Patient Mobility and Medical Tourism for the Liberation Therapy Procedure by Multiple Sclerosis Patients: A Framing Analysis of Canadian Newspapers

by

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Abstract

Mobility in all of its forms is highly commodified in a globalised system. Much focus on mobility theory has offered a new 'mobilities turn'. Largely absent from this 'mobility turn' is an examination of the relationship between mobility and health. This case study focuses on the Canadian televised and print media attention given to a medically contested procedure: liberation therapy (LT), which emerged as the possible treatment for multiple sclerosis (MS). As a non-insured service, Canadian MS patients wanting access to the procedure must travel to other geographical locations in what is termed as medical tourism. A comprehensive media analysis reveals an overwhelming patient mobility in the hopes of positive outcomes mainly from anecdotal stories. Patients' advocacy for LT intensified and this pressured governments' to fund clinical trials. This highlights the influence of the media in mobilizing patients and directing resources for research in the Canadian health care system.

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Dedication

This thesis is dedicated to my late mum **Joana Pognaah Tiirow** who was called to Eternity on 16th February, 2010.

Mum, you will be forever proud of what I have achieved so far because "I have fought a good fight, I have finished the race, I have kept the faith" 2 Timothy 4:7 (New International Version).

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Chapter 1

Introduction

Medical tourism, a fast growing concept coined by researchers, policy makers and the media often describes international travel of individuals for healthcare in hospitals, clinics and other health care centers (Turner, 2013). The discourse of medical tourism is deeply rooted in the geographic framework of mobility (i.e. travelling between locations over time and space). Mobility thus involves movement from one place to another. Globalization and modernization which is associated with the improvement in transportation and communication has enhanced the mobility of patients across different scales (Ley, 2011). With the advancements in modern communication devices such as the Internet and mobile phones, patients are able to access information about medical facilities and travel through flight to any part of the world for medical care that suits their preferences and budget (Turner, 2007a).

The concept of medical tourism has attracted considerable attention in the media and academia (Horowitz et al., 2007; Karuppan & Karuppan, 2010). The media, including televised and print media, serve as the reference point for accessing updated information about health risk issues and events, scientific and technological discoveries and government policies (Boyd et al., 2009; Collins et al., 2006; Driedger, 2007; Driedger et al., 2009; Wilson et al., 2004). In particular, the media is often viewed as an important source of disseminating health information to the general public (Burns et al., 1995; Gasher et al., 2007; Gonon et al., 2012; Stryker, 2002). Radio, television and newspapers serve as the major source of scientific information to 40% of the general public (Chang et al., 2014). In the presentation of health information, journalists mostly rely on peer reviewed scientific publications and press releases as their major and most reliable sources of information (Stryker, 2002). In addition, controversial scientific discoveries rejected

by peer reviewed journals or fascinating discoveries yet to be published often find their way into the media (Nelkin, 1996).

The media play a powerful role in influencing health related legislation, funding of research and clinical trials and attitudinal and behavioral change in individual lifestyles (Stryker, 2002). The media is often constrained by time and space and may not be able to give detailed reports on various health issues. As a result, the media can be selective in what it chooses to highlight. In controversial or new risk events, the media often provide front page coverage, and this may last a short period before coverage moves to other issues (Mistry, 2007). The media portrayal of a contested health theory promoting one perspective (e.g. positive results) over another (e.g. negative results) can send wrong signals to the 'lay public' (Burns et al., 1995). The orientation of news stories by the media on biomedical advances or health policies can have an overwhelming influence on public policy and opinion over time (Chang et al., 2014). Moreover, journalists' selection of certain sources and amplification of voices over others in the media can also have the potential to create controversy (Kennedy & Bero, 1999).

The mass media in contemporary times has become the main source through which various interest groups lobby for support to advance their agenda (Pullman et al., 2013). Patients in particular rely on these various media sources for a lot of information prior to seeking treatment either at home or abroad (Marrie et al., 2013). Overall, the influence of the media in present day society cannot be overemphasized.

This thesis seeks to highlight some of the key dynamics the media plays with respect to medically contested procedures and patients' engagement in medical tourism for such therapies. The research will particularly explore a controversial treatment for multiple sclerosis (MS). MS

is a disease that affects more than 2.5 million people globally, and it is the major cause of non-traumatic disability among young adults in the western developed world (Trapp & Nave, 2008). According to the Canadian Community Health Survey, approximately 93,535 Canadians have MS, with 1000 new cases diagnosed annually; thus making it one of the highest prevalence in the world (MS Society of Canada, 2006; Statistics Canada, 2010).

The introduction of the chronic cerebrospinal venous insufficiency (CCSVI) hypothesis and the liberation therapy (LT) procedure by Paolo Zamboni in 2009 as a new surgical treatment for patients with MS attracted an unprecedented interest in the media, particularly in Canada. While some media stories presented LT as a cure for MS, others suggested that more research is needed. The Canadian news media has framed this medically contested procedure as a conflict between the scientific/medical community and MS patients/advocacy groups. The media played a powerful role in providing the general public with the perspectives of various stakeholders (i.e., the government, advocacy groups, MS patients and medical experts/ researchers). An international study of news media coverage of the CCSVI and LT shows that the Canadian mainstream print news media coverage was more intense than in Italy, Germany, U.S. and U.K. (Chafe et al., 2011). Given its controversial positioning, it is not surprising that LT has attracted more attention in both print and televised news media than any other medical theory in Canada (Fox, 2011).

The study of medical tourism in this thesis has been necessitated by a clarion call that urges researchers and scholars in the field of bioethics, public health, medical anthropology, medical sociology and medical geography to critically evaluate the burgeoning medical tourism industry (Runnels & Turner, 2011). The authors further implore scholars to go beyond the framing of medical tourism as an economic driven enterprise. Medical geographers have particularly been

charged to gauge at the local, regional and international scales, the implications of marketing health services in a globalized world (Runnels & Turner, 2011).

Moreover, a great deal of academic literature on mobilities theory has explored the relationship between mobilities and practices, subjects and spaces (See Cresswell & Merriman, 2011). Despite a couple of exceptions (Gatrell, 2011, 2013), relatively little attention has been paid on the intersection between mobilities and health. Mobility and health are fundamentally interrelated at many levels; the spread of disease is usually enhanced by mode of transportation; accessibility to a health care facility needs a suitable means of transport and online health care is delivered by using technologies that cut across space (Gatrell, 2011). In this study, I seek to explore the interrelationship between mobility and health by examining the news media portrayal of Canadian MS patients' engagement in medical tourism. In particular, I focus on the conflicting tensions that occur when mobile (i.e. people, ideas) and immobile (i.e. health care policy) spaces collide.

Justifications of the Study

Patient mobility for LT procedure to treat CCSVI continues to attract media attention in Canada. There has been a crusade led by MS patients and advocacy groups to make LT available within the Canadian health care system. Despite the increasing role the media is playing in this controversial CCSVI and LT debate, there is only one in depth media analysis on Canadian print media portrayal of the CCSVI and LT procedure to date (Tulk, 2013). That study focused exclusively on the Globe and Mail newspaper as a case study for how the mainstream news media constructed CCSVI and LT as a scientific controversy. Similarly, drawing inspiration from MS patient interviews and analysis of both news and online social media, Hande (2012) has demonstrated how CCSVI and LT has become the focal point for mobilizing patient movement

and activism in Canada. However, a knowledge gap exists in both studies as they did not address issues of medical tourism and/or patient mobility explicitly.

In addition, while there have been various media studies on medical tourism in the developed and developing countries (Imision & Scheinsberg, 2013), cosmetic and bariatric surgeries (Turner, 2012b) and health care globalization (Mainil et al., 2011), the same cannot be said of LT within the Canadian context. Medical tourism in this study will represent the first of its kind to assess a medically contested theory that has gained significant space in the Canadian print media.

Research Goal and Objectives

Following from the above developments, the goal of the proposed case study seeks to examine how the theory of mobility, engaged through the specific act of medical tourism, facilitated by the easy spread of ideas about LT, challenges the traditional boundaries of a health care system or health policies in a globalised world. This becomes especially important because, in Canada the various provincial and territorial public health care systems fund health services that are fiscally possible within the bounds of those services that have been proven to be efficacious. Medical tourism, a manifestation of globalization, has made provisions for the rapid trade in health care services (Lunt & Carrera, 2010). The global health care system is creating opportunities for people with the necessary financial resources to purchase health care elsewhere. As health care is increasingly commodified in a globalised market, this has offered consumers the choice to purchase health services regardless of the location. In addition, the rapid growth of the medical tourism industry means that there will be massive competition among nations in order to attract medical tourists. Many countries may however market health services that might not meet the standards of safety more broadly.

The purpose of the study is to assess how the media presents the reactions of different groups' to CCSVI and LT, facilitated by mobile networks/structures, in a way that put pressure on governments to modify existing policy and decision making processes for the health care system. Against the backdrop of a news media analysis of the CCSVI and LT issue in Canada, this study, gauged through the lens of mobility theory, seeks to accomplish the following objectives;

1. Examine the frequency (i.e. quantity of news stories) of the Canadian print media coverage on CCSVI and LT and how it has changed over time.
2. Document how the perspectives of different key stakeholders on the discourse of mobility and/or medical tourism are framed in the media.
3. Analyze the various media frames that enhance or discourage patient mobility for CCSVI and LT.

This thesis is part of a larger study entitled "Improving Health Policy Decision Making in the Face of Uncertainty: A Case Study of Liberation Therapy for Multiple Sclerosis", that is aiming to advance a better understanding of how health policy decisions are made in the face of uncertainty. The larger research is being conducted by an interdisciplinary team led by Dr. Michelle Driedger (University of Manitoba). The other members of the project team include: Dr. Ruth Ann Marrie (University of Manitoba), Drs. Melissa C. Brouwers and Mita Giacomini (McMaster University), Dr. Jeffrey Hoch (University of Toronto), Drs. Jeffrey Sisler and Donna Turner (CancerCare Manitoba), Dr. Sarah Morrow (London MS Clinic), and Dr. Joel Kettner (University of Manitoba). This larger project has been funded by the MS Society of Canada and Research Manitoba.

Chapter Synopsis

The thesis is structured in a way that seeks to answer the main aim and the research questions. The thesis is organized by the following chapters; (i) general introduction; (ii) theoretical frameworks; (iii) background and review of the literature; (iv) methods; (v) results; (vi) discussions and (vii) conclusions, recommendations, limitations and areas for future research. These are outlined in brief below.

Chapter 1

Chapter one presents a brief introduction to the thesis. It provides the justification, main goal and objectives the study seeks to accomplish. The chapter provides the context for the main argument: how media presentations of various groups' reactions to CCSVI and LT, facilitated by mobile networks/structures can pressure policy makers to modify existing processes and decisions in managing the health system. The chapter highlights that people (i.e. patients) and ideas (i.e. LT) have considerable mobility facilitated by a globalized private health care system. By contrast, the Canadian health care system is embedded with immobile health policies. For this particular case study, the mobile and immobile tension will illustrate how policy choices such as resource allocation and research priorities within an immobile health care system may be challenged against significant pressure in the absence of open and transparent processes. An overview of the thesis layout and the subsequent chapters to follow are also presented in this chapter.

Chapter 2

Chapter two provides the theoretical foundations for the study. It introduces mobility theory with its underpinnings on the new mobility turn. This new mobility turn conceptualizes mobility in terms of the movement of people (e.g. medical tourists), medical procedures (i.e. LT), ideas,

information and capital. The chapter also introduces patient mobility for health services on different scales. Finally, framing is presented as a theoretically informed tool used in analyzing media data. The study of media framing is inspired by Entman's (1993) definition of framing about using communication text to portray some aspects of a situation and making it more salient. The media framing concept is however guided by a mobility interpretative lens. This is to ensure that media text is read not just for its surface content, but also for latent meanings in how patient mobility for CCSVI and LT through medical tourism is framed in the new media. Latent meanings of text will also help in understanding how patients' ideas and actions are framed over time. Patients' ideas about the procedure and their subsequent decision to engage in medical tourism can be viewed in different ways- reckless, risk takers, adventurers or victims. The debate over CCSVI and LT are influenced by the various stakeholders and particularly government policies regarding funding and availability of the procedure domestically. Government policies overtime affects media framing of the issue and patient mobility both positively or negatively.

Chapter 3

Chapter three provides the necessary background and review of literature relevant to this particular study. The aim is to provide detailed information to help better understand the context of the thesis. The chapter gives an overview of multiple sclerosis and CCSVI and LT. Medical tourism or patient mobility is described, by outlining how the concept has developed over the years. The chapter situates medical tourism in present time as patients from the Global North travel to the Global South for various surgical procedures. The push and pull factors that motivate Canadian engagement in medical tourism are described with special emphasis on CCSVI and LT. Generally, the chapter stresses the various ways in which the provincial and federal governments responded to the issue. Clinical trials were initiated at the federal level. New

Brunswick sponsored patients for LT overseas. Saskatchewan also supported patients to participate in clinical trials; whilst Newfoundland and Labrador, Alberta and Vancouver set up registries to assess the outcomes of patients who had LT abroad. These policy decisions were undertaken at as a result of patients' advocacy, through the media, for the availability of the procedure. It indicates the power of patients in influencing the direction of research priorities in the health care system.

Chapter 4

Chapter four presents the methods used in the analysis of this study. This particular case study design used multiple data sources and different strategies in gathering the data. Print media stories from national and provincial newspapers were searched using ProQuest Canadian Newsstand and Major Dailies database. A televised documentary that first introduced CCSVI and LT to the Canadian public was also reviewed and transcribed verbatim. The data sources were imported into NVivo software for analysis. Thematic analysis informed by framing and mobility theory was adopted in analyzing the dataset. The chapter also highlights the mechanisms used in this research to ensure validity and reliability and concludes with the methodological limitations of this study.

Chapter 5

Results organized by the objectives of the study are presented in chapter five. The analysis from the televised data shows that the documentary was the referenced focal point for initial media framing and coverage of the issue. The issue received much coverage in the early stages but substantially dropped over time and space. The perspectives of various key stakeholders regarding the harms and benefits of the procedure are highlighted in the chapter. Patients were generally hopeful about the prospects of the procedure. On the contrary, the government and the

scientific community were skeptical. The media adopted positive and negative frames in presenting the issue. Framing the procedure as hope (i.e. news stories reporting on people who express confidence about LT as a cure to MS), liberation (i.e. packaging of LT as freeing people) and miracle (i.e. making LT sound extraordinary and capable of saving patients from all the problems caused by MS) enhances patients' engagement in medical tourism. The hoax (i.e. media portrayal of LT as fake or placebo) and wait and see (i.e. people being urged to have patience for more evidence about the treatment) frames discourages patient mobility. However as patient pressure intensified, governments responded with the announcement of clinical trials.

Chapter 6

The key issues raised from the results chapter are addressed in this chapter. The results from this study were compared to previous studies. Considering the trend in media coverage of scientific discoveries it was not surprising that the coverage of the issue substantially dropped. The chapter also highlights the stringent measures in approving medical procedures within the Canadian health care system. Nonetheless, patients make mobile decisions regarding health care. Reflecting on the mobility theory, it was found that information and communication technologies have contributed most to the ease and movement of people, goods and services.

Chapter 7

The issues raised by the research objectives are addressed in this chapter. The analysis recorded low coverage on the issue but predictions are that the coverage may increase if results from the ongoing clinical trials indicate LT as the 'cure' to MS. For the second and third objectives regarding key stakeholders perspectives and media framing respectively, the study highlights a general pattern between the perspectives and media framing: stakeholders positive or negative towards LT are typically framed in equally positive or negative terms by the media. This study

adds substantively to research that examines the engagement of Canadians in medical tourism. It also contributes to the scant literature that assesses the relationship between mobility and health within the new mobility turn. In terms of policy decision making, the study advocates that researchers and clinicians should engage and dialogue with the public in their research. This chapter concludes with the limitations of using media data. Despite the limitations, the study emphasized that the media is a powerful tool in communicating scientific information to the general public. In comparison to existing literature (Pullman et al., 2013), this case study emphasizes the need for an improvement in how scientific information can be communicated in order to achieve a better informed decision making process. In particular, plain language communication of scientific information through the media and journal publications can help people understand health issues more clearly. Added to this, the tensions between mobile (information, ideas and patients) and immobile (health care policies) forces within the media dataset illuminates the importance of resource allocation and research priorities within the Canadian health care system.

Chapter 2

Theoretical Frameworks

Theoretical frameworks provide a lens through which an issue is to be examined. The theoretical basis for the analysis of this thesis rests on two foundational concepts of mobility and media framing. These concepts are fundamental because media framing of medical procedures can significantly influence patient mobility and decisions to purchase health services or health procedures. For instance, positively framed messages can persuade patient mobility to purchase a health care procedure especially when it is not available domestically, whereas negatively framed messages may require the need for more information in order to make a decision (Chang, 2007).

The first section of this chapter thesis describes the mobility framework. It is founded on the new mobility turn proposed by mobility theorists (See Hannam et al., 2006; Urry and Sheller, 2006). With the launch of the *Mobilities* journal in 2006, thereby formalizing a mobility turn, there are a series of studies dedicated to the new mobility turn (Cresswell, 2010). In this mobility turn, researchers have been charged to study the relationship between diverse forms of movement of people and messages, information and images across different levels of scales (i.e. body to global), as well as their implications (Cresswell, 2010; Urry, 2007). Mobility theory enables us to better conceptualize mobility as constituting 'imaginative travel, movements of images and information, virtual objects, and corporeal bodies' (D'Mello & Sahay, 2007, p.163).

The chapter also presents media framing as a technique in analyzing media stories. The framing analysis is guided by a theoretical positioning in mobility around this case study. Mobility theory is the most relevant to the issue of medical tourism or patient mobility through this case study of a medically contested procedure (CCSVI and LT) as played out through the Canadian news

media. The use of mobility interpretative lens is also to ensure that texts are read not just for their surface content but also for their theoretical meanings in how patient mobility and/or medical tourism for CCSVI and LT is portrayed in the news media.

Mobility Theory

This thesis is deeply rooted in the geographic lens of mobility theory. Mobility involves the movement or displacement from one location to another (Cresswell, 2006). The location can be geographic spaces (i.e. towns, cities, villages, hamlets) or points (i.e. A to B) which are far apart. The movement specifically involves moving your hand, walking, dancing, exercising, driving to work, moving home, going on holiday, marching, running away, immigrating, traveling, exploring or attending conferences (Cresswell, 2006). An interesting phenomenon is the overlapping of mobility from diverse academic backgrounds especially in the area of geographies of travel, transport and empire, sociologies of infrastructure, the politics of commodity circulation and sustainable transport policy (Revill, 2011).

The pace of mobility is dictated by power (Creswell, 2010) but that power is exercised through decisions to be mobile. For example, not everybody has an equal right to movement. In theorizing the politics of mobility, power is a resource which is differently accessed and distributed along various social relations such as classes, gender, ethnicities, nationalities, and religious groups (Cresswell, 2010). As a result, movement of minority groups is determined by their ability to possess documentations such as travel passports, visas and other residential and work permits (Stephenson, 2006; Urry, 2007). In the context of patient mobility for health care, individuals with the financial and economic means have the potential to be mobile and can access quality health care in any part of the world (Turner, 2007b), whilst the less privileged have to rely on the domestic health care system for their health needs. When patients exercise

mobile decisions to purchase health on the global market, they put pressure on local immobile structures-both home and away.

The world over the last century has experienced an increased movement-whether planned or unplanned. For instance, 4 million people travel on a daily basis via commercial airline flights, 31 million as refugees moving to other parts of the world and the ownership of cars shot up with the ratio of one car to every 8.6 people (Sheller & Urry, 2006). The world has witnessed a rapid growth of international travel from 25 million in 1950 to 846 million in 2006 and this figure is projected to reach 1.6 billion by 2020 (Gale, 2009). There is also the high scale movement of asylum seekers, international students, terrorists, sports stars, business men, peace keepers, scholars, workers, friends and families (Hannam et al., 2006; Urry, 2007). These mobilities have overarching effects on energizing human bodies and life, altering scheduled travels, spreading illnesses and risks across borders, changing patterns of refugees, tourists and migrants, transforming the youth educational and social life, restructuring institutions, transforming local communities, spaces and nations, connecting distant family and friends among others (Hannam et al., 2006).

An important attribute to the conceptualization of the mobility theory is the development of virtual mobilities (i.e. access to information and places through the use of information and communication technologies) (Gilbert et al., 2008). The Internet especially has experienced over a billion usages globally. Mobile phones also provide the avenue for the spread of information through interaction and communication. As people and information become mobile, so do materials. Goods and services facilitated by modern forms of transport and communication are also witnessing movements from one geographical space to another. In the health context, people who are mobile can either "introduce new or previously eradicated diseases to the region of

destination, or contract diseases unknown to the migrants' region of origin." (Grondin et al., 2003, p.85). For instance, the rapid spread of diseases and medical procedures from one area to another has been enabled by mobility. Specifically, LT which is the focus of this thesis is regarded as a mobile medical procedure. Initially developed in Italy, the procedure has spread to different parts of the world. This study critically examines the linkage between the mobility of ideas (i.e. LT) that precipitates the mobility of people (i.e. MS patients). The increasing power of mobile networks that transmit and spread ideas has considerable implications for the health care system which was designed for a much less mobile world. Mobility, (whether real or virtual) is thus at the centre stage of everything in the world (Hannam et al., 2006; Sheller & Urry, 2006). Mobility is central in the field of the social sciences, particularly Geography (i.e. movement, migration, tourism and transport geographies) (Cresswell, 2010) and it also affects all aspects of human life irrespective of race, nationality, gender and economic status (Revill, 2011).

A new mobility paradigm was proposed within the social sciences to study the relationship between travelling and the modes of transportation facilitating or mitigating movements (Hannam et al., 2006; Sheller & Urry, 2006; Urry, 2007). The new mobility paradigm examines "both the large-scale movements of people, objects, capital and information across the world, as well as the more local processes of daily transportation, movement through public space and the travel of material things within everyday life" (Hannam et al., 2006, p. 1). According to Cresswell (2010, p.18), this new mobility paradigm has brought different geography sub disciplines 'into a more holistic understanding of mobilities'. He succinctly noted that:

> In migration theory, movement occurred because one place pushed people out and another place pulled people in. So, despite being about movement, it was really about places. Similarly, transport studies have too often thought of time in transit as 'dead time' in which nothing happens-a problem that can be solved technically. Mobility

> studies have begun to take the actual fact of movement seriously (Cresswell, 2010, p.18).

Within this paradigm, mobility researchers seek to move from the hitherto sedentarism (fixity and stability) to a more world view based on nomadism with movement and fluidity (Cresswell, 2002; Sheller & Urry, 2006). Social science research orientation of the world was predominated with the assumption that things and people were tied to specific places. More especially, health geographers were concerned with the study of health care at fixed locations (i.e. hospitals and health care centers) (Gatrell, 2011). The paradigm arose in response to this static ontology of social sciences, that relegated movement as well as ignoring or trivializing "the importance of the systematic movements of people for work and family life, for leisure and pleasure, and for politics and protest" (Sheller and Urry, 2006, p.208).

The new mobility paradigm also explains how the "mobility turn connects the analysis of different forms of travel, transport and communications with the multiple ways in which economic and social life is performed and organized through time and across various spaces" (Urry, 2007, p. 6). In this mobility paradigm, Urry (2007) has classified mobilities under five interdependent core dimensions which are associated with travel: corporeal travel of people 'for work, leisure, family life, pleasure, migration and escape' (p.47); the physical movement of objects; imaginative travel enabled by print and visual media; virtual travel across time and space in a geographical distance and communicative travel through the exchange of messages from one person to another.

Characteristically, the paradigm first and foremost presumes that the world is made up of social relations that involve diverse networks and connections of people and places from distances into a 'global village' (Sheller & Urry, 2006). It seeks in a broader theoretical context to

conceptualize intersections between various geographical barriers and the direction of flow of material goods and services. The connections of these networks are facilitated by various modes of transportation. Mobile objects such as cars, trains, aircrafts, buses, trains, mobile phones and computers all serve as connection and networks that link people from different places. In the field of health the use of the mobile phone and Internet technological facilities enables the provision of health care at a distance (i.e., telehealth care, telemedicine, and telesurgery). These modern day technologies can be used to transmit images to different physicians at different locations for analysis without the presence of the corporal body and this helps save time and travelling cost (Gatrell, 2011).

Second, all the various forms of mobilities are facilitated by moorings such as airports for aircrafts, car parks for cars and ports and harbors for ships (Cresswell & Merriman, 2011). Beside these moorings, spaces are also needed in order for mobility to take place. As such, immigration entry and exit points or borders, cities, roads, the air, the sea, railway lines, and bridges are all necessary spaces that can drive or constrain mobilities. These spaces are practically mobile even though it is easy to view them as static entities. Studies on airports highlights how they have become cities, providing the avenue to connect people to other parts of the world, whilst providing technological facilities such as WiFi hotspots, CCTV, Internet Cafes, GPS and other software for scanning and surveillance purpose (Hannam et al., 2006). The airports have also become the focal point for connecting people and places all over the world. Borders can be viewed as ‘filters’ that control undesirable movements, whilst they fast track the movement of desirable bodies (Kloppenburg, 2013). In the context of mobility of medical tourists, borders both facilitate or impede the movement of people by ‘welcoming the border

crossing of tourists, while restricting the border crossing of migrants' (Kloppenburg, 2013, p. 55).

As well as the movement of people, the new mobility paradigm place emphasis on movement of objects, information, policies, politics, medical procedures, ideas and capital on different spatial scales (Cresswell, 2010). It can be local, as in a trip to a nearby place within the same locality. Mobility at the national scale involves movement to another region within the same country. Mobility operates at the international scale when it involves travelling out of the country.

Last but not least, the paradigm considers the various practices of movement e.g. biking, riding, flying and driving as well as the emotions, meanings and experiences that are imbued in the movement (Cresswell, 2010; Gatrell, 2013). Stemming from this, as patients travel for out of country health care, an array of meanings is attached to the journey and this may vary from person to person. Some will have the feelings of accessing the best quality of health care, whilst others may see it as gambling with their life. Mobility and uncertainty are particularly vital in understanding patient engagement in medical tourism for medical procedures. In their search for 'cures', patients may face the challenge of traveling to purchase medical procedures abroad even when the effectiveness and safety of such therapies are uncertain. The uncertainty underlying the risks or benefits of medical procedures can also play a major role in influencing patient mobile decision making process particularly for those with deteriorating health conditions. Uncertainty therefore provides potential medical tourists the opportunity to make mobile decisions based on the information available at their disposal even though the outcomes or consequences of the medical procedure are unpredictable.

Conceptualizing Patient Mobility and/or Medical Tourism

The patient cross border mobility conceptualization process is inspired by a framework on patient mobility within European Union Member States (Bertinato et al., 2005; Suñol et al., 2009). In this framework, patient mobility can be categorized under five different scales: people who temporarily visit a different location for holiday and decide to utilize available health care services in that location; people who travel from their country to a different country to stay permanently; migrants who returned to their country of origin for medical services; patients who are sent abroad by their own health care funder/provider to outsource medical care; and patients who are mobile through their own volition (Glinos et al., 2010; Lunt & Carrera, 2010). The framework's emphasis is on the scale of patients mobility based on their own volition or government arrangement to send patients abroad for medical care. Patient mobility in this context is vital because the treatment is not available or easily accessible; patients wanting to avoid long waiting times in accessing treatment or avoid the high cost of the treatment in their home country (Lunt & Carrera, 2010).

The analytical focus of this particular research will be MS patients' mobility from Canada to different geographical borders for medical care (i.e. LT procedure) based on their own choice, which is pre-arranged by the patient, third party (e.g. tourism marketing company) or the provincial government, with a physician in a medical facility, as represented in the news. Canadian MS patients wanting LT must seek this care elsewhere. Their decision is often made after accessing information about the country of destination, cost, as well as the risks and benefits of the procedure. Common sources of information include anecdotal stories on the Internet, past medical tourists, tourism marketing companies and physicians. Their mobility is

facilitated through the use of immobile transportation networks and the availability of special visas that ease the movement of people to purchase health care on a global scale.

Media Framing

Framing is a powerful tool in media research and its function has been well documented (Driedger & Eyles, 2003; Entman, 1993; Price et al., 1997; Scheufele, 1999; Scheufele & Tewksbury, 2007). Framing typically places emphasis on how issues are presented and interpreted in the media (Entman, 1993; Neuman et al., 1992; Pan & Kosicki, 1993; Scheufele, 1999; Scheufele & Tewksbury, 2007). Framing refers to the ways in which an issue is presented or 'packaged' for the consumption of audiences (Scheufele, 1999; Scheufele & Tewksbury, 2007). In this thesis, the definition of framing is based on Entman (1993, p.52): "to frame is to select some aspects of a perceived reality and make them more salient in a communicating text, in such a way as to promote a particular problem definition, causal interpretation, moral evaluation, or treatment recommendation for the item described." Entman further identified four locations of the communication process in which the frame is manifested, with illustrative examples relevant to this research topic provided: the communicator (i.e. the reporter and the sources used in the media stories), the text (e.g. the individual news stories), the receiver (e.g. MS patients, family, friends, the public, government officials, etc.) and the culture (e.g. a group of people who believe that health care systems should attach a sense of urgency to medical discoveries or a system of people who view access to desired health care as a right). Framing, in effect, defines how a certain piece of media content is packaged to an audience so as to allow certain desirable interpretations and rule out others. Frames help audiences to "locate, perceive, identify, and label" the information around them (Goffman, 1974, p.21). News framing also

conceptually offers the opportunity to 'convey, interpret and evaluate information' presented to the public (Neuman et al., 1992, p. 60).

Framing has been used in different contexts relating to health and it is operationalized in different ways in health research. In some studies, frames such as economy, blame, trust, health and government were the main focus in the presentation of how a risk issue was portrayed in the media (Boyd et al., 2009; Driedger et al., 2009; Mistry & Driedger, 2012). Within this study context, positive and negative framing of health services in the media can influence consumers' cognitions, intentions and dispositions to purchase health care procedures (Mason & Wright, 2011). As regards to mobility theory, medical procedures with positively framed messages such as low risks of medical procedures tend to encourage patients' engagement in medical tourism for such services (Chang, 2007). On the contrary, information about health procedures with a high propensity of risk may be "negatively framed […increasing] consumers' need for information about the relevant attribute of the product, its negative consequences, and ways to avoid their occurrence" (Chang, 2007, p.52).

Frames are important in the "interaction between journalists, public and stakeholders", hence media frames serve as a "reference that readers or viewers use to interpret and discuss events" and issues (Kuttschreuter et al., 2011, p.203). Media frames also set the pace regarding "what will be discussed, how it will be discussed, and above all, how it will not be discussed" (Altheide, 1996, p.31). The media therefore play a vital role in communication issues and events through the use of frames. This makes framing as a relevant analytical lens to incorporate in the media analysis of patient mobility for this particular case study.

Chapter 3

Background and Literature Review

Multiple Sclerosis, Chronic Cerebrospinal Venous Insufficiency and Liberation Therapy

Multiple sclerosis (MS) is an inflammatory demyelinating disease affecting the central nervous system; that is, the brain, spinal cord and optic nerves (Noseworthy, 1999). The disease is prevalent in colder climates, disproportionately affecting women more than men, and is most often presents in adults between their 20s and 40s (Zuvich et al., 2009). MS negatively affects productivity, employment and quality of life (Uccelli et al, 2009; Macías-Islas et al., 2013).

MS can be classified by disease course. Relapsing-remitting MS course occurs in 85% of patients and it is often characterized by an unpredictable exacerbations and remissions that may last from weeks to months (Goodin et al., 2002). These patients transition into secondary progressive MS when their disability worsens steadily over time even in the absence of relapses (Fox et al., 2006). In approximately 15% of MS patients disability progression is worsens gradual from onset and this is not associated with relapses (primary progressive MS) (Lublin & Reingold, 1996).

Notable symptoms of MS which vary from person to person include fatigue, pain, headache, dizziness, numbness, spasticity, stiffness, weakness, cognitive dysfunction, sexual dysfunction, paralysis, balance and coordination problems, bladder dysfunction, bowel dysfunction, vision and speech problems (Crayton & Rossman, 2006; Pullman et al., 2013; Rae-Grant et al., 1999; Zuvich et al., 2009). There is no definitive cure but there are approved medical therapies in the market which can help minimize the symptoms and modify the disease course. These drug therapies include Avonex, Betaseron, Copaxone, Rebif and Tsysabri (Schneider & Young, 2010) and recently Alemtuzumab (Coles, 2013). They require approval by Health Canada before they

can be administered to patients. Researchers also continue to develop new therapies, all aimed at finding a cure to the disease. There are also therapeutic treatments administered by allied health providers and psychologists (Compston & Coles, 2002).

The etiology of the disease has yet to be established but it is believed to occur as a consequence of environmental exposures in a genetically susceptible individual. Etiologic factors of interest include infectious agents, vitamin D deficiency, vascular disorders, environmental and genetic factors (Compston & Coles, 2002; Marrie, 2004; Noseworthy, 1999; Poppe et al., 2008; Pullman et al., 2013; Zuvich et al., 2009). MS is believed to be an autoimmune disorder in which the myelin sheath (i.e. the protective layer of the central nervous system) is attacked (Fox & Rae-Grant, 2011; Greer & McCombe, 2011). An Italian vascular surgeon, Paolo Zamboni in 2009 challenged the autoimmune origin of the disease. He saw MS as a vascular disorder (i.e. disease that affects the veins) after conducting a non-randomized clinical trial on a small number of MS patients. According to Zamboni's hypothesis, MS is worsened by the buildup of iron in the brain as a result of blocked or narrowed veins, which prevents the flow of blood from the central nervous system (Zamboni et al., 2009). He called this condition Chronic Cerebrospinal Venous Insufficiency (CCSVI). This condition was revealed in all the MS patients who participated in their study. Zamboni further asserted that, the symptoms of MS patients can be improved through endovascular interventional treatment by inserting a tiny balloon or angioplasty into the blocked or narrowed veins to allow blood flow to the heart. He named this surgical procedure liberation therapy (LT). The LT procedure is regarded as controversial because scientists have not been able to replicate the association between MS and CCSVI (Barrachini et al., 2013; Doepp et al., 2010; Sundström et al., 2010). The experimental treatment of 65 MS patients by

Zamboni was limited substantially in the study design, in that it was non-blinded and there was no provision for the control of placebo effects (Pullman et al., 2013; Zarzeczny, 2012).

This new medical procedure has not been sufficiently tested in Canada and as such it is not covered under the Canadian health care system as an insured service. Prior to the availability of a procedure that uses a new medical technology/device (or an existing device in a manner that is off-label) or drug therapy in the health care system, it must undergo four different phases/stages of clinical trials. The first phase involves recruitment and administration of the therapy to healthy patients/volunteers; this is to ensure that the new therapy does not cause danger or harm to the individual (Friedman et al., 2010). The second phase which is also a randomized trial is generally conducted on a fairly small number of people afflicted with the disease in order to test the efficacy of the therapy and further assess safety. Once the therapy is demonstrated to be safe, it is then administered under randomized trials in the third phase to assess efficacy and associated side effects (Health Canada, 2006). The fourth phase is administered when a therapy is approved by appropriate regulatory authorities for its long term usage to assess the risks and benefits at a population level (Friedman et al., 2010), as well as identifying the best ways of using the therapy.

LT has yet to undergo these stages outlined in order to be considered for coverage under the health care system. Currently the government has decided to fund phase I and phase II trials on the effectiveness and safety of LT. There is another new two-phase clinical trial called the Prospective Randomized Endovascular therapy in MS (PREMiSe) study at Buffalo, New York (US). This study employed standardized imaging techniques in a well-controlled double-blinded clinical trial of the procedure. Results published recently from the study revealed that LT does not benefit patients (Siddiqui et al., 2014). However, some MS patients based on anecdotal

evidence in the social and mainstream news media continue to engage in medical tourism for LT (Chafe et al., 2011; Fragoso, 2011; Laupacis & Slutsky, 2010; Pullman et al., 2013).

Medical Tourism

Background Introduction and Definition of Medical Tourism

Medical tourism or patient cross-border mobility involves patients who intentionally travel out of their geographical borders for a pre-arranged non-emergency health service, which mostly is paid out of pocket or by a health insurance company (Crooks et al., 2010; Dawn & Pal, 2011; Glinos et al., 2010; Lunt & Carrera, 2010; Snyder et al., 2011a). Medical tourism also has a "tourism" component whereby in seeking care in a spatial location, patients and their accompanied friends/or families are offered the opportunity to have fun, pleasure and relaxation (Buzinde & Yarnal, 2012).

Patients' crossing different geographical locations for medical care is not a new phenomenon (Swain & Sahu, 2008). Etymologically, medical tourism in the early ancient days involved seeking treatment at therapeutic landscapes. According to Gesler (1993, p. 171), therapeutic landscapes are places with "an enduring reputation for achieving physical, mental, and spiritual healing". In other words, some sites were believed to be places that enhanced healing. Therapeutic landscapes conceptualized the relationship between place and health, hence sites such as spas, yogas, zoos, youth camps, and religious sites became well noted for the psychological maintenance of health and wellbeing of the individual body (Williams, 2007). In applying the therapeutic landscape model, it is thus on record that as far as thousands of years back, where people travelled from all over the Mediterranean region to the Greek town of Epidaurus (a reputable place with perceived therapeutic functions) for healing at the sanctuary god of Asclepius which had a praying temple and gymnasium (Mason & Wright, 2011; Swain &

Sahu, 2008). Also, places such as the Roman Baths at Bath (England), Marian Shrine at Lourdes (France) and other prominent European towns became sites that enhanced healing among westerners (Mason & Wright, 2011). Patients' engagement in medical tourism in the early days was basically seeking non-medical interventions at various 'physical spaces' and 'sites' (Wendt & Gone, 2012, p. 1025).

As the medical tourism industry began to grow, patients from the developing world journeyed to the developed world for biomedical services (Reddy et al., 2010). These were mostly upper and middle class patients who could afford a medical procedure in the developed world. This type of medical tourism was based on the notion that the developed world is equipped with state-of-the-art medical facilities, highly qualified physicians and quality services (Einsiedel & Adamson, 2012). Medical facilities such as Harley Street in the UK, the Cleveland Clinic, Massachusetts General Hospital, Mayo Clinic and Memorial Sloan-Kettering Cancer Center in the U.S. which are noted for their high standard of care attracted patients from the developing world (Lunt et al., 2013; Turner, 2007a). This pattern of patient mobility is often referred to as the traditional model of medical tourism (Horowitz et al., 2008; Reddy et al., 2010).

In the 21st century, the concept of medical tourism took a new paradigm that involves patients from the Global North travelling to the Global South for biomedical services, mostly in private facilities (Herrick, 2007; Hopkins et al., 2010; Ramirez, 2007). This new trend, also known as West-East or North-South medical tourism, is mostly well planned, self-financed and often involves surgeries (Crooks et al., 2010). The notable countries of origin of the geographical Global North medical tourists are located in North America and Western Europe, whilst South East Asia, Latin America and Africa are the geographical locations of medical tourism destinations in the Global South. This pattern of patient flow has become the main focus of

medical tourism literature among scholars in contemporary times (e.g. Johnston et al., 2010; Labonte et al., 2013). The common services and procedures/surgeries patients often seek include cardiovascular (by-pass, valve replacement), orthopedic (hip and knee replacement), eye, organ and tissue transplantation (stem cell injection, kidney, heart, liver transplantations), reproductive system (fertility, gender reassignment), cosmetic (tummy tuck, breast, face and liposuction), bariatric (gastric by-pass, gastric banding), dentistry (cosmetic, reconstruction) and diagnostic and routine check-ups (Gupta & Das, 2012; Lunt & Carrera, 2010; Reddy et al., 2010). The notable origin countries of medical tourists are located in North America (US and Canada), Western Europe (UK, Germany) and Oceania (Australia, New Zealand) whilst South and Southeast Asia (China, Hong Kong, India, Malaysia, Singapore, Taiwan, Thailand), Central and Latin America (Argentina, Bolivia, Brazil, Chile, Columbia, Costa Rica, Cuba, Mexico, Panama), Eastern Europe (Hungary, Lithuania, Poland, Romania, Slovenia, Turkey), the Middle East (Dubai, Jordan) and Africa (Egypt, South Africa, Tunisia) are the geographical locations of medical tourism destinations (Burkett, 2007; Heung et al., 2011; Lunt & Carrera, 2010; Reddy et al., 2010). These destinations are imbued with unique characteristics in terms of patients' outcomes, types of services and patients' perceptions that distinguish them. For Canadian medical tourists, physician reputation becomes the key driving factor that may influence patient decision making process in choosing a destination (Johnston et al., 2012).

A litany of academic literature demonstrates that the direction of patients' flow from the Global North to the Global South is on the rising scale, even though data on this influx remains scanty and unreliable (Helble, 2011; Johnston et al., 2010; Lunt & Carrera, 2010; Smith et al., 2011). This is because the increasing porosity of borders has further compounded the tracking of the exact numbers of medical tourists. For instance, the liberalization of trade through free trade

agreements has enhanced the free mobility of goods and services (Runnels & Turner, 2011). This makes it difficult to gauge the actual number of people who travel for health care. Medical tourism is nascent in the academic literature; hence most of the figures about patient mobility are often based on speculations (Crooks et al., 2010). Despite this, there are anecdotal reports which show an increased influx of patients for biomedical services especially in the developing world. For instance in 2007 alone 750, 000 patients outsourced medical care in Thailand and India, and this number was expected to hit 1.6 million by 2012 (Helble, 2011). These projected figures indicate that most developing countries are positioning themselves to take advantage of the benefits offered by medical tourism. These countries have therefore developed various marketing strategies aimed at attracting patients. Particularly, the ministries of tourism in both India and Singapore have also promoted medical tourism using flyers at major airports in North America (Smith et al., 2011). Crooks et al (2011) noted that in 2009, the first ever medical tourism trade show was organised by the Indo-Canada Chamber of Commerce in Toronto (Canada). This conference highlighted India as the preferred destination for Canadians seeking affordable health care (Crooks et al., 2011).

Nevertheless, the increasing influx of patients from one geographical area to another for biomedical services has health implications for both sending and receiving countries of medical tourists. On the positive side, it is first contended that medical tourism will reduce fiscal deficits and increase the growth of national economies of the destination countries above 25% (Johnston et al., 2010). This is due to income and foreign exchange earnings realized from the development of the medical tourism industry, which can also be used to improve the health care facilities for both citizens and foreigners (Ramirez, 2007). For instance, the medical tourism industry is expected to bring in an estimated amount of US$4.4 billion to major destination countries in

South and Southeast Asia by 2012 (Heung et al., 2011). Also the Apollo (India) and Bumrungrad (Thailand) hospitals have realised an increment in their annual revenue generation by 20-25% (Herrick, 2007).

Second, it is argued that the quality of health care offered in the major destinations of medical tourists as a result of state of the art medical facilities and physicians can lead to high quality health care delivery (Bookman & Bookman, 2007). Third, and in consonance with the neoliberal framework, the increasing growth of medical tourism in the developing world will lead to the growth in various national incomes that would enable people equal access to private health care (Turner, 2007b). Finally, the burgeoning medical tourism in the developing world can lead to the retention of physicians thereby halting 'brain drain' (Johnston et al., 2010). This is based on the notion that many physicians after undergoing training locally remains in the country to serve both nationals and foreigners. It is argued that patients' mobility into the developing world for health care is seen as a solution to the problems of health systems in the developed world, particularly waiting times as in the UK and Canada and skyrocketing cost of medical care and health insurance in the US (Crooks et al., 2010). There are some procedures such as organ transplantation which are unavailable in the developed world as a result of legal and social constraints or inadequate supply. Medical tourism has emerged as an antidote to these challenges; especially in Canada, patients are reimbursed after seeking treatment outside, provided the treatment was pre-authorized by a specialist (Johnston et al., 2010).

Despite the arguments advanced above in support of the growth of the medical tourism market, there have been a lot of concerns regarding the 'trickle down' effects on the host and origin countries. Patients' engagement in medical tourism is shrouded with ethical concerns. In particular the unavailability of certain procedures in the developed world such as human organs

for transplantation and stem cell therapies necessitate patients' engagement in medical tourism in the developing world. In the event of any post surgical complications out of the surgeries, patients usually relied on their health care system of origin for care (Turner, 2007a). This raises the question of whether the health care system should continue to bear this indirect cost. Another major problem associated with medical tourism is the spread of infectious disease such as malaria, dengue fever, enteric fever and other infectious diseases which are acquired in major destination countries that lie in the tropical and subtropical regions (Chen & Wilson, 2013).

Again the rapid development of the medical tourism industry can be viewed as a conduit for diversion of resources and inequities in the use of public health care facilities (Connell, 2011). Various national governments often use resources to train physicians to augment the shortage of medical professionals in the country. These physicians after their training often establish private health care centers to take advantage of the booming medical tourism market leading to internal 'brain drain' (Johnston et al., 2010). This raises the cost of medical care to citizens because the motive of the private sector in the neoliberal system is profit maximisation. These private health care facilities levy patients at full cost; often leading to inequities in the use of medical facilities.

Advanced technology and quality of care, especially in Asia, is regarded as a magnet that attracts medical tourists. This situation has created unequal access to healthcare because it creates a conduit for multi-tier health care system in destination countries. As medical tourism is private sector driven, most of the health facilities are owned by private individuals or entities. Hence the net effect is that local residents with the financial resources can purchase higher quality care together with medical tourists, while many of the resource-poor local citizens will continue to receive a lower quality of care (Herrick, 2007). The inequities in accessing health care are compounded by the spatial distribution of health care facilities as most of them are located in the

urban centers. As a result, rural accessibility to health care is often limited. These are major concerns created by medical tourism, and in effect they violate the UN Declaration of universal human rights which include the right to health care (Smith, 2012).

Patients from the developed world seeking medical care in third world countries also undermine their own health care system (Crooks et al., 2010). In Canada for instance, patient engagement in medical tourism tends to also create a multi-tier health care system. This especially pertains to patients who cannot withstand the long wait times nor afford procedures not covered under Medicare. These people often engage in medical tourism thereby 'skirting' the core principles enshrined in the Canadian Health Act. Under the Act, all provinces and territories in Canada can receive federal funding for health services provided they uphold five core principles- public administration, comprehensiveness, universality, portability and accessibility (Wilson and Rosenberg, 2004). The public administration component requires that all provincial health insurance plans be carried out by a public authority on a not for profit basis with their accounts and records audited. Comprehensiveness ensures that all necessary health services (i.e. hospitals, physicians) must be insured. Universality deals with entitlement to the same level of health care. Portability entitles a resident to health care in a different province or territory for a minimum waiting time. Lastly, accessibility sets out for people to have reasonable access to health care facilities (i.e. physicians and hospitals) (Wilson and Rosenberg, 2004).

Medical tourism marketing companies' agents or brokers also play a very vital role in the development of the industry. These companies or third parties mostly pre-arrange care for patients abroad; playing the role as the intermediaries between patients and physicians outside their country (Turner, 2007b). As part of their marketing strategies, these companies advertise the various destination hospitals, procedures offered and their respective prices (Herrick, 2007).

These companies also assist patients in accessing physicians and quality care outside their territorial borders. Most of the medical tourism marketing companies in Canada place emphasis on timely access to health care internationally (Turner, 2012a). When a patient settles on a facility and a specialist for treatment, the company offer the patient "a case manager from the destination country to make arrangements for the procedure, including additional details such as cell phone service, transportation and airport transfers" (Herrick, 2007, p. 7).

Against this review of the medical tourism industry between the Global North and the Global South, the next section broadly highlights the rationale behind the mobility of Canadians for medical services especially in the developing world.

Reasons for Canadian Patients' Engagement in Medical Tourism

A paucity of academic literature has cited countries in the Global South as the major hubs for Canadian medical tourists (Crooks et al., 2010; Hopkins et al., 2010; Johnston et al., 2010, 2012; Turner, 2012a). Patients' cross border mobility for biomedical services in this review will place focus on the push and pull factors framework. The push factors are those conditions (mostly unfavourable) in Canada which motivates patients' mobility to the developing world, whilst the pull factors constitute the favourable conditions created in destination countries that attract patients from Canada (Crooks et al., 2010).

Push Factors

1. Cost of care: Soaring costs of primarily non-insured medical care serve as a major motivator for patients' cross border mobility. Medical tourism is often viewed in an economic sense at both the individual and system level scales; hence high cost of care drives people to find alternative care at lower cost (Runnels & Carrera, 2012). There is an increasing cost of certain procedures

which are covered or not covered under publicly funded systems (e.g. Medicare). As a result, patient mobility serves as the safety net for patients who cannot afford such procedures domestically. Particularly, the high cost of dental and cosmetic care triggers patients' engagement in medical tourism (Snyder et al., 2011b). Canadians are increasingly sourcing medical care in countries such as Brazil, India, Mexico, Philippines, Singapore, South Africa and Thailand (Turner, 2007a). It is now presumed that the countries in the developing world are offering 'First World health care at Third World prices' (Turner, 2007a, p. 310). The cost of a medical procedure to a Canadian patient in the developing countries such as India, Singapore and Thailand is far lower than that of Canada, even taking into consideration the cost of round trip airfare, accommodation, the care itself and miscellaneous expenses (Mason & Wright, 2011). Herrick (2007) identified various reasons that account for the low cost of health care especially in the developing world. First and foremost, the wages of physicians, nurses, casual workers and the other hospital staff are lower in the developing world. The net effect of lower labor and wage costs is that the operation of hospitals becomes cheaper. Second, prices of various medical procedures and packages in the developing world are quoted in a transparent manner. This makes it convenient for patients to compare prices, decide at which facility to have medical care and the portion of their budget they need to spend. For instance, countries in south East Asia such as India, Singapore, Thailand and Malaysia often provide information regarding the cost of medical procedures. This has resulted in competitive pricing among the countries outbidding each other in order to attract patients. Third, patients' mobility for health care is often in private medical facilities which are paid out of pocket. These facilities are specialized in their operations by focusing on a particular service which in turn provides efficiency in health care delivery. Bumrungrad (Thailand) and the Apollo hospitals (India) have specialized in surgeries and this

tends to attract patients who are in need of cost savings. Furthermore, liabilities and sanctions as a result of malpractice are lower in the developing world than in Canada. Consequently, physicians' payment of liability insurance tends to be lower in the developing world than their counterparts in Canada. Last but not least, various governments, especially in the developing world, have offered tax incentives for the importation of medical equipment and as a result this tends to lower the cost of care in the region.

2. Wait times: Delay in accessing medical services such as drugs and procedures tend to make patients mobile. The rise in demand for health care without enough medical facilities and physicians often leads to patients waiting longer to access available health care, especially in publicly funded health care plans (Turner, 2007a). In Canada, studies show that Medicare has led to an increase in demand for health care resulting in long waiting lists (Eggertson, 2006; Johnston et al., 2012; Ramirez, 2007; Runnels & Turner, 2011). Eggertson (2006) argues that the long waiting times in accessing procedures such as cardiac, orthopedic and cosmetic surgeries in Canada have culminated in patient mobility to India (with facilitation from medical tourism marketing companies) to undergo the procedures. Eggertson further noted that patients with osteoarthritis (hip and knee placement) need not be on a waiting list in places like India in order to have the procedure done. India for instance has therefore become 'a nation where it is possible to receive timely, high-quality, affordable medical care' (Runnels & Turner, 2011, p. 43). The various procedures are therefore performed at cheaper and faster rates without apparent associated risks (Eggertson, 2006). Similarly, Medicare produced a backlog of the number of people in long queues waiting to book an appointment with a specialist, in order to receive both emergency and non-emergency health care. As a result, those who cannot wait to have their turn at health care centers tend to jump the long queues in order to have similar care in developing

countries. Seeking offshore care is even evidenced when the condition is deteriorating at a faster rate. Tourists marketing companies such as Speedy Surgery, Timely Medical Alternatives and Surgical Tourism have emerged in Canada to offer medical tourism services (at a fee) to patients who cannot withstand the delay in getting appointments with a physician (Turner, 2007a). It is, however, worth noting that various public opinion polls conducted about people perceptions of accessing health care revealed that, due to claims of delays in accessing health care in Canada, people's confidence level about the Canadian health care system is dwindling at a faster scale (Wilson & Rosenberg, 2004).

3. Non-availability of care: Non-availability of certain procedures in Canada as a result of social, economic, political and legal reasons tends to push patients to the Global South (Horowitz et al., 2008; Johnston et al., 2012). National laws have regarded certain procedures relating to reproductive medicine as unethical or immoral (Cortez, 2008). An empirical study conducted on Canadian patients who engaged in MT shows that non-availability of certain procedures in Canada is caused by "the procedure not being approved by safety regulators, the patient being ineligible for surgery due to age or the absence of a diagnosis, or the lack of domestic surgical expertise to perform the surgery" (Johnston et al., 2012, p.7). The authors concluded that non-availability of services such as liberation therapy for multiple sclerosis and eye surgery for retinitis pigmentosa in Canada served as a major contributory factor for patient mobility. The unavailability of certain procedures has led to a growth in tourism marketing companies in Canada, and they are especially promoting countries in Southeast Asia as the one-stop shop for medical services even at faster and cheaper rates (Turner, 2007a).

Pull Factors

1. Quality of care: The advancement of technology has raised the quality of medical care in the developing world, particularly Asia. Most of the hospitals in Southeast Asia that promote medical tourism have advanced medical technologies that perform procedures that are not available in the Global North. The hospitals can also boast of facilities which are of the same standard or even better than some hospitals in the developed world. For instance medical facilities such as the Wockhardt Hospitals Group in India, Bumrungrad Hospital in Thailand and Penang Adventist Hospital in Malaysia, which are Joint Commission International accredited and renowned for the provision of first class health services to patients (Cortez, 2008; Turner, 2010), and have state of the art medical facilities that are comparable to those in Canada. Due to the influx of medical tourists particularly from Canada, the Indian government has encouraged the growth of the medical tourism industry by giving tax incentives to medical facilities to import high technological medical equipment (Burkett, 2007). This enables medical facilities to perform surgeries with greater efficiency.

2. Accreditation of health care facility: Medical facilities are accredited to showcase that they meet acceptable criteria in terms of quality and competence (Cortez, 2008; Turner, 2010). Burkett (2007) points out that the Joint Commission International, an affiliate of the international division of the Joint Commission Resources, and a reputable organisation based in the US has the mandate of issuing accreditations to hospitals. The number of hospitals accredited by this body as at mid-2012 was at 370 with the majority of them located in Asia (Runnels & Carrera, 2012). The International Standards Organization also accredits hospitals, taking into account their own bench marks, and together with the Joint Commission International about 150 facilities have been given accreditation globally (Herrick, 2007). Countries such as Brazil, India and

Thailand are also setting their own standards in terms of quality delivery of care (Herrick, 2007; Turner, 2010). Accreditation has a preponderant influence to patients choosing a facility for health care. As such many of them would prefer a destination where the standard of care is the same or even higher than what they get domestically (Smith & Forgione, 2007). The accreditation serves as the source in which the various health care facilities market their products to patients, because it is the accreditation by the Joint Commission International that will inform patients about the standard of care in a particular facility (Turner, 2010).

3. Familiarity: Language, culture and religion are important variables patients consider prior to outsourcing medical care (Glinos et al., 2010). Familiarity with treatment may due to linguistic or historical connections. India and Singapore, two former British colonies, use English language as the medium of communication and as a result, health care facilities in those countries attract patients particularly from Canada, a predominantly English speaking country (Burkett, 2007). The familiarity and attraction to these medical facilities stem from the notion that most of the medical practitioners in India had their training in English speaking countries. For instance Canadians are increasingly seeking care in Bumrungrad hospital in Thailand because most of the surgeons of the facility speak English and also had their certification from the US (Connell, 2006). The familiarity with the language allows patients to voice out their conditions without difficulty. The physicians are able to give the best care to these patients. In health care facilities where physicians cannot speak English, there are interpreters to health patients from English speaking countries (Burkett, 2007).

4. Physician training: Physicians trained in the developed world and very conversant with English language are the centres of attraction for patients (Smith & Forgione, 2007). The quality of care just as in the case of the Joint Commission International accreditation is intrinsically

linked to physician training. Most of the physicians in these destination facilities had their training in the developed world. In recent times there is also greater collaboration between universities in Asia and US (Turner, 2010). Turner further shows that the growing number of US medical universities campuses in the developing world is a case in point; for example, establishing a satellite campus of Duke University has trained medical doctors in Singapore. There also other reputable sites that train health personnel and these include National Institutes for Health, Johns Hopkins University and the University of Birmingham (Turner, 2007). These institutions have raised the standard of care and credentials of the developing world as the preferred destination for biomedical services. There are also many medical institutions in the developing world that are designing their curricula along the international standards using English language as the medium of training for physicians (Cortez, 2008).

5. Tourism aspect: Patients from Canada are attracted to a place where they can have 'touristic' activities such as holidaying. In particular, patients are attracted to the developing world because they can boast of the best tourist facilities such as nice beaches and resorts, quality sun shine, mountains, historical and religious sites (Garcia-Altes, 2005; Marlowe & Sullivan, 2007). Connell (2006) also argues that family and friends who accompany patients for medical tourism mostly engage in leisure and fun at resorts whilst the patient is recuperating. Hence marketing strategies of medical tourism have incorporated these cultures. Again, Connell (2006) shows that Thailand, aside from the quality of the medical facilities advertised, is also viewed as the hub of destination for people who are in need of pleasure whilst at the recuperating stage. Similarly, Whittaker (2008) reveals that patients sometimes enjoy vacation times in resorts, whilst they are recovering from their post-operative care. These activities often involve fun and pleasure at beauty spas and golf facilities for patients who can afford to participate in them. The hospitals in

the destinations for medical tourists also provide a favourable atmosphere for patients to have relaxation, whilst hotels are closer to these facilities for people who accompany the patients (Whittaker, 2008).

Medical Tourism and Liberation Therapy

With regard to the LT procedure, it falls under the non-availability of care framework as it is yet to be offered in Canada. As stated earlier, LT is still undergoing clinical trials in Canada in order to test its efficacy. The role of tourism marketing companies is very vital in the facilitation of patients' mobility for LT as a treatment for CCSVI. For instance, the exponential rise in the demand for LT has led to the emergence of two medical tourism marketing companies in Manitoba and Ontario, and these companies provide packages that include the cost of the procedure, airfare and hotel reservations as well as tours (Turner, 2012a).

Patient engagement in medical tourism for LT is often based on individual choice; hence the kind of information received and its utilization is vital for patient engagement in medical tourism for the LT procedure. A study conducted by Smith and Forgione (2007) concluded that patient decisions to engage in medical tourism are based on two main factors: choice of a country and choice of a healthcare facility in that country. The choice of the country according to the study is influenced by economic conditions, political climate and regulatory standards whilst accreditation, costs, quality of care and physician training tends to be very influential in deciding on the facility in which care is administered. MS patients usually make decisions as to the place they can have access to the LT procedure taking into consideration information about the country and the facilities available. The decision to choose a particular country and a facility over another is often influenced by the information searched on websites (Lunt et al., 2010). The notable

places for the LT procedure include Brazil, Bulgaria, Costa Rica, Poland, India, Mexico and the United States (Pullman et al., 2013; Turner, 2012a).

MS patients' embarking on medical tourism for LT is often seen as a risk that involves travelling (Crooks et al., 2010). While some MS sufferers experienced minor or no complications after undergoing the LT procedure, others have developed severe complications especially in the heart and neck veins which demanded further operations (Burton et al., 2011; Chafe et al., 2011; Samson, 2010). The post surgical complications that developed as a consequence of LT surgery typically place an indirect cost on the patient's domestic health care system. This is because when patients return with complications, the health care system is bound to provide them with care. In some cases, deaths have been documented as a result of the procedure. For instance, a 35 year old MS patient from Ontario in November 2010 underwent LT in Costa Rica, and later died when he returned for the post-surgical care (Penney et al., 2011; Pullman et al., 2013). Despite this, the LT hypothesis continues to take center stage, which is often discussed in the public domain through the press and other social media, with the Internet becoming a place to propagate LT as a panacea to MS whilst "Zamboni is described as the martyr" (Fragoso, 2011, p. 69). There are signs this may be abating: trials supported by the Saskatchewan government have been halted due to lack of recruitment especially in the US (Graham, 2013).

Nonetheless, the case study showcases mobility on many fronts: mobility between locations, mobility of ideas, and how these ideas are contested between different sets of actors operating within institutionalized spaces (e.g. from science to policy, from media to public etc). It shows that patients have taken the responsibility for their own care from the immobile health care system. As such, those with the necessary financial resources can travel to other geographical locations for procedures that are not available in the Canadian health care system. These patients

can decide the destination and physician to seek treatment after consulting various online mobile sources; effectively transforming invisible mobility (i.e. information transfer through cyberspace within the comfort of their home) into visible movement between locations (i.e. medical tourism). More importantly, the idea of LT has been very mobile. For instance, initially started in Italy, LT was popularized in Canada and other geographical regions. Through the "mobilizing power of the media and the Internet" (Chafe et al., 2011, p.410), LT debate shifted from 'evidence-based science' to 'Internet-based practice' (Reekers, 2012, p.127). Patients (fuelled by online anecdotal stories) put considerable pressure for its availability in the health care system as an insured service. The idea of the procedure further attracted the attention of policy makers and assumed a political dimension. Thus, federal, provincial and territorial governments' were required to respond to the issue.

The Media

Media outlets such as the television, Internet, radio and newspapers entertain and inform the general public. A study found that, compared to friends and relatives, scientific experts, pressure groups or industry as sources of information, the rate of Canadians likely to consult news media (35.1%) for health and risks issues and events tend to be higher (Krewski et al., 2006). The media typically receive news from public relation officials from various institutions and organizations and they tend to give prominence of such news stories to the lay public (Rosenau, 2006).

A major focus of this study is to analyze the print media/newspapers stories. Newspaper stories, like any other story, comprise a beginning, middle and an end. Newspapers typically begin with a headline and a lead that informs the theme of the story and also seeks to influence readers to read the full story (Schudson, 2003). To Schudson, the headline which precedes the lead is

highlighted boldly and seeks to tell the nature of the story, although recent research raises some concerns over an unproblematic treatment of the lead (Mistry & Driedger, 2012). The lead is usually found in the first paragraph of the story and is composed of one or two sentences that provides a brief summary of the whole story covering the "w" questions-"who, what, when, where, and (sometimes) why" (Schudson, 2003, p.185). The lead provides the reader with interesting facts that may motivate him/her to read the story. As such, news editors' typically present 'catchy' headlines that will compel readers to read the news story in its entirety. Newspapers also endeavor to craft their stories in an inverted pyramid style (i.e. the essential information is on the first paragraph and as the reader goes through the story, the subsequent paragraphs become less important till the end of the news story) (Schudson, 2003). While a story may be written by an author, it is the editor who usually composes the story headlines and leads in order to attract the attention of readers, although this too has been progressively shifting to the story writer (Mistry & Driedger, 2012). The use of headlines and leads will help inform the tone of the stories (i.e. positive, negative and neutral) that the media outlet presents in relation to CCSVI, LT and medical tourism.

The process of gathering and disseminating news often involve negotiations and struggles between news media organizations and their sources (Erickson et al., 1989). News outlets are often regarded as very powerful in influencing public opinion and policy decision making as they determine issues that are to be covered (Siegel, 1996). News sources on the other hand have the power to control information by not cooperating with a reporter (e.g. not granting interviews to journalists) (Ericson et al., 1989). To balance this, both news sources and media outlets often engage in a constant state of negotiation and re-negotiation and informal rules of engagement in order to produce news for the general public. News sources serve as an important component in

the construction of the news and as such journalists rely on different sources they consider as authoritative (Ericson et al., 1989). To make their stories stand the test of time, journalists often use sources "who can be trusted, who command respect, and who can present information in a packaged, easy-to-edit-and-digest fashion" (Bishop, 2001, p.25). They also use direct quotations to make firm the legitimacy, authenticity and credibility of their source while distancing themselves from the story covered (Bishop, 2001; Ericson et al., 1989). However, journalists' objective reportage can be compromised when news stories are centered on tragedy, public health issues or threat to the security of a state (Shudson, 2003). Under these circumstances the media typically present 'one sided' stories that can be aimed at achieving the common interest of the journalists and the general public at large (Schudson, 2003).

There are two main categories of sources: elite and non-elite types (Driedger, 2008). The elite sources are those bureaucratic organizations with needed resources (e.g. a communication department staffed with official and unofficial spoke persons). Non-elite sources typically lack committed or sustained financial resources and are often individuals or non-governmental organizations (Bishop, 2001; Driedger, 2008; Schudson, 2003). The media rely mostly on the elite types (as they are more easily accessible); hence these sources often organize themselves to prevent intrusion by the media to access certain information that can damage its reputation (Ericson et al., 1989). Ericson et al. (1989) developed a model comprising of regions and closures which are meant to curtail journalists' access to information in a bureaucratic organization. According to the model, the elite news sources typically have public relations departments or "front regions" which are easily accessible to journalists for information whilst various strategies are put in place in the "back regions" to prevent journalists from accessing information and knowledge that is strictly meant for authorized personnel only within the

organizational set up. However, media outlets can have access through other means within the organization. Although the media often rely on the elite source types to construct their stories, they also incorporate non-elite sources in order to balance the media's overall presentation of stories. This study will analyze how these two source types are portrayed in the media to assess if some source types are promoted more than others, or if the positions advocated by certain source types are more privileged than others with an aim to examine how these framings support (or not) patient mobility for a contested medical procedure.

The media equally has an influence in risk communication. Risk communication refers to ''the exchange of information among interested parties about the nature, magnitude, significance, or control of a risk'' (Covello, 1992, p. 359). In risk communication, the credibility and reliability of information sources, the quality and clarity of the message and the effectiveness and efficiency of the channel of communication are variables that have an impact on how risk is communicated to the lay public (McCarthy et al., 2008). A major component exerted by the media in risk communication is the application of the social amplification of risk framework (Kasperson et al., 1988; Pidgeon et al., 2003). The framework suggests that in communicating health risk issues or events, the media as a formal channel of communication can amplify or attenuate the voices of the experts and the 'lay public' (Kasperson et al., 1988; Lewis and Tyshenko, 2009; Pidgeon et al., 2003). The emphasis of the framework is on the "metaphor of amplification: signals are received, interpreted, amplified, and passed on by different social actors" (Vasterman et al., 2005, p.111). In the framework, risk amplification occurs when experts regard events to be of low risk, but the public judge such events as high and pay more attention to them. Risk attenuation occurs when the lay public concludes that events are not that serious, hence less attention is given to them but the experts think the public should give them the needed

attention. The importance of risk communication in the thesis is to offer an understanding on how the Canadian media (informed by the concept of framing) amplifies or attenuates the experts and the 'lay public' voices on LT as a risky/not risky medical procedure. The actions of patients to embark on medical tourism can be regarded by others as reckless, risk takers, adventurers etc. This is because the procedure has not been scientifically proven to be effective, yet patients are willing to take the risk and bear the financial cost. Media framings of patient actions or the reactions of others (e.g. scientists) through the social amplification of risk framework lens helps to conceptualize different perspectives of the 'risk' involved.

Media and Scientific Discoveries

The general public and health professionals rely on the media as a primary source of information on research findings and new therapies (Phillips et al., 1991). Health journalists are often required to provide balanced, quality and comprehensive coverage of medical advances; this is because it is the media that mostly influences the public and health professionals' perceptions about new health treatments (Cassels, 2007). However, there seems to be poor media communications of scientific information to the general public. The barriers to quality health news coverage include: lack of full time health beat reporters in some media organizations, lack of technical training for journalists, commercial motives drive the selection of some stories and headlines, insufficient space and time to cover health issues, use of a single source of information, an editor's demand for sensational stories, etc. (Larsson et al., 2003; Picard, 2005).

Too often, journalists give prominence to positive medical advances over negative results; the likely result is unbalanced reporting to the general public especially of controversial scientific discoveries (Koren & Klein, 1991). Unbalanced media reports on biomedical advances can also

inflate unnecessary expectations especially when it is distorted, exaggerated and oversimplified (Cassels, 2007; Chang et al., 2014).

Newspapers reporting on anecdotal stories about treatments in a positive context can send wrong signals and hype unproven medical treatments (Chang et al., 2014). For example, a study conducted on 36 Canadians' responses to media anecdotal stories on stem cell therapy suggests that the majority of the participants will engage in medical tourism for the procedure; this is against the backdrop of copious materials that participants read about the risks of the procedure from the International Society for Stem Cell Research (Einsiedel & Adamson, 2012). The paucity of 'one sided' media reports on new treatments can also raise false hopes and relegates the costs, complications and the dilemmas of accessing such therapies (van Trigt et al., 1995). For instance, when trastuzumab (Herceptin) was discovered in 1995 as the new therapy for the treatment of breast cancer, the Canadian media focused on the perceived benefits of this new therapy despite its limitations as compared to existing therapies at that time (Cassels, 2007). The massive coverage of this new therapy for the next half of the year stirred controversy and pressure was brought to bear on provincial health plans and cancer agencies to fund the therapy without regard to further trials (Cassels, 2007).

As noted earlier on, the debate as to whether there is an association between CCSVI and MS has generated significant attention in the media. Documented in the portrayal of LT in the media, MS patients and advocacy groups brought pressure on the federal, provincial and the territorial governments of Canada to spend part of their budgets on phase I and phase II trials (Health Canada, 2011). The federal government in a press release in September, 2012 devoted $6 million dollars to have trials conducted in select provinces with two years monitoring of patients who participated in the trials (Canadian Institutes of Health Research (CIHR), 2012).

At the provincial level, governments through various press releases also allocated funds for clinical trials, observational studies and setting up registries. In April 2011, Manitoba set up $5 million to partner with Saskatchewan in advancing clinical trials research on LT (Province of Manitoba, 2011). Saskatchewan in early 2012 further announced a $2.2 million out of the $5 million package for clinical trials of 86 Saskatchewan patients at a medical centre in Albany, New York (Government of Saskatchewan, 2012); however the trial was suspended due to lack of volunteers in the US (Graham, 2013). Alberta also devoted $1 million in support of 3 years observational studies to track the experiences of MS patients who had LT (Alberta Health Service, 2011). Similarly, Newfoundland and Labrador commissioned and provided $400,000 to support an observational study of patients who sought LT overseas, whilst New Brunswick decided to set up a fund to subsidize MS patients travelling offshore for treatment (Pullman et al., 2013). In addition, British Columbia set up a registry and invested $700, 000 to monitor MS patients who had LT (Vancouver Costal Health, 2011). These policy decisions by the federal and provincial governments provided the media with a vital role in helping to shape the relationship between science and policy (Pullman et al., 2013). Likewise, while Saskatchewan supported mobility of patients to participate in research trials, New Brunswick supported the mobility of patients to purchase LT on the global market. Arguably, the action of New Brunswick undermines its own health care system. The policy decision has the potential to create an artificial two-tier system around a particular disease treatment, and effectively undermines the policy that enjoins all insured residents entitlement to the same level of health care accessibility.

Media and Agenda Setting

Agenda setting research can be traced back to the early 18th century when the late Robert E. Park first examined the role of the media as gatekeepers. According to Park (1922), media gate

keeping highlights the tendency of the media to generate an extensive coverage of certain issues, whilst pay little attention or ignoring others. In his classical book, Park emphasized this point in the following words:

> Out of all the events that happened and are recorded every day by correspondents, reporters, and the news agencies, the editor chooses certain items for publication which he regards as more important or more interesting than others. The remainder he condemns to oblivion and the waste basket. There is an enormous amount of news "killed" every day (Park, 1922, p.328).

Over time, the gate keeping role of the media was effaced with agenda setting which in broad terms refers to the ability of the media to give prominence to certain news stories over others, and the importance attached to such news stories by the audience (Scheufele & Tewksbury, 2007). The power of the media to set the agenda has been challenged by others, as they argue for a more nuanced understanding for how the media and its sources may help shape or build agendas (Driedger, 2008; Lang & Lang, 1981, 1983). Nonetheless, the agenda function of the media suggests there is a direct correlation between the salience of the issue in the media and the importance attributed to the issue by the general public especially over a short time frame (Collins et al., 2006).

The time and space dedicated to a news story by the media determines its potential importance for its audience. Large media outlets often have beat reporters who are usually assigned to areas in which they have expertise (Ericson et al., 1989). For instance in covering health issues, the print media outlets assign beat reporters in areas such as medical research, the health care system, public policy, lifestyle and alternative healing methods (Gasher et al., 2007). There are also beat reporters in departments such as general news (local and foreign), sports, entertainment, business and features (Schudson, 2003). News beat reporters assigned to elite sources (e.g. the police, court, legislature and the private sector) becomes part and parcel of the organization and

as such they are also involved in the production of news (Ericson et al., 1989). Whilst the beat reporters help shape the agenda in their areas of expertise, the final decision to make salient the news item is often shifted to the editor of the news outlet. The decision to select a story can limit its definition and meaning, and depending on the kind of information included or excluded, the story can be subjected to different interpretations (An & Gower, 2009).

An important characteristic of the media in its agenda shaping role is the newsworthiness of a topic, which is the likelihood that an event, issue or people may attract much attention in the media. Stryker (2002, p.521), argues that "medical information that is topical, unusual, controversial (in subject matter or in results), or affects a large number of people is likely to receive media coverage." In addition, Bennett & Calman (2005) identified health issues, events and people that can trigger media attention. These include: blame, human interest, high profile personalities and issues, secrets and cover-ups, visual impact, sex/crime, conflicts and exposure to risks.

The worthiness of news also involves a process in which something highly unusual or strange happens (Schudson, 2003; Vasterman et al., 2005). In this case, the phrase 'what a story' (Tuchman, 1973, 1978) becomes the norm and as such news media outlets tend to abandon covering other story topics and rather concentrate on that particular event for days, weeks or months (Driedger et al., 2009; Frank, 2003). In a 'what a story' package, the media usually respond to big, breaking news, and this coverage transcends from local level to the region, state or country levels of scale (Frank, 2003; Tuchman, 1978).

The media coverage of CCSVI and LT had the main features that entail newsworthiness. The story was first broadcast on November 21, 2009 CTV network 30-minute documentary entitled

"The Liberation Treatment: A Whole New Approach to MS", and was subsequently followed by Globe and Mail newspaper story with the headline "Researcher's labor of love leads to MS breakthrough" (Pullman et al., 2013). The stories which received much front page coverage portrayed how the introduction of CCSVI and LT by Zamboni will 'liberate' MS patients from their sufferings. Both the broadcast media and print news stories on CCSVI and LT also captured some of the elements of news triggers as highlighted by Bennett & Calman (2005): human interest (Zamboni as a hero, MS patients as victims, government and the scientific community as villains), conflict (scientific/medical community vs. MS patients/advocacy groups), strong visual impacts (MS patients suffering in wheel chairs who can then walk following the LT procedure) and high profile personalities (provincial and federal government officials).

In agenda setting, the media "may not be successful much of the time in telling people what to think, but it is stunningly successful in telling its readers what to think about." (Cohen, 1963, p.13). According to Nesbitt-Larking (2007), agenda setting involves different actors and mostly depends on issues at stake. Nesbitt-Larking further posits that the general public set the agenda on economic issues such as unemployment and inflation, for debt and deficit and national unity, it is the government whilst the media sets the agenda on issues that focus on AIDS and crime. The role of agenda setting is to quantify the salience and presence of an issue and how it changes over time (Dearing & Rogers, 1996; McMahon & Chow-White, 2011). The agenda function for this study will focus on the changes in media stories in relation to the number of media stories, story placement, word count, tone of story (i.e. positive, negative or neutral) and the type of story (i.e. new story, editorial or profile story).

Chapter 4

Methodology

Study Design

This research follows a case study design which involves an in-depth "exploration of a phenomenon within its context using a variety of data sources" (Baxter & Jack, 2008, p. 544). A case study is usually appropriate for an in-depth study of an issue or a phenomenon (Crowe et al., 2011). Stake (2000) has identified three main categories of case studies-intrinsic, instrumental and collective case studies. Intrinsic case studies involve cases that are very unique and of special interest to the researcher. For instrumental case studies, the aim is to provide an insight into an issue or event or refine a theory. Regarded as an extension of instrumental case study, the collective case study involves an amalgamation of multiple cases for the purpose of investigating a phenomenon, population or a general condition. The use of this method allows for better appreciation of the case when different issues are compared across different levels of scales (Crowe et al., 2011).

This study adopts the instrumental case study, which as Stake (2010, p.437) notes: "the case is of secondary interest, it plays a supporting role, and it facilitates our understanding of something else. The case still is looked at in depth, its contexts scrutinized, its ordinary activities detailed, but all because this helps the researcher to pursue the external interest". The decision to select this case study mirrors the main goal of the study, which is to help us better understand how the theory of mobility, engaged through the specific act of medical tourism, facilitated by the easy spread of ideas about LT, challenges the traditional boundaries of a health care system or health policies in a globalised world. As a result, medical tourism or patient mobility for CCSVI and LT will be examined in depth.

The approach for this particular case study involves both qualitative and quantitative methods. The quantitative component delves into measuring the frequency of print media coverage on the issue, whilst the qualitative aspect deals with a more nuanced interpretation of themes and frames from both print media and televised stories. In using a mixed-methods design, the quality of the analysis is strengthened because themes coming from the data are authenticated through the different levels of analysis. In this regard, print media will be used as the main sources of data. To accomplish this and the objectives of the research, news stories from over a four year period (i.e. October 1, 2009 to October 31, 2013) were examined from national and various geographic regions of Canada (i.e. Alberta, British Columbia, Manitoba, New Brunswick, Ontario, Saskatchewan and Quebec)[1]. The focus of the research on these provinces is feasible because first and foremost, they have higher rates of MS in Canada. Second, three of these provinces (British Columbia, Manitoba and Quebec) have been earmarked for the Pan-Canadian trials of CCSVI and LT. Other provinces (New Brunswick and Saskatchewan) have attached a sense of urgency to funding clinical trials and sponsoring patients for the procedure outside the country. As a result, there is considerable media coverage of news stories on the issue primarily in these provinces than other regions of Canada.

The analysis was supplemented with one special televised documentary on CCSVI and LT from W5 CTV National News. This news story set the parameters and reference point for the debate in the media.

[1] Canada has 10 Provinces and 3 Territories that can be broadly grouped into different geographical distinct regions based on their locations. While these groupings can be debated, for the purposes of the thesis, the regions are organized as follows: the Atlantic Coast (Newfoundland & Labrador, Prince Edward Island, Nova Scotia and New Brunswick), Central Canada (Ontario and Quebec), Prairie (Alberta, Manitoba and Saskatchewan), Pacific Coast (British Columbia) and the North/Territories (Northwest Territories, Nunavut and Yukon).

Data Sources

This study relied on two main sources of data; the W5 CTV televised broadcast and the print media newspaper stories.

Televised News Media:

The thesis incorporates a W5 CTV National News (a televised media) Special Report entitled "The Liberation Treatment: A whole new approach to MS" by Avis Favaro, a medical/health reporter. This particular report was vital to the thesis because it has been characterized as a 'defining moment' for the CCSVI and LT debate and also it was arguably the longest news special to be run globally.

Print News Media:

The focus of the study is on published articles in some selected print newspapers that represent the various geographic regions of Canada. The newspapers included are the Globe and Mail and National Post (National coverage), Vancouver Sun (British Columbia), Calgary Herald and Edmonton Journal (Alberta), Regina Leader-Post (Saskatchewan), Winnipeg Free Press (Manitoba), Toronto Star (Ontario), Montreal Gazette (Quebec) and Telegraph Journal (New Brunswick). The details of the newspapers are shown in Table 4.1.

Table 4.1: Newspaper Circulation in Canada

Name of Newspaper	Province	Frequency	Ownership	Weekly Total
Globe and Mail	National	Mon-Sat	Globemedia Inc.	1,813,141
National Post	National	Mon-Sat	Postmedia Network Inc.	1,017,394
Vancouver Sun	British Columbia	Mon-Sat	Postmedia Network Inc.	987,040
Calgary Herald	Alberta	Mon-Sun	Postmedia Network Inc.	890,027
Edmonton Journal	Alberta	Mon-Sun	Postmedia Network Inc.	713,653
Regina Leader-Post	Saskatchewan	Mon-Sat	Postmedia Network Inc.	249,589
Winnipeg Free Press	Manitoba	Mon- Sat	FP Canadian NP LP	679,505
Toronto Star	Ontario	Mon-Sun	Torstar Corporation	2,503,284
Montreal Gazette	Quebec	Mon-Sat	Postmedia Network Inc.	683,327
Telegraph Journal	New Brunswick	Mon-Sat	Brunswick News Inc.	168,003
Total				9,704,963

Source: 2012 Daily Newspaper Circulation Report (Newspapers Canada, April 2013)

These newspapers were used for several reasons. First, they are easily accessible on a daily basis, they reach a significant number of readers and have a cumulative average weekly circulation of over nine million copies in 2012 (Newspapers Canada, 2013). Second, these newspapers are available for electronic searching through the ProQuest Canadian Newsstand and Major Dailies database. Third, the use of the print media is preferred because one previous study demonstrated that the print media provided more comprehensive process-oriented stories than televised stories, even though the relative content was similar for both source types (Driedger, 2007). Last, the decision to study newspapers is based on the great depth of academic knowledge which highlights the importance of newspapers in influencing public perception and public opinion (Rowe et al., 2000; Siegel, 1996).

Data Collection

The collection of data for the study commenced with the broadcast documentary and was followed by print media stories.

Televised News Media:

The special report on CCSVI and LT which appeared on CTV National News in November, 2009 was reviewed and transcribed verbatim for analysis.

Print News Media:

News stories were searched from the ProQuest Canadian Newsstand and Major Dailies database, using "Liberation" and "Multiple Sclerosis" as the main key words. The use of "Liberation" is preferred as one previous study identified that it yielded more stories than "Liberation Therapy" or "Liberation Treatment" or "Liberation Procedure" (Tulk, 2013). It is important to note that rather than using manually searched microfilm, the use of the electronic database in searching for the articles is preferred because it is less cumbersome and more reliable. Inclusion and exclusion criteria were defined and applied to the news story articles. To be included in the study, 60% of the news story's content has to address issues regarding MS, CCSVI and LT. The news stories must be published in English language and must also be between October 1, 2009 to October 31, 2013 timeframe. This period is chosen because it coincided with the introduction of LT, the government's 'wait and see' approach and finally the government's decision to fund phase I and II clinical trials which are still in progress.

Data Analysis Procedures

The data from the print media was formatted in Microsoft Word™ 2010 and imported in NVivo™ 9. The NVivo™ 9 is a computerized qualitative data management software programme designed for analyzing textual data (Bazeley, 2007). The use of this software replaces the cumbersome traditional method of manual coding (i.e. paper coding) as it offers "the genesis of the new age in qualitative research" (Jones, 2007, p.69). The software enables better management of large amount of data, saves time and energy, offers flexibility, provides greater accuracy and transparency, and yields faster and comprehensive methods of data inquiry (Jones, 2007). Though the software does not 'do' the analysis of the data, it helps in the organization and retrieval of data for analysis. The software can also provide space for the creation of theoretical and conceptual memos which helps in data analysis.

The strategy selected for the analysis of the data was thematic analysis informed by a media framing interpretative lens. Thematic analysis is mostly used with qualitative data and it involves the identification of themes or patterns emerging from a dataset or text which are put into various categories for analysis (Fereday & Muir-Cochrane, 2006). Thematic analysis also involves a process whereby patterns or themes are identified, analyzed and reported within the data (Braun & Clarke, 2006). A unique characteristic of thematic analysis is the ability to provide an in depth account of data, which can be organized in terms of themes, sub-themes (Braun & Clarke, 2006) and frames.

Thematic analysis for the data followed a model developed after Braun & Clarke (2006). In this model, Braun and Clarke provide a number of decisions to be considered when conducting analysis. These include the following features:

a. What counts as a theme: In conducting thematic analysis, themes are considered to be essential components of the data and they also capture the necessary elements in the research question. The prevalence of themes are mostly measured in terms of their number of appearance in each dataset, or the number of people who gave their opinion on a particular theme. For this particular case study, the themes were the unique patterns that portrayed key stakeholders' perspectives on patient mobility for CCSVI and LT.

b. Whether to focus on inductive or deductive analysis: Inductive analysis, a 'bottom up' approach, deals with the data. The coding scheme and development of themes are dictated by the content of the data gathered rather than the researcher's preconceptions. On the other spectrum, the deductive or theoretical, a 'top down' approach employs pre-determined concepts or ideas in developing and coding themes. Deductive analysis allows for a large dataset to be refined into manageable a size, and as a result, it does not provide a sense of rich description of the data. For the purpose of this study, the decision was made to carry out inductive analysis. This process was preferred because themes were inductively developed by repeatedly reading the dataset.

c. The decision to focus on semantic or latent level of themes: With the semantic level, the focus is explicitly on the surface meaning of the data. On the other hand, the latent is a more detailed and nuanced account of the semantic content. It entails the key ideas, conceptions, theories and assumptions that underpin the data. With the latent approach, a more complex and insightful analysis is conducted and this goes beyond the scope of mere observation of the data. This current case study focuses on media framing analysis on patient mobility for CCSVI and LT. As a result of this, the latent level was used to interpret the media frames and key stakeholders opinions of this medically contested procedure not available to Canadian

MS patients. With this approach, text was read for latent meanings in how patient mobility for CCSVI and LT is framed in the Canadian mainstream news media.

Following from the decisions outlined above, Braun and Clarke (2006) further developed a six-phase framework used for the development of codes for thematic categories and frames (See Appendix 1 attached). These phases are as follows:

1. Familiarization with the data: This involves an iterative process of reading and rereading of all the news stories to have a full grasp of the content whilst noting down some emerging key ideas and interesting messages. In this stage, notes that might serve as potential codes are written down. Familiarization also entails the importation of the data into the NVivo software program.

2. Developing initial codes after rigorous reviewing of the articles: Codes or nodes as they are referred to in the NVivo software were developed and later 'test run' by other researchers involved in the study and me since the thesis represents one part of a larger project. These codes or nodes organize the data into smaller and meaningful groups. They also contain vital information concerning each theme or frame and references to these were assembled in the code or node developed for that purpose (Mistry, 2007). Coding which involves selecting, highlighting and assigning a text to a code was finally conducted.

3. Identifying the major themes and frames: After the construction of different codes, they were sorted and grouped into different themes and sub-themes and frames. The major themes and frames for this particular thesis were operationally determined and defined.

4. Revising and refining of initial themes and frames: This process involved a systematic examination of the themes and frames with the view to making sure that there was enough data to support them. As a result, some themes and sub-themes and frames which were considered to be irrelevant to the analysis process were merged, dissolved, reworked or discarded.

5. Refining and restructuring of the themes and frames in details: This was done by identifying the themes that were relevant to the research goal and objectives. The final themes and frames that were useful for the analysis were then considered.

6. Analyzing the data and writing up of the major findings based on the research objectives and existing literature: These are outlined in the results section. The major findings are outlined (in the Results Chapter) with quotations to support these results. The findings are also compared to existing literature on CCSVI, LT, medical tourism, media framing and mobility theoretical frameworks in the Discussions Chapter.

These phases were rigorously followed, with the completion of each phase before moving on to the next phase. They were however times when the process has to move back and forth in order to revise or review that particular process. Moreover, in applying the six-phase thematic analysis framework, operationalized codes/nodes were further supplemented with some key concepts relevant in carrying out more detailed analysis for the thesis (e.g. static and mobile ontologies etc.). Appendix 2 shows the code book that was applied in this research.

In addition, the analysis as related to the agenda settings role of the media included operationalizing the quantitative aspects of the print media data. For placement analysis, the page numbers of stories were categorized as ‘A’ Section, ‘B’ Section and ‘Other’ Section. Articles on

the ‘A’ Section were located on the front and inside pages of the A section of the newspaper. Placement on ‘B’ Section denotes the front and inside pages of the ‘B’ Section of the newspaper. Articles that were labeled outside the above categorization were placed in the ‘Other’ category e.g. articles in C1, C2, D1, D2 etc. With respect to story type, articles were coded as a news story, profile or editorial. News stories included occurrences of information at local, national or international scales. References to factual information presented were coded as news stories. While editorial or opinion piece coded references to the stance of an editor on the issue, profile stories focused on an in depth feature about people from diverse backgrounds. Consideration was given to the length of the story in terms of word count. Stories were categorized as short, medium or long based on the operationalized definition by Mistry & Driedger (2012): short (250 words or less); medium (251-750 words) and long (750 words or over). The overall tone of the news story was either defined as positive, negative or neutral. Positive stories are generally framed as favorable. These stories include such things as improved symptoms after LT. Negative stories expresses unfavorable aspect towards an issue. Examples of such a story are when studies dismissed the link between blocked veins and MS; people died or developed complications after LT. Neutral stories are framed in a manner whereby both the favorable and unfavorable aspects appeared in a balance form. Such stories made references to factual statements about the government decision to fund clinical trials.

Story leads and headlines were also reviewed and coded into their respective tones and later quantified and interpreted. The tones assigned to the headlines and leads were similarly coded based on the operationalized definitions assigned to the overall tone of stories as indicated above. For example a positively toned headline is “‘It changed my life’; MS patient vouches for experimental surgery” (Montreal Gazette, April 15, 2010). Headlines such as “MS patients had

serious complications after therapy" (Edmonton Journal, Aug 24, 2011), "Woman dies after controversial MS treatment" (Vancouver Sun, July 9, 2011) and "Study shoots holes in MS 'liberation therapy'" (Edmonton Journal, April 24, 2011) were interpreted as negatively toned. Neutral toned stories were coded in factual headlines such as "Alberta to Fund Study on Zamboni MS Treatment." (National Post, Dec 17, 2010) or both positively and negatively balanced headlines such as "Cure vs. Hype; Is new MS research the real thing, or a media-driven frenzy?" (National Post, Jan 23, 2011) were presented. Similarly, an example of a positive lead is "A potentially breakthrough treatment for multiple sclerosis has given thousands of Manitoba sufferers renewed hope their painful symptoms could be cured." (Winnipeg Free Press, Nov 25, 2009). An example of negative lead is "An Ontario man has died in Costa Rica after undergoing controversial surgery to alleviate the symptoms of multiple sclerosis." (Toronto Star, Nov 19, 2010). Neutral leads include "A Newfoundland University has started recruiting participants for a study of a controversial multiple sclerosis treatment." (Globe and Mail, Nov 25, 2010).

In a similar fashion, qualitative story frames were also identified using operationalized definitions. The key frames used for the analysis include: *miracle, hope, liberation, rights, wait and see, adversarial and hoax.* The *miracle* frame described stories that make LT sound extraordinary, a cure and a means to new life or salvation from all problems caused by MS. The *hope* frame identified instances in which people expressed confidence about LT as a cure to their disease. The *liberation* frame was referenced with respect to stories portraying LT as liberating or freeing people from their disease. The frame of *rights* focused on access to health care as a fundamental human right. This frame emphasized people who were denied access to LT as well as people filing human rights cases in protest to government policy decision. The *wait and see* frame was centered on the need to wait for more studies or information on the efficacy of LT.

Text was coded in this frame anytime LT was expressed that "we need more evidence" or references to waiting for evidence about the treatment that is being gathered. Content was coded as *adversarial* when the story depicted instances whereby people were pitted against each other over the LT issue. An example is when patients and doctors expressed a strong disagreement over the efficacy of LT, effectively highlighting conflicting tensions in the debate. The *hoax* frame was mainly identified in instances where LT was described as fake, such that it deceived people. Text was analyzed under this frame when it referenced improved symptoms from LT as the placebo effect.

Following Driedger (2007), the research team (including me) conducted an intercoder reliability test. The principal investigator of the project (Dr. Michelle Driedger) and two other researchers evaluated and categorized newspaper articles. This was to ensure consistency and accuracy in the selection and coding of news stories based on the criteria outline above. Story selection went through several considerations.

The selection of the stories took into consideration the various geographic regions of Canada. To gain a broader perspective on the issue, stories were selected from the Atlantic and Pacific Coasts, Prairie and Central regions of Canada. The principal investigator and I also selected a sample of stories (n=10) that featured in most of the newspapers (e.g. death of patients after LT, government to fund clinical trials etc) as well as the story length. This was to systematically test the code book against the stories for intercoder reliability. For the calculation of the intercoder reliability, Miles and Huberman (1994) method was adopted.

$$\text{Thus, Reliability} = \frac{\text{Number of agreements}}{\text{Total number of agreements+disagreements}}$$

Through this process, the story selection yielded a 95% reliability rate, whilst a 90% reliability rate was achieved in the coding of the sample data. In both scenarios, the reliability rates are within the 90% domain outlined by Miles and Huberman (1994). In order to ensure consistency in the coding, I coded the rest of the articles. However, there were instances when I was uncertain as to where to code a text or passage. A node was created for that purpose and through discussion; the principal investigator and I decided the most appropriate node to code that data.

It is important to note that the code book developed was further expanded in terms of operationalized definitions based on new information during the coding process. Once all the surface content was coded, different types of queries were run in NVivo™ 9 to explore the analytical questions relevant to this thesis (i.e. different frames e.g. hope, hoax, liberation etc) against the people promoting them (e.g. patients, government, health care providers, researchers etc.). These queries and the development of conceptual memos were helpful in the stages 3-6 of the Braun and Clarke framework.

Establishing Validity and Reliability

This study adopted some strategies to ensure that the research findings are 'worth paying attention to' (Baxter & Eyles, 1997, p.506). Following Lincoln and Guba (1985), Baxter & Eyles (1997) developed a set of criteria for evaluating methodological rigor, and these include credibility, transferability, dependability and confirmability.

Credibility is to ensure that the results of research are credible or believable. Research findings are deemed credible when the "description of human experience is such that those having the experience would recognize it immediately and those outside the experience can understand it" (Baxter & Eyles, 1997, p.512). A critical layer to credibility is the direct involvement of human

subjects as the primary source of information and use of strategies such as member-checking, prolonged engagement, peer debriefing and persistent observation (Baxter and Eyles, 1997). This thesis involves the use of non-human subjects and secondary data sources as the primary dataset. Nevertheless, credibility of the findings was achieved and strengthened by sharing and reviewing the study results with my advisor and advisory committee, using verbatim quotations and multiple newspapers as sources.

Transferability involves the extent to which findings can fit into other contexts or situations beyond the original one (Baxter & Eyles, 1997). The aim of this is to demonstrate how the findings can be applied in other disease contexts where medical tourism may play a role. Within the principle of transferability, "the phenomenon under investigation is provided to allow readers to have a proper understanding of it, thereby enabling them to compare the instances of the phenomenon described in the research report with those that they have seen emerge in their situations" (Shenton, 2004, p.69). With this in mind, this case study seeks to examine the issue of patient mobility for CCSVI and LT in greater depth, and this will serve as a spring board upon which other studies analogous to this one can build upon. The transferability in this particular study was gauged through detailed and thick description of the research methodology and findings (Baxter & Eyles, 1997; Shenton, 2004).

Dependability ensures that the results of the study are consistent and can be replicated by an independent researcher using the same methods (Shenton, 2004). In dependability, similar results are yielded when a research topic is studied in a similar context, method and participants. Baxter and Eyles (1997, p.512) points out that the aim of dependability is to avoid 'idiosyncrasies in interpretation' and analysis of the data. To ensure dependability, this study utilizes a 15-point checklist developed by Braun and Clarke (2006) (See Appendix 3). Particularly the guideline

such as “each data item has been given equal attention in the coding process” (p.36) was rigorously followed.

Confirmability refers to the extent in which the data interpretations or questions can be supported by the data collected (Baxter & Eyles, 1997). To achieve this, an audit trail was completed (i.e. keeping track of records of all the decisions made during the coding process and analysis of the data). This was to ensure that any external researcher can make deductions as to what data was collected and how it was treated or analyzed is reflected in the presentation and discussion of the results.

Methodological Limitations

Despite the above mentioned strategies put in place to ensure trustworthiness of the results in this study, some limitations were encountered in this study. To begin with, there were conscious efforts to consistently code the data into their respective nodes and frames. However, there was the possibility of over coding or missing out some text being coded into its rightful node or frame. This potential challenge could emanate from how a particular text was interpreted. To mitigate this, a node was created to gather all the text where I was unsure about where to code it. This was later discussed with my supervisor and based on the agreement the text was coded at the appropriate node. In conducting more detailed analyses, steps were also put in place to ensure that any text not appropriately coded during the retrieval of queries were either deleted or recoded into its respective node.

Secondly, the study relied on media reports from some selected provinces. Even though an explanation has been offered for the criteria used in selecting the newspaper stories, there are other provincial newspapers that could have provided a different context. While the two national

newspapers (i.e. the Globe & Mail and National Post) were added to reflect a national perspective about the issue, being largely based in Ontario and the Greater Toronto Area could potentially bias these papers to a more Ontario-centric stance. Moreover, newspapers from the Territorial Regions were explicitly excluded in the analysis.

Finally, only Canadian English language newspaper publications were retrieved and included in the analysis. As a bilingual country, French published newspapers were excluded. This is especially important considering that two (i.e. Quebec City and Montreal) of the four sites cities earmarked for clinical trials of LT in Canada are located in Quebec, a French dominated province. The consultation of French newspapers may have given a much broader perspectives on how the issue was portrayed in the mainstream news media.

This case study is to assess through mobility and framing interpretative lens how the media presentation of different groups' reactions to CCSVI and LT tends to put pressure on government to modify existing processes and decisions in the health care system. To achieve this, print media stories supplemented with a televised story were downloaded into Nvivo software for thematic analysis based on the pattern developed by Braun and Clarke (2006). The results which are based on the goal and objectives set out are presented in the next chapter.

Chapter 5

Results

The results of the study are presented in several ways. The perspectives and media frames from the CTV W5 Documentary are presented first. This is followed by an examination of the quantitative semantic content analysis, which forms the basis for examining the qualitative latent analysis results.

CTV W5 Documentary

On November 21, 2009, Lloyd Robertson (host of CTV documentary program W5) and Avis Favaro (Medical news correspondent) hosted a documentary episode on CTV W5 entitled "The Liberation Treatment: A Whole New Approach to MS." The documentary firmly described LT as a "stunning medical discovery" and a "revolutionary treatment" for MS. The introduction of the documentary outlined that Canadians are mostly affected by the disease and this makes it difficult for MS patients to "see, stand, or even swallow" while many often "end up wheel-chair bound." The documentary vividly recounts Zamboni's personal story inspired by the love of his wife who has lived with MS. As Favaro noted, "For Zamboni, it's more than a medical quest, it's a journey fuelled by love." The desire to help MS patients with their disease motivated Zamboni to find a solution. The documentary portrays patients who have undergone the procedure and started experiencing dramatic improvements, whilst others felt all but cured with their disease. There were also clips of supportive physicians trained under Zamboni.

Positive frames resonated in this documentary. The documentary particularly captured the liberation frame when Favaro insisted that "it could free patients from a lifetime of suffering." The hope frame also surfaced in the episode as it highlighted patients and doctors expressing confidence about the potency of LT. For instance, Dr. Fabrizio Salvi, an ally of Zamboni

emphasized that "It (LT) may be the cure for MS." Alongside raising the hopes of many patients, the miracle frame was evidenced in clips that showed how patients in wheel chairs were miraculously healed after LT. Overall, the CTV W5 episode framed CCSVI and LT in a positive tone and this triggered patient demand and mobility for the procedure. This position was re-emphasized by many of the print media stories analyzed.

The print media recounted that the aftermath of the documentary was the motivation for patients wanting more information about the procedure. As a result, physicians' offices were inundated with calls, emails and discussions from patients.

> Stephen Kennedy, spokesman for the Multiple Sclerosis Society's Manitoba chapter, said he's received a flood of phone calls and emails from local MS sufferers eager to learn more about the surgery since a segment first aired on CTV's current affairs show W5. (Winnipeg Free Press, Nov 25, 2009).

> The Winnipeg MS clinic had to stay open two or three hours later than usual many days recently as every patient insisted on a lengthy discussion of the news. "It was presented as very new and exciting research and ready to go," said neurologist Dr. Ruth Ann Marrie, the clinic's director. (National Post, Jan 23, 2010).

It is important to mention that this documentary set the 'stage' for how the print news media followed and differed in its coverage of the issue. The following sections detail the quantity and type of print media coverage following the release of the CTV W5 Documentary.

Total Number of Print Media Stories

After applying the inclusion and exclusion criteria described in chapter 4, a total of 378 stories forming the dataset were used for analysis. The breakdown of the total number of media stories

downloaded compared to those included in the study is shown in Table 5.1. A little over 72% of all stories were included.

Table 5.1: Total number of Stories used for Analysis by Newspaper

ProQuest Canadian Newsstand and Major Dailies Database		
Date Range: Oct 1, 2009 - October 31, 2013		
Search Parameters: "multiple sclerosis" and "liberation"		
Newspaper	**Raw Numbers**	**Final data set used**
Globe & Mail	60	44
National Post	67	30
Vancouver Sun	30	22
Calgary Herald	55	40
Edmonton Journal	69	51
Regina Leader-Post	90	74
Winnipeg Free Press	40	33
Toronto Star	32	24
Montreal Gazette	30	20
Telegraph Journal	47	31
Totals:	**520**	**378**

Overall, the results are organized in two ways. First, the results from the quantitative aspect of the study that was employed to media content have been quantified and displayed in figures. This is done to assess the frequency of coverage of the issue, how it varies over time and space, as well as the agenda setting role of the media. Second, the results from the latent or more textual interpretative method serve to identify the major themes and frames emerging from the media data.

Frequency of Print Media Coverage

Examining how the frequency of coverage changes over time aims to measure the agenda setting role of the media regarding this particular case study. The prominence of the issue is therefore measured in terms of the number of stories, statement placement, story length, tone and typology.

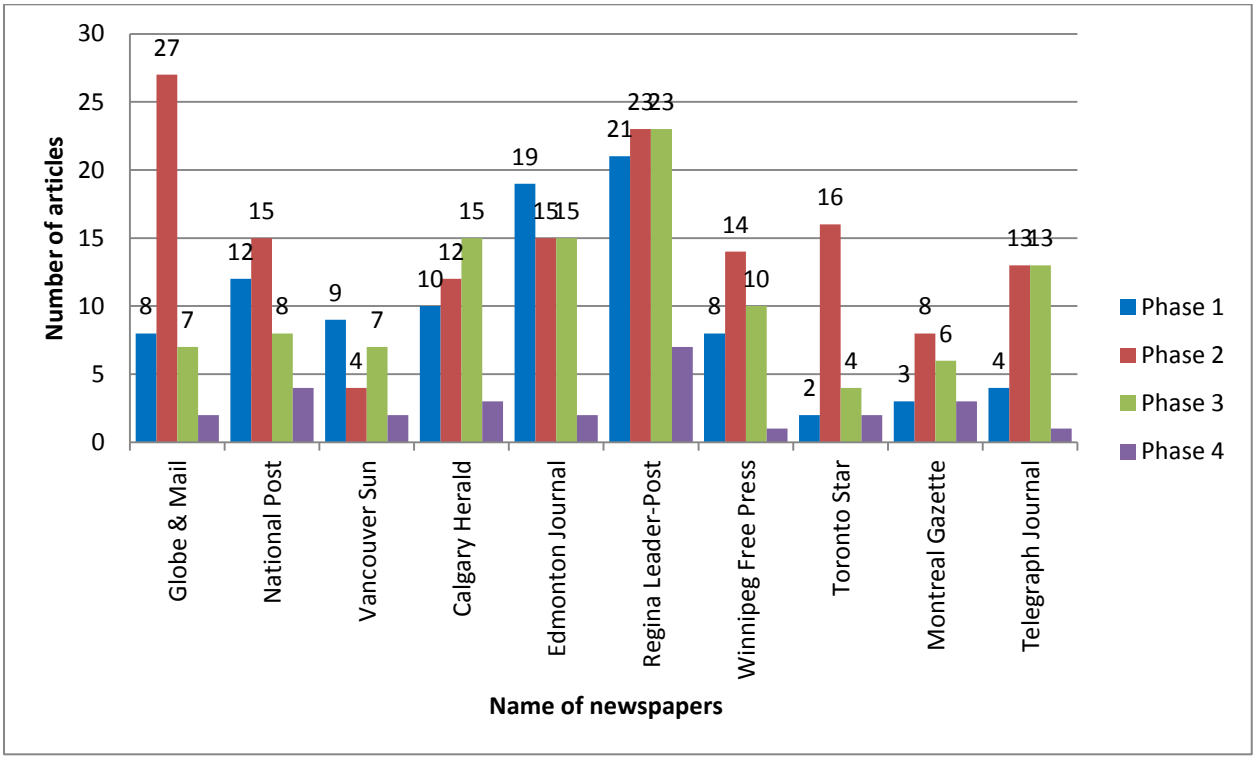
The frequency of print media coverage of the issue is grouped into 4 significant phases. Phase 1 (November, 2009-August, 2010) encompasses the push period. Under this phase, CCSVI and LT were introduced as a medical breakthrough with patients advocating and pushing for research and the availability of the procedure in Canada. Phase 2 (September, 2010-May, 2011) captures the pressure period that witnessed patients and their advocates reaction against government's decision not to fund clinical trials. Phase 3 which spans from June, 2011-July, 2013 captured how the pressure from patients led to government's reversal to fund clinical trials. Phase 4 (August, 2013-October, 2013) the shortest of all the periods provided two notable Canadian scientific research outcomes debunking the association between CCSVI and LT.

The frequency of coverage is discussed and displayed in the following figures under their respective phases.

1. Newspaper Coverage over Time

Figure 5.1 shows how the media coverage of CCSVI and LT and their corresponding media outlet has changed over the period.

Figure 5.1: Frequency of News Coverage by Newspapers in Phases



The story of CCSVI and LT attracted the attention in media in late 2009 (i.e. November, 2009). The first news story which was appeared on the November 21, 2009 edition of the Globe & Mail newspaper introduced the issue to the general public and also set the tone for the debate. According to the story lead:

> Canada has the highest incidence of multiple sclerosis in the world. Half the population knows someone with the disease. And it affects more than three women for every man. Now one doctor in Italy has made an astounding discovery, one that suggests MS can be cured or even prevented. He did it out of love for his wife. And it has given people everywhere hope; Dr. Paolo Zamboni's work shows MS to be a vascular condition, contrary to common belief. (Globe and Mail, November 21, 2009).

This particular lead identified Zamboni's LT as offering hope to people living with MS. Subsequent news media coverage in 2009 sensationalized LT as a 'cure' to MS. In fact, only the

Vancouver Sun, Winnipeg Free Press and the Telegraph Journal regional newspapers even covered the story in 2009.

Phase 1 recorded a total of 96 stories over the issue. This phase presented LT as a medical breakthrough for MS. News content was also characterized by clarion calls from MS patients and advocacy groups for further research into the efficacy and the availability of the procedure. National and provincial news stories documented patients protest demanding for the research and accessibility of the procedure in Canada.

> MS activists demand access to 'liberation' therapy; 'This illness won't wait,' says one patient at rally in support of controversial experimental treatment. (Globe and Mail, May 6, 2010).

> Sharon Ober is eager to be liberated from MS....The Regina woman was among a small group rallying in front of the Legislative Building Wednesday for the worldwide CCSVI Day-to raise awareness of research done by Dr. Paola Zamboni of Italy. (Regina Leader Post, May 6, 2010).

> Protesters demand access to new MS treatment; Simple surgical procedure seen as breakthrough....About 200 people, many in wheelchairs, called on the federal government to get behind a new treatment they believe can cure the degenerative disease (Edmonton Journal, May 6, 2010).

Saskatchewan, a province with one of the highest prevalence rates of MS in Canada, announced its willingness to support trials against the advice of the Canadian Institutes of Health Research (CIHR).

> In a striking departure from his political counterparts across the country, Saskatchewan Premier Brad Wall says his government will finance clinical trials of liberation therapy, a contentious experimental procedure for multiple sclerosis patients. (Globe and Mail, July 28, 2010).

This policy decision attracted media coverage (especially in the Prairie Region) which focused on the debate over the government's decision to fund clinical trials. Consequently, it was not surprising that LT received the highest coverage in the Prairie newspapers (i.e. Calgary Herald, Edmonton Journal, Regina Leader-Post and Winnipeg Free Press) over the other regional and national news outlets during the period.

Phase 2 was flooded with news stories on the federal government's decision to not fund clinical trials and the adoption of the dominant 'wait and see' frame. On September 1, 2010, the federal health research agency, CIHR noted that:

> Canada's leading multiple sclerosis scientists and researchers have recommended there be no Canada wide clinical trials of a controversial treatment for the disease because of the overwhelming lack of scientific evidence on the procedure's safety. (Calgary Herald, Sept 1, 2010).

This decision sparked the debate regarding the association between CCSVI and LT as well as the effectiveness of the procedure. As a result, this phase recorded the highest number of news stories (147). Newspapers portrayed stories that pitted patients/advocacy groups against the government/scientific community. In one instance, a patient described her physician as "being so closed-minded" because "he doesn't believe in this (LT)" (Globe and Mail, Sept 20, 2010).

However, bowing to pressure from MS patients and their advocates, the federal government in June 2011, announced that "there there is now enough preliminary scientific evidence to move ahead government-funded clinical trials." (Telegraph Journal, June 30, 2011). The funding of clinical trials became the focal point for phase 3. This decision was seen as "a victory for patients with the debilitating disease, who have been paying out of pocket to get the procedure" (Toronto Star, June 30, 2011). As patients won the 'battle', the number of newspapers publishing articles

on the topic dropped from 147 in phase 2 to 108 in phase 3. Aside news content focus on the federal government's funding of Pan-Canadian trials, the 3rd phase also highlighted some provincial government's policies to track the progress of patients who had LT overseas. For instance, Alberta launched observational studies whilst British Columbia launched registries. Again, the Regina Leader-Post news paper recorded the highest number of stories. Most of the news coverage in that year gave prominence to the provincial government's decision to fund clinical trials for Saskatchewan MS patients in Albany.

With the federal government's decision to fund clinical trials, newspapers coverage of the issue further reduced. Unsurprisingly, the total number of stories dropped substantially from 108 in phase 3 to only 27 in phase 4. This was expected considering the span of the phase (i.e. Aug-Oct, 2013) compared to the previous phases. Within this phase, researchers (including two experienced vascular ultrasound technicians and a radiologist trained under the supervision of Zamboni in Italy) from McMaster University in Hamilton conducted one of the largest studies on Zamboni's hypothesis and "found no significant differences in blood flow" between MS patients and people without MS (Regina Leader-Post, August 15, 2013). Again, the leader of the Pan-Canada trials using Zamboni's 'cookbook' approach could not replicate Zamboni's results. These two negative studies (Montreal Gazette, Aug 15 & Oct 9, 2013) were the main focus of most news stories in this phase. The phase also suggested that it would take until 2016 for the release of the Pan-Canadian results. These stories also highlighted the four participating cities selected to hold the clinical trials: Vancouver, Winnipeg, Montreal and Quebec City.

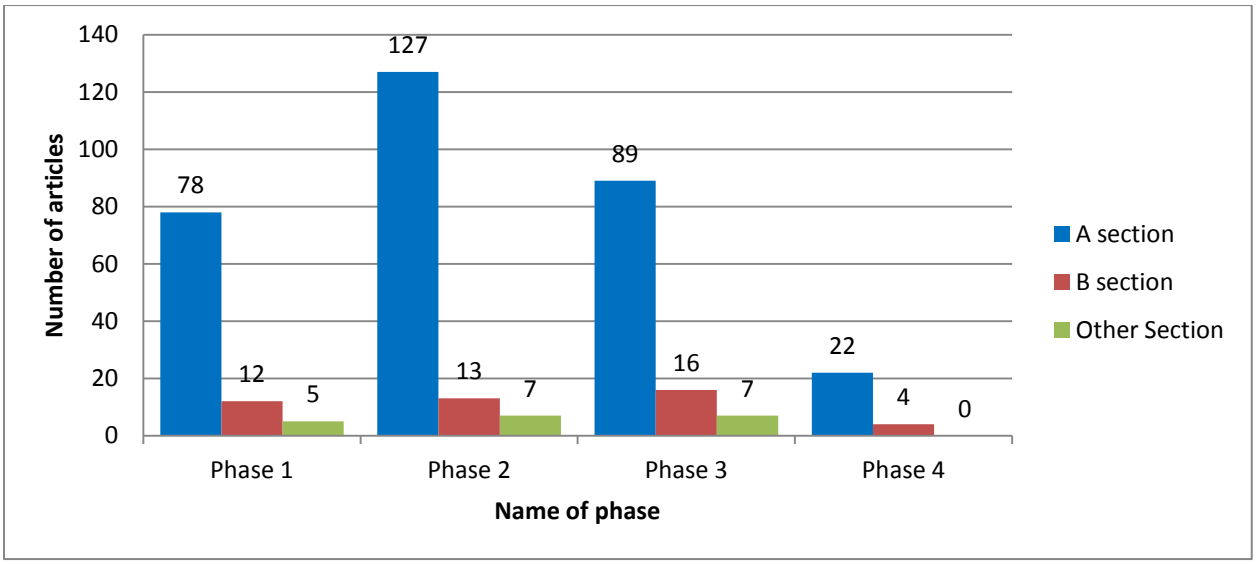
The agenda setting role of the media can be seen through how the coverage of the issue decreases over time and space. As remarked by a neurologist "It's getting fewer and fewer because every month a negative study is coming out….Every study has tended to be negative."

(Globe and Mail, March 25, 2013). Consequently, the issue becomes less news worthy and therefore attracts less media coverage.

2. Story Placement

The manner in which a news story is placed in a newspaper also has an influence on agenda setting. Most often stories that are placed on the front page banner or headline have the tendency to attract the attention of passersby thus giving much prominence to on an issue (Clayman and Reisner, 1998). In agenda setting the media gives primacy to some topics over others. The placement of articles changed over space. The change is shown in figure 5.2.

Figure 5.2: Story Placement in Phases



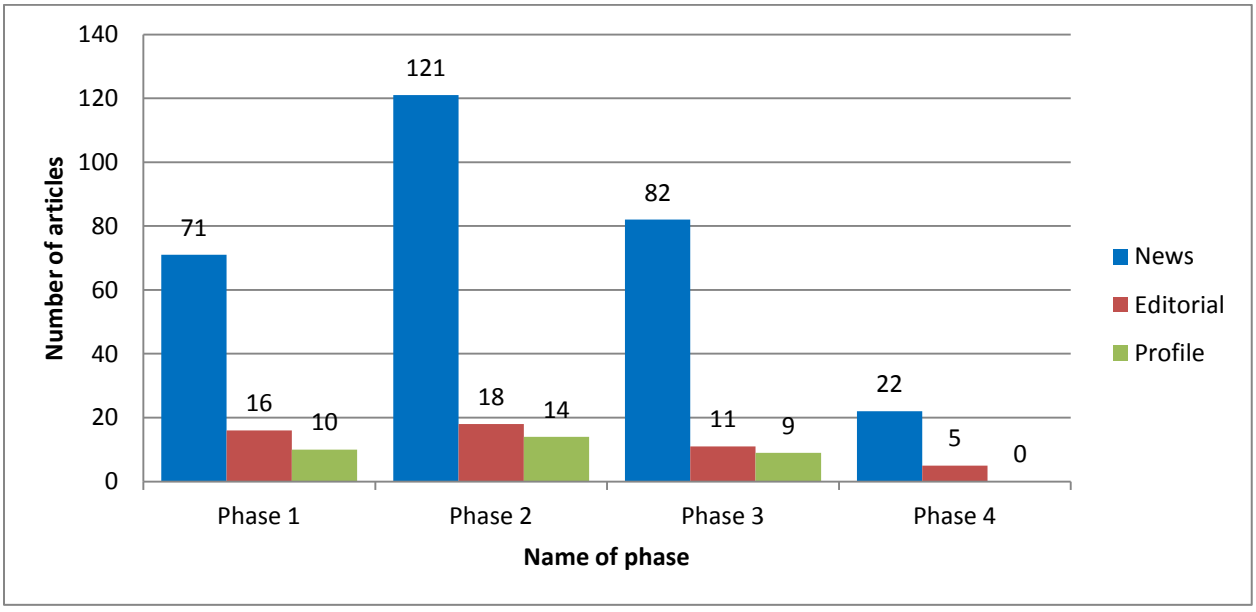
All the media outlets provided significant 'A' section coverage with a total of 316 news stories, as shown in Figure 5.2. Front page coverage accounted for 47 stories. The variations of the 'A' section newspaper coverage along the various phases are in consonance with the frequency of news coverage discussed earlier. On the other hand, the 'B' and 'Other' sections covered the issue fairly consistently in the first 3 phases but varied in the final phase recording only 4 and 0 respectively. In terms of regional variations, the Prairie Province newspapers (Calgary Herald,

Edmonton Journal, Regina Leader Post and Winnipeg Free Press) notably recorded the highest frequency of the 'A' section coverage (162). The two national newspapers (i.e. Globe and Mail and National Post) also received substantial coverage with 75 news stories. However, the 'A' section coverage dropped over time primarily from regional newspapers in Ontario, Quebec, the Pacific and Atlantic Coasts. The number of news stories drastically lowered in the 'B' section (45) and 'Other' sections (17) of newspapers. Except for the Regina Leader Post, all the other media outlets recorded less than 10 news stories in 'B' and 'Other' sections in total.

3. Type of Story

The agenda setting role can also be quantified by considering the mechanisms used by newspapers in presenting a story. News reporters and editors can present a story issue in various ways: news story, editorial or profile. The breakdown by story type is presented in Figure 5.3.

Figure 5.3: Story Type in Phases



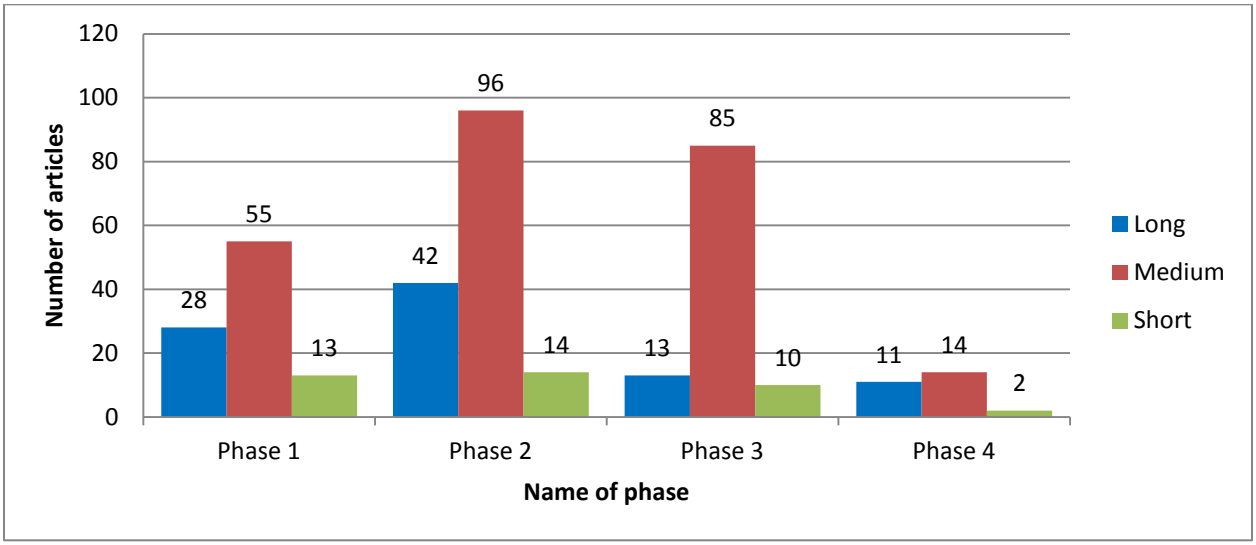
Highlighted in Figure 5.3 is that the majority of story coverage on the topic were portrayed in the form of news stories. For this study period, 296 stories were published as news stories with all

the newspapers substantially publishing more stories as news stories in all the 4 phases. Editorials and Profile stories were covered less frequently with 50 and 32 stories respectively. Both the Editorials and Profile stories were also fairly covered in the first 3 phases. Much of the news content was focused on the debate about the issue as well as major policies and decisions advanced by stakeholders. Most of the profile stories were in depth pieces, often in the form of personal stories of MS patients who shared their experiences after engaging in medical tourism for LT. Notably, one profile story in a newspaper compiled personal experiences of patients who had LT with positive anecdotal accounts such as "A new lease of life" "brain fog vanished" "astonishing quality of life" (Globe and Mail, November 27, 2010). By contrast, the majority of editorials either scolds or applauds government decisions regarding the funding of clinical trials or in sponsoring MS patients to access LT abroad. For example, the New Brunswick's government's decision to fund patients for LT was scolded as placing the "province on the verge of bankruptcy." (Telegraph Journal, Dec 9, 2010). On the other hand, the Saskatchewan government's decision to fund clinical trials was applauded in an editorial as "the right move at the right time." (Toronto Star, Dec 21, 2010).

4. Length of Story

Related to the news typology in agenda setting of the media is the amount of coverage an issue receives attention. This can be measured in the number of stories, story placement and story type as shown in Figures 5.1-5.3 above, as well as in terms of the length of stories published in newspapers. One study suggested that newspaper stories with more than a 500 word count is likely to give a detailed and comprehensive coverage, and this can shape people's understanding of a policy (Rosenau, 2006). Figure 5.4 documents the word count of stories by newspaper.

Figure 5.4: Story Length by Word Count in Phases



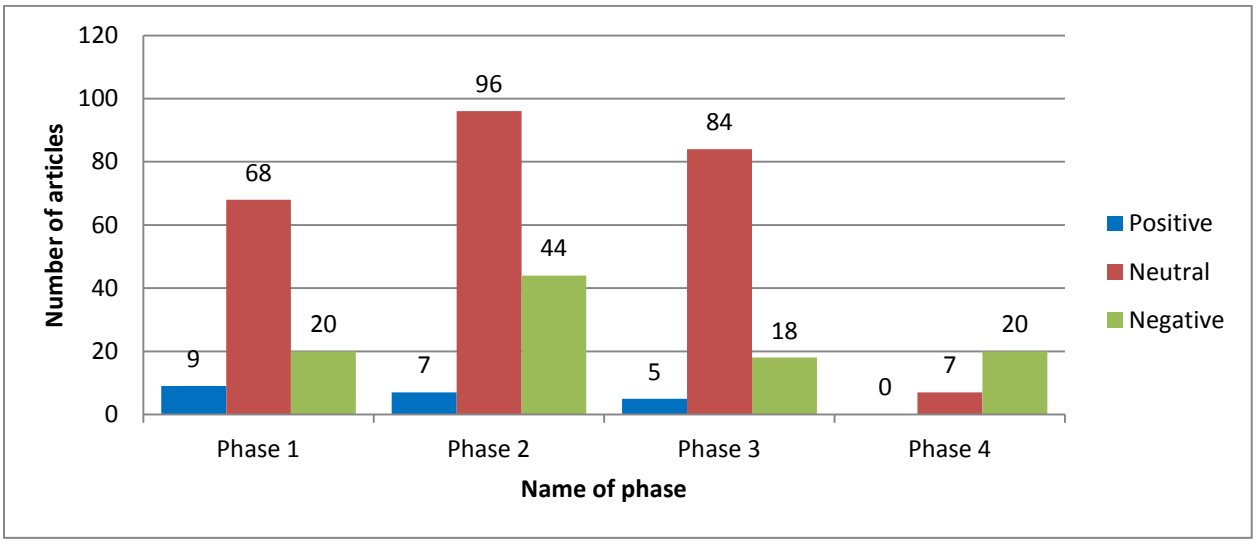
Among the 378 articles, medium length stories were the most frequently written at 250. Long stories and short stories accounted for 89 and 39 respectively. With regard to coverage by phases, story length over the issue was fairly covered in the first 3 phases of short stories, phases 2 and 3 of medium stories as well as phases 3 and 4 of long stories. The medium length stories written in newspapers placed much more emphasis on the merits and demerits of LT. Much of the debate of the issue was found in the medium stories. News content in the majority of the long stories was in the form of news stories. The rest of the published stories were almost shared equally between profiles and editorials. The short length stories published in the newspapers were mostly in-brief news stories that provided a very short summary of the issue. The shortest word count (95 words) for instance published a brief story on Quebec contemplating joining national randomized clinical trials of LT (Montreal Gazette, Aug 19, 2010). By contrast, profile stories contain the highest individual word counts with content highlighting personal stories and testimonials. The highest individual word count (3,992) provided an in depth profile piece of a patient who had LT and concluded that "Even though the CCSVI angioplasty did not transform

my life, I was happy I had tried it." (Winnipeg Free Press, August 6, 2011). The average word count across the dataset was 480 words.

5. Tone of Story

The perception attributed to a news story indicates a very vital component of the media in agenda setting. The tone of a story can be framed as positive, negative or neutral. Figure 5.5 shows the different overall tones that were used in framing CCSVI and LT.

Figure 5.5: Overall Story Tone in Phases

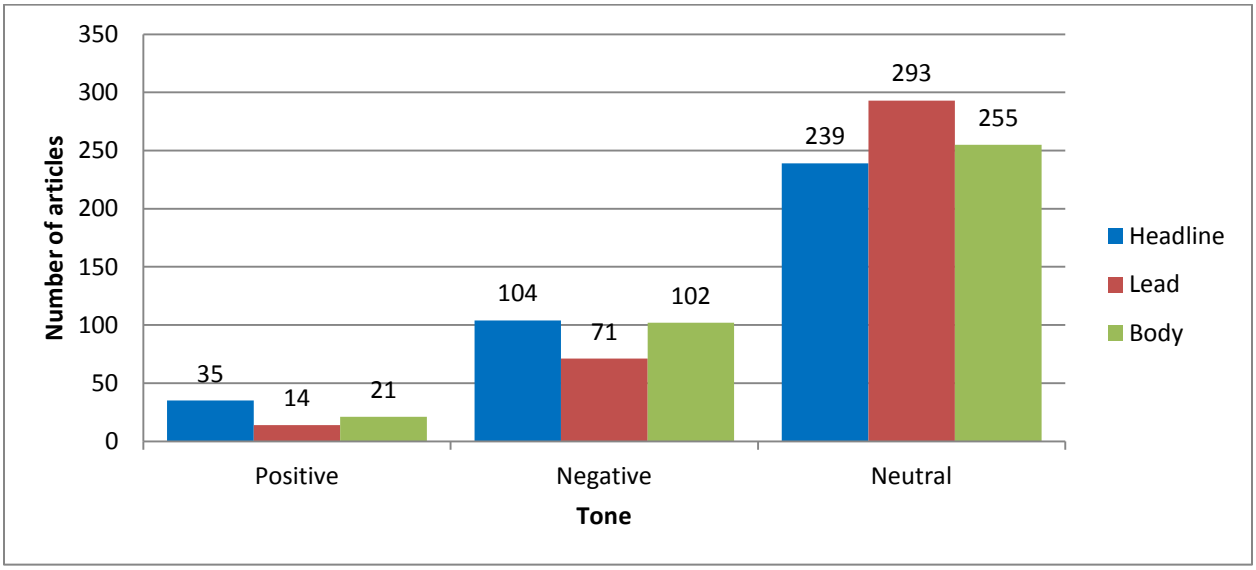


In total numbers, figure 5.5 shows that positive, negative and neutral tone story, respectively, comprised 21, 102 and 255 stories. Except for phase 4, neutral stories were overwhelmingly covered by all the media outlets. The majority of the neutral-toned stories presented the LT issue in factual terms and in a balanced format with little or without any emotional coloring. It is worth noting that despite patients' overwhelmingly positive anecdotal evidence highlighted in media stories especially in phases 1 and 2, the positive tone recorded the lowest. The Globe and Mail which ran the first story on the issue set the agenda for the positive tone, and not surprisingly an overall of 10 positive stories came from this news outlet. However, the other news outlets all

combined recorded only 11 positive stories. Negative stories which were covered by all media outlets focused more on unfavorable experiences patients had after going for LT abroad. For instance, negative stories significantly attracted media attention in phase 2 because a Canadian died after undergoing LT in Costa Rica in November 2010. As this was the first death recorded, media coverage was cautious and skeptical hence the increase in negative stories in phase 2. Another stunning negative issue covered by all the news outlets in phase 3 was the death of a woman who went for LT in the US. As studies dismissed the association between blocked veins and MS, phase 4 also received overwhelming negative stories.

In addition to the overall story tone, the tones of headlines and leads also recorded some variations. It was found that the majority of the headlines (239) were neutral, while positive and negative toned headlines were 35 and 104 respectively. In terms of story leads, neutral toned leads counted at 293, while positive leads counted 14 with 71 leads analyzed as negative. As indicated in figure 5.6, there were more positive and neutral toned headlines (139) than the leads (85). However, neutral toned leads were documented more than headlines.

Figure 5.6: Overall Story Tone by Story Leads, Headlines and Body



Overall, there were more neutral toned stories than negative and positive toned stories combined. Again, there were substantial differences between the story headlines and leads. For instance, positive tones were given prominence in the story headlines over the leads. When compared to the tone of the story body, similar patterns were recorded. For example, there were more positive toned headlines (35) than the story body (21). In terms of story lead to article content, positive toned story content (21) was recorded more than positive toned story leads (14). The comparison of story headline and the body is to illustrate that when the headline of the story is exclusively read, it will highlight more positive tones than what is actually found in the body of the story. Likewise, when the story content is independently read from the lead, it will stress a more positive tone.

Perspectives of Major Stakeholders on Patient Mobility and/or Medical Tourism

A major objective of this research was to assess how the different stakeholder perspectives regarding patient mobility was framed in the media. The major stakeholders identified in the debate include: researchers/physicians, Zamboni, MS patients (family and friends) and advocates (LT pro groups-MS Society) and government. These stakeholders' views were portrayed differently by the media. These views are described more fully in the remainder of the chapter. These perspectives are organized by source type categories frequently used by media reporters: elite and non-elite source types.

Elite Sources

Medical Experts/Researchers

The efficacy of LT as a treatment to MS sharply divided the medical community into 'pro' and 'anti' Zamboni camps. However, media documentation regarding Canadian physicians and medical researchers' perspectives on patient mobility for LT were broadly negative. The medical

community cautioned Canadians against engaging in medical tourism for the procedure. The quotes below capture accounts of the medical community in Canada cautioning patients against the procedure.

> Knox (Director of Saskatoon's MS Clinic)… advises MS patients not to travel out of the country for the unvalidated procedure, since the long-term effects - or even if it's effective -aren't scientifically proven. The anecdotal reports of miraculous improvements aren't useful without a control group. (Regina Leader Post Aug 26, 2010).

> But despite feeling sympathy for patients seeking hope in foreign clinics, Bernard (Quebec physician)…warned against medical tourism for an experimental treatment. Do not seek procedures to open blocked veins outside of controlled research studies (Montreal Gazette, Nov 10, 2010). Stay away from medical tourism clinics providing treatment without scientific evidence. (Montreal Gazette, July 2, 2011).

> Fox (U.S. neurologist) is warning patients away from the procedure. "There are patients who have died from complications from this procedure, there are patients who have had very serious complications needing open-heart surgery as a result of this procedure,"…. "It is not risk free." (Regina Leader Post, Winnipeg Free Press, Oct 4, 2011).

> "Please do not rush out and spend your hard-earned money, mortgage your house, your life savings to get this procedure done out of country at private clinics," Traboulsee (MS clinician and researcher)…. "Research is the way to answer this. We will have answers to these questions, but hang tight." (Toronto Star, Oct 10, 2013).

The medical experts' and researchers' perspectives against patient mobility for LT were taken to another level. The medical community urged government to rather release funds for proven treatment options rather than funding patients for LT which they believed was harmful. This was evident particularly in New Brunswick, a province that allocated funds and sponsored patients for LT in other geographical locations outside of a research/trial setting. In other words, New

Brunswick was funding patients' to have access to LT elsewhere. In their opposition to this decision, the New Brunswick Medical Society remarked:

> "We (New Brunswick Medical Society) continue to urge our provincial government to stop using scarce health dollars to fund travel associated with this disproven treatment. We are unsure how many more studies need to be published before this occurs".... (Telegraph Journal, Oct 10, 2013).

Various solutions were proffered by physicians to patients who were contemplating seeking LT elsewhere. As LT could endanger their lives, the medical profession encouraged patients to wait for alternative therapies that could alleviate their symptoms.

> The good news is there are some new medications and some new treatments on the horizon that may prove to be much more effective in the treatment of the disease. (Telegraph Journal, May 25, 2013).

Whilst the medical community in Canada was sounding these warning tones, their counterparts in other jurisdictions were taking advantage of the situation. The medical tourism industry sprung up and many facilities and companies were rigorously marketing and raking in thousands of dollars from Canadian MS patients who were looking for a cure to their MS. These physicians were competing for patients urging them to visit their facilities for LT.

> American doctors are clamouring for Canadian multiple sclerosis patients travelling abroad for a controversial treatment they can't get at home…. "Every IR (interventional radiologist) in every town is competing with each other, 'Who can see more Canadians?' …. "Half of our patients in southern California are coming from Canada," …. "That's just not right, especially when it's being prevented by a very small number of angry neurologists in Canada"…. of 298 patients treated at a clinic in Cabo San Lucas, Mexico, "96 per cent were Canadians." (Calgary Herald Feb 9, 2011).

> Clinics around the world, many of them charging high fees, began offering the procedure and patients flocked to them from countries such as Canada, which doesn't cover the treatment due to a lack of solid evidence. (Globe and Mail, Oct 4, 2011).

> …physicians in Europe and Asia have set up shop. Many offer packages that include airfare and hotel. (Toronto Star, July 11, 2010)

Zamboni

Zamboni was portrayed in the media as a complex stakeholder. On one hand he was promoting LT with the emphasis that "I am confident that this could be a revolution for the research and diagnosis of multiple sclerosis"…. (Globe and Mail, November 21, 2009). Aside expressing higher expectations of the procedure, Zamboni applied pressure on governments to make the procedure available to Canadians. Zamboni also expressed surprised that the treatment is not covered in the Canadian health care system.

> "I cannot understand why a country like Canada with a very good public-health system refuses to support a treatment study on 500 people," …. "I think that is not a good thing. It's not the correct answer." (Globe and Mail, Nov 24, 2010).

His contribution to mobility is clearly manifested in how the procedure moved from Italy to other parts of the globe, aided by physicians trained under his auspices. On the other hand, Zamboni on few instances was cautioning people against medical tourism for the procedure because of the dangers to their health and additional risks for complications resulting from travel.

> … the long voyage many patients must take can make things worse because it increases the danger of blood clots and other complications. "When you perform a procedure on veins,"… "to have air travel shortly after the procedure, I think, is dangerous." (Globe and Mail, May 10, 2011).

He further urged patients not to shell out considerable money for the procedure until further trials are carried out. After the death of a patient as documented in the media he further warned against the use of stents in the veins of patients. Despite this, it did not deter patient mobility since they were determined to receive the procedure.

Zamboni commented on the need for patients for to wait noting that "We need to collect more data." (Globe Mail, May 9, 2011). He therefore admonished people for patience while further clinical trials are carried out to test the efficacy of the procedure. Patients were not enthused with this perspective as one remarked: "It leaves us in the position of wait and see. That puts us in a very uncomfortable position." (Edmonton Journal, Nov 17, 2010).

Government Officials

Both federal and provincial governments took different approaches regarding patient mobility for LT. Patient anecdotes were evident in media stories about medical tourism. The federal health minister became an advocate when she remarked:

> We have all heard the passionate testimony from Canadians who report positive experiences following the [liberation therapy] treatment overseas. We are speaking with one voice on MS. (Globe and Mail, Sept 15, 2010).

Later on, the federal government resisted supporting clinical trials because there was not enough evidence about the efficacy of LT. Instead, patients have been urged to wait for government sponsored studies. Patients who could no longer wait decided to embark on medical tourism for the procedure. The death of an Ontario man who had LT in Costa Rica provided a case for government to advise patients against medical tourism. Consoling family and friends of the deceased, the federal health minister suggested that:

> Multiple sclerosis patients who are considering travelling abroad for the controversial liberation therapy treatment… should put their passports away…. Based on the information I have received from the experts, personally I would not recommend it. (Globe and Mail, National Post, November 20, 2010).

Despite the personal level of caution against LT by the federal health minister, the perception of patients and advocates about the success rates of LT was overwhelming. This was popular in social media which provided information about patients who had the procedure and were immediately "cured". This created pressure on government to take a stand on the treatment. In June, 2011 the federal government acting on the advice of CIHR decided to fund clinical trials. This major policy shift shows how patient mobilization and activism put pressure on politicians and other government officials to reverse their earlier positions. In announcing this, the president of CIHR clearly outlined the rationale behind this decision as he noted:

> It's really the hypothesis of Zamboni that prompted this and the fact that so many patients were going outside the country to get the angioplasty treatment and the anecdotal report of success. So the next step, now that there seems indeed to be some relationship between venous abnormality of MS -which is to say nothing about what causes what, it could very well be MS that causes the venous abnormality -but the committee felt that there was enough to not waste time. (Globe and Mail, June 30, 2011).

It must be also noted that an opposition MP, Kirstin Duncan who has been an MS advocate also corroborated the success rates of LT over traditional therapies.

> 12,500 'liberation' procedures have been performed worldwide in more than 50 countries, and that "80 to 97 per cent of MS patients show one or more venous abnormalities." "If you talk to the interventional radiologists -the people who actually do the liberation procedure -- about one-third of MS patients seem to respond very well," she said. "This is significantly better than the outcomes for the drugs that exist today." (Calgary Herald, Feb 9, 2011).

Duncan further advocated for the collection of information on patients who had LT overseas.

> The federal Conservative government should be tracking Canadian patients like Docherty who travel to other countries for the so-called 'liberation' treatment, in addition to funding trials of the procedure at home. "We've been calling for a registry. That means that everyone who went overseas, we could have captured their information,"…. the last thing she wants is to 'hope monger.' "But there are results. Canada should have been collecting the data and if we had been collecting the data would we still be calling this anecdotal evidence?" (Regina Leader Post, Oct 15, 2010).

Whilst the trials are underway at the time of writing this thesis, patients' mobility continues, albeit in lower numbers.

At the provincial level, various governments took independent actions with regard to mobility for LT. Saskatchewan took a giant step in encouraging patient mobility for LT. With one of the highest prevalences of MS in Canada, the provincial government attached a sense of urgency to the issue. The government announced a $2.2million package for 86 patients to undergo LT at the Albany Medical Centre in the US. This package was designed to cover travel costs and expenses for patients who would undergo the treatment. This policy decision was taken because it is the prerogative of the government to let patients know the potency of the procedure.

> "Patients need answers as soon as possible about the efficacy of the liberation therapy as a treatment for MS,"…. "We owe it to them to explore every opportunity to advance MS research and find answers about this treatment. This clinical study will enable Saskatchewan patients to be involved quite quickly in a controlled, reputable research process." (Calgary Herald and Edmonton Journal, September 24, 2011).

Over 600 patients applied to take part which did not come as a surprise to a Member of the Legislative Assembly, Mark Docherty, who received the treatment overseas.

> "I figured that people with MS would be more than happy to add their names to the list,"…. "I think we're all supportive of this. It's very exciting for every-body throughout the province. All they're hoping for is to find out a cause and a cure. We've got to get some answers toward, 'Why?' (Edmonton Journal, Feb 9, 2012).

The study was however halted late 2013 as there were not enough volunteers in the US who were willing to participate in the trials. Nonetheless, the government's search for other options for MS treatment remains on the radar.

> "Our priority is to try to find a similar type of study, but we're realistic to know that might not be possible." (Regina Leader Post, Sept 10, 2013).

Like Saskatchewan, the Alward government of New Brunswick offered to pay for patients to access LT abroad. In its encouragement for patient mobility, the government decided to spend the tax payers' money to subsidize patient access to have the procedure overseas provided the patient can mobilize funds from the community or third party.

> The Tory election platform promised to provide $500,000 to "help New Brunswickers afford procedures, such as liberation treatment for MS sufferers that will match funds raised by individuals and communities supporting them." (Telegraph Journal, Dec 10, 2010).

As earlier noted in the literature (Pullman et al., 2013), rather than sponsoring or subsidizing for patients access to LT, some provinces set up registries to gather information about the progress of patients who paid out of pocket for LT overseas. Media data for instance narrated that the provincial health minister of Newfoundland and Labrador encounter with a patient and lawyer whose symptoms were improved after LT compelled the government to take the policy of setting up a registry.

> It was a conversation with a St. John's lawyer whose own multiple sclerosis symptoms significantly decreased after he underwent liberation therapy that convinced Mr. Kennedy

> (health minister) to ask neurologists whether something could be gained by examining people who have had the treatment. (Globe and Mail, Sept 14, 2010).

In the same fashion, compelling stories provided by patients who had LT overseas became the driving force for the politicians to take a stance on the issue. The provincial health minister of Alberta for instance demonstrated positive testimonials from patients needed much attention.

> "We have to respect the scientists' and medical experts' opinions, but at the same time, we cannot ignore the glowing testimonials and the hope that those who underwent Zamboni treatment have shown us." (Edmonton Journal, Sept 17, 2010).

Considering these personal level of encounters with patients and the testimonials provided, it did not come as a surprise, then, when both provincial governments took the decision to set up the registries.

Non-Elite Sources

MS Patients/Advocacy Groups (Family and Friends)

Patients' perspectives regarding LT were almost entirely positive. Their demand for LT was unprecedented and there was clear evidence of patients' influx to other geographical locations for the treatment and with estimated numbers.

> Canadians suffering from MS have travelled to places such as Bulgaria, Poland, Mexico, the United States and other countries for this treatment (LT) (Montreal Gazette, Nov 26, 2011). As many as 5,000 Canadian patients have gone to get the angioplasty at for profit medical centres (Montreal Gazette, Nov 26, 2013).

The rationale behind patient mobility was highlighted in the media. For instance, media outlets emphasized that patients' motivations to seek the treatment were largely influenced by a flurry of anecdotal evidence and testimonials by past medical tourists posted online. This is demonstrated in the following quotes:

> Canadians have been travelling to countries where the procedure is performed and are returning with anecdotal reports of immediate results, such as restored warmth to their feet and hands, improved vision and decreased fatigue. (National Post, September 2, 2010).
>
> Waiting was not an option for some Canadians with MS, however, so they paid thousands of dollars to travel to places that offered the procedure, such as Costa Rica and Poland. Some posted before-and-after videos online, showing them jumping or doing yoga poses -activities that were impossible before. (Calgary Herald, Feb 15, 2012).

Patient mobility is highly influenced by several decision making processes. Prior to medical tourism, patients often considered certain factors. The characteristics of a specific location determined the direction of flow of patients. One patient explained her circumstances surrounding the decision to choose a particular LT destination.

> "The wait times could be circumvented by using the services of the suddenly flourishing medical tourism industry by going for a long trip to a foreign country. I know that might work for others, but I felt uncomfortable with the idea of travelling through multiple time zones to end up somewhere where I couldn't speak the language. And I didn't feel right about spending thousands of dollars in a developing country like India or Egypt for a procedure the local residents couldn't afford." (Winnipeg Free Press, Aug 6, 2011).

For her, the language and travel distance were on top of her priority in her decision making process. Some patients also took into consideration the wait times and post surgical recovery period when choosing one location over another. For this one patient:

> "She opted for Costa Rica over Poland owing to the shorter waiting list and the required two-week recovery period. Other options could see her flying home two days after the operation, something she didn't want to experience." (Winnipeg Free Press, Dec 26, 2010).

Patients also placed a premium on the quality and standardization of destination facilities. This was seen as a vital component because patients often expected the highest standard of care that is at par or exceeded that of their home facilities. For MS patients such as Nadine, her decision was largely influenced by the quality of care.

> "She's got inquiries in with clinics in Poland, Bulgaria and the U.S. But she's considering going to Mexico, where a medical tourist company is organizing trips for MS patients. "I'm a little leery about it, being Mexico. They told me on the phone, they've done two patients already. That's not a lot to go on," …. "I'd sure like it to be a place that's got a better track record standing behind it." (Regina Leader Post, June 9, 2010).

Patient mobility for LT was inevitable as other therapies could not cure them of their disease. Such patients considered LT as their last hope and decided to try it. A patient explained how he tried other therapies but they did not help his disease.

> "I've been on chemo three times to kill my immune system and all it did was make me lose my hair. I've been on drugs specifically made for relapsing or remitting. I've done steroids, IV treatments-they're all Band-Aids; they don't work." (Edmonton Journal, June 7, 2010).

Not surprisingly, "Hundreds of people with MS have decided they can't just sit and watch their mobility and independence ebb away, so they're trying to pull together thousands of dollars to travel out of country for the controversial surgery." (Edmonton Journal, June 7, 2010).

Seeking LT overseas involved some costs ranging from $10,000-$30,000 which was not covered by private health insurance. Media stories recounted a series of strategies patients engaged in order to mobilize funds for LT.

> People are remortgaging their houses, taking out of their retirement funds to go to Poland and Italy." (Regina Leader Post, May 6, 2010).

> People have literally mortgaged their homes; people have sold all their possessions ... people have rendered themselves in utter poverty for the sake of this. (Toronto Star, Sept 1, 2010).

In addition to these strategies, patients used their tax claims to pay for the procedure. In some cases, fund raising activities were organized, while others borrowed money from financial institutions, family and friends all aimed at finding a cure to their disease. In one scenario a woman from St. Stephen (New Brunswick) "with a limited income plundered most of her precious savings to receive treatment in Rhode Island for multiple sclerosis, a disease that left her debilitated for years" (Telegraph Journal, July 14, 2011). Some even used pennies in order to pay for LT:

> A 25-year-old Brandonite hopes her fellow citizens can part with the copper coins, generally considered a nuisance, so she can put them to good use. "I figured I know so many people who just throw them away. Why not throw them at me? I'll catch them and use them," Roy said. (Winnipeg Free Press, Sept 18, 2010).

It is important to note that the outcomes of patients who engaged in medical tourism were chronicled as nothing more than positive. Patients could vouch for LT as it dramatically and empirically improved their symptoms that afflicted them for many decades. Karen especially after engaging in medical tourism for LT confesses that "…it is the best the best decision I have ever made in my life" because all her symptoms vanished and she became 'brand new' (Toronto Star, Sept 21, 2010).

On the contrary, medical tourism for LT produced negative outcomes. Some patients developed complications and later died. In one case reported in the media, a 26-year-old who went to India for the treatment ended up with worsened MS symptoms, persistent cervical pain and permanent nerve damage after oversized stents were inserted in the patient's neck veins (Calgary Herald,

Aug 24, 2011). Documented in the print media, two patients from Calgary and Niagara Falls died after undergoing LT in the US and Costa Rica respectively.

Some patients expressed concern about the quality of care in some of the medical facilities. Media stories shared some experiences a patient had in a medical facility in India:

> Although the hospital was modern and well-staffed, and everyone was kind and caring, the clinical standards struck him as extremely lax. No one had reviewed his file. No one even knew if his veins were blocked, and there was no mention of any kind of follow-up. They found out his veins weren't blocked. He'd flown to India for nothing. (Globe and Mail, Sept 30, 2010).

Patient mobility for LT has reached an all time low in recent times, and this could be attributed to the media accounts of a published study that "sounds a death knell for the hypothesis of chronic cerebrospinal venous insufficiency (CCSVI) as a disease entity" (Telegraph Journal, Oct 10, 2013). That notwithstanding, it is believed that people will continue to engage in medical tourism as long as the treatment is not available in the country.

Generally, the main elite sources comprise the both federal and provincial governments. Patients and their advocates including family and friends were the notable non-elite sources identified in the analysis.

Media Framing and Patient Mobility and/or Medical Tourism for CCSVI and LT

The main stream print media employed various ways of presenting the issue of CCSVI and LT as well as positioning the perspectives of major stakeholders. The media employed several frames in presenting the issue. This section presents the frames employed by the media in describing and articulating the issue. These frames are discussed under various timelines.

Phase 1 (November, 2009-August, 2010)

The period witnessed media introduction of Zamboni's hypothesis to the general public. In this phase, positive frames dominated in the discourse. These frames are highlighted below alongside their national and regional variations.

Miracle Frame: In its coverage of the issue, the national newspapers particularly the Globe and Mail, framed the LT issue as a miracle cure. This frame dominated the discourse until the federal government announced plans to fund clinical trials in mid 2011. This frame was exemplified by patients' anecdotal stories:

> After the procedures (LT) … he was reborn. "I don't remember what it's like to have MS,"…. "It gave me a second life."...."I felt good. I felt totally normal. I felt like I did years ago," …. He has not had an attack since. (Globe Mail, Nov 21, 2009).

Besides, other patients' recorded astonishing improvements in their quality of life as encouraging evidence in support of patient mobility. The Globe and Mail, which first broke the story on the issue, set the agenda for this frame and it was a motivational factor for patient mobility. This frame was missing in the other national paper (i.e. the National Post), however it was reechoed by the various regional newspapers as one patient accounts on how LT has give her a new life.

> "I don't have MS symptoms anymore. It's a big list," she said Tuesday. "I do not have debilitating fatigue. I do not have neuropathic pain. I do not have heat intolerance. I'm able to swallow properly. I'm able to speak with a strong voice. My cognitive fog is gone. I'm able to think more clearly. My eyesight is better. My hearing is better and I no longer limp. That's just some of it, I didn't even touch it all." (Regina Leader Post, June 9, 2010).

Hope Frame: Overlapping the miracle frame in the dataset was the framing of the issue as "hope". LT was seen as offering hope to patients when other proven therapies had not been effective for them. Like the miracle frame, this frame was central within the newspapers analyzed. Nationally, the Globe and Mail newspaper laid the foundation of hope frame. This was typified by Zamboni and Ashton Embry (LT advocate) respectively expressing high expectations about the procedure as "a revolution for the research and diagnosis of multiple sclerosis" (Globe and Mail, Nov 21, 2009) and how "CCSVI has the potential to completely change how we see MS and how to treat it." (Globe and Mail, Nov 24, 2009). In addition was the clarion call from the MS Society of Canada "on scientists to research it thoroughly and promising to back their work with significant research dollars." (Globe and Mail, Nov 24, 2009). The hope frame was also portrayed in profile stories of patients who had undergone LT and immediately "increased mobility, subsiding fatigue, and "a new lease of life" (Globe and Mail, November 27, 2010). Interestingly, the National Post recounted how media stories raised the hope of patients to engage in medical tourism for LT. As framed in the newspaper, a neurologist acknowledged that "It (LT) was presented as very new and exciting research and ready to go,"…. "Those stories generated an enormous amount of hope." (National Post, January 23, 2010).

The hope frame also dominated in provinces that decided to fund clinical trials and patient mobility. The following quotations highlight how the governments of Saskatchewan and New Brunswick (the two provinces that encouraged patient mobility for LT) perspectives of hope were framed in their respective provincial newspapers:

> Saskatchewan Party government is willing to fund clinical trials of a controversial treatment for multiple sclerosis, calling the liberation procedure an "avenue of hope" for patients stricken with the disease. (Regina Leader Post, July 28, 2010).

> "There's a new intervention that has created a lot of hope for people,"…. "We are asking people to ask questions and we are going to continue to ask those questions ourselves of what works, but obviously the message we want to give them is that we know there is a financial burden, we know that they are suffering a lot." (Telegraph Journal, Aug 29, 2010).

Liberation Frame: Another favorable frame that encouraged patient mobility and dominated in the first phase was the liberation frame. Framing the procedure as 'liberation', LT is seen as powerful medical surgery that could free patients from MS. In terms of newspaper coverage of this frame, there were coverage similarities in both national and regional newspapers. Various media outlets gave a vivid account of a study by Chafe and colleagues and further emphasized the genesis and circumstances that set the stage and media framing for this particular frame. This frame also recounted how LT liberated patients and improved their MS symptoms.

> They are hearing from dozens and dozens of patients who have undergone treatment and the results, ranging from minimal improvement to a complete "liberation" from symptoms. Many patients have reported improvements in walking, vision, taste and smell, balance, bladder control, mental alertness, memory, energy, and virtually every other symptom related to MS. (Edmonton Journal, May 20, 2010).

Rights Frame: As patients saw the procedure as liberating them from their MS, the emphasis of media framing shifted to LT as a fundamental human right. The rights frame became salient throughout the media dataset and was showcased in instances where patients revolted against the government and the medical community and demand for the availability of the procedure increased. Although this frame was relatively minor within the dataset, it added another dimension to the issue as patients complained how the health care system has failed. From the perspective of MS patients', living with the disease was an emotional one, and as such the non availability of LT by the health care system was an infringement of their human rights especially

in terms of the right to access health care. Patients challenged the status quo and demanded their medical plans cover it. Legal challenges became necessary and in Vancouver a patient decided to file a human rights complaint against the British Columbia Ministry of Health "for being denied access to LT" (Vancouver Sun, Aug 5, 2010). Patients also mounted pressure on the government and affirmed that "It's our bodies. The government should let us see for ourselves if it works"…. "They (government) want us to wait a few years, but this illness won't wait. We see this as a way out, the only way out."(Globe and Mail, May 6, 2010). Other patients echoed similar sentiments and asserted that "They (government) should not have the right to tell us we can't do this. It is my right as a human being to try this (LT)." (National Post, Jan 23, 2010).

Phase 2 (September, 2010-May, 2011)

This phase started with government's decision not to fund clinical trials. It was also a period where the debate about the efficacy of LT reached its peak. Frames that dominated in this phase included wait and see and adversarial.

Wait and See Frame: This frame viewed as negative from patients' perspective received media attention under the second phase. The frame highlighted the need for more evidence and scientific based research into the efficacy of LT. Media stories on this frame recounted that renowned scientists and researchers from the CIHR and the MS Society of Canada urged the government not to fund clinical trials because there was "an overwhelming lack of scientific evidence" about the safety of LT. (Globe and Mail, Sept 2, 2010). This major policy statement attracted the attention of almost all national and regional newspapers. The 'wait and see' approach adopted by the government after this announcement became consistent in the news story framing of the issue.

As part of the federal government's 'wait and see' approach, provincial governments were also implored to wait for further studies.

> ...wait for the results of seven Canadian research projects looking into the efficacy of the so-called liberation treatment before clinical trials proceed. (Edmonton Journal and Montreal Gazette, Sept 2, 2010).
>
> More research on the possible mechanics of the theory behind the treatment-that is, on the phenomenon of CCSVI-is required." (Globe and Mail, Sept 8, 2010).

Following from this, provincial governments "have agreed to co-operate on clinical trials, if and when they get the scientific go-ahead. They are awaiting the results-expected in a matter of months-of seven diagnostic studies that are expected to help their decision on whether to proceed." (Winnipeg Free Press, Oct 16, 2010). In a stark contrast, the Saskatchewan premier took its own initiative and decided to unilaterally "fund clinical trials for a controversial treatment (LT) for people suffering from multiple sclerosis." (Toronto Star, Dec 21, 2010). While the decision was made, patients in that province were urged to wait until the clinical trial is complete before deciding on travelling for the procedure. It is worth noting that this frame became irrelevant once the federal government announced the funding of clinical trials. With patients demands accepted for clinical trials, the emphasis was placed on the validity of Zamboni's hypothesis between CCSVI and MS.

Adversarial Frame: The central frame perhaps for this issue was the adversarial frame. The controversy surrounding the effectiveness of LT was built around this frame. Media portrayed it as a conflict between: a) those in favor of LT (especially MS patients) as the treatment to MS where demands were made for immediate clinical trials and access to the procedure and; b) those who cast doubt on the efficacy of the procedure (i.e. medical experts) and urged for more research since the risks far outweighed the benefits. Media succinctly captured how mobile

(patients equipped with reckless and risky ideas) and immobile (health care system) forces were pitted against each other.

> Today's medical landscape features at least two competing forces. The debate over the Zamboni MS treatment reflects this. On the one side, consumer patients equip themselves with information no further away than a mouse click. On the other, the government and the medical establishment insist they're just protecting customers from themselves. (National Post, Sept 28, 2010).

The momentum of the controversy which can be described as unprecedented was blamed squarely on the social media. Government and medical experts narrated how the media generated the debate and mobilized patients into advocacy groups to agitate for access to LT in Canada. A physician noted that:

> The media "have created a nightmare for our patients, clinics, the MS Society, and the government …" (Globe and Mail, Sept 20, 2010)

At the national level, newspaper presentations of the adversarial frame were evident in demonstrations in which patients' were positioned in opposition to the federal government. Media data articulated how patients organized and pressured the government for access to LT domestically.

> Multiple sclerosis patients have become an increasingly organized and angry force as they agitate to have a controversial new treatment known as liberation therapy made available in Canada. (Globe and Mail, Sept 20, 2010).

> Patients flex muscle in 'war' over treatment; No longer content to sit by as authorities advocate caution over the Zamboni theory, proponents wield social media as a weapon. The public campaign to bring the controversial new "liberation" treatment for multiple sclerosis to Canada has been declared "a war" -and Anna Delorme is pleased to be serving on the front line. (Globe and Mail, May 11, 2011).

Patients also directed their anger towards the medical community and described them as being so closed-minded. Patients became furious and attacked physicians who were skeptical about the potency of LT and advised patients against medical tourism for LT. The quote below illustrates how patients attacked and labeled a neurologist who expressed doubt about LT and discouraged patient mobility for the procedure.

> There were the angry letters and phone calls. There were patients who told him he was fired, and others who accused him of conspiring with drug companies to keep them ill in the name of profit. There was the vitriol being poured into online forums, where he was called a pompous windbag with the bedside manner of Adolf Hitler, a pill pusher and, even, the "King of all Turds." (Toronto Star, Sept 25, 2010).

The neurologist rebutted as follows:

> "What did we do - other than point out the obvious careful approach to treatment - to warrant this kind of aggressiveness from their part?" …. "What have we done to lose that trust? I think we have worked very hard to gain that trust through our meticulous research, our careful approach, our conservative and inquisitive nature, our demand for high standards." (Toronto Star, Sept 25, 2010).

In the prairie region, and particularly in Alberta, the adversarial frame dominated newspaper presentations as a battlefield between Zamboni and the Alberta Health Services. The Alberta Health Services in a news release warned patients against LT because it contained some level of risk. The agency advised patients to consult with their physicians prior to medical tourism. Patients were further advised to be circumspect about the available resources online that provides information on CCSVI and LT.

> Alberta Health Services has cautioned MS patients to be wary of some of the information around the treatment and noted the procedure could cause severe medical problems. (Calgary Herald, Sept 13, 2010).

In rebuttal Zamboni described their statement as "extremely confusing and irresponsible because it mixes facts, fiction and assumptions" (Calgary Herald, Oct 30, 2010). Zamboni further described their position statement as unfounded:

> "It is simply naive not to think that CCSVI (the narrowing of veins) significantly affects MS and (to) discourage research in the field. Moreover, it is irresponsible to criticize the pilot study on the value of angioplasty, given the fact that the current standard of care for MS is incapable of preventing progression to disability." (Calgary Herald, Oct 30, 2010).

The adversarial frame again becomes the focal point whereby the government received backlash from the medical community. In particular, Saskatchewan's decision to fund LT trials garnered physicians' accusations. In one instance a physician expressed shocked at the action taken by the government of Saskatchewan to fund clinical trials. Dr. Jock Murray, a physician, was quoted in the media chastising the government for playing politics with scientific process.

This government-physician acrimony extended to the Atlantic Coast particularly New Brunswick, where that government decided to fund patients willing to engage in medical tourism for LT. In a commentary published in the Telegraph-Journal, the government's policy was criticized as follows:

> Premier Alward, by providing funds for the "Liberation Treatment" you are actively condoning facilities in other countries to cheat patients and the taxpayers of this province. (Telegraph Journal, December 9, 2010).

It is worth noting that although the frame appears in all the phases, it dominated under the phase two. This was not surprising because the controversy over the efficacy of LT was the focal point of this phase.

Phases 3 and 4 (June, 2011-October, 2013)

Media coverage of the issue under phases 3 and 4 focused on clinical trials and Canadian scientific outcomes. On June 30, 2011, Canada's Health Minister announced that the federal government would begin funding Phase I and II clinical trials for LT. However in August and October, 2013 newspaper articles published two research findings that cast doubt on the validity of Zamboni's hypothesis. As a result, the number of articles published and media frames waned. Nevertheless, the hoax frame dominated during this period more than any other frame.

Hoax Frame: This was the notable media frame that dispelled patients from travelling outside for LT. This frame was certainly present during phases 1 and 2 but was most prominent in phases 3 and 4 after studies could not replicate Zamboni's hypothesis. As mentioned earlier, the medical community perspectives on the potency of LT were negative. Medical experts contended that the benefits patients experienced from LT were as a result of the placebo effect (i.e. the power of belief in the treatment as 'real'). In framing LT as a hoax, these medical experts advised patients against the influx of Canadians into other countries for LT. Within the national newspapers, the National Post led the crusade for the hoax frame associated with LT. An editorial article published in this newspaper squarely placed the blame on the CCSVI and LT episode aired on CTV. Debunking the documentary, the newspaper described it as media 'hope-mongering' and nothing more than "junk science". The hoax frame dominated within the National Post as it subsequently covered the issue.

Besides medical experts, some patients also expressed skepticism about the efficacy of LT. The Globe and Mail described an MS patient (Mark Pickup) as "a staunch unbeliever in liberation

therapy" and stressed that LT like previous cures "has turned out to be a hoax or overstated." (Globe and Mail, Sept 30, 2011).

The hoax frame was present in the regional newspapers as well. For instance in New Brunswick, "Patti Forgeron is an outspoken opponent of liberation therapy... dismisses the procedure as "medical quackery." (Telegraph Journal, June 13, 2011). This position was also in the Prairie regions were the treatment was dismissed by the medical community as "nothing more than snake oil salesmen" and "anecdotal accounts of improvements as not real" but "was just the 'placebo effect' at work…." (Winnipeg Free Press, Aug 6, 2011). News stories equally illuminated on effects of LT on patients:

> However, some critics have said liberation therapy advocates don't mention the fact that Canadians have died from the procedure, the procedure doesn't work for everyone and, even if it does, the effects don't always last. (Regina Leader Post, Feb 9, 2012).

As studies debunked the association between CCSVI and LT, this frame was further highlighted in scientific journal publications by physicians and researchers.

> In a Lancet commentary called "the final curtain" on CCSVI, Dr. Frieidemann Paul, of Germany, and Dr. Mike Wattjes, of the Netherlands, said CCSVI is nothing more than a phantom condition. (Montreal Gazette, Oct 9, 2013).

Generally, results from the stakeholders perspectives were organized and analyzed based on national and regional newspapers coverage. Additionally, the media frequency of coverage and media frames changed over space and time alongside four main phases. The first phase (November 2009-August, 2010) coincides with the introduction of CCSVI and LT to the general public. This was where the story first appeared in the Globe and Mail newspaper and subsequently covered by other papers. The second phase spanned from September 2010-May 2011. This phase captures when the government adopted the 'wait and see' approach. This

general phase highlights when the debate peaked regarding the effectiveness of the LT. The third phase (June 2011-July 2013) provides how federal and provincial governments ('systems') responded to patient mobility for LT to conduct their studies. For instance, clinical trials were announced by the federal government, including the general process to begin the trials. Policy initiatives by provincial governments include setting up registries (British Columbia), launching observational studies (Alberta) and sponsoring patients for clinical trials (Saskatchewan). Doubts about the association between CCSVI and MS emerged in the final phase (August, 2013-October, 2013). Despite the negative outcomes, research into the efficacy of LT is still ongoing and the results are expected to be released in the summer of 2016.

The frequency of coverage and media frames also changed along national and regional variations. The number of stories for instance declined substantially whilst the adversarial frame remained consistently throughout the debate. Initially, it was the positive frames that dominated the discourse. As complications and deaths were recorded, there was a shift in media framing towards the negative frames. These frames reinforce the perspectives of major stakeholders' perspectives regarding mobility for LT and the Canadian health care system. The chapter that follows discusses some of these issues in more details.

Chapter 6

Discussion

The study was designed to assess how the media presentation of various groups' reactions CCSVI and LT, facilitated by mobile networks/structures can pressure governments to modify health care policies and processes. To achieve this goal, the analysis focused on how patient mobility for LT was framed in the media by major key stakeholders involved in the debate. The focus in this chapter is to discuss the major findings in relation to existing literature on medical tourism and contextualized by the media framing analysis.

Media Coverage of Liberation Therapy

The introduction of CCSVI and LT dominated in the Canadian mainstream media. The media presentation of the issue emphasizes how news media coverage can galvanize the public to pressure policy makers to make health care decisions that challenge the fundamental values underpinning this immobile system. This particular case study highlighted how patient anecdotal evidence fuelled by the news media led to different levels of government to make policy decisions supporting the mobility of patients even though the safety of LT remains uncertain.

Following the pattern of Pullman et al. (2013), the findings suggest how 'evidence' about LT is analyzed and interpreted by the different stakeholders. For the medical community and research community, rigorous experiments that corroborate a particular hypothesis become real evidence. As a result, the medical community maintained its immobile cautious approach urging for more data to ascertain the association between blocked veins and MS. For the medical community, research and the collection of evidence can be done in a highly mobile way but the willingness to have the Canadian immobile health system change until that evidence was gathered was rigidly protected. The general public and patients mostly relied on visual and written anecdotal stories

from highly mobile sources through social media and virtual online groups that neither occupies any particular space but which is constantly moving across time and scale. CCSVI and LT narratives in news stories also provided such powerful anecdotes as their main source of evidence effectively taking the mobile virtual spaces from the Internet and displaying those perspectives within immobile local scales. Finally, politicians based their evidence on the voices that was given prominence by the media. The media communicates powerful anecdotes, hence patients' voices dominated in the discourse. This led to pressure on governments to fund clinical trials. This pressure highlights how the increasing proliferation of mobile networks can alter the processes within the health care system. The increased information and ideas in these mobile networks also have mobility implications for the immobile health care system. For instance, it can create a two-tier system, and this can result in inequities in mobility and quality of health care accessibility (Johnston et al., 2010). This is facilitated by easy access information on the Internet and capacity to mobilize for treatments amongst the wealthy health consumer, whereas those without the necessary financial resources have to rely on the domestic health care system. Although, this pattern is generally true, the mobility pattern for LT demonstrated how less-affluent MS patients were able to mobilize family and community support networks to fundraise to support their mobile consumption.

It is clear from the analysis that there was sustained frequency and coverage of the issue in its early stages (i.e. Phases 2 and 3) highlighting how the media treated the issue as news worthy for the attention of the general public (Clayman & Reisner, 1998). However, the intensity in media coverage dropped over time. Clinical studies published recently on the LT issue have shown no association between blocked veins and MS (Traboulsee et al., 2014). Given the negative outcomes of studies so far, it is not surprising that media stories on the issue have dwindled. This

accords with previous studies that have documented how scientific discoveries with promising results often generate much media coverage in its initial stage, but wane over space and time when subsequent studies refute the discoveries (Gonon et al., 2012; Ioannidis, 2005). In addition, the issue became less news- worthy when the federal government decided to fund clinical trials, which are still ongoing at the time of writing the thesis. This major decision, a moral victory for patients whose voices were amplified by the media, made the LT story less relevant (Tulk, 2012). As such, there was less emphasis on media stories portraying patients agitating governments for LT. This pattern is also typical with journalistic style of reporting, whereby journalists report on news that is new, original and fresh rather than stale stories, where a "repetition taboo" might risk become boring (Gans, 2004, p.169).

Despite the waning media interest on the issue, it nevertheless highlights the importance of the media in portraying medical discoveries to the general public, as well as influencing scientific and health policies and funding health research (Chang et al., 2014). It is however expected that more media stories on the issue will surface when the final results are release in the summer of 2016. Considering media norms of reporting on positive scientific findings, it can be predicted that there will be massive media coverage on the issue if the results affirm a strong correlation between CCSVI and MS (Stryker, 2002); however, if the trial findings do not support the hypothesis, the issue might receive a few cursory stories and fade away.

Unsurprisingly, there were substantial variations among story leads, headlines and body. Given that headlines are written by the editors of newspapers whilst the reporters typically write the stories, this could explain the mismatch between the tone of the headlines and stories. However, for a better appreciation of story content, the leads and headlines might provide the context (Sieff, 2003). Additionally, the difference between the story lead and the story body was

expected as Mistry and Driedger (2012) in their study concluded that media story leads play an important role in public understanding of an issue, but might not be a good measure for the content of the whole story.

Location of Media Frames in Communication Process and Implications for Mobility

Media frames are manifested in four main locations (communicator, text, receiver and culture). In this evaluation, the communicator represents the reporters and the sources used in the media stories. In the dataset the media stories the media relied on either elite or non-elite sources. Stressing the need not to ignore non-elite sources (Driedger, 2008), the media consistently referenced the patient perspective as the most used non-elite source within the data. Much of the media stories focused on patient anecdotal evidence as proof that LT "really works". Government officials, researchers and physicians were relied upon as the major elite sources. From the dataset, the media made references to government news releases and published scientific results as their main focus on elite sources. Use of elite sources has been well documented as the most important source of information for news reporting (Miller & Riechert, 2000; van Dijk, 1991). By conventional journalistic practice, the elite sources were mostly used in the construction of news stories because these sources are viewed as both credible and easily available (Miller & Riechert, 2000).

In terms of Entman's text, this is both the stories as well as where dominant frames are positioned. In the construction of the news stories, journalists used certain key words and phrases to highlight the major frames. These frames tended to be located in the body. This was expected as much of the text was within the body of the news stories. From the analysis, the frames were easily identified by the manner in which journalists portrayed the stories. For instance, positive frames encouraging mobility were identified by the use of words and phrases such as "improved

symptoms", "liberation", "new beginning" whilst "death" and "placebo" were used to denote negative frames. Similar to van Dijk (1991), media stories often reflect journalists' use of style and rhetoric within a text to highlight the importance of some aspects over others. For instance the use of literary devices emphasizes some aspects of an article, thereby contributing to the overall framing of the story (van Dijk, 1991).

With regard to Entman's "receiver", various stakeholders were identified as the receivers. MS patients, family, friends, the public, government officials, etc were identified in the analysis. Entman (1993) argues that the receiver's conclusion may or may not reflect the framing intention of the communicator. Mirroring this, frames over the effectiveness of LT was portrayed with varying opinions by the receivers. For instance, whilst patients perceived LT as a simple procedure, the scientific community viewed it as a dangerous and risky procedure. In this particular case study, the media framed LT within these perspectives as hope vs. hoax. By and large, the frames could influence how the receivers interpreted the messages communicated in the media.

The final manifestation of a frame in a communication process was the culture, which Entman (1993, p.52) described as "stock of commonly invoked frames." Culture for this study is manifested in the belief that the health care system needs to be proactive in serving the perceived needs of patients. Within an urgency frame, patients and their advocates urge for a change in the bureaucratic process of approving medical procedures in the health care system. They further charge researchers and clinicians to expedite the research process and make the treatment available as quickly as possible. Whilst the scientific community sympathized with the perceived needs and wants of patients, the values that underlie the Canadian immobile health care system also needed protection. The system particularly values the safety of Canadians and as a result the

scientific processes of approving medical procedures were to be followed. This position from the scientific community was vindicated as one of the largest studies in Canada could not replicate CCSVI and MS correlation (Traboulsee et al., 2014) and subsequent media coverage presented the issue as a hoax. While there was a broader vindication of the scientific process, the static management of the health care system nonetheless "pushed" patients (especially those who could not withstand the system) into the mobile global health care system to discretionarily pursue their perceived needs and wants. Culture also entailed patients' access to health care as their fundamental human rights. Patients argued that the non-availability of LT in the health care system is an affront to their fundamental human rights. As earlier pointed out, a patient filed human right case in court for being denied access to the procedure in Canada.

Media Framing and the Canadian Health Care System

The relevance of media frames in patient mobility for LT was also explored in the study. Different frames that enhance or discourage patient mobility were highlighted within the data. However, the adversarial frame was prominent among the key stakeholders identified. This frame dominated the discourse until the government was sufficiently pressured to fund clinical trials. In some instances emphasis was placed on the hope and hoax frames as the key frames driving the debate over the efficacy of LT. Within the hope frame, patients expressed higher expectations about LT as a 'cure' to their disease and heavy pressure was put on the government to fund clinical trials. The analysis of how the media presented emotional stories demonstrated a series of steps in motion. Patient anecdotal stories in the news serve to bypass typical steps in the scientific process of approving therapies. This has called for the need to communicate scientific information in a language that is easily comprehensible, and within the confines of mobile networks (i.e. social networking sites and blogosphere) that are readily accessible and available

to the general public. For patients hope became the motivating factor for their engagement in medical tourism for unproven procedures (Fox, 2011). Nonetheless, pressure from patients and advocates have shown how rallying behind LT has the potential of changing the authority of health professionals. The study highlights the static nature of physicians in reacting to medical procedures. Physicians' cautious approach to medical procedures is an established norm that ensures that data gathered, analyzed and interpreted follow standardized rigorous processes (Pullman et al., 2013). Patients on the contrary are dynamic in their decision making process, and are sourcing for health care in other jurisdictions. Media stories portrayal of the dynamic-static tensions serves as the basis for the main argument of patient mobility for LT. Patients' mobile decision making process pose a challenge to health care providers to be proactive in dealing with patients' perceived needs. For instance, Cameroon and colleagues (2014, p.98) in their study argue that patients are challenging the expertise of physicians and shed light on the need for health care providers to "adjust care and information-sharing practices to accommodate patients who regard themselves as experts or wish to take self directed approach." Media stories provided space for patients to express their expertise on their perceived health care needs by evaluating various medical tourism destinations and consulting various mobile networks. Given their expertise and mobile decision making process, patients held the view that the physicians neglected their perceived needs and they ethically justified their engagement in medical tourism (Snyder et al., 2012). As the system cannot prohibit Canadians engagement in medical tourism, this raises policy questions regarding the creation of a system that would oblige patients to sign away their rights to universal health care in cases where they have received non-approved treatments abroad.

In addition to this, patients are challenging the status quo of the health care system, which is embedded with stringent measures in approving therapies. In other words, the health care system has been static in terms of approving medical procedures. The static system is to ensure that the safety of patients is not compromised. Nonetheless, the increased mobility of patients and ideas has challenged the health care system which was designed for a less mobile world. The study therefore argues for the modification of a health care system that would respond to the perceived needs of patients but in a way that would not necessarily bend to that will. In agreement, Brendan Leier, a professor at the John Dossetor Health Ethics Centre at the University of Alberta, acknowledged that the issue of LT enabled by social media is a good omen for the health care system because "it forces a very, very conservative institution to respond and to be critical of themselves and to articulate appropriate responses." (Sinnema, 2010, A1). There is particularly the need to consider balancing patients perceived needs against unnecessary risks that unproven therapies such as LT can cause to them. Considering the negative scientific outcomes on the issue so far, the decision to conduct clinical trials before it can be made available and accessible in the health care system is a step in the right direction.

More intriguing about the study is how news stories documented the frustrations of Canadian patients who travelled outside for LT with the health care system. These patients felt abandoned by the health care system and they had no choice other than to seek the procedure elsewhere. Similar patterns were found in a previous study that indicates that due to the limitations in a health system, patients are compelled to seek health care in other jurisdictions (Perfetto & Dholakia, 2010). In fact, patients emphasized in the media that the Canadian health care system is outdated and not responsive to their perceived health care needs. As a result, they were relying on the international health care system to meet their perceived therapeutic needs. In an

anthropological study with MS patients, researchers chronicled how patients expressed dissatisfaction with the Canadian health care system (Hande, 2012). In the narratives, MS patients wondered why the LT procedure was being carried out in many countries but were not available in the Canadian health care system. These patients not only criticized the health care system as being dogmatic and immune to changes, but they also expressed dissatisfaction with having to rely on decentralized health care facilities overseas (Hande, 2012).

However, patients seeking medical procedures outside Canada have an overwhelming effect on their own health care system. Treating patients with post operative complications after LT can cost the publicly funded health care system thousands, if not millions of dollars. News stories certainly raised this tension as they documented patients returning with complications after LT and having to rely on the health system for post surgical care. This raises the ethical question of who ought to pay for post operative care of patients engaging in medical tourism for unproven procedures such as LT. In one instance, ten patients who had bariatric surgery abroad and developed complications cost the Canadian health care system to a tune of $162,791 in handling their post operative complications (Birch et al., 2010; Turner, 2013). This gives an overall sense of estimating the cost of LT post surgical complications to the Canadian health care system.

The Role of the Media and Social Amplification of Risk Framework

One unique perspective that came out of the analysis of media stories was how LT is perceived in terms of the level of risk. The dataset provided a stark difference between the experts' and patients' perceptions of risks. The role of the media in portraying the experts and lay perspectives over any risk is well documented (Frewer et al., 2002; Lewis and Tyshenko, 2009). Echoing the social amplification of risk framework, media narratives show how patients and medical experts' voices are amplified or attenuated. The media in particular emphasize more on

attenuating patients' voices over amplifying experts' opinions regarding the risks of the procedure. For instance, medical experts' assess the procedure as carrying some degree of risk. Quoting the voice of physicians, a media story recounted that the procedure entails "... unknown risks that patients are being exposed to that we're not aware of yet." (Montreal Gazette, Aug 26, 2011). More so, Burton and colleagues (2011) investigated five patients and the results indicated that they developed complications such as internal jugular vein stent thrombosis, cerebral sinovenous thrombosis, stent migration, cranial nerve injury and injury associated with venous catheterization. This study garnered the attention of media stories reviewed. The articles amplified the experts' voices with a common theme being that many MS patients who had LT developed complications. To buttress the risks of LT, the media further demonstrated patients who died from the procedure. Print media stories also recounted how a relative of a deceased lamented over the risk of the procedure, as he noted "No one ever mentioned this was a risk" (Calgary Herald, July 9, 2011). Overall, the perspectives of the experts regarding the associated risks of LT were consistent in media stories.

Contrarily, the experts' voices were attenuated by patients who downplayed LT as a safe, simple and inexpensive surgical procedure and that the benefits far outweighed the risks. For instance, a patient who had LT remarked that: "It's not a serious procedure. Getting my wisdom teeth out was more serious,".... (Vancouver Sun, Aug 15, 2013). Patients and their advocates argued that the procedure was not risky and in some instances they doubted the credibility of the medical experts. In one case, "Mr. Thornton and other advocates argue the procedure isn't particularly dangerous and patients should be allowed to assess the risks themselves" (Globe and Mail, Oct 16, 2010). As patients lost the trust of the medical experts and became their own experts, they were willing to take their chances. On the whole, patients responded by attenuating the

associated risks of the procedure. As a formal channel of communication, the media transmits, communicates and interprets information about the risks (Mistry, 2007). In a review of the application of the social amplification of risk framework to other risks context, Lewis and Tyshenko (2009) posited that the role of the media is evidenced in how it influences risk perception and carries risk information to the general public. The authors further identified that the varying degree of risk perception between the experts and the non-experts may be due to availability of information. In tandem with this, the availability of information about LT especially online highlights how patients perceived the risks of LT. Patients in the media stories made reference to the CTV W5 Documentary as evidence in support of LT as a less risky medical procedure. The media broadly might have attenuated patients risk perception because of online anecdotally supporting evidence that underscores the potency of the procedure.

Liberation Therapy and Medical Tourism

Decision Making Process

Patients rely on various types of information to help make decisions regarding mobility for health care. Rather than the advice of medical experts, news stories documented various sources that patients relied upon to make a better informed decision. First, the Internet was the main source of information that helped patients to make their decision to undertake medical tourism for LT. Considering the massive use of the Internet for health information, patients have become 'experts' after evaluating online information (Cameron et al., 2014). It is worth noting that while patients expressed skepticism of the trustworthiness of Internet information, their reliance on it was consistent. Through social networks, online journals and Google sites, patients were able to access a lot of information about medical facilities and the reputation of physicians. This is consistent with previous reports that stressed the importance of the Internet in disseminating

health information (Marrie et al., 2013) for Canadian medical tourists' decision making processes (Crooks et al., 2011). Second, while family doctors and physicians are key components in providing patients with information about the risks and benefits of procedures within the Canadian health care system, patients rarely consulted them in their decision making process to engage in medical tourism (Johnston et al., 2012). However, Marrie et al. (2013) demonstrated that health care providers have traditionally been the most trusted source of information for patients. Given that physicians were generally negative towards the procedure, few patients sought information from them prior to engaging in medical tourism. Further, firsthand accounts through word of mouth of patients who had LT overseas was identified as valuable information sources. The value patients placed on word of mouth by past medical tourists was equally identified in previous studies among Canadians who had orthopedic surgeries, including hip replacement and resurfacing and knee replacement (Crooks et al., 2011, 2012).

Patient decision making processes and information sources are tied to the role of virtual mobilities in medical tourism. The advancement of Information and Communication Technologies (ICTs) has profoundly changed the movement of the world. Instead of physical movement, people are able to get relevant information through the use of the Internet. With the help of ICTs, patients are able to communicate with physicians in other locations and also shop for the best facility that suit their taste. The Internet plays an important role in connecting patients to physicians and medical facilities. Highlighted in this research is that with growing virtual mobilities, LT is easily accessed within the shortest possible time in other jurisdictions. Patients were able to link up with physicians in places where the procedure was accessible. More intriguing about the Internet is how it enables the mobility of the procedure. The Internet especially aids the spread of LT ideas in different geographical regions. This is more evident in

the number of available online social media sites (approximately 5000 YouTube videos and more than 500 dedicated Facebook group pages) that provide CCSVI and MS related information (Gafson & Giovannoni, 2014). These online social media sites also serve as the platform for patients to discuss their experiences and share ideas about the procedure irrespective of their location.

The relevance of specific medical tourism destination characteristics for Canadian MS patients to seek medical care is underscored in the analysis. The decision of MS patients' to seek care is influenced by a particular destination language, geographical location, and economic development, reputation and accreditation of medical facility and physician, quality of care etc. The findings are empirically supported by medical tourism conceptual models that highlight the relevance of a country's characteristics for medical tourists (Heung et al., 2011; Smith &Forgione, 2008).

Reasons for the Flow of Patients to the Global South for Liberation Therapy

The global south flow of Canadian patients for health care was highlighted in the analysis. This trend comes as no surprise because the flow of patients to the global south is often attributed to several factors. First, with the improvement in air transportation and competition in the aviation industry, there are several promotions that attract medical tourists to many destinations. Many medical tourists can afford cheap economy flight tickets to most places. Second, the increased mobility of the Global South by Canadians is due to currency exchange rates. Many destination countries have been experiencing currency depreciation since the imposition of structural adjustment programs, and this places the Canadian dollar value on a higher scale vis-a- vis local currencies (Gogia, 2006). As a result, many Canadian medical tourists can afford procedures and living expenses in such countries. Third, there are lax entry visa requirements to most

destinations of the Global South (Gogia, 2006). The less cumbersome procedures in acquiring entry visas enhance the mobility of medical tourists. In some instances Canadians do not require visas to enter to some countries for a short visit. In those countries where a visa is required, Canadian citizens are required to fill only a one page document with minor application fees and a visa is issued in less than three days (Gogia, 2006). Likewise, other destination countries like those in South East Asia have different visa packages for medical tourists. For instance, India has a special visa (M-Visa or Medical Visa) for medical tourists valid for the entire duration of medical care in the country (Burkett, 2007; Turner, 2010).

Resource Mobilization and Medical Tourism Marketing Companies

This study provides insights into how patients mobilized funds to engage in medical tourism for LT. Desperate MS patients who could no longer withstand the government's "wait and see" strategy often sold their belongings, engaged in fundraising activities or even borrowed money from the bank and friends/relatives in order to seek out of the country care. This is understandable because patients are always willing to try treatment options available at their disposal (Bernat, 2010). This point challenges the traditional notion that outsourcing health care is only the purview of those already having the necessary financial resources at their disposal.

As patients generate financial resources for LT, medical tourism marketing companies and agents have sprung to take advantage of the situation. These companies and individuals liaise with medical facilities abroad and prepare the necessary paperwork (i.e. visas, accommodation and tourist sites) (Johnston et al., 2010; Snyder et al., 2011a). Given that patients have a choice to access health care elsewhere, these marketing companies are offering a variety of services for medical procedures without stressing the possible negative outcomes. Marketing companies are

charging hefty prices for patients willing to have the procedure overseas. Individuals desperate for a cure often fall prey to these marketing companies and this raises ethical concerns regarding exploitation of the vulnerable situation for financial gains. These results are similar to previous studies that found that Canadian medical tourism companies are specialized in marketing some unproven procedures to patients without equally highlighting the risks, harms and uncertainties surrounding such procedures (Turner, 2012a).

Liberation Therapy and Post Surgical Complications

The medical tourism industry has offered people with the choice to access health care globally. However, a major concern from this study pertains to the management of post surgical complications after medical tourism. Whilst the media was abuzz with patient reports of positive improvements after LT, news stories also documented reports of medical tourists returning to Canada with complications requiring emergency treatment at the cost of the Canadian health care system. Most of the media reports identified a Niagara Falls man who died after he was unable to see a physician in Canada to handle his post surgical care. The man went back to Costa Rica for the post operative care and died shortly thereafter. This death highlights the challenges faced by patients seeking post surgical care after they travelled for the surgery. Other patients reechoed sentiments about physicians' refusal to handle their post surgical complications after LT. This scenario is not surprising because physicians can be target of lawsuits; hence they are reluctant to treat patients who had surgeries outside with complications (Turner, 2013). However it is important to note that in response to these concerns, the medical society came out with policies highlighting the mechanisms that would guide the post surgical care. Though this came as good news to patients, it was the responsibility of patients to have their medical records from the

visiting location, and be willing to share their medical information with their physicians in order to ensure continuity of care.

A growing body of academic scholarship has also pointed to negative clinical outcomes of Canadians who engaged in medical tourism for unapproved procedures and raises ethical questions surrounding physicians' competency, quality of care and patient safety in these tourists' destinations (Turner, 2013). In addition, there is always the risk that travelling shortly after surgery exposes the patient to potentially developing deep vein thrombosis and pulmonary embolisms (Crooks et al., 2010).

The study demonstrates the agenda setting role of the media and argues that there is low coverage of the issue which is informed by the ongoing clinical trials. In addition the mobility for health care has created static and dynamic interactions between the medical community and patients respectively. The media in highlighting positive and negative perceptions of LT in news stories pivoted the debate and tension. This clearly shows the differences in how patients and medical experts construct risk perceptions regarding the procedure.

Chapter 7

Conclusions

Zamboni in his study linked MS to a condition called CCSVI or blocked veins. He developed LT as a possible method to unblock the veins. This generated considerable media attention in Canada. The CTV W5 program first aired the documentary on November 21, 2009 and was subsequently followed up by a front-page Globe and Mail story the next day. The initial media coverage of the procedure was nothing less than a miracle cure. This created excitement among patients who had been trying conventional therapies to no avail. Physician offices were 'flooded' with patients trying to find more information about a procedure that could 'liberate' them from their disease.

The introduction of LT in late 2009 provided a window of opportunity to study how the news media covered the issue. Positively-oriented stories on the issue brought a lot of hope to patients. This led to patients mobilizing for funds to access the treatment in other countries. LT became a source of tension in Canada due to patient and public pressure on the health system to respond resulting in different policy decisions across Canada.

The main aim of the study is to assess how the media presentation of various groups' reactions to CCSVI and LT, facilitated by mobile networks/structures can pressure policy makers to modify existing processes and decisions in managing the health system resources. Generally, the study shows the static nature of physicians in reacting to medical procedures. Medical researchers in most cases either dismissed Zamboni's hypothesis completely or emphasized the need to follow the established scientific protocols in approving medical procedures. Without scientific evidence to either support or debunk the hypothesis, the medical community was hesitant in drawing conclusions (Pullman et al., 2013). Patients on the contrary are dynamic in making mobile

decisions. The advancement of mobile networks and structures such as airports and communication technologies provided an avenue for easy movement of people and information at various scales. Additionally, the global health care system is offering MS patients the opportunity to access LT. As a result, many patients are travelling to various destinations for the procedure. The static-dynamic tensions pressured various levels of government to eventually fund clinical trials which are still ongoing. Through the use of both quantitative and qualitative methods, an analysis of the media data was undertaken to answer the following objectives.

The first objective was to quantify the amount of media coverage of the issue and how it has changed over time and space. This was to specifically measure the agenda setting role of the print media with respect to frequency, placement, types, length and tone of newspaper stories. A high frequency of coverage in the initial stages (i.e. phases 2 and 3) was revealed in the results; however the saliency of the issue over time substantially dropped once as the government decision to fund clinical trials was made. As there was no longer the same level of patient demands for decision makers to act, the media moved its attention to other stories. Nonetheless, it is expected that if trial results find favorable for LT, media attention will increase, whilst negative results may tend to attract low media coverage. It was anticipated that the changes in the number of newspaper stories would affect the placement of stories. There was reduction in front page coverage which may be due to editorial policies which place news stories of the issue over time further from the front page (Clayman & Reisner, 1998). Along similar lines, the length of stories relatively reduced as time progressed. For instance, much media coverage of long, medium and short stories were realized in phase 2, but these stories were later dropped in phases 3 and 4. There was however consistency in terms of positive and neutral story tones in the first 3 phases and negative toned stories in phases 1, 3 and 4. In a similar fashion, news, editorials and

profile story types were consistent in the first 3 phases. Overall, there were variations in the frequency of media coverage on the issue in phase 4 as compared to the consistency of coverage in the first 3 phases. The prominence of the issue in the early stages shows how the general public, especially patients and their advocates, attached importance to the issue. It also highlights the importance of the media in influencing the public about medical discoveries as well as policy decisions regarding such discoveries.

The second objective was to document how various key stakeholder perspectives regarding medical tourism or mobility are portrayed in the media. The results identified different key stakeholders (medical experts/researchers, patients/advocacy groups, government and Zamboni) who portrayed varying opinions over the effectiveness of LT. Generally, the perspectives of the stakeholders were not overwhelmingly surprising. The medical community in Canada as would be expected was skeptical about the procedure and urged patients not to engage in medical tourism since the possible harms outweighed the potential benefits. Their perspectives about mobility were on the whole static. Nonetheless, their counterparts in other jurisdictions profited from LT. Patients on the other hand were much more positive about LT as a potential cure to their disease and their views on mobility were highlighted in media stories as very dynamic. At the centre of the debate was the government over how to respond to the issue. As expected, Zamboni (as portrayed in news media stories) tremendously promoted and defended his procedure that fuelled the hope of patients. He further admonished the Canadian immobile health care system to attach a sense of urgency and make it available domestically. Zamboni however advised patients against long travels to obtain the procedure since that may posed health risks. While it is impossible to fully know Zamboni's motives, by adopting this strategy – criticizing the Canadian system for not looking after its patients all the while advising patients against travel

for the procedure – it could be viewed as a clever ploy to implicitly encourage patients to add more pressure on the Canadian government to fund the procedure locally, thereby 'freeing' the immobile system.

Media framing of patient mobility was the focus of the third objective. Overall, the promoted frames served to enhance and discourage patient mobility. The dominant frames that enhanced patient mobility were the miracle, hope and liberation frames. It was also found that framing the issue as a hoax and encouraging people to 'wait and see' discouraged patient from LT. The televised media coverage of the issue as a 'miracle cure' raised the hopes of many patients. This documentary became the reference point for the portrayal of the positive frames in the print media. The negative frames began to emerge once patients started developing complications from the procedure. In general terms, the media coverage and framing of the issue was fair and objective. Although positive stories were initially covered, the perspectives of the different groups for or against the procedure allowed readers to potentially make well informed decisions about the issue.

Contributions of the Study

Substantive

The medical tourism industry is still nascent. This thesis research contributes substantially to the growing body of knowledge on the medical tourism from Canadian perspectives. Drawing inspirations from the Simon Fraser University Medical Tourism Research Group, this study adds to their already growing research on Canadian engagement in medical tourism for various approved and unapproved procedures. Some of these studies are worthy of highlighting.

Crooks et al. (2010) in a scoping review documented the experiences of patient who had various procedures overseas. In a similar scoping review, Johnston et al. (2010) synthesizes the effects of medical tourism on both destination and departure countries. Snyder et al. (2011a) in an interview with medical tourism facilitators and companies in Canada discovered that their roles thematically relates to the patient, health system and the medical tourism industry in general. Johnston et al. (2012) examines Canadian medical tourists' decision making process with respect to seeking surgery abroad. The study is the first of its kind to empirically evaluate from the medical tourism stakeholders point of view, the source and quality of information available to Canadian medical tourists. As an extension of the study, Crooks et al. (2012) compared patients' decision making process to a study of Canadians who had engaged in medical tourism for hip or knee surgery to treat osteoarthritis. This was aimed at determining the attitudinal characteristics of patients. Crooks et al. (2013) conducted a focus group discussion with health professionals in Vancouver, revealing that Canadian medical tourists returning home with infections pose public health risks. Finally, Cameron et al. (2014) in an interview with patients who travel abroad for knee replacement or hip replacement or resurfacing highlights three broad talk strategies that emerged from the data: motivation, justification and normalization. What is more fascinating about this recent study is the need for researchers to focus on how the motivation theme can be conceptualized in other diseases context. Without mincing any words, Cameron and colleagues urge health geographers to explore the factors that motivate patients to engage in medical tourism for LT or procedures that are not covered under the Canadian health care system. The studies highlighted above have an overwhelming influence on the medical tourism research in Canada. Although qualitative in nature, these studies serve as the watershed for tracking the actual numbers of Canadians who are travelling overseas for surgeries. This can help in

evaluating the benefits and burdens of the medical tourism industry to the Canadian health care system.

The CCSVI and LT study highlighted in this thesis also contributes to current studies that explore the 'geography of mobilities' which is widely informed by the 'mobility turn'. As earlier noted, there exists a lacuna on the linkages between mobility and health. The study of mobility was buoyed by Gatrell's (2011) conceptualization of mobility and health. Incorporating a wide range of academic literature from the social and medical sciences, Gatrell aimed to shift the traditional understanding of health geography from 'health in place' to 'space of human health and well-being' (Wilson, 2012, p. 624). Within this conceptualization, the LT case study shows that the mobility of patients for LT in different geographic spaces involves both risks and benefits to the general well being of the body. Along similar lines, this study shows that patients' returning home after LT with complications can pose an indirect cost to the tax payer. While not the same, it is akin to the conception raised by Gatrell (2013) about how medical tourists can become major players in the spread of diseases from place to place. Moreover, highlighted in the analysis is that not only does mobility constitute bodily movement, it also encompasses the invisible and almost 'placeless' movement of information and ideas to different geographic areas which then encourages physical movement between locations for medical tourism. Information and communication technology is changing the ways in how scientific information is distributed and used. The analysis in particular illuminates the importance of the media in spreading information about various LT destinations. Through the Internet, patients are able to source information about the reputation of medical facilities and physicians. They obtain this through online anecdotal evidence and first hand information from the experiences of past medical tourists.

As a novel contribution to the 'mobilities turn', the prominence dedicated to the idea of LT in the Canadian news media added to the online movement of information could create a supportive environment that encouraged patient mobility. Media stories certainly showcased how patients challenged the Canadian immobile health care system. The mobility of patients and ideas within the 'mobility turn' has revealed how mobile structures can pressure immobile systems to alter its priorities as well as how resources are allocated within the Canadian health system. Especially, mobility of LT ideas within social networking sites and blogosphere has generated enormous pressure for modification of the immobile health care system to meet the perceived needs and wants of patients.

Policy Decision Making Processes

The results of the study are discussed in terms of their relevance to policy making. This thesis builds on the role of virtual mobilities in the dissemination of health information and risk communication. As the study demonstrated, patients mostly rely on the Internet for expert advice on LT rather than health care providers. Marrie et al. (2013) argue that MS patients' reliance on the Internet for health information has several implications: medical experts need to acknowledge that patients often have first hand information online prior to information from physicians; besides the high level of trust in physician information vis-a-vis online information, patients always want more information from physicians within the shortest possible time; because of the low trust and usage of traditional modes of information (e.g. television, newspapers and radio), they are considered as less effective in communicating risks. Chafe et al. (2011, p.411) argue that "In this new social-media environment, researchers and clinicians need to engage more actively with the public to articulate the science validating, or debunking, novel treatments-and to ensure that patients' concerns and priorities are heard."

These findings call into question the appropriate ways of communicating risk information to the general public. The way in which the issue attracted media attention calls for experts to effectively handle and communicate information to the public. Whilst the medical community dismissed the procedure, patients' anecdotal evidence was abundant. This aggravated more tension and leaves a communication gap between the experts and the lay public over the risks of the procedure. Patients' anecdotal evidence especially in the media overshadowed scientists' cautious approach and their pressure for access to LT in Canada is partially met with the decision to fund clinical trials. This pressure has implications as to how scientists/researchers will respond to emerging hypothesis regarding medical procedures in the future. As a matter of policy, there is the need for the medical community to constantly dialogue with the public in order to effectively communicate health information that can be easily understood.

The study contributes to current research on the actual numbers, outcomes and effects of the burgeoning medical tourism industry in Canada. A major concern with the medical tourism industry is the implications of patient mobility for health care on their home health systems. The global health care system has provided patients with opportunities to purchase health care that is within their budget. As a result of this, Canadians are travelling to other countries for medical procedures and are returning with mixed outcomes. The study demonstrated Canadians who are returning home with complications from LT and this calls into question over who ought to pay the post surgical care. Part of this problem is that the medical tourism industry is not regulated and as such many companies are emerging marketing medical facilities and services that might be below acceptable standards or not accredited. Media narratives on the other hand highlighted patients returning with improved symptoms that enabled them to participate actively in life whilst contributing to the economy. Meanwhile, there is no reliable data on the success rates of

Canadians who engaged in medical tourism. Patients reported improved symptoms without any mechanism put in place to verify their anecdotal stories. The decision by Newfoundland and Labrador, Alberta and Vancouver to set up registries and track patients who had LT is a starting point in gathering reliable data. More so, medical tourism destination countries have introduced special visas for medical tourists. Border points can take advantage of this by introducing monitoring systems in gathering reliable evidence on Canadian patients who engaged in medical tourism. These policy interventions can provide useful insights into determining the actual numbers and measuring the outcomes of Canadian medical tourists. They will also help in making better informed policy decisions about the implications of the industry on the health care system.

Limitations and Future Research

The media aspect of the larger project was the main focus of this study. The frequency of coverage, key stakeholders perspectives and framing of the issue shows the importance of the media in influencing policy decision making processes.

As part of a larger project, data was collected from seven different focus group discussions with randomly selected MS patients stratified by disease type and duration. This was held in Winnipeg, Manitoba in June, 2012. Data were similarly gathered from key informant interviews with researchers, clinicians and policymakers. Due to time constraints, these data were excluded from the analysis. The inclusion of the focus group and key informant data would have provided an opportunity to compare how the different stakeholders discussed mobility for CCSVI and LT against media portrayals of these issues. It would be interesting to further study how stakeholder perspectives on the issue vary between the media against focus group discussions and key informant interviews. This becomes necessary because the media 'filter' a lot of information

through various negotiated processes. This can lead to errors in the production of news. Again, due to pressure for reporters and editors to meet deadlines in the production of news, they have limited time to prepare news stories (Turner, 2012b). These factors can lead to errors and inaccuracies in news reportage and a lot of information can be missing. In particular, the voices of key stakeholders' as portrayed in the media might have been distorted from their original intent. The inclusion of the focus group and key informant interviews would have given more detailed accounts on different stakeholder views of the issue.

This case study comprised an analysis of televised and print media from national and regional newspapers. Much of the stories in the print media used for the analysis were written by the various media outlets medical/health reporters. There was consistency in the reportage of the issue by journalists in their respective newspapers. It would be an added advantage for future studies to collect data from these reporters directly. This can help provides a broader understanding on journalists' information sources and how they craft stories regarding scientific discoveries.

Moreover, the roles of social media sites were vital in shaping the debate of the issue. In recent times the social media has replaced the conventional methods of disseminating information to the general public. It has become a prime avenue for patients' mobilization and sharing of information and testimonials about the benefits of LT, whilst attacking the credibility of the scientific community (Chafe et al., 2011). In the analysis, print media stories mentioned the power of the social media influencing the debate in passing. Considering the tremendous influence of the social media in contemporary times, a comprehensive analysis of social media outlets (Facebook, Twitter, YouTube etc.) could be of value to the debate.

This study uncovers some of the nuances surrounding patient mobility for LT. The issue remains vibrant in the Canadian media but in recent times its coverage has substantially changed. Varying perspectives and media frames on CCSVI and LT were portrayed in the media stories. These perspectives highlight the need for effective risk communication between experts and lay public. In particular, the scientific community should recognize the role of the public and engage them more in their research and communication of scientific information. Again, Canadians continue to travel to other jurisdictions for LT and as a matter of policy relevance, this call for more data collection to track the actual numbers to make better informed decisions.

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Appendices

Appendix 1: Phases of Thematic Analysis

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and rereading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Source: Braun & Clarke, 2006, p. 35

Appendix 2: Media Code Book

General Nodes
Access
Advocacy
Bias
Caution
Controversy
Death and Side Effects
Decision Making Process
Dynamic opinion
Emotion
Financial
History
Hypothesis
Information
Junk science
LT & CCSVI
Medical Tourism
MS
Other Health Conditions
Pressure
Proven Therapies
Reminder Flags
Research Process
Risk
Static opinion
Timeline
Trust
Uncertainty
Location for research
Albany
Buffalo
Italy
McMaster
Other
Pan Canadian
Perceptions
Positive
Negative
Neutral

People
Advocacy Groups
Donor
Drug Companies
Family and Friends
Government
Health Care Providers
Internet
Media
Other
Patient
Public
Researchers
Zamboni
Media Frames
Desperation
Downplay
Hoax
Hope
Liberation
Miracle
Objective
Other (Judgment, Critical Eye, Blame)
Responsibility
Rights
Urgency
Wait and see
Adversarial
Language
Analogy
Great Quotes
Media Quote
Personal Stories
Provocative Language
Testimonial

NODE	DESCRIPTION
General Nodes	
Access	Captures statements about the lack of availability in Canada of certain types of health care (be it liberation therapy or other), treatment, diagnostic testing, trained staff, or medication.
Advocacy	Identifies action taken or statements made to support a cause either for or against an issue, to draw decision makers' attention to the issue, or to get others on board to support the cause (Ex. seeking access or funding for LT, or seeking to stop the treatment from being performed). Acts of advocacy include rallies, protests, petitioning, or patient activism.
Bias	When an individual or body either holds a pre-existing belief or conviction, or omits or ignores certain known facts or knowledge, resulting in an answer or conclusion that favors one outcome despite the possibility of other outcomes had such favoring not existed (Ex. Look for instances of personal or professional gain). In the context of research, bias may occur when studies are not properly constructed to ensure double blind or selective, rather than representative sampling (Ex. Look for instances of weak study design).
Caution	Mention of the sounding of a warning about something that carries potential harm. (Ex. where doctors warn their patients about potential consequences to having LT done or to stopping their medications.)
Controversy	Mention of conflict or division of opinion on a subject. Mentions of skepticism are coded here.
Death and Side Effects	Mention of death or side effects resulting from LT, proven therapies or other causes. Keeping separate from LT & CCSVI node because of possible mention of instances of death or side effects not connected to LT.
Decision Making Process	The means by which an individual or group comes to a conclusion about a particular topic by considering a number of influencing factors.
Dynamic opinion	Views that show LT as promising and support for changes to make the procedure available in the health care system or allows MS patient mobility for the procedure. Double code with 'People' node depending on who is expressing the opinion
Emotion	Denotes various kinds of feelings, e.g. joy, fear, sorrow. (Ex. One of our crew people was just in tears WFP Feb 13, 2012)
Financial	Matters related to money, finances or expenditures.
History	A record of events that have taken place in the past. These may include scientific discoveries.
Hypothesis	Mention of Zamboni's idea that MS is vascular rather than neurological. May use the word 'Theory' but we are using 'Hypothesis' to identify this particular theory. Do not code as Hypothesis when only Zamboni's research or experiment is mentioned. If other theories are mentioned, put them here as well.
Information	The process of receiving, learning and utilizing facts, ideas or messages between a source and potential user. Specific information sources are coded often under the Internet and Media nodes and may also include

	others (e.g. friends, family, healthcare providers).
Junk science	Mention of untested or unproven theories, scientific information or research presented as scientific fact or use to advance special interests.
LT & CCSVI	Any mention of the treatment or the condition of Chronic Cerebrospinal Venus insufficiency as well as mention of vascular conditions (ie. Blocked or malfunctioning veins preventing blood flow to the brain, iron deposits, inserting balloons for angioplasty).
Medical Tourism	Mention of MS patients travelling for LT treatment or testing outside home jurisdictions/ Canada. This also includes mention of tourism marketing companies and government decisions to fund patients for clinical trials outside of home jurisdictions/ Canada and places/destinations where LT is available and accessible.
MS	Anything pertaining to MS as a disease. Includes SYMPTOMS, RATES (Mention of the amount of MS cases in Canada, a particular province, or anywhere in the world), Types of MS, and reference to MS as a neurological or Autoimmune disease.
Other Health Conditions	Mention of health conditions that are not MS like Cancer, Diabetes, or other illnesses.
Pressure	Attempts to coerce, persuade, or influence someone to agree to believe or do something another person or body wants them to believe or do. Someone being put under the pressure of other groups or bodies to make a decision the way the group wants. (Ex. MS patients being pressured by family members to have LT done or donors threatening to withdraw funding from the MS Society if it doesn't agree to support LT. Beyond advocating for a cause, pressure is a more subtle attempt by one person or group to control the decision-making of another.
Proven Therapies	Any mention of drug treatment or any other therapy for MS that is already approved for use.
Reminder Flags	Code things here that we need to remember to do during analysis. This node is linked to a Project Log Memo in which we can add notes and reminders about coding. This is now in the MS Uncertainty Media Analysis MASTER file on BAZAAR.
Research Process	Any mention of research, getting ethics, clinical trials, recruitment of participants, applying for grants, and anything else to do with the research process. Includes publication of studies, results and findings in peer reviewed journals.
Risk	Being exposed to harm or danger, whether voluntarily or involuntarily. The harm may be physical, mental, financial, or anything that poses a threat to a person or group of people and their well being.
Static opinion	Views that show LT as unfavorable and advise people against patient mobility for the procedure. People should rather concentrate on proven therapies. Such positions are fixed and no amount of evidence about LT can change their views. Double code with 'People' node depending on who is expressing the opinion
Timeline	The order or chronology of historical events and trends of CCSVI and LT in Canada. It also captures instances such as when patients who have

	gone for LT experience effects that they associate with LT; often will occur with personal story or where HCP discuss length of effect (either positively or negatively).
Trust	Having a firm belief or confidence in someone or something. The word 'Trust' does not need to be used but the concept of trust or distrust must be there.
Uncertainty	Mention of where people are generally unsure or doubtful of something or where a question is left unanswered. (Ex. Mention of MS as a mystery with no known cure.) Not for where a discussion is about the outcome of a research process (because asking questions is part of that) but can be used where well-designed studies still yield different outcomes and why is not known ('Dueling Expert' phenomenon).

Perceptions	**Do not code anything in the parent node. These sub-nodes indicate the bias or attitude that the author of a news article holds or that an interview subject expresses. Perceptions do not need to be applied to every passage if not evident.**
Positive	Any positive attitude expressed about any subject including LT, governments, drug companies, or other People nodes or other ideas (Ex. Improved symptoms after having LT). Includes perceptions as related to Media Frames – for example, Hope can go with Positive and depending on context, also Desperation.
Negative	Any mention of an unfavorable bias or attitude towards anything. Includes LT & CCSVI (ex. treatment failed, a person died from the procedure, government refuses to fund trials, someone thinks it's a hoax), MS generally (Ex. Someone having a terrible time living with MS), or Drug companies, governments, doctors, or other People. Also applies to Media Frames. Negative usually goes with Hoax and depending on context, Desperation.
Neutral	Where either no attitude is expressed, no positive or negative bias is evident, and no emotionally coloring adjectives are used , or where both positive and negative attitudes appear in a balanced way (Ex. usually Wait and See is Neutral).
People	**Parent Node. Do not code anything here.**
Advocacy Groups	Mention of any formally organized group advocating for any side of any debate. May include the MS Society, the National CCSVI Society, Direct MS (and Ashton Embry, spokesperson) or any other group lobbying for or against a cause.
Donor	Mention of individuals or agencies that donate funds to support a cause. May arise in reference to donations being made or cut to the MS Society or other MS charities.
Drug Companies	Mention of Big Pharma or drug companies.
Family and Friends	Family members and friends of MS Patients who may or may not have MS themselves.

Government	Mention of elected and non-elected people of public institutions. Ex. MPs, spokespersons of public agencies such as the FDA, CIHR, MHRC, AHS. It also includes public agencies as well as provincial and federal governments.
Health Care Providers	Mention of doctors, medical experts, nurses, MS Clinic, hospitals or health care facility, physiotherapists, or anyone working to give health care. DOES NOT INCLUDE Researchers. Where a person is mentioned as being a researcher and medical practitioner, then double code with Researcher.
Internet	Includes mention of general or specific websites, and social media (blogs, Facebook, YouTube, Twitter, or any other kind of social media). Also includes communication by email. Where appropriate, double code with Information node.
Media	Includes mention of television, radio, and print media (newspapers), journalists, and media generally. Where appropriate, double code with Information node.
Other	Mention of any person or body that does not fit in the other nodes.
Patient	Reference to MS patients.
Public	Any mention of people who are not MS Patients or doctors, researchers, health care providers, government officials, family and friends. Public consists of other community members or ordinary people who do not have MS. NOTE: There is a separate node for Family and Friends because they often also have MS and we feel the need to distinguish them from the general public.
Researchers	Mention of someone who does research. This is separate from someone who provides health care to patients. DO NOT double code with Zamboni who is a node unto himself.
Zamboni	Mention of Paolo Zamboni or "the Italian researcher" etc. DO NOT double code with Health Care Provider or Researcher because he is a category unto himself. Code Zamboni's wife Elena Ravalli only as 'Zamboni" and locate her later using a text search for 'Zamboni' AND 'wife'.
Media Frames	**"Frames are a way of packaging an issue or event to convey a certain message about that issue, deciding on what is and is not reported" (Mistry & Driedger, 2012, p.585). NOTE: Media Frames can be coded with a Perception where appropriate. Ex. Desperation can be coded with either neg or pos depending on the situation. Wait and See might often be Neutral, Hoax might be Negative, Hope might be Positive. Double code instances where Bias appears as a Media Frame in this parent node along with the Bias node.**
Adversarial	Captures instances where a person or a group contend against each other over an issue e.g. science vs. hope, science vs. politics, patients vs. government officials/health care providers etc.
Desperation	Identifies news stories framed to show that the patients are willing to try anything to cure their MS without caring about the danger of trying

	untested, unproven LT.
Downplay	Where something is described or made out to seem less than what it is, i.e. less serious, less dangerous or less important. For example, if LT is referred to as a 'simple' procedure.
Hoax	News stories where people say the LT treatment is fake, doesn't work, deceives people, that people offering it are preying on the sick, that it is a placebo effect.
Hope	News stories reporting on people who are generally positive about LT and who express confidence or high expectations about LT as a cure for MS (usually goes with the Perception of Positive).
Liberation	Where LT is positioned in news stories as "Liberation procedure" (with quotations) or "Liberating" or any form of that label. The procedure is framed or packaged for the reader as being a liberation (freeing) from MS.
Miracle	Framing that makes LT sound extraordinary, a cure, a means to new life, salvation from all problems caused by MS (Ex. "it gave me a second life.")
Personal Story	Same as Personal Story Node but double code here when it appears as a Frame (ex. Where a section is introduced as a heart-strings pulling hook about a person with MS who was 'cured').
Objective	Where a passage is framed to show only facts or realities as they exist without leaning to any particular angle. Can be double coded with neutral.
Other	Captures when a frame is hard to determine or not immediately obvious. Come back and try to identify it later. Make an annotation as to why you coded it here.
Responsibility	Identify instances where people talk like they have a duty to do something e.g. to conduct trials on CCSVI not based on evidence but because so many patients going to have it done
Rights	A frame demonstrating access to healthcare as a fundamental human right and where denial of access to treatment, testing, or an aspect of health care is a violation of rights. Includes talk of filing a human rights claim, being denied human rights, a sense of being "owed" or deserving of certain rights.
Urgency	When people express the need for immediate action to be taken without delay. The urgency must be concrete and not hypothetical – not "if" but "when."
Wait and See	Media framing where there is an expressed need to wait or where people are urged to have patience while more research or information or evidence about treatment is being gathered. Conveys a sense of "We need more."
Cases (Journals autocoded for cases: author/body/date/lead /page/source/title/ word count	List as sub nodes all the newspapers, television stations (ex. CTV, CBC), focus groups, and social media sources.

Language	**Parent Node. Do not code anything here.**
Analogy	Where one thing is likened to another to create an association for the reader. Often in the news stories the liberation therapy procedure is likened to angioplasty. This can result in Downplay and can be double coded there.
Great Quotes	Any phrase or statement appearing in a source (newspaper article or broadcast transcript) that is remarkable and captures a major idea that is worth saving for future use. A Media Quote could also possibly be a Great Quote if the reporter captured a compelling statement from an interview subject.
Media Quote	Any quotations cited in newspaper articles from interview subjects. Always code with who is making the quote, and what the quote is about.
Personal Stories	Passages relating the personal experiences of people, including background details.
Provocative Language	Where the journalist and people being quoted in the story use colourful words (often adjectives) to raise the reader's emotions or curiosity to sensationalize the story. For example, "Cure vs. Hype", "Media-driven frenzy", "compelling", "striking", "contentious", "controversial".
Testimonial	Where a person gives proof or evidence of either an experience that happened to them, or some other fact, in such a way as to persuade an audience that there is no doubt as to the truth of the statement. (Ex. include MS patients saying they have been cured by LT). It also includes instances of anecdotal evidence i.e. cases coming from critics e.g. people engage in empty but anecdotal evidence
Location for research	**When trials are mentioned as actually happening**
Buffalo	
Albany	
McMaster	
Pan Canadian	
Italy	
other	

CLASSIFICATION and DEFINITION	**CLASSIFICATION VALUE**
Year	N/A 2009 2010 2011 2012 2013
Source Newspaper	See NVivo File for List
Type of Story	N/A News Editorial Profile
Positioning	A1 Front Page Newspaper A2+ Located in the A Section B1 Front Page of the Second B2+ Stories located in the B section
Author *Add values according to each story. Some journalists wrote many articles throughout the data set.*	Add values according to each story. Some journalists wrote many articles throughout the data set.
Date	Assign values as we go.
Word Count: *Because each article is a different word count this has 3 values: Short, Medium and Long. Values are defined according to the Operationalized definition found in Mistry and Driedger 2012 "Do the Leads Tell the Whole Story." Short is 250 wds or less; Medium is 251 to 750; Long is 751 and over.*	Short 250 or less Medium 251-750 Long 751 or more
Perception *The overall sense of perception given by the whole news story.*	N/A Positive Negative Neutral
Media Frame *The overall sense of how the journalist has framed each news story.*	Hope Hoax Desperation Wait and See Urgency Downplay Objective Unknown

Appendix 3: A 15-Point Checklist of Criteria for Good Thematic Analysis

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for all each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analyzed – interpreted, made sense of - rather than just paraphrased or described.
	8	Analysis and data match each other – the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organized story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do and what you show you have done – i.e., described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is positioned as *active* in the research process; themes do not just 'emerge'.

Source: Braun & Clarke, 2006, p.36