (48, PI), used the internet only to seek out information on CCSVI.

The largest age group in this study was individuals in their fifties and over half (ten of nineteen) of the participants in this age group tended to lurk online, instead of posting. Outside of two participants – George (58, OI) and Brandie (52, OI), a founding member of a well-known CCSVI activist group in the United States, very few have a continually active presence online. Brian (52, PI), Carla (52, OI), Mellie (57, PI) and Kyla (55, OI) only post occasionally on discussion boards, Facebook pages, or support groups online. Two participants, Sandra (59, OI) and Caroline (51, OI) discussed the development of friendships through online support groups and discussion boards. One participant stated that she does not use the internet as a research tool; Janetta (51, PI) relied on functions put on by her local MS Society Chapter and her neurologist for information.

The final age bracket, those sixty years and older, contained only one participant with an active presence online, Madilyn (61, OI). The rest either researched or made selective connections online like Anne (64, OI), who came in contact with a major Canadian politician supporting CCSVI online. One participant, Jill (62, PI), did not use the internet to find information, but relied on personal contact with local individuals that have had the CCSVI procedure. Andrew (61, OI) stated that he rarely used the internet as a research tool until he saw the *W5* program on CCSVI. The remainder of the participants in the 60 and older group are considered lurkers that search for information online.

Ethical Considerations

This study received approval from the University of Calgary Conjoint Faculty Research Ethics Board. Each participant was emailed a copy of the informed consent for this study and requested to maintain a copy on the hard drive of their computer. Participants were informed of the goals and objectives of the research project, as well as

how their data will be stored to maintain their confidentiality. Participants were informed that all data obtained through email correspondence was copied and saved in a Microsoft Word document after which the email was deleted to protect their confidentiality (in case my email account was broken into or my computer was attacked by a virus) a tactic used by Hamilton and Bowers' (2006) in their qualitative internet based study. The informed consent stated that upon completion and return of the asynchronous interview guide, participants had consented to partake in my study. The informed consent also stated that any participant could withdraw at anytime. In the case of telephone interviews, the informed consent was emailed to the participant prior to the interview for their perusal. At the beginning of each interview, participants were asked if they read and understood the informed consent before the interview began. Their consent was recorded and appears in the verbatim transcript.

All participants were provided with a first name pseudonym throughout this thesis to protect their confidentiality. In addition, the direct name of the discussion board used to recruit participants is not used to further ensure participants' confidentiality. I am providing "maximum cloaking" to ensure I protect the confidentiality of my participants to the best of my abilities (Kozinets, 2010). I provided this added level of confidentiality for two reasons. First, Giese (1998) found that individual traits are present in nicknames and writing styles of individuals in online forums, so that if the website names were provided there may be a chance that an over eager individual may be able to determine which participant wrote what based on writing style. Second, the internet has a continuum of public and private access making most posts and comments accessible to any user of the internet (Kozinets, 2010; Sveningsson-Elm, 2009), thus providing justification for the added level of confidentiality I used to protect the participants in my study.

Chapter #5: Constructing and Contesting MS Knowledge Online

The use of the internet for medical information has been steadily increasing.

Statistics Canada reported that one of the top three searches online in Canada was for health information (Middleton, Veenhof & Leigh, 2010; Statistics Canada, 2008). When individuals turn to online resources, previous research (Colineau & Paris, 2010; Orgard, 2006; Wright & Bell, 2003) has shown that they are able to find support from a group of individuals who understand what they are going through, in addition to providing them with advice on their disease, treatment options and alternative therapies (Josefsson, 2005; Wright & Bell, 2003; Ziebland et al., 2004). However, access to more information on their disease and its treatments is not the only reason for going online; MS patients have taken to online forums and Facebook pages to press for the CCSVI procedure to be taken up in Canada and specific pro-CCSVI authority figures are emerging and influencing the way that information is being presented in forums.

This chapter aims to examine the information that patients are accessing online and how MS patients' attitudes towards the CCSVI procedure may be influencing which online sources they use. For this reason, the chapter has been broken into two sections, starting with an analysis of how MS patients are turning to online sources to become more informed about their disease and treatments, specifically through support from other patients. Furthermore, people with MS are acquiring and developing their own knowledge of their disease and treatment options, especially CCSVI in which the causative role of the venous system is being debated by MS patients. In a time of reflexive modernity, individuals, in general, are said to turn to the information and communication structure to become more informed. As an individual's knowledge increases, they are able to separate their agency from the structures of modern society, providing autonomy (Lash, 1994). The information

found online is based on a patient's own illness experience and can be influenced by how they view the CCSVI procedure, the neurological community and MS. Consequently, this information may not be reflective of everyone's story and can be used to argue one point of view devoid of any alternatives. For this reason, the second section will address the way the arguments presented in online narratives are being taken up by emerging authority figures and detractors of the CCSVI procedure through an analysis of the most commonly cited websites that MS patients have turned to. On these sites, a debate is emerging over who should be authority figures of MS treatment – the traditional source of MS care – neurologists, or the new advocates of the CCSVI procedure. However, to understand how patients are taking up the arguments presented online, an analysis of what patients are finding through these sources needs to be addressed first.

The Shape of MS Online

Support

People with MS were able to develop reflexive communities online around the shared experiences of their disease and the common background factor of an MS diagnosis. The internet has provided the opportunity for the development of a community of MS patients. Participants in this study met, discussed and supported fellow MS sufferers from locales all over the world as they learned about both their disease and CCSVI, in ways that would have been difficult before the internet. Many participants, such as Caroline (52, OI) discussed the camaraderie found in online communities.

I have found an excellent support group online. We all have a common denominator – MS, and there appears to be a very genuine, honest atmosphere with the online contacts (Caroline, 52, OI).

As previous research on patients use of online discussion boards and forums has shown (Colineau & Paris, 2010; Mickelson, 1997; Orgad, 2006; Wright & Bell, 2003), many participants feel that they would not have been able to experience the same level of support without the internet. Although Canada has one of the highest incidence rates of MS in the world, not every person suffering from MS directly knows someone with the disease. Even if they do, they might not experience MS similarly. Lori (56, OI), a woman from Canada who has lived with MS for 30 years, found that although individuals online may not be able to fully understand each patient's unique experience with MS, given its unpredictable nature, "it is more likely I will relate to an online experience just because of the numbers." Due to the sheer volume of people with MS online, the internet has enabled them to find support for unique and differing cases of MS especially after it has entered the progressive stage, as was the case with Lori. The individuals that they communicate with online are living day-to-day with the same illness and are able to provide support that cannot be found from those that have not experienced the same level of uncertainty, suffering and fear that can come from a diagnosis and subsequent progression of a disease like MS. Previous research (Colineau & Paris, 2010; Mickelson, 1997) has found that fellow patients online have been able to provide more support about an illness than family and friends not afflicted with the same illness. Mediated communication enabled MS patients to connect with individuals that they may never have encountered in their day-to-day lives that are able to offer support that they could not find locally. Online communities have facilitated the development of friendship. Angela (39, PI), stated the people she has met online through the common link of MS, their relationship has evolved and, in some instances, they do not even discuss MS or CCSVI anymore.

Participants in this study felt that fellow MS patients online were more knowledgeable than family, friends and medical professionals, especially with regards to CCSVI. Some participants said their family and friends were as understanding as they could be, given the circumstances of not having the disease. Rawnie (47, OI) discussed the support she received from family and friends when her symptoms would flare-up, requiring her to make frequent trips to the washroom, or causing extreme fatigue during which she would sleep for extended periods in a day. Nonetheless, some other participants felt that their family and friends did not fully understand the gravity of their symptoms, especially their fatigue levels. Ayala (39, OI) stated,

People with MS suffer from debilitating fatigue. If they try to tell a friend who does not have MS about this, the friend will likely be very sympathetic and say that they know what you are talking about because they haven't been sleeping well lately and are similarly fatigued.

Participants said that even though a friend or family member may have gone through a similar ordeal, it is not the same as what a person with MS goes through. Many friends and family have good intentions when sympathizing with an individual suffering from MS, but it is difficult for anyone that does not have the disease to understand how oppressive the symptoms and fatigue can be for people with MS. The illness stories posted online provided the support that people with MS needed with the day-to-day symptoms that may be difficult to find from family and friends. Much of the support that patients were able to access online was based on personal experiences of other patients (Hardey, 2001).

The online communities that are developed for people with MS can begin to feel like a family, since it may be difficult for MS sufferers to feel comfortable communicating with family and friends about their disease. In fact, Sierra (49, PI) addressed that the individuals she connected with online provided more support than her family. Sierra

discussed extensively the trouble she has had communicating her health issues and concerns with family members. Many members of her inner circle questioned whether her CCSVI procedure in particular will last, although they do support her desire to explore the treatment and improve her quality of life. She stated that she posts her thoughts and feelings online in hopes that her family will read her posts and understand what she is going through; however, she still does not believe they either read her comments, or understand. Sierra (49, PI) went so far as to remark,

So, I won't be forthright with anybody in my family, I'll speak to people online instead..... Strangers are better than family.

The internet has given patients the opportunity to discuss openly and frankly uncertainties and experiences without fear of negative comments from, or being under the watchful eye of, their loved ones. The internet has also provided a forum for patients like Kiara (41, OI) and Christie (46, OI) to be more honest about their bladder and bowel problems which they wouldn't feel comfortable discussing with their families. Family members and friends, as a general rule, have not lived with MS or invested the time into researching the disease or possible treatment options like the CCSVI procedure and have difficulty understanding the gravity of living day-to-day with a debilitating disease. As previously discussed (Colineau & Paris, 2010; Mickelson, 1997; Orgad, 2006; Wellman, 1997; Wright & Bell, 2003), the internet provides camaraderie for patients and a community in which lasting friendships can be developed.

Online communities provided support on how to live with MS, Caroline (51, OI) was able to find much needed support in online communities that helped her adjust to life with MS and provide a sense of mental wellbeing with the disabling disease. Online communities have provided Caroline (51, OI) with support that has helped her,

[A]ccept the MS diagnoses and keep the fire burning to continue asking questions and to search for procedures and aids that will improve and/or cure MS.

A diagnosis of any disease can be difficult to comprehend or accept. There are countless questions that the newly diagnosed patient is faced with, in addition to uncertainty about how the disease will impact their future prospects and interactions with others. When the diagnosis is a chronic illness such as MS, the uncertainty is increased as medical professionals, and the medical narrative, cannot cure the patient. MS sufferers are able to turn to online resources to negotiate what their illness means in their day-to-day lives and reclaim their illness narrative by telling their stories online for others to read. This can enable people with MS to find the needed support to accept the chaos that MS has brought into their lives and begin to formulate a new narrative (Frank, 1995). The stories found online have helped participants to not only learn about their disease, but to also receive support and advice on how to live with MS and find a new destination on life's map. By accessing these forums, MS sufferers were able to provide support, advice on treating the disease and allowed MS sufferers to become more knowledgeable about their disease and treatment options.

The Internet and Knowledge

Online Knowledge of MS and MS Medications

Previous research has found that the internet can be a source that patients can turn to seek or provide advice on medical treatments, outside of the medical narrative (Ziebland, et al., 2004). The internet can also create a forum in which a shared condition of their symptoms and suffering can be created (Barker, 2008) and access information on alternative treatments (Hardey, 1999; Hardey, 2001). Online, patients are able to share

knowledge about their disease which can be different than the knowledge presented in a medical setting. Mellie (57, PI) a woman from Ottawa diagnosed with RRMS in 1998, mentioned that once she turned online, she was able to find out about common symptoms of MS that were not discussed in her appointments with her neurologist, such as heat intolerance:

[P]erhaps this is a side thing to meeting these people online, is that I've discovered that a lot of the things that were completely... pooh-poohed as being nothing to do with MS umm everybody has them, you know, and nobody ever told me there was heat sensitivity. I had no idea that was part of MS, or CCSVI..... I find that a lot of things that I have experienced myself umm, you know, the majority of the people who come online have had something very similar.

People with MS are sharing their experiences with their disease online and have enabled others' to learn about symptoms not recognized in the medical narrative.

Many patients were also able to access advice about alternative treatments that had been frowned upon by treating medical professionals. Online, there are either specific websites or online communities that are designed to discuss alternative treatments such as Vitamin D supplements, diet regimes, exercise and LDN (low dose naltrexone), an alternative medication to help alleviate MS symptoms. In fact, the narratives Sierra accessed online led her to believe in the efficacy of LDN to suppress her MS attacks; moreover, she was able to access a prescription for LDN online.

The information people with MS accessed online aided in making a decision about standard medical treatments as well, such as DMDs. The advice that Trina (49, PI) and her husband received from online sources helped inform their decision about her use of MS medications.

[M]y husband and I had really gone around with if I should go off the Copaxane and, you know, just sort of think forget this. And, so reading

medical and just people's opinions, it just, all of that definitely helped in making [our] decision.

As Frank (1995), Bury (2001) and Hyden (1997) have discussed, the narratives that patients tell differs from that of medical professionals, as patients have experienced the illness, medications and treatments first hand and have a different form of knowledge, outside of the medical narrative, that they can share with others as a form of advice on how to live with and handle their disease. Moreover, by having access to discussions from a variety of MS patients and medical articles, patients like Trina now feel comfortable making decisions about their healthcare with the aid of online resources. Mellie (57, PI) discussed during her interview that her treating neurologist took her off of her interferon medication because he had decided to take all his older patients, whose MS had been stable, off of DMDs. Although Mellie did not go off her medication based on advice found online, she did turn online to be reassured about the decision not to be on DMDs.

I didn't come off my medications because of the internet, I came off because of my doctor, but I think the fact that other people had perhaps made me more umm reassured (Mellie, 57, PI).

Once again, the personal stories found in online resources can serve as a kind of second opinion on the decisions made by medical professionals, reassuring Mellie that she was doing the right thing not being on a DMD. As previously discussed, patients have a specific knowledge with their disease and medications that may differ from the medical industry which patients are able to access and discuss online (Josefsson, 2005; Wright & Bell, 2003).

The Internet and the CCSVI Phenomenon

The CCSVI procedure provides a unique case study because treating medical professionals – neurologists – are providing very limited information on the procedure and

patients are instead turning to the internet for access to information on the procedure – to most neurologists’ alarm. Numerous participants cited that the internet was their main or only source of information on CCSVI, through such statements as:

Everything I needed was available online (Kurt, 50, OI).

I could not have done anything CCSVI-related without the internet (Janelle, 45, OI).

There has been a lot of political push and pull regarding CCSVI, especially in Canada. This led Sierra (49, PI), who has had the CCSVI procedure twice, to state when asked if there was a different type of knowledge and information online, to respond with “the truth.” By having access to this information, some participants in this study were able to question the advice that their doctors had provided. The internet became a key research tool for MS patients as they searched, learned about, and ultimately decided whether or not to have, the ‘controversial’ CCSVI procedure. By being able to access information online, patients were able to become more informed about their disease and treatment options. In the process, this information enabled them to develop autonomy from the dominant social structure of medicine and provided them with the added knowledge they needed to enact their agency (Lash, 1994). The internet enabled certain patients’ to develop their own knowledge of the CCSVI procedure.

Previous research (Lewis, 2006) has found that internet searches based on a health condition are triggered by media stories, and MS and the CCSVI procedure is no exception. One participant discussed her actions after *W5* aired its episode on CCSVI; her first reaction was to contact her neurologist but she soon received a discouraging response that she described as:

[I]t’s new and people have died and stuff like that and [the neurologist] was very negative and if that’s the only sort of umm you know, anything I could

figure out from then it just would have been a dead issue right there (Trina, 49, PI).

But it did not die right there, in fact, it grew, due in large part to the online presence of people with MS sharing their experiences with the CCSVI procedure. The internet has increased access to information from a variety of sources from all over the world which would not have been available several decades ago. Online people with MS can access knowledge which can increase the scope of information they can access, and, in turn, decrease their reliance on one form of knowledge, found in one location – local neurologists at MS clinics.

Previous research has shown that patients turn to online resources to become reflexive consumers of their healthcare (Colineau & Paris, 2010; Hardey, 1999; Hardey, 2001; Josefsson, 2005; Kivits, 2004; Kivits, 2009; Lewis, 2006; Seckin, 2009).

Information and communications systems have enabled patients to feel as though they are ‘go getters’ of information and are no longer passive recipients of information solely chosen and presented by experts. People with MS are able to find the information they need to make critical and informed decisions about their healthcare.

I did go to some sites that umm, oh, the Hubbard Foundation was one, and I researched that through the internet and what they were doing.... I guess it was just in my own mind that whether I felt comfortable with it or not. I mean, I’m not easily swayed and right from the start I was excited but I wasn’t convinced that that was the cure. So, maybe, I guess just in my own mind I was kind of trying to justify both sides (Allison, 54, PI).

Immediately after the CCSVI story broke, Allison (54, PI) turned to online resources to interpret, verify and determine the efficacy of the treatment through both information provided by the MS Society of Canada and general searches of information on websites promoting the treatment. By accessing this information, Allison was able to acquire more knowledge and interpret the CCSVI controversy for herself by accessing what she feels is

both sides of the debate – those for and those against the procedure. The added knowledge that Allison acquired allowed her to feel comfortable coming to her own conclusions regarding the treatment – she decided not to explore the CCSVI procedure.

MS patients have also provided information on treating interventional radiologists. At first, when the CCSVI story broke in November 2009, there were no lists of doctors performing the CCSVI procedure for MS patients since these facilities were being closed down. Now, patients like Trina (49, PI) will provide names and locations of the closest treatment facilities and doctors performing CCSVI to any patient that asks her on the Facebook pages she frequents. Sierra (49, PI) also heard about a frontrunner of the CCSVI procedure in the United States – Dr. McGuckin – through a friend of hers online.

By accessing information and knowledge online, patients say they are able to critically analyze not only the facility and skill of the doctor but information about the vascular theory. Christina (32, OI) used online resources to search and learn about both the vascular and autoimmune theories of MS. From the information she found, she was able to question and, in her eyes, provide answers to the concerns she had about the autoimmune theory.

I had always had my doubts about the cause of MS being a faulty immune system, which targeted just one part of someone's anatomy. From my observations it seemed that the immune system was indeed implicated; its job of course is to clear up dead cells and in the process it also attacks healthy neighbouring cells, but something was triggering the process, in other words the immune system was doing its job because there were dying cells to clear up. The reason why the cells were dying could be due to any number of causes, hypoxia, stroke, infection, BBB breakdown which allowed infective agents and other substances to invade places where they were not meant to be. All this information is available on the internet if you know which questions to ask (Christina, 32, OI).

Christina was able to address questions that she had regarding the aetiology of MS while at the same time becoming more informed about her health and wellbeing. Patients are now

able to question the information that they have access to by researching what different experts have to say on a subject. By accessing information online and understanding the history behind the vascular theory of MS, Christina (32, OI) felt comfortable making a decision to travel to Poland for the CCSVI procedure.

In online communities people with MS are able to develop knowledge based on their shared experiences and understandings. Previous research has found that through patient narratives and lay experiences, patients online can acquire knowledge based on the common symptoms and suffering patients experience with their disease (Barker, 2002; Bulow, 2004; Prodinger & Stamm, 2010). Ayala (39, OI), a woman from Yehud, Israel who was diagnosed with RRMS two years ago, has had the CCSVI procedure twice, tapped into her online network and with the aid of her husband, a veterinarian, and his academic colleagues to learn about the CCSVI procedure. Ayala is leery of fully trusting online resources due to the abundance of positive patient narratives, however, she feels that there are benefits associated with online information as patients can provide a list of common benefits they have experienced from the CCSVI procedure that are not explained in medical articles.

Without the online communities it would not be possible to list the common benefits of [the] treatment. Even Prof[essor] Zamboni's papers are quite limited in what information he provides in terms of the effects of treatment. He has measured them using standard neurological assessments when in fact, some of the benefits are not neurological.

Medical articles cannot provide a list of all the benefits, or impacts, that this procedure may have in a patient's life, especially since many of the benefits patients experience are subjective – cognitive improvements, less fatigue – that do not lend themselves to statistical testing the way that a mobility scale might. By accessing personal stories online that discussed the benefits of the CCSVI procedure, as well as the basic knowledge acquired

from medical articles, Ayala and her husband studied the CCSVI controversy from what they believe is a scientific and objective perspective. Her husband was able to develop survey measures to test the effectiveness of venous angioplasty on MS symptoms. Ayala (39, OI) stated that, she and her husband felt that they were able to access, through online resources a group of MS patients that either had had the CCSVI procedure, or were interested in having the CCSVI procedure and found that the internet,

[P]rovided ready access to a large number of people world-wide who were studying CCSVI, had been treated for CCSVI, or were sceptics or had negative reactions that typically were not being reported in the online communities.

Through what she refers to as direct contact with people with MS in online forums, Ayala and her husband felt they were able to get a cross-section of participants that are both for and against the procedure. Through access to online information and a knowledgeable network or experts, Ayala and her husband felt they were able to critically analyze the data they compiled. They developed their own understanding and knowledge of the CCSVI procedure, its plusses and minuses, through online consultation with patients. Ayala presented her husband as practical and competent researcher. This, in turn, provided her with the confidence to make her decision to have the CCSVI procedure.

Christina, and Ayala and her husband, demonstrated that in a time of reflexive modernity, patients no longer have to solely trust their medical professionals. Instead, they can turn to online resources to access and interpret information on a medical treatment for their disease. By having access to this information they are able to reduce their reliance on the expert system of neurology and instead rely on their own knowledge, creating autonomy from the dominant structure of medicine.

The expansion of information and communication systems has enabled individuals from different parts of the world to interact with each other and share knowledge (Orgad,

2006; Schaffer, Kuczynski & Skinner, 2007), but patients have also been able, through online resources, to interact with medical professionals from all over the world who can provide follow-up care (Breen & Matcsitz, 2010; Cartwright, 2000). Participants were able to send subsequent Doppler Ultrasound, via email, they had performed locally, to their treating IR all over the world to view and provide any follow-up recommendations. As Giddens (1991) remarks mediated communication can put individuals in contact with others they may never have met in their day-to-day lives. In fact, several participants discussed directly contacting treating interventional radiologists all over the world through email. Elle (52, OI) provided an in-depth discussion of this. She, like Allison (54, PI), is a self-motivated researcher of the CCSVI procedure. Her methods involved the traditional online searches employed by Allison, but Elle went one step further and contacted fifteen treating interventional radiologists from all over the world to access information directly from them about their treatment facility, methods and surgical abilities.

I liked getting the feedback, being able to ask questions of a variety of people and getting variety of points of view (Elle, 52, OI).

Patients like Elle, Allison, Ayala and Christina do not want to be passive recipients of healthcare and became active agents in the information gathering and processing through online resources. Patients are able to check, verify and interpret what this information may mean in their lives and, in turn, develop the autonomy they need to enact their agency in making critical and informed decisions on issues relating to their health.

Perceptions of CCSVI

The information and knowledge that MS patients have accessed online has impacted their view on whether CCSVI has a causative role in the course of their MS. Numerous MS patients have turned to the internet for information on their disease and the CCSVI

procedure and for most of the participants in this study, the information they found made them question and challenge the traditional forms of MS treatment. Gillian (76, OI), Victor (44, OI) and Kiara (41, OI), all of whom have had the CCSVI procedure, stated that due in large part to the information they accessed online, their views of MS are constantly changing. This ever-changing view of MS has caused many patients to refer to their disease as a puzzle and led them to question why MS care is solely in the hands of neurologists.

From the information participants have accessed online, two groups of participants emerged – those supporting a vascular aetiology of MS and those that feel CCSVI is a specific vascular condition. For many participants, the information that they were able to access online regarding the vascular theory of MS was the first time that a cause of MS made sense to them. Melissa (48, PI) went into an in-depth discussion of how the vascular system can cause the immune system to become involved in the course of MS.

[T]he immune system comes in to take care of the inflammation and, and you know, it recognizes, oh there's the iron where it shouldn't be and we have to take, the immune system kind of goes in to take care of that all.

She cannot understand how scientists are unable to see the connection between the vascular system and MS, especially after the relief she has experienced after having venous angioplasty. She believes that a vascular theory of MS will supplant the autoimmune theory. Many people with MS who experienced benefits from CCSVI are beginning to believe that MS may, in fact, have a vascular origin. These patients discussed that the autoimmune response is secondary and caused by the build up of blood in an MS patient's CNS from poor drainage between the BBB, leading to the attack of healthy cells and the development of MS lesions.

Not all participants support the vascular aetiology, especially those that have not had the CCSVI procedure. Instead, participants like Janetta (51, PI), Allison (54, PI) and Erin (49, PI), question both the connection between CCSVI and MS since not all MS patients are experiencing symptom relief, and the appropriateness of a medical intervention that has produced varied outcomes and complications among MS patients. Janetta (51, PI) stated she is not pursuing CCSVI anymore after the complications that have been discussed in the media, making her feel that the treatment is, in fact, dangerous. A similar comment was made by Erin (49, PI) in which she does not feel that CCSVI is worth the exploration or the cost because of the dangers that have arisen in treatment and aftercare.

Still others addressed that CCSVI was a separate vascular condition. Christina (32, OI), Callie (38, PI), Trina (49, PI), Brian (52, PI) and Diane (60, OI), all of whom have had the CCSVI procedure believe there is a link between CCSVI and MS due to the amount of patients that have experienced symptom relief. Each of them stated they had an interest in CCSVI from the moment they heard about it; however, they do not support the vascular aetiology of MS at this moment. In fact, they say that CCSVI is a separate vascular condition from MS and that it should be treated as such.

CCSVI treatment is not a cure for MS but a treatment for a venous condition which might have a role in the pathology leading to MS symptoms (Christina, 32, OI).

[I]t's a completely separate diagnosis, CCSVI, and it shouldn't be looked at as MS and I agree with that. That the research needs to be done to see how that does tie in to it for further down the road (Callie, 38, PI).

All of the participants who have had the CCSVI procedure acknowledged that they still have MS, but stated that the procedure does provide relief from the debilitating symptoms of MS. Kurt (50, OI), a man from London, Canada who has had the CCSVI procedure and lived with MS for twenty-five years, comments that although CCSVI is not a cure for MS,

it may be one of the keys to unlocking MS treatments. He discussed his belief that multiple treatments may be needed and not just from one discipline. Many participants believe that MS patients should have access to the treatment, but in Canada the road to accessing the CCSVI procedure for people with MS has been blocked as a result of the attitudes of Health Canada and neurologists. Much like the work discussed by Latour (1988; 1999), some people with MS are, in turn, trying to find other ways to access the procedure by arguing that CCSVI is a separate vascular condition in which any person with occluded or malformed veins should have access to venous angioplasty whether or not they have MS. They are displacing the goals of ardent supporters and realigning with new goals that will allow the treatment to be done in Canada. MS patients are taking a slight detour by aligning themselves with the concept of a vascular condition to ensure that patients can have access to a treatment that seems to provide symptom relief, and further knowledge on the possible connection between MS and CCSVI. However, the participants in this study would not have been able to access information on the CCSVI procedure without the internet, but the internet is not a forum in which all posts and information are honest. In fact, many participants have challenged the information that has been posted online and question the transparency, honesty and integrity of some posts.

The Politics of the Internet

The internet is filled with websites that provide information on CCSVI such as news sites, facebook pages, and discussion boards. Above, I gave an overview of how MS sufferers use the internet for support and to develop new knowledge, an understanding of their disease and the CCSVI procedure. Now, I turn to the question of what people with MS are saying about the most popular and commonly cited websites. Previous research by

Henry Jenkins (2004) found that the internet is a forum that can garner supporters for a cause at a faster rate than ever before; CCSVI is no exception.

Both ANT (Latour, 1987; 2005) and narrative analysis researchers (Frank, 1995; 2010) have stated that each individual can read and interpret information differently. This was shown throughout the interviews I conducted with MS patients. There was not a uniform view of the websites that provide information on CCSVI, and there are factions of patients for and against the CCSVI procedure. Participants raised questions about the posts and actions (or lack of action in some cases) taken on these websites. In this section I will trace the arguments, opinions and comments made about the most commonly cited types of websites that patients accessed for information on the CCSVI procedure. This section will employ methods similar to Steven Epstein's (1996) work in *Impure Science* in which he traced the development of the retrovirus hypothesis as the obligatory point of passage for AIDS research through Bruno Latour's (1987) concept of context of citation. Epstein examined the different ways that Gallos' argument of AIDS as a virus was being taken up, as either supporting the retrovirus hypothesis or detracting from it, to conclude when the retrovirus had become an obligatory point of passage.

In my analysis, I divided respondents into four networks based on their attitudes towards the CCSVI procedure and how they view the internet in the CCSVI debate – advocates, middle of the road, critical of the internet, and against the CCSVI procedure. I then examine how people in each of these networks view types of internet resources. The first network, the advocates, was participants that had either petitioned their local governments to provide patients with access to CCSVI or have created websites and Facebook pages to promote the theory of CCSVI. The advocates found the internet to be a vital resource in information gathering and dissemination. The second network is

participants considered middle of the road; they are happy that there is discussion and research into the disease which may lead to more hope for MS patients, but they neither advocated for nor were completely against the CCSVI procedure. They are just glad CCSVI is being explored and there is discussion of MS treatments they can access on the internet. People in the final two networks read the same content as the others but question the role the internet has played in the CCSVI debate or questioned the CCSVI procedure altogether, along with the online presentation of the procedure. The participants in the third network – critical of the internet – supported the option of having the CCSVI procedure but questioned the role the internet played in disseminating information. They challenged what major advocates were saying and questioned some of the information posted about the CCSVI procedure. Finally, those against the CCSVI procedure, although a much smaller group, stated that they felt the procedure is dangerous and were critical of much of the actions taken by fellow patients online.

Patient-Based Websites

Patient-based websites, such as the popular MS discussion board TIMS, blogs, and Facebook pages elicited a multitude of responses from participants. The comments found on these websites provided information and advice on the CCSVI procedure that was primarily based on patients' personal experiences. These sites were used by leading CCSVI advocates, like Joan Beal who has been a frontrunner in the CCSVI movement from its inception and whose husband was one of the first patients treated for CCSVI in America, and Marie Rhodes, a registered nurse who published a book on the science behind the connection between CCSVI and MS. These women provided, in some individuals' eyes, a factual interpretation of the evidence related to CCSVI. Medical professionals such as Dr. Sclafani, a noted vascular surgeon in New York, opened an account on TIMS to

answer questions MS patients have about the procedure. Dr. Bill Code, an anaesthesiologist from Canada that also lives with MS and has travelled abroad for the CCSVI procedure, is an active member of the National CCSVI Society and has befriended MS patients on Facebook where he also answers their MS-related questions. All of the above sites also contained a multitude of posts in which patients discuss their experiences with MS and the CCSVI procedure.

Advocates provided numerous ringing endorsements for these sites, especially TIMS. Janelle (41, OI), an advocate of CCSVI that now sits on the board of a not-for-profit organization developed to further knowledge on CCSVI in the United States, commented that the information on TIMS was “groundbreaking.” People with MS had access to not only personal stories of patients having the procedure, but also members that provided information in a relatable, non-jargon laden language. By referring to TIMS so positively, she is providing further backing to the claims made by advocates on the success of the procedure which helps take the information about the CCSVI procedure online further away from its conditions of production. For the advocates, and many people with MS, TIMS provided patients with a place to turn that offered knowledgeable information to help make their decision.

The positive feedback for TIMS stretched beyond just CCSVI and included support and advice that emerged about MS in general. Sandra (59, OI) addressed the impact of patient stories found on the discussion board when she stated that being able to follow illness experiences was fundamental:

There is nothing better than first-hand reports of what works [or] doesn't work for others.

Furthermore, Todd (43, OI) found that the beginning of his journey into understanding his MS began on TIMS. He remarked,

I would never have become as informed, as I am, from any other source
(Todd, 43, OI).

The success stories, information and support from TIMS aided both of these participants in their acquisition of knowledge and their decision to have the CCSVI procedure. Members of the middle of the road network also spoke of TIMS in a positive light, saying they relied on the information found on TIMS and that it was fundamental to understanding their disease. Fellow MS sufferers talking about and supporting the information found on this website increased the number of allies and supporters for the CCSVI procedure. As Latour (1987) says by increasing the number of allies for an argument, the greater the likelihood it will be taken up as a fact. By referring to the information they found on these websites as fundamental to their understanding of their disease, the members of the advocate and middle of the road networks created positive modalities for the information that people with MS and advocates provide on TIMS since it helped to further the arguments and information for CCSVI away from the conditions of production.

Many of the same arguments were made about Facebook pages and patient-based websites. On those sites advocates are able to directly influence other patients, since there are no moderators to delete posts. Several participants in both the advocate and middle of the road networks addressed one site, *CCSVI in MS*, run by a leading advocate in the CCSVI movement – Joan Beal – as being a valuable source of information. Lori (56, OI), Todd (43, OI) and Carrie (44, OI) all stated that Joan Beal provided the most accurate, trustworthy information, by posting links to appropriate articles on CCSVI and allowing people with MS to openly (it would seem) discuss their experiences on her Facebook page.

By stating how integral this website was to their knowledge on CCSVI, participants are once again providing positive modalities, by helping to further the arguments being made on advocates' websites and Facebook pages regarding the success of CCSVI. This, in turn, helped to reinforce the arguments of authority figures and the CCSVI procedure as they gained active followers of their Facebook pages. Advocates and the members of the middle of the road networks provided a uniform view of patient-based websites as being fundamental to their education and understanding not only of CCSVI but of MS as well. Such a positive view of the information that patients provided on these websites suggests they are akin to the work done by activists in the AIDS (Epstein, 1996; Petchey et al., 1998; Watney, 1996) and breast cancer (Anglin, 1997; Kolker, 2004) movements. These activists provided information about treatments, trials, (both medical and patient-based), and information on how to live with the disease through media sources such as grassroots newspapers. The CCSVI advocates and authority figures are providing similar information online, and this information can reach patients faster than grassroots newspapers. Many have speculated that if it was not for the online response, the clinical trial of the CCSVI procedure would not be going forward in Canada.

However, MS sufferers' use of online resources may not be as beneficial or useful as the advocates think. The participants that were either critical of the internet or against the CCSVI procedure had a different reading of the information online and, in turn, developed a different network. Not all participants that used these websites provided positive comments. In fact, they addressed many concerns that have been brought up in the literature, namely that the massive amount of information found online can be a hindrance to patients (Hardey, 1999; Henwood et al., 2003; Kivits, 2009) and that lay knowledge provided in patient narratives may be false (Prior, 2003; Hardey, 1999; Lewis, 2006).

Indeed, both those critical of the internet and against the CCSVI procedure provided negative comments or negative modalities that depicted the arguments of advocates as fiction. These comments focused primarily on TIMS and Facebook pages. Elle (52, OI), Brian (52, PI), and Haley (32, OI), all of whom support the CCSVI procedure but are critical of the internet, and Erin (49, PI), Carla (53, OI) and Madilyn (61, OI), who are against the CCSVI procedure, question the information posted online. Elle questioned the direction TIMS has taken since it is now difficult to find reliable information about the treatment. She feels that TIMS is,

[T]oo junky and too many opinions.... it is now impossible to sort through the volume of garbage (Elle, 52, OI).

Elle says that too many MS sufferers have entered the TIMS forum and caused the quality of information to be degraded. She does not find it a useful resource and questions some of the stories that have been posted on the site due to their overly optimistic nature.

Brian (52, PI), a man from Oxford England who was diagnosed with RRMS in 1995, furthers this argument. He addressed the ample amount of misinformation online, and questions comments made by many of the advocates on TIMS and in published work.

[S]ome people who are regarded as umm oracles, umm the CCSVI Alliance, people like ah Joan Beal, she, sometimes I say 'this is just silly,' and [I'm] always critical of Marie Rhode's book because you know, it just goes too far, it makes leaps of science which, for which there is no basis.

Brian (52, PI), a man who studied pharmaceuticals at university, questions the science that major advocates are discussing about the CCSVI procedure. Throughout his interview, he provided several negative modalities which are meant to weaken the arguments posted by many of the CCSVI advocates by returning the argument to its condition of production. He decreased the weight of the advocates' arguments by referring to the numerous unresolved questions regarding the link between MS and CCSVI. He is a supporter of the CCSVI

procedure and has, in fact, had the procedure twice himself, but commented that the narratives that are emerging online are too optimistic and not reflective of a patient's actual experience. He feels they are espousing immediate results which he stated has caused the CCSVI movement to be set back. He questioned the weight advocates are placing behind personal experiences with the CCSVI procedure and the knowledge they have amassed on the subject through online resources.

Brian's main sources of information on CCSVI and venous angioplasty are medical papers. Through these sources he was able to find Zamboni and colleagues' (2009) original study on CCSVI in MS patients in which there was no discussion of the immediate effects of the procedure on patients' cognitive or physical abilities. Tests were only conducted at the six, twelve and eighteen months in which Zamboni found that patients with RRMS had a significant improvement in cognitive and physical function after eighteen months but that PPMS and SPMS patients had little to no improvements after eighteen months. Brian is using the medical knowledge he acquired while studying pharmaceuticals at university to study his disease and CCSVI, as well as his personal experience with the both the disease and the CCSVI procedure to question the arguments of certain authority figures. Throughout the negative modalities discussed above, Brain calls for more scientific research into the link between MS and CCSVI, bringing it back to its conditions of production, before the procedure should be argued with the finality some advocates are putting behind it and, in turn, weakening the advocates' claims.

Erin (49, PI) addressed similar questions about the motives of authority figures who post on TIMS and Facebook pages. Erin extensively researched CCSVI for a year before becoming leery of the procedure after to the deaths of both local and online friends due to complications of the CCSVI procedure. She stated that she became curious about the

actions of leading advocates online, and began investigating their posts. She found that advocates either avoided making posts that may be portray CCSVI in a negative light, or when they did make posts that may not be beneficial to the CCSVI movement they tried to hide or minimize them. For Erin,

[T]he turning point for me was when [a leading advocate's son]..., was treated and ah, two times which nobody knew that and it failed. The treatment failed, that's why he had to go back for a second treatment and the second treatment failed. And she never put that up on Joan's page, or the CCSVI Toronto page which is the second biggest page. What she did do, is she put a little note, a one page, on Sandra Birrell's page umm a couple lines deep only saying that [her son] has demanded that I put this disclosure up that '[her son] was treated twice and it failed, it just isn't working the second time' (Erin, 49, PI).

The information that the treatment has been unsuccessful on two separate occasions for a leading advocate's son is not good for the arguments that authority figures are making. Hiding this information on a less popular CCSVI website does not threaten their movement as much as posting on a popular page would. Erin, like Brian, is providing a negative modality towards the knowledge that authority figures have on CCSVI by discussing how they are aware of the procedure being unsuccessful in patients and they choose to edit where, or if they will post the information. Erin (49, PI) stated later in her interview that advocates are manipulating the information towards what they want, not what is best for patients. She commented that the actions of advocates online are dangerous as they have a strong interest in the procedure, to the point that they risk misinforming fellow patients. Erin, later in her interview discussed, going back to the first posts about CCSVI on TIMS and was alarmed at what she found,

They were fudging the codes. I also learned about [that] online which I didn't know but they were coding using special codes that were false. From Stanford, code 292, that's what Joan would put out, tell everybody to tell their doctor to bill.

Erin found that leading advocates were telling patients how doctors could ‘fudge’ medical codes to ensure access to the procedure. This finding is similar to previous research into patient actions in online forums; patients provided information to fellow patients about how to gain access to medical intervention or compensation (Dumit, 2006). By searching and discovering the actions of CCSVI advocates online, Erin states that she is now sceptical of the CCSVI procedure and will not explore it. Her personal narrative of CCSVI has changed due to the posts and stories that she has read online. Erin points out that anyone can post anything online that may influence patients which can, in turn, make people with MS more susceptible to manipulation (Hardey, 1999; Lewis, 2006). By searching for this information online, Erin’s narrative of the CCSVI procedure was altered, or in Frank’s (2010: 58) words, “ambushed” by the actions of leading advocates and the occurrence of patient deaths, causing her to re-evaluate her stance on the procedure.

On both TIMS and Facebook pages, people with MS that are against the CCSVI procedure have been bullied by some of the major advocates to the point where they will not post their opinions anymore. Although advocates state they want an open discussion of CCSVI on their websites, some participants like Erin (49, PI), Madilyn (61, OI), Carla (52, OI) and Matthew (40, OI) have speculated that authority figures may, in fact, be silencing patients that experience negative results to create a uniform narrative about CCSVI online. Madilyn (61, OI) posits,

CCSVI has swept through the online MS world, practically obliterating any other ideas in the best forums like TIMS, running off some of the most informative and brilliant posters, and dividing the community to the point that dissent is almost silenced in places.

Advocates, in some participants’ eyes, are solely focused on the success of the procedure to the point where they attempt to silence anyone who has a negative view about the CCSVI

procedure. Carla (52, OI), who has not had the CCSVI procedure, and Matthew (40, OI), who had an unsuccessful CCSVI procedure, made it clear in their interviews that either their comments online, or their face-to-face encounters with other patients, are not welcome if they wish to discuss their opinions of CCSVI.

I have made some posts on some facebook groups regarding my decision not to pursue the so-called "Liberation" treatment until there is further testing. I have been told that if I don't have CCSVI, I don't have MS. I have been told I am stupid for not pursuing anything further (Carla, 52, OI).

I feel no particular urge to share my results; although in some interactions I've had it become clear to me my negative report was not very welcome. That was the case in person as well. I have not, for example, followed up with a fellow in Calgary, the brother of a former co-worker, who is a booster for CCSVI. I talked to him before I had the procedure (Matthew, 40, OI).

Carla and Matthew's statements demonstrate that people with MS are being bullied online into not talking about their experiences or opinions in forums that were designed to provide them with a place to openly talk about their disease. These two participants are not alone; in fact, Erin (49, PI) was once an active member of the online community, but now no longer posts her opinion after she received negative comments from online friends when she referred to the treatment as dangerous. Negative experiences and opinions are frowned upon. As a result at least some MS patients are not comfortable discussing their experiences and may, in fact, avoid contacting other people with MS or ardent supporters of CCSVI. Their experiences would detract from the claims advocates have made and some participants have speculated that advocates may be trying to control the public's access to information. However, not all participants against the CCSVI procedure have stopped posting; Carla (52, OI) still posts her opinion online although many do not.

The fact that certain MS sufferers either do not post their negative experiences online, or are discouraged from posting their experiences, reinforces arguments brought up

in previous research on how patients use the internet; namely, that the stories posted online are not representative of the whole (Josefsson, 2005; Orgad, 2006; Pitts, 2004). Patients that have positive experiences are far more likely to post about it than those with negative experiences, a point addressed by many participants such as Ayala (39, OI) and Brandie (52, OI). These two participants warned that all personal information posted by other patients online needs to be taken with a grain of salt. Likewise, Lori (56, OI) stated that after having a neutral experience with her CCSVI procedure it took her several months to find anyone that had a similar experience to her own.

My experience was neutral. No real change, yet the [Facebook] page for the treatment site I went to were full of positive result stories. It took several months for me to find someone else who related to my experience and then a few others who related to this as well. There seem to be more of those stories now. I do think the people who are excited about their results write about it, while those disappointed tend not to.

Many people with MS may not post about their experience if the treatment was not beneficial making it difficult for the full picture of the procedure to unfold online and may, in fact, minimize the support that people with such experiences may receive. The whole picture of the CCSVI procedure is not being presented to people with MS online. Even in cases like Ayala's, discussed above, where her and her husband developed survey measures to test the CCSVI procedure, they relied on individuals they contacted in online forums. Thus, it was based on their discretion of a representative sample of MS patients and, once again, may not represent the whole of story of the CCSVI procedure.

Many MS sufferers may also feel uncomfortable sharing their narratives online if they are not beneficial due to the comments they have noticed or experienced from authority figures. The internet is not a neutral forum in which anyone can post their opinion; there are individuals that may have more power due to their knowledge or, as

Latour (1988) states, have a larger network of supporters online that influence how and what may be said. Questions about how the narratives are being produced are raised when there seems to be such varied results from the procedure but few deviations from the positive reports found online. The medical narrative of CCSVI is still being created through clinical trials in the United States and Europe, thus a full comparison between the outcomes that people with MS are experiencing and espousing in their narratives online with results from medical tests is difficult to make at this time, but would be valuable.

Treatment Facilities in Online Forums

When the participants in this study, no matter which of the four networks they were from, accessed websites for treatment facilities it was for similar purposes – for information on the treatment, costs, and testing procedures – but participants like Brian (52, PI), Allison (54, PI), Erin (49, PI), Angela (39, PI), Tamara (53, OI), Andrew (61, OI) and Janetta (51, PI) commented on the actions of treatment facilities in online forums. Victoria Pitts (2004) addressed the way that information was presented online as it may imply that patients can use the internet to search for a cure. Some participants, in my study, feel medical professionals may be trying to take advantage of patients that are in a vulnerable situation in the interest of making more money. Brian (52, PI) comments on the actions of some treatment facilities, which try to recruit patients in discussion boards like TIMS solely on the basis of cost of the procedure, not the skill of the treating IR.

It's easier for them to make it commercial [online], because they can go onto chat rooms and say 'oh this is available', I mean there was one recently on *This is MS*, for 4000 Euros in Warsaw, Poland. And, you know, why's that going to be better and what's their experiences and all those sort of things? They're really just pitching price, which I don't like in medicine.

For Brian (52, PI) the internet has made it far easier for products, including medical treatments, to be sold to the public. For him, facilities should recruit patients not on the

basis of price, but on the basis of skills and abilities of the treating medical professional. In turn, Brian addressed his concern that CCSVI has become too commercial too fast and it is detrimental to patients. There is less discussion about the skills of the doctor and more about the cost and added bonuses, like physiotherapy, that may be included in a treatment package, increasing the chances of a patient becoming a victim of medical tourism.

Even advocates like Angela (39, OI) question the motives of some treating IRs. Through her online friends, Angela was able to access information on the respectability of treating doctors, which she passes on to fellow MS sufferers who query her about the procedure.

[T]here's a doctor that's taking advantage of people in New York.... [taking] financial [advantage] and also umm under treating, knowing fully well that they are under treating and that they would have to, that the person would have to come back, so then they would be able to double whammy them (Angela, 39, PI).

The internet can be a useful resource to find information and access treatment facilities. However they can also provide cautionary tales for people with MS. Through the stories that Angela read, she was able to find out about doctors who were taking advantage of patients by not expanding the veins enough to ensure optimal blood flow which would result in multiple treatments. Angela is now able to pass this information on to people with MS when asked. Other studies made similar observations (Barker, 2008; Schaffer, Kucyznski & Skinner, 2007); the internet now allows patients to share information about the quality and respectability of treating medical professionals.

The MS Society

Previous research (Kivits, 2004; Sillence et al., 2007; Nettleton, Burrows & O'Mally, 2005) has found that patients tend to trust information that is posted by organizations that support patients' afflicted with a specific disease, or medical

professionals that treat the illness; however, this does not appear to be the case for many people with MS. Far fewer advocates cited using the MS Society website for information about the CCSVI procedure than patient-based sites and when they did mention the MS Society, they provided negative modalities to detract from and question the quality of information found there. Those in the middle of the road network discussed the MS Society's website in a little more detail. Andrew (61, OI), a man from Dewberry, Canada, who was diagnosed with RRMS thirty years ago, remarked that the information on the MS Society's website is outdated.

I have always checked the MS Society website and its links to read MS info[r]mation etc. but I don't feel it is an up-to-date resource anymore.

By questioning the quality of the information found on the MS Society and its affiliated websites, Andrew emphasized the lack of knowledge the MS Society has about CCSVI and attempted to minimize their importance in research and discussion on MS. Participants raised concerns about the connection between the MS Society and neurologists, which made them wary of the Society's motives and intentions towards MS patients. Andrew, and some advocates – Paul (44, OI) and Christina (32, OI) – felt they were unable to access unbiased information about MS and CCSVI from the MS Society's website.

Moreover, Todd (43, OI), a fellow member of the middle of the road network, made a similar comment to Andrew's regarding the quality of information found on the MS Society's website. Todd found that they did not provide useful information about alternative ways to help patients. He, in turn, found that TIMS was where a variety of treatment options were discussed as well as access to quality information on MS care was provided. Todd questioned the quality of information about treatments provided by the MS Society and neurologists in general, instead he looked outside of traditional sources of MS

care to find the support he wanted. He placed his trust in the authority figures on TIMS and, in turn, increased the number of allies for the information espoused on that site. In fact, by discussing the MS Society's connection with the neurological community, participants were detracting from two of the traditional authority figures in the MS debate – the Society that was supposed to speak for the patients, and the neurologists that treat patients (to be discussed in the next chapter). Instead, they are now turning to emerging authority figures.

However, there are still participants that turned to 'official' websites for information on the CCSVI procedure. Members of the middle of the road network, like Ashley (52, OI) a woman from Calgary who was diagnosed with RRMS only four years ago and who has decided not have the CCSVI procedure, found patient stories posted on the MS Society's CCSVI website and an information panel at a conference run by the MS Society to be useful sources of information. Ashley is not the only participant to find the MS Society a useful resource. Allison (54, PI) discussed being the president of her local MS Chapter and her role as an MS ambassador for the MS Society. Due to her duties as an MS ambassador she receives links and updates from the MS Society on a regular basis and finds it a trustworthy source of information that provides both sides of the CCSVI debate.

Those against the CCSVI procedure also viewed the MS Society more favourably than advocates. Tamara (53, OI) relied on a local MS ambassador that provided her with up-to-date links to relevant MS-related websites. Carla (52, OI), an MS ambassador like Allison, finds the newsletter and links to other websites are trustworthy resources. These participants support the MS Society and place merit behind the information disseminated on their website which, in turn, increased the allies for the knowledge and information that is put forth by the MS Society and neurologists.

Participants' attitudes towards the CCSVI procedure played a role in how they read, interpreted, and used the sources at their disposal. The participants that spoke of the MS Society's website in a positive light have not had the CCSVI procedure and many of them have been sceptical of it from the beginning. They are waiting for more research to be conducted into the link between MS and CCSVI. Similar cases emerged with individuals that are for the CCSVI procedure, whether they are advocates or middle of the road participants; they turned to patient-based websites as a source to learn about the procedure since they were hopeful that they may be able to stop or slow the progression of their disease and could not understand why medical professionals and the MS Society of Canada were acting so slowly.

The internet has become a forum that people with MS are turning to as they learn about their disease and possible treatment options through support and advice from other individuals in a similar plight. Through this information, participants were able to develop knowledge on their MS and the CCSVI procedure which has been used to challenge the traditional sources of MS care and discuss whether MS is either a vascular disease or a vascular condition while questioning the autoimmune theory of MS. People with MS are spreading their stories and information they have acquired in online forums for others to read and are, in turn, developing their own authority figures. The internet has become a forum in which the struggle over who deserves to be authority figures in the field of MS is played out. The authority figures in the traditional medical community – neurologists – have been challenged by ardent supporters of CCSVI who question their intentions and motives online. However, these supporters are not without challenge as well since some participants still support, trust and listen to the expertise that is espoused by the MS Society and subsequently neurologists. Thus, the controversy still wages on, as ardent supporters

of CCSVI have challenged the formally accepted knowledge presented by the neurological community, while others have turned to online resources but ultimately trusted the expertise of the mainstream medical community, a topic to be discussed in the next chapter.

Chapter #6: Medical Knowledge and the Doctor-Patient Relationship

The Changing Doctor-Patient Dynamic

Patients' views of their disease are constantly changing, as well as their hope for new treatment options that may arise for MS. When medical professionals do not listen or provide advice on new alternatives, like CCSVI, patients' frustration increases as they attempt to battle their challenging and disabling disease. The internet can provide a challenge to the doctor's authority. Previous research (Hardey, 1999; Kivits, 2004; Seckin, 2009) has speculated that since patients can turn to the internet for medical information this can cause the traditional roles of the doctor and the patient to be challenged, especially at the specialist level since patients are now negotiation agents in a clinical setting. The internet has enabled new, alternative, or controversial treatments to be researched by patients, whereas before they were reliant on medical professionals to offer advice about both treating options and how to deal with their illness or disease (Hardey, 1999; Hardey, 2001; Lewis, 2006; Kivits, 2009). The patient stories that are posted online provide immediate information about a treatment; one participant, Erin (49, PI), from Calgary, said that because of the internet, she did not need to wait five to ten years to know if a treatment is effective, because online this information is "instantaneous." This sentiment was echoed by two other participants; Carrie, (44, OI), who commented that people with MS no longer need to wait for their doctor's support on medical decisions and can, in fact, turn to the internet for that advice, and, Elle (52, OI), also from Calgary, says, "you don't have to believe what your Dr. says as gospel." This raises questions about the traditional doctor-patient roles in which the doctor is the source of information and treatment options. The question now becomes: how has the internet impacted or changed the doctor-patient relationship at both the specialist and generalist levels?

Research has shown that medical information is now available online for patients to access, learn and question what has been presented to them by either their treating specialist or their general practitioner (GP) (Hardey, 1999; Kivits, 2004; Lewis, 2006). Lori (56, OI) comments,

Medicine has operated in this sacred realm with the attitude that the masses know very little to nothing and it is dangerous to tell them too much. Many doctors still consider medical decisions for their patients to be entirely the doctor's. The internet throws the doors open and gives ordinary people access to that information.

For Lori, the information online can be enlightening and provide a level of independence that has not been provided to patients before and can, in turn broaden a patient's treatment horizons. Many participants voiced their concern and frustration about how they cannot turn to their medical professionals for expert advice. In fact, Kiara (41, OI), stated, "We're in a weird time when patients know more about a condition than most doctors do." The desire and hope that CCSVI has provided MS patients have led many participants to devour all of the literature, stories or articles they can find. The speed with which CCSVI has hit the internet has made it challenging, if not impossible for a regular medical professional to keep up, causing many MS sufferers to categorize medical professionals in two distinct ways – those willing to learn and those that are entrenched in their own point of view.

The Attitudes of Neurologists

Most participants discussed their negative views of the neurological community at length, throughout the interviews. These views stemmed not only from the neurologists' perceived attitudes towards CCSVI, but also the way neurologists seemed to handle general patient care. In fact, negative views of the neurological community are not new. Unsurprisingly however, those respondents who have not had the CCSVI procedure were

not as negative about neurologists, like Janetta (51, PI) and Allison (54, PI), who discussed their relationship with their neurologist as open and honest. They said they discussed everything from CCSVI to alternative therapies like Vitamin D supplements with their neurologists. Even participants who have had the treatment, like Janelle (41, OI) can report a supportive relationship with their neurologist. Janelle (41, OI), was diagnosed with RRMS over 21 years ago and stated that her neurologist actually helped her find and receive the CCSVI procedure at her local hospital instead of travelling from her home in Washington D.C. to New York for it.

However, these positive sentiments were in the minority. The majority of participants questioned their neurologists' commitment to them and the treatment options they provided. MS patients see their neurologist once a year, some even less, and the appointments are approximately fifteen minutes in length, which left some participants feeling flustered and needing to bring in a list of prepared questions. Moreover, participants, especially those that have entered the progressive stage of the disease, remarked that their neurologists appeared to lack knowledge about the different stages of the disease as demonstrated by Sandra (59, OI), originally diagnosed with PPMS in 1999:

My neuro [logist] prescribed a DMD at the outset, which was exactly the wrong thing to do, since they are not beneficial for PPMS, and in fact can cause serious problems.

For Sandra, the neurologist did not know how to properly treat the disease leading to concerns that he lacked knowledge about the basics of the disease such as stages and treatment regimes, which raised questions about his overall knowledge of MS. Elle (52, OI) makes a similar argument about her neurologist's knowledge of the disease.

[E]very time I spoke to him, he frustrated me – every question I asked got an answer of “We don’t know that yet.”

Previous studies (Turner, 1987; Wynne, 1983) have found that patients turn to medical professionals for expert advice, but when that advice is not provided, in this case due in part to the unpredictable nature and course of MS, frustration ensues as the uncertainty of the illness and the individual's future increases.

Parsons (1951) discussed that patients turn to medical professionals to provide treatment that is based on universal, scientific facts. However, with the increase in contested and chronic illnesses in which scientific knowledge can provide few answers, previous studies (Asbring & Narvanen, 2003) has speculated that physicians can develop emotional and physical distance from their patients. Todd (43, OI), originally diagnosed with RRMS and re-diagnosed that same year with PPMS, speculated about why neurologists may be emotionally distant.

Neurologists see people like me every day. They act somewhat immune and distant towards patients like me. Seeing that they cannot even provide me with any useful treatment or info[rmation], and because they don't have any time to waste by chatting with their patients to really comprehend what someone like me is living with.

Todd stated that the distant and aloof attitude of the neurologists may be a coping mechanism. Neurologists may attempt to deal with the inability to help certain patients within the realms of their training.

However, this charitable attitude towards neurologists is not shared by all MS patients. Some participants found the emotional distance of neurologists to be alarming and led them to question the motives of neurologists. Many participants commented that they were required to blindly accept prescription after prescription for DMDs, and drugs that treat symptoms like spasticity and muscle stiffness, as their only options. DMDs work for some, such as Allison (54, PI) who has been on a DMD for over twelve years with few side effects, but they do not work for all patients. Ayala (39, OI) described the many side

effects she experienced on MS medication such as suicidal tendencies, nausea and insomnia; additionally, Sierra (49, PI) stated that she dropped to “forty kilos” while on a DMD. Participants like Paul (44, OI) and Elle (52, OI) question the efficacy of these drugs since they both found information online stating that trials of DMDs have shown only 30% efficacy, a finding previously discussed by Goodin et al. (2002) and discussed by others in the literature on pharmaceutical research (Epstein, 2007; Moynihan, 2003; Palmlund, 2006). Once participants turned to the internet, it provided information that was not freely given by treating medical professionals and called into question the effectiveness of the treatments that their neurologists prescribe, as well as their motives.

Previous research (Karnieli-Mille & Eisikovits, 2009; Bryan et al., 2006) has examined the paternalistic attitudes of medical professionals in which they provided the sole treatment option with little to no consultation with the patient. Due to the perceived emotional distance discussed by participants and little time neurologists spend getting to know their patients on a personal level, participants felt they did not receive the needed advice or care on how to live day-to-day with MS. In turn, participants presented their exchanges with their neurologists as lacking empathy and support as examples of the paternalistic attitude of medical professionals.

When the specialist asked if I'd ever had any other problems with my eyes I told her I'd had optic neuritis when I was fifteen. She said, “Oh, well then, you have MS.” Just like that. Matter of fact. Like it was nothing..... I saw two neurologists, [and] they both said the same thing [to take DMDs]. I asked about lifestyle changes, they didn't seem to think that would do it (Victor, 44, OI).

I haven't seen a neurologist since 1999 and he just basically put a piece of paper in front of me and said 'you have MS and here is a list of drugs you can go on' and that was that (Sierra, 49, PI).

Victor and Sierra presented their exchanges with their neurologists as involving no discussion of what else to do or advice on how to live with the disease. Neither Victor nor Sierra sees a neurologist any longer due in large part to their blunt and distant attitudes towards the disease and also because neither participant wished to take DMDs. Previous studies have reaffirmed that doctors often do not listen to the patient's own experiences with their illness (Allen et al., 2011; Bryan, et al., 2006), nor are doctors willing to provide care outside of the traditional confines of what they perceive as medical and objective scientific facts (Zavestoski, et al., 2004).

Second, and intricately associated with the use of prescription medications, several participants discussed how they felt they were a number for neurologically and pharmaceutically based research projects and discussed that the medical professionals who treat their MS may, in fact, be pushing their own medical agendas to create information that supports their point of view (Conrad & Barker, 2010). Todd (43, OI) said his,

[N]ew neuro[logist] wants me to absolutely partake in some clinical trials seeing that I am a rarer case study. Unfortunately, I do not subscribe to the notion that I should become a sacrificial lab rat, to please "Big Pharma", in their quest of trying to outdo one another in getting a better relapse response, and a bigger cut of the MS pie.

Todd commented that he feels as though he is a number to help aid in the development and distribution of new drugs, furthering the stranglehold of pharmaceuticals in the treatment of MS. Todd is not alone. Other participants addressed the connection between neurologists and 'Big Pharma,' the pharmaceutical giants like Merck Serono, Bayer and Novartis that produce a large share of MS drugs sold around the world. Participants like Todd remarked that their best interests are being placed on the backburner due to the financial interest of neurologists and pharmaceutical companies. With the phenomenon of CCSVI, patients have increased their speculation about neurologists' connections with Big Pharma, as they

know the industry stands to lose millions of dollars if the CCSVI procedure becomes common practice. By raising this speculation, the participants are also questioning the altruistic nature of medical professionals that Parsons (1951) felt was necessary to maintain a functional industry, reduce illness in society, and not exploit patients. Much speculation has been made about the prescribing habits of doctors and specialists in the literature (Moynihan, 2003; Palmlund, 2006; Vallance, 2005; Vaithianathan, 2004) and has caused many patients to be leery of accepting prescriptions from their specialists.

It should be noted that the MS patients I interviewed are not against medical research, in fact, many are partaking in IRB approved studies in countries all over the world, although these trials are for the CCSVI procedure. Victor (44, OI), Sierra (49, PI), Kiara (41, OI) and Gwen (48, OI), have stated that they are part of clinical trials because they wish to further the knowledge and techniques of the CCSVI procedure for MS patients. Due to the number of patents on treatment techniques and instruments that many treating IRs have received to study the link between CCSVI and MS, participants have commented that the speed of research has been astronomical. Angela (39, PI), when asked if there is a facility she would recommend to patients, remarked,

[Dr. McGuckin] does [the most veins] at this moment in time which, you know, if you would have asked me this question six months ago, I would have said Synergy because at that time they were the ones that were taking care of the most. Everything is evolving so quickly.

The techniques, veins involved, and skill needed to perform this procedure are changing quickly. New advances are being made in treatment options. This is pushing the science forward at an incredibly fast rate, within a few short months the best recommended treating facility, and doctor, can change. People with MS are turning to IRs to help further the vascular science behind MS (but also to experience some symptom relief), as IRs study the

connection between MS and CCSVI and as they attempt to have their treatment become indispensable for MS patients.

Patients seeking out alternative treatments for MS is not new, in fact, people with MS have been raising questions about the neurological strangle hold over MS care for some time. Studies have shown that there may be multiple ways to treat a disease depending on the medical specialists the patient decides to visit (Barbot & Dodier, 2002; Mol, 2002; Nicolson & McLaughlin, 1988). In fact, due to the multiple ways of treating an illness and the easy access to medical information online some researchers (Coburn, 2006) have speculated that medical dominance has decreased. Gillian (76, OI) described how, upon her original diagnosis in 1988, she searched for alternative MS treatments and found that a medical professional in Quebec had written a book about a diet that many MS patients were experiencing relief with, but when she contacted her local MS Society Chapter to acquire more information, she states that she was told:

[T]hat it was unavailable from them because it had not been approved by the neurologists.

Participants discussed how their neurologists frown upon alternative treatments, to the point where in 1988 the national society that supports MS patients did not have access to a book on an alternative treatment since it was not sanctioned by the neurological community. Many participants feel that this attitude has not changed with the emergence of CCSVI and have caused many to question the MS Society too. Carrie (44, OI) discussed how leery she was of the connection between the MS Society, neurologists and big pharma,

I've also changed my view point about big pharm., the MS Society (MSS), our doctors and the DMDs out there for MS. I was not fully aware of how the system worked and how the MSS is pharmaceutically funded and there are many conflicts of interest therefore finding a cure or promoting a treatment over a drug are not in their best interest. They are a business and not a charity looking to cure MS.

The information that patients have found and share online has made them question not only the neurological community, but the MS Society as well, as they feel that all parties would stand to lose a lot financially if CCSVI is taken up. Parsons (1951) stipulated that it is important for the patient to trust the medical professionals and following the advice that they are prescribed; however, many participants in this study do not trust their neurologists or follow the treatment options dictated by their specialists. It would appear that the system of MS care between the patient and the specialist is not functioning properly as both parties may not be enacting their roles.

In fact, many participants commented on how quickly the link between MS and vascular issues have been dismissed. The attitudes that neurologists took towards CCSVI ranged from towing the company line to hostile and rude. Participants, such as Callie (38, PI), Angela (39, PI), Rawnie (47, OI) and Diane (60, OI), have stated that they have received no advice or information regarding CCSVI from their neurologists which caused them to turn to the internet for advice. Callie (38, PI) discussed her neurologist's original reaction towards CCSVI as being optimistic and supportive since she had entered the SPMS stage of the disease and there were no other options outside of chemotherapy. However, upon returning from having CCSVI she said that her neurologist stated:

‘[O]h you think it's a cure now, you [are] cured now!’ It was just nasty; I actually walked up and left his office. He was still yelling at me, I just left (Callie, 38, PI).

Callie expressed the hostility that some patients have experienced in encounters with their neurologists. The negative responses patients have received from neurologists have caused a rift between the two parties to the point where some patients are not informing their neurologist when they have the CCSVI procedure.

Medical knowledge is respected in our society and studies have shown that medical professionals can use this authority to diminish the experiences and narratives that patients create (Horton-Salway, 2004). Some participants discussed how their neurologists have presented the benefits they have received from CCSVI as having no relation to the disease, which can be viewed as medical professionals using their knowledge to trump the lived experiences of people with MS. Ayala (39, OI), suffered extensively from migraines, fatigue, choking when eating or drinking, vision problems, balance and “cog fog”, a term people with MS use to describe the difficulty they may experience when retrieving memories or concentrating. Ayala’s neurologist presented her migraines, fatigue, and choking as originating in the vascular system and have no relation to her MS. By having the CCSVI procedure, she said that he stated that she was treating symptoms that affected her day-to-day life, but not her MS. Neurologists’ attitudes towards CCSVI have puzzled many patients, as they do not understand why the neurological community is so against a treatment that provides patients with symptom relief.

Brian (52, PI) even stated that when researching CCSVI, he only relies on information from interventional radiology, vascular and endovascular journals and does not read articles regarding CCSVI written by neurologists. He said,

I’m very sceptical of what any neurologist says about CCSVI, they basically have a mind set of umm, well I don’t know, they’ve got a closed mind set, they think that this cannot possibly be true and they are just against it without really analyzing could it do anything positive for their patients and um that’s, that’s a shame really. And, then their publications that they are coming out with, the neurologists are coming out with, are very umm reflective of a closed mind approach. They are basically saying that at the moment we can’t find this problem..... I really don’t have much respect for them because I don’t believe they are being very scientific in their approach.

From his academic background in pharmaceuticals and prior knowledge, stored in his inner library, of the actions and comments of neurologists, Brian stated that he does not trust

what neurologists have to say about CCSVI and discounts any article published within the neurological community. Brian questions the ability of neurologists to discuss a condition that has a vascular origin.

Comments like these have led to much speculation on the part of participants as to why neurologists may have the attitudes they do towards CCSVI by stating:

[I]t doesn't make sense from a neurology perspective (Haley, 36, OI).

[M]y doctors want to help me as *their* professions have taught them (Matthew, 40, OI, emphasis added).

These two statements address the opening of the black box of MS care, in that CCSVI has presented a challenge to the traditional form of knowledge established by the neurological community. Speciality areas of medicine, such as neurology, traditionally study a phenomenon exclusively from that perspective (see Nicolson & McLaughlin, 1988 for a discussion). When an alternative arises, it presents a challenge to the traditional way of treating the disease and can threaten the exclusivity that specialists have become accustomed to, in which the medical community is divided into separate and segregated fields (Turner, 1987). Neurology addresses, as many participants stated, the electrical system of the body which sends messages through a network to other parts of the body, whereas the vascular system is the plumbing that helps maintain the flow of oxygen throughout the body. The theories of one speciality cannot explain the other, as they are from two different domains of medical science and under the domain of different specialists.

Neurology has traditionally had a stronger network of MS care and maintained a black box over MS treatments for over 50 years. Their specialists have spent many years studying MS to devise treatment options and hopefully find a cure for the disease.

Participants addressed that neurologists' reactions may be rooted in the fact that they may be losing control of their domain:

[N]eurologists, I don't know, I think they see it as, as it's not going to be their thing anymore. I mean, one day we are going to end up going to our GPs and interventional radiologists and vascular surgeons and what not, and ah because they, I don't know, I think there going to be screaming about it long after it's umm, care, standard care for MS patients (Melissa, 49, PI).

Patients are speculating about the neurologists' fears of losing control over MS care as one of the reasons why people with MS are experiencing hostility towards CCSVI from their treating specialists. Melissa felt she found enough evidence online to that supported the vascular theory of MS rather than the autoimmune theory espoused by neurologists and, in turn, she 'quit' her neurologist. Just like Callie's experience discussed earlier, Melissa's neurologist originally appeared to support her in her decision to get the 'liberation' therapy, when he began to fill out her forms for out of country treatment coverage. But she said that he later informed her he would not complete them after he discussed the paperwork with his colleagues and found out few, if any, members of the neurological community were supporting CCSVI. In response, Melissa found a GP that was not only willing to provide her with the information she needed for her forms but also supported CCSVI.

The way doctors and patients interact is changing as patients will not settle for one treating specialist. Kiara (41, OI), remarked that after experiencing a negative exchange with her neurologist, who she said only wanted her to take DMDs, she went "'shopping' for a new neurologist" and was happy to find one that was willing to learn about CCSVI in hopes of helping other patients. Acquiring a second opinion from another medical professional is becoming more and more prevalent. Melissa and Kiara were not the only participants to "quit" or "fire" their neurologist, in fact, at least eight participants explicitly mentioned that they have quit seeing their neurologist. Previous research (Robertson,

Dixon & Le Grand, 2008; Safran et al., 2001; Calnan & Rowe, 2008) has found that patients are now search for physicians and specialists they feel they can trust and have their own best interest at heart.

That being said, patients are not the only ones to ‘quit’ or ‘fire’ their neurologists, apparently neurologists have, indeed, quit their patients too. Erin (49, PI) stated:

People have been banned. Patients have been banned, at the MS centre in Calgary. They’re not allowed, like Ginger MacQueen is not allowed to come back. She’s no longer; she’s been kicked out as a patient.

Ginger MacQueen is a noted CCSVI advocate. Moreover, Trina (49, PI) discussed her first appointment with her neurologist after she had the CCSVI procedure. She hoped to inform him of the symptom relief she had experienced post procedure but her neurologist did not even show up to the appointment, but instead sent his assistant. After discussing the relief she experienced with his assistant, she stated that she did not receive a reminder from her local MS Clinic for her annual appointment the next year.

It is no wonder that people with MS are turning to the internet for treatment options even though the alternatives may be frowned upon by treating specialists. The limited support and advice patients have received from the neurological community and its unabashed negative attitude towards CCSVI leaves patients in a desperate situation in which they are trying to stave off disablement without the aid of their treating specialists. Patients, in turn, have gone online for information and support, as well as turning to GPs for their medical advice.

Generalists

Participants in this study stated in their interviews that GPs, or family doctors, on the whole seemed open and understanding towards the daily plight of MS patients, and

displayed a desire to learn about CCSVI. Participants discussed a fondness for their GP in that they felt they had a more open relationship, since they saw them on a far more regular basis. Most participants stated that their GP had their best interests at heart and were willing to work with them to learn and provide the best care possible, although some participants, like Elle (52, OI) were critical of their GP. She stated that she would not trust her doctor to prescribe drugs or physiotherapy for her MS but appreciated the fact that he would provide aftercare if she made the decision to have the CCSVI procedure. Elle was not the only participant to state that their GP would not prescribe drugs for MS or outright recommend the CCSVI procedure; many GPs apparently recommended MS patients consult their neurologist when it comes to medication and treatments. Nevertheless, when it came to CCSVI, for the most part GPs were reportedly willing to learn, refer, provide advice and follow-up care when needed and track changes in their patients.

Numerous participants stated that they helped to educate their physician not only about CCSVI, but about their MS. Brian (52, PI) pointedly said that his GP openly admits that he does not know as much about MS as he does and is “in listening mode when [he] talks about MS and CCSVI.” Brian’s said that his GP has actually had him come and help tutor medical students at Oxford University about MS due to the amount of research Brian has done on both MS and CCSVI. Brian has been forced into early retirement because of his MS and thus has ample amounts of free time, while his academic background in pharmaceuticals provides him with the tools to read and interpret the information he finds in medical articles on MS and CCSVI.

The fondness that many participants have towards their GPs results not only from their physician’s willingness to learn, but also for their trust in what the patient says about their own health and body. Emily (OI), a 51-year-old woman from Edmonton diagnosed

with PPMS 18 years ago, addressed the fact that on a broader level regarding her general health and wellbeing her GP trusts the information that she provides him and furthers his own knowledge by researching it himself on the side. Although people with MS may be finding information from other sources such as the internet, there still appears, in general, to be a respect for the position and advice that medical professionals can offer their patients which has been discussed at length in previous literature (Hardey, 1999; Hardey, 2001; Josefsson, 2005; Kivits, 2004; Nettleton, Burrows & O'Mally, 2005; Schaffer, Kuczynski & Skinner, 2007).

When specifically examining how the information found online regarding CCSVI may be shaping or changing the dynamics of the doctor-patient relationship, most of the participants in this study were more than willing to bring information to their GPs for their perusal, or to receive a proper explanation of the information. Trina (49, PI), a woman from Dawson Creek that was diagnosed with RRMS eleven years ago, discussed at length her interactions with her GP. She would bring information into her doctor and in a friendly, joking manner say, ““you can figure this out better than me cuz the medical school I went to didn’t touch on this quite so much.”” Trina is demonstrating the development of a relationship with her doctor, stepping outside of the traditional view of the doctor-patient relationship which Parsons (1951) described as one in which the physician was supposed to maintain an emotional distance from his patient as an individual, but is also reaffirming the medical authority of her GP by jokingly deferring to his training. Trina stated that her GP attended her fundraiser for her CCSVI procedure and made a donation in which he asked her to “make me a believer” in the CCSVI procedure. Trina and her GP discuss research and share information on CCSVI during their appointments.

I have given him stuff and he has given me stuff, and sometimes either what I have brought him to see or what he has brought me to see, he has for me, and I have for him, it's kind of like doubled cuz we both, you know, saw the same thing (Trina, 49, PI).

The cases presented by Trina and Brian elegantly demonstrate that the doctor and the patient are able to develop a relationship in which the GP supports, provides aid and truly hopes for the best for their patients. In fact, the relationship that Trina and Brian were able to develop could actually increase their trust and defer to their GPs more due to their strong relationship. The majority of participants in this study discussed that their GPs were willing to advise and provide support for their decisions to have the CCSVI procedure and they hope that patients had to obtain some symptom relief. This is supported by previous research in which patients' support the decisions their doctors made based on the trusting relationship that has developed (Robertson, Dixon & Le Grand, 2008; Safran et al., 2001; Calnan & Rowe, 2008).

However, some participants like Sierra (39, PI) and Angela (49, PI) did not report a trusting relationship with their GPs, although both women have seen their GPs for numerous years. GPs, as a general rule have gruelling work schedules that make it difficult to consult with patients outside of their allotted time. More often than not, it is difficult for relationships like those that both Trina and Brian had with their GPs to develop. Sierra (39, PI) remarked,

[O]ur physicians don't have the time of the day. They're busy, we're rushed in and out. I mean, if, he'll listen, he, he, he'll listen to me, but I don't whine.

Due to the volume of patients most GPs see, patients, like Sierra, are rushed in and out. Although Sierra has a long standing relationship with her GP dating back to 1996, she still feels as though her appointments are rushed, and in fact, goes to her appointments with a check list of items she wants to discuss with him. That being said, Sierra stated that

although her GP was originally concerned about her having the CCSVI procedure since there has been little research conducted on its relationship to MS, when she informed him that she was part of a clinical trial being conducted at the Hubbard Foundation in the United States, she says he became more comfortable with her exploring CCSVI.

Angela (49, PI) also addressed the rushed nature of her GP's office and how her doctor, due in large part to his old age, has difficulty remembering that he is, in fact, her fulltime GP.

I mean half the time I don't think [her GP] knows, you know, who, well he's asked me specifically like 'who's your family physician?' And I look at him like really, like hello, I'm looking at him (Angela, 49, PI).

Medical professionals, in general, are busy and normally do not have the time to see their patients for extended periods of time which can be a cause for concern for some participants like Angela. However, later on in the interview, Angela did discuss bringing information about the CCSVI procedure to her GP in which he informed her that it made perfect sense to him. Her GP may not always be aware of their long-standing relationship, but he was, nonetheless, supportive of her decision to explore the CCSVI procedure.

GPs have not specialized in one area of medicine that examines one specific bodily system the way that neurologists have. GPs also see their patients on a far more regular basis for a variety of ailments unlike, specialists who study and treat patients based on the knowledge of their segregated field of medicine. For this reason, GPs have far less to lose if another domain of science takes control over MS treatments; they will still see these patients for regular illnesses whereas specialists would lose the patients they treat and a domain of their expert medical knowledge.

Trust in the Doctor-Patient Relationship

Many participants questioned how their GPs and neurologists reacted to CCSVI, thus they brought medical reports to their appointments to inform their GPs about the CCSVI procedure; however, this was not the case for all participants, some still believed in the traditional doctor-patient roles in which the knowledge and authority of the doctors training should be trusted (Mendick, et al., 2010; Pinquart et al., 2004; Step, et al., 2009). Moreover, researchers have found that the medical industry, as a general rule, is viewed with respect by patients, still who rarely question the decisions or advice offered (Turner, 1987; Wynne, 1988). Two participants spoke at length about their discussions with both their GP and neurologist regarding MS and CCSVI; Janetta (51, PI) from Valiview, diagnosed with RRMS 4 years ago, has decided not to have the CCSVI procedure and Allison (54, PI) from Moren, diagnosed with RRMS over 17 years ago, who has also decided not to have the CCSVI procedure. Janetta stated that she sees her neurologist every six months: “I have faith in [her neurologist], I sure the heck hope he knows what he’s talking about.” She is referring to her trust in his expertise and training in a specific field. She stated that her neurologist is far more knowledgeable on the subject of MS than she is, and therefore trusts the advice she is given. She believes this trust was warranted since she had a conversation with her neurologist about CCSVI in which he openly mentioned both sides of the CCSVI debate. Janetta, at a later point in her interview addressed how overwhelming the information found online can be,

I think the reason why I have a hard time going online and reading about it is because there is so much to read all in one and that’s hard for me to keep focused and concentrating on that, so that’s why I don’t go online too much.

Instead, she had decided to rely on the information provided by her neurologist since it has its basis in knowledgeable facts, a finding that has been reaffirmed in the literature (Henwood, et al., 2003).

Additionally, Allison (54, PI) states that she brings any information that she thinks could be of interest to both her GP and her neurologist. In her interview, she frames her discussions with her treating specialist as though she is ultimately making the decision, but there is a continual underlying theme of trust in the medical profession and the advice they provide, as is shown in the excerpt below:

[D]epending on what it is they'll give me their thoughts on it, umm again there, I don't know maybe I'm just a stubborn old thing and they look at me that way, but they let me make my own choices, for the most part. I can't really say that they, they'll give me information, or look up more information if I ask about it. There's some things, like for example this is an MS drug that I found that was supposed to help with walking, and my neurologist looked it up and then she said 'well there is a chance of seizures with taking this,' ... things like that, like they'll look it up and say well this might be, you know, right now, lets just wait for a little bit longer. If it's something that they think might hurt me they don't want me to do it which makes sense.

Although Allison brought information to her neurologist, upon further discussion she followed her neurologist's suggestion to wait and see, demonstrating her trust in the advice and expertise of her treating neurologist, since as she states later in the interview, she feels her team of medical professionals have her best interests at heart. Patients may become reflexive consumers of medical information to be more informed about their healthcare but as Allison demonstrated, and previous research has shown, patients still depend on medical professionals for advice (Lupton, 1997; McKneally et al., 2004; Sinding et al., 2010).

Even participants that are in favour of the CCSVI procedure may find it difficult to discuss information found online with their neurologist and respect a more traditional kind of interaction. Mellie (57, PI), a woman from Ottawa who was diagnosed with RRMS 14

years ago, is leery of bringing information to her GP and neurologist. Upon further probing she revealed two reasons why. First, she feels confident in her abilities to synthesize the information she has found due to her background as a nurse. Second and more importantly, she discussed that:

[I]n the back of [her] head, [she] has this view that because you've grown up with it, especially if you're my age, that [doctors are] in such a high position that it's kind of, umm what's the word, it might seem degrading to bring stuff that, you know, you want them to read.

Mellie acknowledges the social position of medical professionals as one that deserves respect and, in turn, has made the decision to respect their position by editing the information she finds to the most important points instead of “degrading” their knowledge by providing them with information that she feels they should focus on. Thus, the knowledge and expertise that a specialist or physician possesses is still looked upon with respect by some participants.

Conclusion

On the whole, MS patients are disgruntled with their treating specialists since they discussed the limited amount of they had to talk with their neurologist and learn about their disease, in addition to feeling as though they are a number required only for medical testing. Patients have questioned the motives of neurologists since they appear reluctant to discuss the CCSVI procedure, a procedure which has provided much relief to many of the participants in this study. They are questioning the neurologists' desire to treat and care for people with MS since they do not listen or provide advice and support on how MS patients should handle their illness on a day-to-day basis.

Although patients are questioning the medical industry at the specialist level and accessing information online, many patients still trust members of the medical profession. Participants reported that GPs are more open and willing to learn about a medical treatment outside of their normal purview. MS patients, for the most part, still rely on medical professionals for advice, but they rely on ones they feel have their best interests at heart, and not ones that they feel have a vested interest in maintaining control over MS care.

Still, as several previous studies (Marrie, Hadjimichael & Vollmer, 2003; Schwarz et al, 2008) have shown, people with MS want to learn about alternative treatments. The internet has opened patients up to a world of information on their illness and treatment options which many feel they would not otherwise have had access to. By being able to access and learn about these treatment options, many participants felt comfortable travelling abroad to locations all over the world to receive the CCSVI procedure, against the wishes of their treating specialists. Thus, people with MS still rely on the doctor-patient relationship for knowledge and advice on their disease, but patients are being more reflexive and relying on doctors that they feel they can trust, not ones that they discussed are solely focused on maintaining control over the treatment of MS. In turn, GPs have become a source many MS patients are turning to if they need clarification on information they have found online. Nonetheless while GPs may be providing clarification of medical terminology and are willing to discuss the procedure with their patients they are, like many within the medical community not providing direct advice on whether someone with MS should have the CCSVI procedure. Instead GPs tend to state that the decision is entirely up to the patient, causing many of the participants in this study to turn to online resources to learn as much as possible before they make their decision about having the CCSVI procedure.

Chapter #7: The ‘Controversial’ Decision

The Internet and the Decision to have CCSVI

I really have been guided. I mean, it's hard to say I've been guided by the internet because that makes me sound like I've been listening to all sorts of hooky stuff, right? Which I haven't, but I have been guided by information I've found on the internet (Mellie, 57, PI).

The internet can be a place in which quack theories emerge and dupe patients into believing them. Previous research has questioned the use of the internet as a research tool for health information for numerous reasons including the misinformation that can be posted online (Hardey, 1999; Lewis, 2006), the sheer volume of information (Henwood et al., 2003; Kivits, 2004; Lewis, 2006), and the ability for anyone to post information (Lewis, 2006). There are still questions surrounding the accuracy and reliability of information found online. However, most medical professionals are not or cannot advise MS patients about the CCSVI procedure. Consequently, MS patients have turned to online resources to learn about CCSVI.

The chapter examines if and how these online internet sources impacted participants' decisions about whether to undergo the procedure. There is no simple answer for how people with MS came to the decision to have the CCSVI procedure. Some participants seemed to use online resources to guide their decision, but many others seemed to use internet sources to reinforce or justify a predisposition about the treatment. Most of the participants in this study have had the CCSVI procedure, and many of their responses suggest the decision was rooted in the desire to enact control over their disease and attempt to stop or slow the progression of their MS. They thought the CCSVI procedure might be able to mend the break that has occurred in their ontological security and reconnect with their sense of self.

It is noteworthy that many participants in the study felt they had to legitimate their reliance on the internet for information about CCSVI because of the negative connotations surrounding online health information and because they wanted to present their decision about CCSVI as rational and informed. They used different tactics to justify using the internet as a research tool. Some said they accessed information only from 'legitimate sources' such as medical articles. Participants including Mellie (57, PI), Brian (52, PI), Erin (49, PI) and Tamara (53, OI), specifically brought up their medical backgrounds (as a registered nurse, having a pharmacy degree, or scientific background from university) as tools they used to read, synthesize and comprehend the information they found in the medical articles online. By citing their training to comprehend the scientific information in medical articles, these participants are demonstrating that they are not outsiders but are, in fact, experts able to sift through the information they found and come to their own conclusions about the CCSVI procedure.

Participants without medical or scientific backgrounds also worked to present themselves as reflexive consumers of online medical information. Participants such as Angela (39, PI) and Elle (52, OI) referred to the need to examine multiple sources on all sides of the CCSVI debate in their search for information. Angela admitted that she turned to articles that were easier to read, or what she referred to as "medical 101," in which the article was not jargon laden and could be easily understood by a layperson, but she found it important to reflexively search for multiple stories, articles and pieces on the procedure to ensure that it was a viable option for her. She made sure to be aware of the source that was publishing the articles, in addition to stating,

[I]f I hear the same story usually about 3 or 4 times say the same thing but in different words, but basically the same thing, umm then, then I tend to give it

more credence. But, I have to hear it more than once, otherwise ah it's just you know, I mean it may very well be a passing fancy (Angela, 39, PI).

Angela discussed at length the fact that the internet can be populated with individuals that do not have the patient's best interests at heart and it is the patient's responsibility to diligently review as many sources and as much information as possible to ensure that they are not duped by what she refers to as "unsavoury characters" online.

Angela (39, PI) also speculated that some people who use the internet do not do their homework and follow any fad that appears to help their condition. Elle (52, OI) who also verifies her information from multiple sources openly made such a statement on two separate occasions during her interview.

[Y]ou need to verify, get a second or third opinion, check sources – take some responsibility and buyer beware. People who blindly go forward have no one to blame but themselves.

Much like newspapers I realize you can't believe everything you read. I try to verify info[rmation] from at least 3 independent sources, and I'd say that 99% of those out there don't (Elle, 52, OI).

The internet can be considered by many to be an unreliable source that can lead a patient astray. However, by stating that some people blindly use the internet, Elle presents herself and her decision as being based on verified evidence in contrast to others who may make rash decisions based on only one source. By making a distinction between their actions and the assumed actions of other people with MS online, Elle and Angela are justifying their decision to have the CCSVI procedure. By stating that they use multiple sources as a means to research medical information and sources online, they address the fact that there are untrustworthy individuals online, but by finding different sources that verify the same information they feel they are not falling victim to scams devised by untrustworthy people.

Nevertheless, it also became clear that people were not always using the internet to gather information to make a decision, but to confirm or justify an existing perspective or desire. While Brian presented himself as someone with the training to objectively assess medical articles and what he felt were reliable sources, it could be argued he was using the internet primarily to search out information that painted the procedure in a positive light, by relying solely on medical articles published by endovascular and vascular specialists and chose to not read anything published by neurologists. Mellie (57, PI), who also had the CCSVI procedure, had a similar attitude. These two participants searched out information that confirmed what they had already thought, namely that the procedure was safe. However, when participants that were leery of the procedure accessed medical articles, they did not solely examine articles published by vascular and endovascular specialists. Participants who were leery of the procedure, like Tamara (53, OI) and Erin (49, PI) both read any scientific papers they could find on CCSVI, regardless of who published them. Tamara (53, OI) addressed her concerns with the information published on the CCSVI procedure,

I've been researching [CCSVI] since it came to light [but], have yet to find it peer-reviewed on pubmed as reproducible.

Tamara did not set out to confirm the success of the CCSVI procedure; rather she has been sceptical of the procedure and chose to examine information that was published through all sorts of peer-reviewed journals. Examining all forms of information released on CCSVI confirmed her previous belief that there was little to no evidence supporting Zamboni's claims.

The information that participants chose to look at reveals a lot about their stance on CCSVI. Those that examined information that confirmed the procedure published by

endovascular and vascular specialists appeared more inclined to have the procedure, whereas those that examined information produced in the neurological community were far more likely to be sceptical of the CCSVI procedure. Those medical professionals who worry that patients are being driven to CCSVI because of media hype and misleading information on the internet do not understand that for people with MS, much more of the decision about CCSVI stems from the uncertainty the disease causes and the desire to regain their ontological security. When participants who did not have the CCSVI procedure discussed their decision, they emphasized the uncertainty of the procedure itself, because, it seemed, their sense of self was not (yet) as threatened by their disease.

The Decision

The decision to have the CCSVI procedure was not taken lightly by any participant in this study; however, there were a variety of explanations for why thirty-seven of the forty-nine participants travelled abroad to have the CCSVI procedure. Two participants mentioned that their decision was simply based on a ‘gut feeling.’ Angela (39, PI) and Gwen (48, OI) both state that in their gut, it made sense, and in turn, travelled to Germany for the CCSVI procedure. Gwen admitted that there was little information available when she decided to have the CCSVI procedure and went off of her intuition that there was something wrong with her venous system. Although Angela (39, PI) discussed completing extensive searches for information on the CCSVI procedure, she, as well, openly admitted it was based on her intuition. When asked what arguments and opinions she found most compelling about CCSVI and the CCSVI procedure, Angela responded,

Nothing, I just, well I saw the *W5* show, and in my gut it made sense and I’m one of those people that believes their intuition and their gut and so that was,

it was just done. Based upon the fact that I watched it and the fact that I started researching it, it made more and more sense and so then I booked.

Through her searches of multiple sources, she found information that stated that the majority of people with MS have CCSVI which provided her with the confidence that she had blocked veins. Consequently, she did not get the Doppler Ultrasound before travelling to Germany and only found out that she did, indeed, have blocked veins once at the treatment facility.

Other participants such as Brian (52, PI) and Ayala (39, OI), as previously discussed, did copious amounts of research through various sources, most notably medical articles, and decided that it was a safe procedure to have once an appropriate IR was found. Still others mentioned the need to repair a malformation – blocked veins – in the body as part of the reason why participants had the procedure, apart from having MS. However, the main theme that emerged from participants' discussions of their decision to have the CCSVI procedure was the uncertainty connected to their disease and hope that a successful CCSVI procedure might provide symptom relief. Thus, patients who had the CCSVI procedure felt that they might be able to exercise control over their disease and the internet helped provide information they needed to try.

It has been shown in many narrative analysis studies (Bury, 1982; Bury, 2001; Frank, 1995; Williams, 1984; Williams, 2000) that a chronic illness can lead to a disruption or break in the life plans an individual has made. This uncertainty can threaten what Giddens' (1991) refers to as ontological security so that the continuity of events in an individual's life may be, or is, disrupted. When an individual cannot perform day-to-day functions the way they are expected in society due to a disability or cognitive impairment there is a break between the body and the self that can threaten their ontological security.

When the body does not cooperate the way the individual expects it to, they can experience dissociation from their sense of self. For many participants in this study, the CCSVI procedure presented the opportunity to regain their ontological security.

The uncertainty of a chronic condition can impact an MS patient's life whether they are in the early stages of RRMS or have entered the progressive stage. Participants like Julie (46, OI), who has had RRMS for three years used a walker to get around before having the CCSVI procedure, and Kiara (41, OI), who has had RRMS for five years, experienced pain and episodes of fatigue and the disease affected her balance. Both women discussed that they had exhausted all of their treatment options to slow the progression of their disease, and hoped that CCSVI could provide them with a return of mobility and normal day-to-day functioning. Paul (44, OI) and Callie (38, PI) shared similar hope that the CCSVI procedure might provide some relief from their oppressive symptoms. They had both entered the progressive stage of the disease and had no more treatment options other than chemotherapy to try and slow the progression of their disease.

For many participants their disease was progressing steadily and they were facing the prospect of compromised cognitive function and in some instances living the remainder of their lives in a wheelchair. In fact, Paul (44, OI) said that his neurologist told him in February 2009 that he would "be in a wheelchair in about 5 years, when I was 42." After having the CCSVI procedure, Paul stated that does not need to use the wheelchair he had been using a third of the time before the procedure and instead only needs a cane for walking. Stories like Paul's, which patients were able to access online reflect how an individual can exercise control over their disabling disease.

Previous studies (Sinding & Wiernikoski, 2009; van Kleffens, van Baarsen & van Leeuwen, 2004) have shown that when individuals hear experiences of other patients' on a

similar treatment regime for illnesses, it can provide insight into their own treatment decisions. The participants in this study are no different; personal stories found on discussion boards, Facebook pages, and YouTube videos allowed MS patients to see the improvements in others' quality of life and aided in their decision to have the CCSVI procedure. MS is unique in every person and as previously mentioned it is far easier to find someone with similar symptoms online. Callie (38, PI) relied equally on medical articles and personal stories, but when she found a before and after video online by a fellow patient who had similar symptoms and disease progression and experienced relief after having the CCSVI procedure, she stated that it played a pivotal role in her decision.

There was one video that really stood out in my mind, it was a lady that had, that has secondary progressive MS and exact same limb, exact same numbness, like she almost had the exact same symptoms as I did, it was scary...., when I saw her before and I saw her post her after, I was crying.... I call my husband and was like 'you gotta see this' and we must have watched her video about 20 times and my husband was crying too. He says 'we gotta do this,' he says 'we, we have to try because if we don't try and it and what's the worst [that's] going to happen, it doesn't work,' he said 'but look if it does work, look at how much this can help you,' and that's, yeah that was it, that's what sealed the deal for me when I saw somebody that in the exact same situation as I was in (Callie, 38, PI).

Personal stories and videos of MS patients' successful CCSVI procedures provided hope, not only for Callie, but also for many participants in this study. These videos offered MS patients the opportunity to watch individuals in similar situations either slow the progression of their disease or have mobility improvements.

It was not only videos that influenced MS patients' decisions to have the CCSVI procedure, but also the documented improvements in Dr. Zamboni's wife after her venous angioplasty. For Sierra (49, PI) patient stories were helpful in making her decision to have the CCSVI procedure, but when she read about the improvement in Zamboni's wife, who had similar symptoms, it helped convince her to have the CCSVI procedure.

And back to Zamboni and how it helped his wife. Right, as soon as I read that cuz his wife has the same type of MS symptoms that I had.

Both Callie and Sierra accessed personal stories online of patients who have similar symptoms to their own, which informed their decision to travel abroad for the CCSVI procedure. The online stories patient accessed provided hope that others may experience the same relief as they attempt to regain control over the uncertainty that has plagued their lives and reconnect with aspects of their body.

Studies (Conrad, 1985; Radley & Payne, 2009) have found that the desire to take control over an all-encompassing disease and improve quality of life is an important factor for patients when making decisions about medical treatments (Sinding & Wiernikowski, 2009). When presented with the possibility to stave off disablement, reconnect the body with the self and return some sense of normalcy to their lives, some participants were willing to try almost anything that might help. When asked what arguments and opinions about CCSVI he found most compelling, Brian (52, PI) did not mention any information from the various medical articles he had read, only the desire to slow the progression of his disease. He had been forced to retire early from his job and uses trekking poles to maintain his balance when walking, which causes him great frustration in his day-to-day life. Potentially being able to either have returned mobility, or improved cognitive function, was a driving force for him to have the CCSVI procedure. Although he did not regain much of his mobility, he did say that he was able to regain some cognitive function which he saw as an enormous improvement.

I mean this conversation wouldn't have kept going; I would have had to stop it. I wouldn't have been able to concentrate and be relatively lucid (Brian, 52, PI).

The CCSVI procedure gave Brian part of his life back allowing him to reconnect with a part of himself, particularly as he can now concentrate and focus for extended periods of time. For him, the ability to regain some control over his concentration made it worth having the CCSVI procedure.

Brian was not the only participant to address the desire to stop progression as the most compelling reason to have the procedure. Trina (49, PI) has had the CCSVI procedure twice and talked about the uncertainty of when the disease will progress, the uncertainty of an MS patient's future, and the hope invested in the CCSVI procedure when she said,

[B]ottom line is you hoped it would stop the progression. I think whatever point you're at, if, if you're walking; you're hoping to never need a cane. If you have a cane, you're hoping to never need a walker. If you have a walker, you're hoping to never need a wheelchair. If you're in a wheelchair, you're hoping to never be bed ridden and probably when you're bed ridden some of them are hoping not to be dead (Trina, 49, PI).

No participant in this study who has had the CCSVI procedure reported that they were cured of their MS. Instead, having the CCSVI procedure was about being able to take some control over their disease and return a sense of quality and normalcy to their lives. MS, with its all-encompassing symptoms, can take so much from a person's life that when an option is presented, as long as it appears reasonable, most participants in this study were willing to try.

The toll that MS can take on a person's body, life and psychological make-up can interfere with their daily habits and predispositions, which can impact how they view their body and their sense of self (Giddens, 1991). The tension between the disease's influence and the person's sense of self was elegantly demonstrated by Callie (38, PI), a woman who has lived with MS for twenty years. She was fitted for a wheelchair before she left for her

first treatment in July of 2010, and was on chemotherapy to slow the progression of her disease, which had entered the progressive stage. Callie said of her decision to have the CCSVI procedure,

Because I was going down hill fast. I was in bed 16 hours a day with my MS and I couldn't play with my two young kids anymore. And, I knew I was dying (Callie, 38, PI).

Although Callie addressed how the personal stories she found online impacted her desire to have the CCSVI procedure, the ultimate reason why she had the procedure was to try and return some normalcy to her life and that of her family. The habits and predispositions of being a mother were threatened by her disease as Callie was unable to play with her children, and partake in family activities; instead she slept for the majority of the day. To put it succinctly, she wanted to participate in her life the way a 38-year-old young mother should, instead of passively watching her children grow up. MS, like many chronic conditions, can slowly strip away the normal daily functions of an individual's life and impact the quality of their life and their family's. The impact that a chronic condition like MS can have on social relationships is huge as has been shown in previous research (Bury, 1982; Williams, 1984). CCSVI and the information that patients have found online enabled them to take action over their lives and their disease, instead of being passive recipients of medical information and knowledge.

A diagnosis of MS can alter an individual's life plans and be viewed as a fateful moment since they are unable to maintain their self-identity through their body. Giddens' (1991) discusses the break that can occur between the body and the self which makes the invisible task of maintaining their self-identity visible through the disabling symptoms of their disease. The examples provided by Callie, Trina and Brian demonstrate how MS patients may be using the CCSVI procedure to mend a break in their ontological security

that had been taken away by their MS. The CCSVI procedure provided the opportunity to return normalcy to participants' lives and provided them with the chance to gain control over their mobility and bodily functions to help them regain a part of their self-identity they lost and to colonize the future the way they had planned.

In fact, the uncertainty caused by the disease and hope that accompanied the CCSVI procedure affected some participants' decisions on when and where to travel for the CCSVI procedure. Callie (38, PI) discussed being on the waiting list at multiple treatment facilities all over the world. She was first offered an appointment by a facility in New York; however, she turned that appointment down when a facility in Bulgaria contacted her with an opening over a month earlier.

[I]t's kind of funny cuz Albany, New York got back to me first, and gave me an appointment in August of 2010 and then two days after that the Bulgarian doctors emailed me and said we can get you in, ah in July so that was a six week difference. And, you know, my husband and I, you know I didn't make the decision right away which one I wanted to go to, I just, I knew in my heart when I had my name on three lists that whatever one I was meant to go to would get back to me. So, then when two of them got back to me, my husband and I really weighed and talked about it and I said 'I know it's, Albany is closer and I know it's going to be a little cheaper, but this is six weeks of my life.' This is six weeks of, you know, what if I go down hill in that six, what if I get worse and I get so bad I can't even travel? And, then my husband said, 'yeah I don't care we're going, we're going to wherever you get in first,' and that's where we decided to go (Callie, 38, PI).

Faced with the choice of travelling the far shorter distance from Saskatchewan to Albany, New York, or to Sophia, Bulgaria, Callie chose to receive the procedure as soon as possible to ensure that less damage was done by the disease. She did not know when, or if, she would have another flare-up of her MS in the six weeks between the two appointments so she stated that she decided to have the treatment sooner rather than later.

Many of the participants in this study who have had CCSVI reported symptom relief and those who did not still stated that it were worth a try. Since having the CCSVI

procedure, Callie (38, PI) says she is now able to feel her children kiss her cheek, a sensation she could not feel before because of the numbness associated with her MS. Brian (52, PI), as previously mentioned, is able to concentrate and carry on a conversation for more than half an hour. Trina (49, PI) stated that she can now use her right hand again, which she could not before her treatment since the muscles in her right hand and arm had atrophied causing her hand to stiffen into a claw shape. Participants such as Lori (56, OI), Sandra (59, OI), Emily (51, OI) and Anne (64, OI), who did not experience symptom relief, said they would still recommend that people with MS explore the CCSVI procedure, as each patient can experience different results. Even Emily (51, OI), who had a negative experience, would be willing to have the CCSVI procedure again. As Trina (49, PI) remarked in her interview,

[There are] the miracle stories that they were not even so much full time in a wheelchair, but they were in a wheelchair a majority of the time but now they are mowing their lawn, or something. Those things are huge. But, then you see smaller things that, that you know is huge. Someone will say, I mean the fact that my hand works and, and to me there has been maybe what people would see as smaller things than that but that someone gets, it's just like, it's just so encouraging. That it's, it's a little thing to someone but it is huge to you if, if you didn't have that.

Experiencing even small improvements in mobility or day-to-day functioning is an important draw for many of the participants, as Trina described. Even if the improvement is small, the individual can reconnect with an aspect of their body or self that they were not able to before. In fact, these benefits were more than enough for Trina to return to New York and receive the CCSVI procedure again after she relapsed. After a second venous angioplasty, Trina stated she experienced more than just mobility improvements, her said her fatigue levels were far less than before she had the procedure.

Its things like umm the fatigue is, is way better and so, whereas before, you know, our youngest would still be up and I would be thinking 'please go to

bed, I want to go to bed.' And, now you're sort of up as one of the last adults and it just feels so nice to have that little bit of normality again in your life.

The reduction in fatigue has allowed Trina to reconnect with her sense of self as an adult and a mother being able to stay up, spend more time with her family and experience life the way she feels normal adults do. Sierra (49, PI) even stated,

I started physiotherapy after my second [CCSVI procedure], you know, so I started feeling optimistic. And, I mean, I am in a chair and it's going to take a while to get back out of it, so cuz I have to build up muscle again.... would I ever have been able to [go to physiotherapy] before, probably not I wouldn't have had the energy.

Both women feel that without having the CCSVI procedure, they would not have been able to partake in these activities. The procedure provided them with the ability to work towards a future in which they may be able to completely reconnect with their body and their sense self.

Small improvements in quality of life created hope for people with MS as they battle their debilitating disease. The ability to even have some hope with this disease is a cause of excitement for many of the participants in my study. Callie (38, PI) and Carrie (44, OI) both commented on the hope CCSVI provided,

And, you know, to give them hope, you know, to give [people with MS] hope with this awful disease because that is something that we never had (Callie, 38, PI).

I have more hope and less cope. The MS community now lives with hope for the future rather than what we call 'diagnose and adios' (Carrie, 44, OI).

As previously discussed many MS sufferers feel disenfranchised by the medical community, which they feel only wants to prescribe drugs instead of providing patients with symptom relief. Many people with MS feel that there is now hope that they may not end up in a wheelchair, they may be able to continue working full or part-time for a longer

periods, and may be able to spend more time with their family and friends. CCSVI gave these MS patients hope that they can return a sense of normalcy to their lives, reconnect their body with their sense of self and help to establish a new destination on their life map which they had not been able to find within the traditional medical narrative of MS.

The Decision Against the CCSVI Procedure

However, not all participants had similar feelings about the procedure; many of the participants who have not had the CCSVI procedure suggest the benefits that others have experienced are small or non-existent. These participants raised questions, not about the uncertainty of their disease, but about the uncertainty of the procedure. They addressed the short length of time MS patients may be symptom free after having CCSVI, or the inability of CCSVI to help all MS sufferers. The improvements many are experiencing are subjective, which can make it very difficult for others to truly assess how the procedure may impact their life. Janetta (51, PI) commented,

[H]er [older sister's] friend's daughter has MS and she went and had the treatment done and she said she's doing just fabulous and she says you should think about maybe going. So, I'm like ah ha, I said keep in touch with her and then let me know how she's doing in a couple of months. You know, cuz I'm just not sure, eh, I'm just not convinced.

Janetta does not believe that CCSVI is the cure for MS, and is sceptical of the results and length of time that patients are symptom-free after having the CCSVI procedure. For Janetta, spending over \$10,000 on a treatment that does not cure a patient is not worth the mild or short term benefits other people with MS have been experiencing. She is not convinced that the treatment effects will last longer than a few months. Erin (49, PI) made a similar comment in her interview. When asked if she thinks she would ever explore CCSVI for herself, she responded,

[I]f it becomes a standard therapy down the line and it is proven that when they do 200 patients and they follow them, that the veins can stay open long enough and that there is enough benefit, less risk, more benefit... then I would proceed to have it. But that would take, I'm sure, at least three to five years of follow-up data to tell me that, that those veins are not hyperplasing more.

Erin is not writing off the treatment completely, but instead she, like Janetta (51, PI), states that she is very sceptical of the success rate of patients that have had the CCSVI procedure. The simple fact that patients are experiencing symptom relief from the procedure is not enough for them to be convinced to have the procedure. Instead, the stories of multiple treatments have raised questions about its effectiveness and caused these women to remark that they are either hoping for some other treatment options to be discovered, or are waiting for more research to be done that proves that it is safe and beneficial. Erin, as well as other participants who have not had the CCSVI procedure, addressed the need for more research into the vascular component of MS in general.

Janetta (51, PI) and Erin (49, PI), as well as Ashley (52, OI) who was diagnosed with RRMS four years ago, similarly said that the progression of their disease is not bad enough for them to explore CCSVI – even though both Janetta and Erin are no longer working and on disability due to their MS symptoms. These three women said that they did not think their mobility, cognitive impairment or vision were bad enough to warrant travelling out of the country for venous angioplasty. In fact, they all made similar statements,

So then I thought okay, I'm, I don't feel like I'm really, really bad, like I'm not in a wheelchair or anything, and if I were I would probably look into it more, but since I'm not, I'm not umm yeah, I'm not gonna go for that at this point (Janetta, 51, PI).

I'm not desperate; maybe I'm not desperate enough. Maybe I'm not lying in a bed blind and paralyzed (Erin, 49, PI).

I am not “disabled” enough to consider it. Cost is a huge factor (Ashley, 52, OI).

For most of the participants in this study, their fear of disablement and progression of their disease were factors that they addressed that influenced their decision whether to have the CCSVI procedure. Janetta (51, PI), Erin (49, PI), and Ashley (52, OI) stated that they were not wholly against CCSVI when it first came to light in the media. In fact, they all mentioned that if their health was in a worse state, they might have explored it for themselves. However, this was not the case; these women felt that their disease had not progressed to a point that required a medical intervention before it had been properly tested throughout the medical community. These women addressed that the treatment regimes they are on – supplements, DMDs, or diet – are providing a suitable amount of care and control of their disease and symptoms. They are all fully ambulatory and can function day-to-day without much difficulty, causing them to not feel the need for the treatment at this time. Unlike the heart attack participants in Clark’s (2001) study, or many participants discussed above, who felt that their sense of self as a person was threatened by their disease or symptoms, these women did not and thus choose not have the CCSVI procedure.

Of course, how a participant views the state and progression of their disease is subjective. Some participants like Ayala (39, OI) who was diagnosed with RRMS two years ago and Kiara (41, OI) who was diagnosed with RRMS five years ago, both experienced balance problems, pain or migraines and felt that the severity of their symptoms warranted having the CCSVI procedure. Whereas Ashley, (52, OI), who has been diagnosed with RRMS for a similar length of time and experienced similar symptoms, said that she did not feel the CCSVI procedure would necessarily help her. Even at the progressive stage the severity of the disease can be hard to measure. Erin (49, PI) and Tamara (53, OI) had entered the progressive stage but addressed the fact that their disease

did not cause a break in their sense of self the way other participants in the progressive stage, like Callie (38, PI) and Paul (44, OI), did. Callie and Paul were both provided chemotherapy to try and slow the progression of their disease and were confronted with the possibility of needing a wheelchair to get around. For Callie and Paul, their inability to perform normal day-to-day functions the way someone their ages should presented a break in their sense of self which they felt that the CCSVI procedure might be able to mend. Thus, there is no clear black and white reason as to why people with MS are exploring the CCSVI procedure; it appears for different individuals the stage, progression, symptom severity, or impact on their day-to-day life all played a part in the decision to have the CCSVI procedure.

Chronic diseases, like MS, can engulf a patient with uncertainty about their future, and their relationships with others, as well as threaten an individual's sense of self. The opportunity to become active agents in the battle against their disease caused many participants to turn to the internet through a variety of means such as medical articles and multiple sites, to become informed about the CCSVI procedure and what benefits they may experience. Much previous research as well as this study found that many people with MS made the difficult decision, after researching CCSVI as much as possible, that it was the right treatment for them. The CCSVI procedure provided them with the opportunity to, at the very least, enact some control over their disease. Those participants who stated that their sense of self had been compromised or threatened due to their MS found that the CCSVI procedure was a way to attempt to reacquire their ontological security and provided them with the hope that they will be able to live their lives how they choose in the future. Although the participants in this study considered medical articles, personal stories and a multitude of sources on MS and CCSVI, when it came to making their decision, many

addressed the desire to experience symptom relief and a return of normalcy to their lives as the main reason why they had the procedure. The level of disablement and cognitive impairment is not uniform, but subjective. The subjective experiences of participants that did not have the procedure surrounded the uncertainty of the procedure, whereas the subjective experiences of living day-to-day with MS, and the fear and uncertainty of the disease played a role in participants' decision to have a 'controversial' medical treatment.

Chapter #8: Discussion and Conclusion

This thesis aimed to address three research questions. Chapter five addressed how narratives and information found online impacted patients' perceptions and knowledge of MS and the CCSVI procedure. In addition, chapter five addressed how advocates of CCSVI are using, modifying, and manipulating the arguments about the CCSVI procedure that can be found online, causing a debate to emerge on who should be considered authority figures in MS treatment. This argument was further developed in chapter six to examine the extent to which people with MS use online information to challenge medical knowledge, especially that of the traditional authority figures in defining MS – neurologists. Finally, chapter seven addressed my final research question: does MS patients' use of the internet as a research tool for the 'controversial' CCSVI procedure impact their medical decisions? Through the information participants accessed, they became more informed, and separated their agency from the dominant structure of medicine, developed autonomy and enacted control over their disease. However, the need to control their disease was not uniform for all participants; instead some participants mentioned the uncertainty of the disease, the desire to slow the progression of their disease and hoped to mend breaks in their sense of self that resulted from the disease's progression as a reason to have the CCSVI procedure. Whereas, those that were sceptical addressed the uncertainty of the procedure as a reason not to have the CCSVI procedure. A more detailed summary of the findings will be provided in the pages that follow.

This chapter summarizes this project's findings about MS patients' use of the internet to access information on the CCSVI procedure. Additionally, it briefly discusses this project's contribution to sociological literature and suggests future study areas, particularly as they apply to health illness, and mediated communication. The thesis

provides insights into how the internet is influencing the production and dissemination of medical knowledge in the twenty-first century.

Summary of Project

When medical knowledge is not available from traditional sources, patients now, in reflexive modernity, can access information they need through the information and communication structure. MS patients have become reflexive consumers of the CCSVI procedure as they turn to the internet to learn more about their disease and thus create their own knowledge of the procedure by sharing their experiences with other patients online. Many participants found this an empowering exercise because they could acquire some control over their disease and attempt to return quality and normalcy to their lives. They researched, asked questions, and shifted the power of medical treatment decision-making from the ‘paternalistic doctor knows best approach’ to an informed and reflexive consumer one (Koenig, 2011). Many participants questioned the exclusivity of MS treatment in the hands of neurologists. The vascular theory of MS demonstrated that other medical factions can produce and provide, in some participants’ eyes, an effective treatment for their disease (Barbot & Dodier, 2002; Mol, 2002; Nicolson & McLaughlin, 1988; Wynne, 1988). In effect, there are multiple ways of knowing and treating diseases, which are easily accessible to patients through the internet (Coburn, 2006). Ultimately, from the data presented in the preceding three chapters, this thesis came to four distinct conclusions about internet use as a research tool for MS, and the new reflexive and informed patient that such tools enabled.

First, the internet can be a useful and valuable resource for patients to learn, accept and understand their illness in a personalized manner, devoid of medical jargon (Hyden, 1997). Online discussion boards, PubMed, Facebook pages, and other sites can put patients

in contact with patients going through the same day-to-day plight (Colineau & Paris, 2010; Mickelson, 1997; Orgad, 2006; Wright & Bell, 2003). Within these online groups patients are able to develop friendships that can help them comprehend, understand, and, in certain instances come to terms with an illness that friends and family may not be able to understand (Colineau & Paris, 2010; Mickelson, 1997). Further, discussion in online forums can foster positive coping strategies (Josefsson, 2005, Kim et al., 2011). The stories that some participants read online helped them begin to redraw their life's map, accept the diagnosis of MS, and openly talk about their disease. Some participants comprehended the incoherent speech, or chaos narrative (Frank, 1995) that may accompany a diagnosis of a chronic condition and began to develop new narratives that allowed them to accept their ill state. MS patients in online forums found a way to speak for themselves as well as for others through support and advice that was embedded in personal experiences.

In effect, the previously exclusive domain of medical knowledge has become accessible to laypeople through online resources (Hardey, 1999; Hardey, 2001; Lewis, 2006). Empowered participants could create their own knowledge from these groups. This knowledge was different than that presented in medical settings and included an acknowledgement of participants' shared suffering and symptoms (Barker, 2002; Barker, 2008; Bulow, 2004; Prodinger & Stamm, 2010). In certain instances, participants used their expertise and skills to develop their own knowledge of the disease and the CCSVI procedure as a tool to take control in their quest to become more informed (Barker, 2002; Barker, 2008; Prodinger & Stamm, 2010).

However, not all participants found the internet to be an empowering tool, instead, finding it a burden. Thus, the second research finding suggests that the internet can be an overwhelming source. There is an abundance of articles, websites and stories regarding

CCSVI, MS and a plethora of other MS treatment options online. There are numerous voices in online forums arguing both for and against the CCSVI procedure that may have a vested interest in either the success or failure of the procedure. In fact, the mountain of information that patients can access online can be overwhelming, making some participants feel unsure of which sources to trust and which to disbelieve (Hardey, 1999; Henwood et al., 2003; Lewis, 2006). A breadth of previous research (Henwood et al., 2003; Lewis, 2006; Pitts, 2004) has questioned the use of the internet as a research tool for health information for this very reason. The current study confirmed many of these same concerns. Victoria Pitts (2004) argues that when patients search for health information online that it can take a social problem of studying and researching the causes of a disease and make it a personal issue that can be researched. In fact, Lewis (2006) found that many patients who use online resources for health information may become misinformed because anyone can post on a website. Many participants in this study described the internet as being dominated solely by success stories about the effectiveness of the CCSVI procedure while negative experiences were largely unreported. Some participants fear that advocates may be pushing to close the black box of CCSVI by creating a uniform narrative of the CCSVI procedure online before accounting for all of the facts about the condition and procedure.

Patients lack explicit training in medical knowledge and terminology which can present difficulties in determining the pitfalls and drawbacks of medical treatments. Relying solely on their own judgement can become difficult and, in turn, they may put themselves at risk. Participants ran the risk of falling victim to medical tourism, in which treatment facilities may take advantage of their vulnerable state and market the cost of the procedure above the skill of the treating medical professional. Although some participants

addressed specific actions they took to compensate for their lack of training – relying on multiple sources, or their academic backgrounds – others were overwhelmed and uncertain about which information to trust. Not every participant in this study wanted to be as informed as others and thus relied on medical professionals.

In fact, much research (McKneally et al, 2004; Mendick et al, 2010; Piquart et al, 2004; Sinding et al, 2010; Step et al, 2009) has examined how patients still rely on medical professionals to provide advice and knowledge about treatment options; thus, not all participants, or patients for that matter, want, or desire to enact their own agency when it comes to matters of treatment options. They are not professional medical experts and some cannot comprehend the intricate medical knowledge that can be found in academic papers, and thus rely heavily on medical professionals for their expertise and training. However, this proved to be extremely difficult for some participants in this study, particularly as many neurologists would not even discuss the CCSVI procedure with their patients. This caused some participants to search for medical professionals who would help guide them in their decisions.

Third, the participants in this study were autonomous, to a certain extent, they accessed information online but still relied on medical professionals for advice. They sought guidance and clarification for the information they found online from their GPs, reaffirming much of the extant literature (Hardey, 1999; Hardey, 2001; Josefsson, 2005; Kivits, 2004; Lewis, 2006; Nettleton, Burrows & O'Mally, 2005; Schaffer, Kuczynski & Skinner, 2007) on patients' use of the internet. Patients still rely on some form of medical professional for information and advice, but in this case they only trusted medical professionals who they felt had their best interests at heart and cared about their health and wellbeing, rather than access to research dollars.

The participants in this study, for the most part, do not trust their specialists since they fear that their neurologists are trying to maintain control over MS treatment. The literature that examines the doctor-patient relationship focuses primarily on the patients relying on medical professionals for decisions regarding their health because of the presumably 'special' expert knowledge they possess (Kivits, 2009; Henwood et al., 2003; McKneally et al, 2004; Mendick et al, 2010; Pinguart et al, 2004; Sinding et al, 2010; Step et al, 2009). Or, it shows that doctors often do not listen to a patient's own experiences with their illness (Allen et al., 2011; Zavestoski, et al., 2004) and provide the treatment option they think is best, without any other option (Karnieli-Mille & Eisikovits, 2009; Bryan et al, 2006). This thesis addresses a gap in the literature on the doctor-patient relationship because the majority of participants in this study do not trust the advice or recommendations made by their neurologists, who are traditionally the source of knowledge on MS care and treatment. The lack of empathy and discussion of the CCSVI procedure caused much frustration and annoyance among participants. Consequently, they turned to their GPs for advice. Here, GPs often became knowledgeable consultants for patients on medical terminology, but offered no direct advice on having the procedure, or sometimes, on MS more generally. This, in turn, leaves the decision to have the CCSVI procedure almost up entirely to the patient.

Finally, a patient's decision to have the CCSVI procedure is complex. When a person is diagnosed with a chronic condition such as MS, there can be a break in their ontological security as they often perceive that there will be no continuity or order in their lives. This, in turn, can lead to uncertainty. This uncertainty can take many forms that have been shown in previous studies (Bury, 1982, Bury, 2001; Frank, 1995; Williams, 1984), for example, uncertainty about the future and how the disease will impact family life

and can permeate a patient's consciousness. This uncertainty led many participants to become more informed about MS, the CCSVI procedure, and the vascular theory of MS, all of which provided hope for symptom relief. Through the use of medical articles and personal stories, people with MS could read and see others' successes which, in turn, often played a role in justifying their decision to have the CCSVI procedure, a finding displayed in previous research of cancer patients use of experiential knowledge in their treatment decisions (van Kleffens, van Baarsen & van Leeuwen, 2004; Sinding & Wiernikowski, 2009).

Many participants deeply desired to return qualities to their lives that had been interrupted by their disabling disease. The CCSVI procedure enabled attempts to regain their ontological security that had been threatened by their MS and ensure plans for futures they had originally hoped for. Many participants sought to restore their narratives in a way the traditional medical narrative could not. Still, others addressed the uncertainty of the procedure, the lack of peer-reviewed work on CCSVI, and the apparently short length of time a patient may stay symptom free, as reasons not to have the CCSVI procedure. In essence, they did not feel that their sense of self was threatened by their MS symptoms. To provide a succinct statement about how people living with MS came to the decision to have the CCSVI procedure would not do justice to the many unique, remarkable, and heartbreaking stories that participants told. Like the disease, the narrative is unique in every person because the disease affects every person differently. Conversely, the media and medical professionals presented the CCSVI procedure as controversial because it challenges neurologists' traditional views of MS and its treatment. For most of the participants in my study, who are affected by the disease on a daily basis, the decision to have CCSVI was, in fact, not 'controversial' but hopeful.

Contributions

This thesis adds to the breadth of literature on the use of a vast and unpredictable medium – the internet – in day-to-day patient healthcare. The internet has previously been found to be a complementary rather than supplemental source of medical information for patients (Lewis, 2006). This was partially the case in this study; many patients found medical knowledge about the vascular theory of MS and the CCSVI procedure online and brought the information they found online back to their treating GP for clarification, or accessed treating IRs online that could answer their questions. These findings reaffirm much of the previous literature on patient use of online resources for health information (Hardey, 1999; Hardey, 2001; Josefsson, 2005; Kivits, 2004; Lewis, 2006; Nettleton, Burrows & O'Mally, 2005; Schaffer, Kuczynski & Skinner, 2007).

But, by studying the patients' stories of not only using online resources to access information on their disease, but the impact that the CCSVI procedure has had on their lives, it provides new insight into the complications of living with a chronic, disabling condition in reflexive modernity where access to and desire for information has vastly increased. The hope that the internet, alternative treatments, and other departments of medicine can provide in a time of reflexive modernity, when the power and influence of expert systems has decreased (Lash, 1994) and the access to multiple forms of knowledge has increased (Coburn, 2006), has changed not only the perceptions of MS but also those of CCSVI and medical professionals. The role of the internet in decision-making may often still be considered complementary to other 'expert' sources, but I feel, like many narrative analysis researchers (Frank, 1995; Frank, 2010; Hyden, 1997) that patients can provide their own expertise. They live day-to-day with a disease in which flare-ups can occur at anytime; thus MS patients are experts in the uncertainty that they experience on a regular

basis, as well as the experiential knowledge they have amassed of their disease. Patients have knowledge that differs from medical knowledge in that it is based in their lived experiences, and, as this study has shown, patients have the ability to interact with the information and communications structures to access information that may allow them to enact their agency against their chronic condition. Thus when examining the use of the internet, patients' own subjective opinions of living day-to-day with a disease need to be considered in an analysis of any new and 'controversial' treatment option as the hope can often outweigh objective, scientific medical facts.

This study adds to the growing literature on patients' use of the internet to become as informed as possible in reflexive modernity. The internet is an influential and ever growing medium in individuals' lives, especially in relation to health matters. This research addresses the way the internet and patient stories may be changing and shaping medical care in the twenty-first century, but much more work is needed.

Future Research

Because research into the CCSVI procedure is still ongoing, little is known about how long the symptom relief may last. Zamboni and colleagues' (2009) stated that only 27% of RRMS patients did not relapse within a year after having venous angioplasty, in addition, few, if any, progressive patients had lasting results in their original study. Countless research projects are underway across the globe to develop new techniques and testing protocols for the CCSVI procedure. Much of this research will further the medical knowledge on the CCSVI procedure while hopefully increasing symptom relief in patients.

This study laid groundwork for analyzing the making of scientific facts by addressing the challenges patients have made to the neurological community and

previously dominant views of MS. However, the CCSVI theory of MS is not itself a new black box. There are still questions, studies, and arguments being made for and against the CCSVI procedure. Future retrospective research should analyze the paths, detours and authority figures that helped to black box the vascular theory of MS or reclose the black box of the neurological approach to MS care. Future research should examine and address which field of scientific inquiry develops the strongest network around explaining and treating MS. One thing is for certain; the networks, voices and opinions that have dominated online discussion boards and Facebook pages regarding the CCSVI procedure are determined not to allow this treatment to vanish.

Moreover, the hype and hope surrounding the CCSVI procedure needs to be addressed in future research. When the CCSVI story first broke, the internet provided countless positive experiences with the procedure which then produced numerous CCSVI supporters, but not all MS patients have positive results. In fact, a number of participants in this study have had multiple treatments and still fear symptoms' return. Thus, this project was able to demonstrate that the internet can aid an MS patient in redrawing their life's map, and that the CCSVI procedure can provide the added hope of normalcy that the medical narrative could not provide patients. Yet there is no way to know if this will last. The patients' stories do not end when the interview is over; they continue to be told, shaped and changed over time and personal experiences (Frank, 2010). The narrative trajectory that MS patients found may continue towards hope and excitement, or fall into a chaotic state if the CCSVI procedure does not, in the end, produce the results they, as well as many advocates and authority figures, desire.

Concluding Remarks

The internet is a powerful tool that patients can use to find information about their disease and treatment options (be they medical or otherwise). This study has shown that when patients use the internet to search for information and share their stories, it can be beneficial way to enact their agency against a dominant structure that offers little in the way of hope or relief for people with MS and that many fear is invested in keeping them sick. However, it can also be detrimental by placing the responsibility of finding, arranging, and receiving care on the patient. Medical knowledge is more accessible to patients through the expansion of the information and communication structure, but through such accessibility patients have increased burdens as they navigate new fields of knowledge with little help from medical professionals who treat MS. Patients know their experiences of the disease, which are important tool for understanding their choices and desires to have the CCSVI procedure, but medical knowledge is still needed to physically provide treatments to patients.

This study has described how patients use and understand online resources, but further research needs to examine the long-term effects this procedure may have in a patient's life. Little is known about the long term benefits or ramifications that the CCSVI procedure may have on patients' health, wellbeing and mental state. The decision to have a 'controversial' medical treatment for a patient with a chronic degenerative disease may stem largely and simply from the uncertainty of the disease and the need to enact some control over their disease. Joint research into how this may impact the future trajectories of MS patients as they live day-to-day with their disease is needed. Patient narratives can provide information on the impact of medical treatments and the day-to-day lives of patients living with chronic conditions, which should garner attention from both researchers

and practitioners. Open communication between patients and medical professionals about the strengths and weaknesses of medical interventions is needed for medical knowledge to move forward, especially with the increased access patients have to formally exclusive medical knowledge.

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Appendix One: Interview Guide

INTERVIEW GUIDE – GUIDELINES

This interview guide contains five sections of open-ended questions that address particular areas of interest for my research project. It should be noted that section four is applicable only if you have been treated or tested for CCSVI. The questions are phrased to be as open as possible and allow you to answer in the way you see fit. Below each question there is a list of more specific sub-questions that you may use (but don't have to) in writing your answer. You may write as little or as much as you like (all text boxes automatically extend if you wish to write more than the space provided). This is an exploratory study, I am not looking for any predetermined responses, and thus there are no right or wrong answers.

You may find it helpful to read through the entire interview guide before beginning.

You can answer the questions at your own convenience, although I do request that the completed interview guide be returned to me in approximately two to three weeks from the time you receive this document. The interview guide can either be filled out as a word document and returned to me in an email attachment, or handwritten and returned to me via fax or mail (the methods for returning the interview guide are provided at the end of the interview guide). This interview style is meant to provide you with the opportunity to think through your answers and provide as much insight and detail as you wish. You are free to skip certain questions, or contact me at jekelly@ucalgary.ca for further clarification.

Any feedback that you would like to provide about the questions or study would also be welcome and helpful.

By submitting this interview guide, you are providing your consent to participate in this study. Please read through the consent form carefully to fully understand what your participation in this study will entail.

Section Two

Section two addresses the posts, information and opinions about CCSVI found online. This section seeks to examine if these online resources have played a role in changing your perception of MS, CCSVI and CCSVI treatment.

2.1 How did you first hear about CCSVI?

2.2 What MS-related websites do you visit? (Please provide a list in the area below).

2.3 What type of information have you found about CCSVI and its treatment from online resources? What is the most valuable type of CCSVI-related information or posts you have found online? (Some examples of CCSVI-related information online might be are they medical journal articles, personal experiences from others living with MS, current news reports, or a mixture of these or other types of posts. Do they discuss which medical professionals may support CCSVI? Is there information that you have found online about CCSVI that you would not have found out otherwise?)

2.4 Have the postings or information online changed how you view MS, CCSVI and the CCSVI treatment? If so, how? (Are they helpful, optimistic, encouraging, discouraging and why? If you have not been tested or treated for CCSVI, are you contemplating doing so? Why or why not?)

Section Three

In this section, I would like to address how the knowledge, information, arguments and opinions in online resources may differ from that you receive from your immediate contacts like family, friends and medical professionals that treat MS.

3.1 What type of information and support do your family and friends provide with respect to MS and CCSVI? (Do they understand what you are going through? Do they help you in your search for information? Are your family and friends supportive of your decision to not explore the CCSVI treatment? How much do you talk to them about MS? Are they encouraging or discouraging about CCSVI and the CCSVI treatment? If so, how?)

3.2 What type of information and support do you receive from medical professionals with respect to MS and CCSVI? (Do physicians and specialists listen to what you are going through with MS? What types of treatments do they discuss with you? Do medical professionals offer support and advice on how to live with MS? Do they discuss CCSVI with you, if so what do they tell you? Do different medical professionals react differently to CCSVI? And, if so, how? If you find information online, do you bring the information to your neurologist or physician?)

3.3 In your opinion, what are the most important differences between the information and support you receive from friends, family or medical professionals versus what you have found online? Do you find more support from online groups and sources than from personal contacts? (Do you frequent online support groups? If so, do they provide different information than local supports groups? Do the individuals online provide support and advice that is relatable? Do their posts help aid in your decision about medication and treatments? Is there certain type of knowledge shared in online communities that is not shared amongst family, friends and medical professionals, if so what is it?)

Section Four

Section four specifically addresses CCSVI and CCSVI treatment. The two questions in this section are for the respondents that answered yes to both or either one of questions 1.6 or 1.7. If you have not been tested for CCSVI, or had the treatment, please go on to section five.

4.1 What led to your decision to be treated or tested for CCSVI? What arguments and opinions about CCSVI have you found most compelling and why? (I am interested in the extent to which online resources played in your decision to be tested or treated for CCSVI, but also any other factors that may have impacted your decision. How much did online resources play in your decision to have the treatment? Was it based on family or friends' attitudes toward the procedure? Where did you have the procedure done and why did you choose that location?)

4.2 If you have been treated for CCSVI, how has the treatment impacted your life? (Were the results what you expected? Why, or why not? Have your symptoms changed; if so are they better or worse? Are you able to do more activities? Did you notice a change right away? Did your symptoms return and if so how long after the treatment? Would you recommend the procedure to other people with MS?)

Section Five

Section five is provided for you to add any additional comments that relate to the use of online resources and MS.

5.1 Is there anything else about your use of online resources or experience with MS that you would like to add?

5.2 Are you willing to be contacted (via email) by myself within two months of returning this questionnaire if I have any follow-up questions?

Yes [] or No []

Email address:

Section One

Section one is the most structured section and will ask basic demographic questions about yourself, as well as your background with MS.

1.1 What is your gender?

1.2 What month and year were you born in?

1.3 What city and country do you live in?

1.4 What year were you diagnosed with MS?

1.5 What type of MS were you diagnosed with?

1.6 Have you been tested for CCSVI?

Yes ☐ No ☐

1.7 Have you been treated for CCSVI?

Yes ☐ No ☐

Note: If you have been tested and/or treated for CCSVI, additional questions on this topic are in section four of this interview guide.

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