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From Narrowed Veins to Liberation: An Anthropological Analysis of the Canadian Liberation Therapy Movement

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Supporters of Paolo Zamboni's "liberation therapy" for multiple sclerosis rally on Parliament Hill in Ottawa on May 5, 2011. Photo: Florence d'Eon

"The will to live, to be healthy, to return to the security of the

kingdom of the well, is unspeakably powerful. In Canada, we have seen this collectively expressed by the masses of people afflicted with multiple sclerosis, who are demanding access to a controversial and experimental treatment developed by an Italian doctor” (Stern, September 10, 2010:A15).

In 2009, Dr. Paolo Zamboni, an Italian vascular surgeon, published an article with a new twist on the treatment of Multiple Sclerosis (MS). MS is conventionally considered to be a neurological, autoimmune disease. Zamboni instead linked MS to the narrowing of veins that allow blood to drain from the central nervous system, referring to this compromised blood flow as Chronic Cerebro-Spinal Venous Insufficiency (CCSVI). He proposed a balloon angioplasty treatment that would open the veins, “liberating” blood flow and relieving MS symptoms (Zamboni et al., 2009). Unlike other balloon angioplasties in arteries (i.e. used in treating obstructive heart disease), Zamboni called his approach the “liberation procedure” (Zamboni, 2009:73). Soon after, on November 21, CTV television network’s [W5](#) aired a documentary on Zamboni’s research called [The Liberation Treatment: A whole new approach to MS](#). The documentary described a “revolutionary treatment” that “liberated” MS patients from a chronic and debilitating disease—Dr. Fabrizio Salvi, an Italian neurologist working with Zamboni, even suggested it could be a cure for MS. Immediately, the term “liberation” and the promise of a cure sparked the imagination of the Canadian media and MS community. Whereas many therapies offer symptom relief, or sometimes a “cure,” Zamboni’s procedure hints at something beyond that. As tens of thousands of patient-activists wanting to be liberated mobilize online (Fragoso, 2011), Zamboni’s idea of *liberation* therapy has engendered a proliferation of discourses of hope, empowerment and intrigue all around the world in “near-miraculous ways” (Paterson, September 24, 2010).

Medical researchers are frantically trying to catch up to overwhelming public interest in liberation therapy and the demand for a therapeutic response. There is little medical consensus as to *why* or *if* it works (del Pilar Cortes Nino et al., 2010), and some dismiss it outright as a placebo (Sinnema, August 12, 2010; Wente, July 29, 2010). In Canada the procedure has yet to be approved by medical authorities, although clinical trials are planned for 2012. Many MS patients, anxious for relief from their debilitating disease, feel that the flow of national resources into research and clinical trials has been cruelly obstructed or stalled (Galloway, September 1, 2010). Media coverage has ignited controversy and debate among MS patients, national and provincial governments, and the scientific community. What is more, the publicity has mobilized an impassioned patient movement organized around *therapeutic* rights. Adoption of the charged term “liberation” to describe this medical

procedure—variously referred to as “Liberation Procedure,” “Liberation Treatment,” or “Liberation Therapy”—has accelerated this mobilization, incited controversy, and inflamed the political debate. By framing this therapy as “liberation” rather than “cure,” these patient-activists effectively blur the biomedical and the biopolitical as they formulate new imperatives of treatment and care.

Liberation therapy has attracted enormous attention in Canada. One journalist has argued that no other story so dominated medical headlines in 2010 (Ubelacker, December 28, 2010), quoting MS Society CEO Yves Savoie as saying, “There’s no question there is unprecedented engagement and mobilization. There’s an unprecedented level of hope and optimism” (Ubelacker, September 16, 2010). Another writer attributes this solely to “that cursed phrase ‘liberation therapy’ for a garden variety angioplasty” (Paterson, September 24, 2010:12).

Within Canada’s public health care system there is ample opportunity for political posturing to trump scientific due diligence. While provinces and territories are largely responsible for medical service delivery in their respective jurisdictions, most rely heavily on supplementary federal funding to implement and manage these services. Scholars have noted that this particular system is often ripe for both provincial and federal governments to “pass the buck” on major decision-making in the health care portfolio (Choudhry, 2002; Lewis et al., 1998). When new treatments—especially controversial ones such as Liberation Therapy—are introduced, action is often slow and sometimes easily avoided. Since 2009, a plethora of news stories comment on the sense of urgency and the frustration of MS patients with what seems to be the Canadian governments’—provincial and national—stalling of studies that might determine the therapy’s efficacy. MS patients and advocates are lobbying provincial and federal governments and the medical community for a compassionate and speedy response to this new “liberating” therapy, successfully moralizing political and medical discourses in the process. Responding to political pressure from liberation therapy lobbyists, provincial and territorial governments in Saskatchewan, Manitoba and Yukon have made claims to be fast-tracking funds for clinic trials for almost two years. The federal government finally joined these efforts on November 25, 2011, when the Canadian government announced its commitment to expeditious, nation-wide clinical trials. Still, MS patients, their families and friends know that it will likely be years before this treatment is made available in Canada, so they continue to raise tens of thousands of dollars to travel to other countries for the treatment. Private clinics in Bulgaria, Costa Rica, Germany, India, Mexico, Poland and the US, see opportunities for quick profits in promoting medical tourism and eagerly await these patients.

How and why has this specific therapy sparked so much controversy, near frenzy and militant mobilization in such a short time? The controversy results from a convergence of several factors, including the limited number of treatment options for MS patients in Canada, the relative ease with which many of them can access the therapy out-of-country, and the potency of online social networking. However, two factors are of particular interest for our purposes here: 1) the therapy's loaded terminology, insofar as it invokes political and emancipatory narratives to foster a politicized therapeutic citizenry; and 2) the trope of "liberation" as a crucial resource in leveraging claims to effective therapy.

This phenomenon has not yet been studied from an anthropological perspective, and in the midst of the ongoing debates it is difficult for us to map out a trajectory or anything more than an exploratory analysis just yet. Further, there are numerous theoretical lenses through which this complex issue could be viewed. However, the concepts of biological citizenship (Petryna, 2002; Rose and Novas, 2004) and therapeutic citizenship (Nguyen, 2004) are particularly useful in shedding light on this controversial topic.

Brendan Leier of the Dossetor Health Ethics Centre, University of Alberta, has pointed out that this type of controversy is "the kindling that turns...a small movement into a massive global movement" (Sinnema, August 12, 2010:A4). The strategic use of the term liberation by Zamboni and his supporters provides the spark to that kindling. The term "liberation" inspires metaphor by transposing political and/or emancipatory discourses into a biological, medical sphere, thus seamlessly linking these traditionally distinctive realms. Again, this procedure is seen by MS patients, not as a *cure*, but rather as *liberation*. James Wilce's (2009) discussion of medical discourse describes how the immediate expression of language is "only the beginning of its signifying activity" (202). Its transposition into the realm of metaphor sets off an almost infinite number of significations. Further, Ann Hunsaker Hawkins (1999) notes that "the less a phenomenon is fully (i.e. scientifically) understood, the more it tends to be described in metaphoric language" (202). It is the ambiguous and unexplained character of MS and this proposed treatment that may be responsible for inspiring this terminology and sparking the imagination of the media and MS community.

The metaphoric language incited by the term liberation also conjures up a diverse set of narrative resources into a "therapeutic economy". On April 10, 2010 CTV's *W5* aired another documentary program about the treatment entitled [The Liberation War](#) which convincingly illustrates how the term liberation has been linked to a volatile political history of national "liberation wars" for freedom and democracy. This use of imagery and metaphor seems to be polarizing MS patients and the scientific

community, at the same time prompting MS activists to rally and protest. At one rally they shouted out, “Bring it on, government. We’re going to take you on!” (Smith, September 21, 2010:A4) while at others they have brandished placards proclaiming “Liberation Now” (McGrath, September 14, 2010). Because liberation is a political imperative in Western society, by Zamboni calling his procedure the “liberation procedure,” whether intentional or not, he has lifted his therapy to the status of what Nguyen calls a biopolitical imperative: Governments and the medical establishment can say “no” to a scientifically unfounded or “garden-variety” angioplasty, but they find it exceedingly difficult to say “no” to *liberation*. Galloway points out that “Government officials say physicians feel threatened by the increasing militancy of their patients,” quoting one doctor who blames the media for creating “a nightmare for our patients, clinics, the MS Society, and the government...” (September 20, 2010:A6)

When MS patients pursuing the liberation procedure describe themselves as “a big family now” (Kirsch, October 30, 2010:A1), this can be understood as a kind of biological citizenship. Adriana Petryna (2002) introduces the notion of biological citizenship to conceptualize how Ukrainian victims of the Chernobyl disaster used their radiation-exposed bodies, “available technologies, knowledge of symptoms, and legal procedures to gain political recognition and access to some form of welfare inclusion” (15). Like the Chernobyl victims, Canadian MS patients have become a politicized collectivity, mobilized around a biological conception of shared identity. In light of the controversial CCSVI theory, MS patients have now adopted a new identity: the CCSVI patient, needing and deserving a new kind of therapy—Liberation. With this therapy unavailable in Canada, their newly reformulated status as CCSVI patients remains tenuous and thus needs to be asserted in political terms. While therapy can be delivered for a disease (MS) that is well researched and has a long accepted medical theory (auto-immune disorder), CCSVI and its corresponding Liberation Therapy require *translation* to medical gatekeepers such as the Canadian government, the MS Society and medical practitioners. This dilemma embroils patients in a kind of moral and political economy of hope, typical of biological citizens fighting for recognition of therapeutic rights. Rose and Novas (2004) describe this moral economy of hope as one “in which ignorance, resignation and hopelessness in the future is deprecated. This is simultaneously an economy in the moral traditional sense, for the hope for the innovation that will treat or cure stimulates the circuits of investment and the creation of biovalue” (5-6). For Canadian MS patients who redefine themselves as CCSVI patients, it becomes a moral duty to pursue and advocate for Liberation Therapy, particularly for those that can not access therapy in other countries. Meanwhile, medical tourism companies earn huge profits as they attract patients who do have the financial means to be treated out-of-country. For patients and medical tourism agents alike, the powerful

terminology of “liberation” becomes a strategic rhetorical resource to marshal and sell in these moral economies of liberation and hope.

Liberation Therapy creates a *therapeutic* economy as well. Nguyen’s (2004) concept of therapeutic citizenship clarifies this dynamic by problematizing the notion that biological status equals particular forms of citizenship. Nguyen makes explicit that, while biological status (in this case being diagnosed with MS) may facilitate a biological identity and collectivity, other resources and actors must be mobilized to make successful claims to rights and therapies—particularly therapies that are controversial; essentialized biological identities cannot guarantee successful claims to therapy or inclusion in projects of biological citizenship. For Nguyen, therapeutic citizenship has “emerged as a rallying point for transnational activism in a neoliberal world in which illness claims carry more weight than those based on poverty, injustice or structural violence” (2004:143). The individual body has assumed the status of nexus for both medical and political intervention—a powerful synchronicity felt and experienced not only by the therapeutic citizens themselves, but also by the political and medical authorities they strive to influence. Key resources (for example, subjectivities, narratives and technologies) must be marshalled for a biological status, such as CCSVI, and for therapies, such as liberation, to be recognized and claimed successfully, thus embedding these citizens within a distinctive therapeutic economy.

These moral and therapeutic economies are evidenced in much of the Canadian news media where the demands by CCSVI therapeutic citizens are largely driven by discourses of hope, underpinned by their liberation narratives—hope that they may be liberated from a debilitating disease, but also from the bureaucratic quagmire of restricted funding and resources. For CCSVI patients, narratives of liberation have successfully become not only bioethical imperatives, but also crucial and powerful rhetorical resources in a therapeutic economy made possible by this controversial medical intervention.

The scientific community continues its attempts to prove or disprove the efficacy of this therapy, urging the public to wait and exercise caution (Fragoso, 2011). However, this academic and medical circumspection carries little weight for CCSVI therapeutic citizens who disregard biomedical “evidence,” insisting that they already “know” that it works and refusing to wait. One hopeful patient states, “I don’t profess to be a medical doctor and know all the details, but I know from the videos I have watched and the people that I have talked to, that this procedure works” (Smith, September 21, 2010:A4). These therapeutic citizens believe that they should be empowered to make these decisions themselves. As one patient states: “It’s our bodies. The government should let us see for

ourselves if it works” (Peritz, May 6, 2010:A9). Most CCSVI patients are battling for the lofty goal of hope, not simply therapeutic efficacy (as determined by medical trials), and this struggle for an imminent, higher quality of life is why many refuse to wait for scientific “proof.” Journalists have documented several examples of CCSVI patients who received Liberation Therapy outside of Canada but were not “liberated.” Some patients state that they have no regrets and that it was the “hope” of successful treatment that was a “wonderful gift” (Galloway, September 1, 2010:A16). Similarly, one journalist moralizes and critiques the government and scientific community in this economy of hope by playing with the image of the narrowed vein and the “liberating” balloon angioplasty to describe the bureaucratic red-tape that “wants to move slowly...deflating hopes of many patients who want to believe it will end their suffering” (Galloway, September 1, 2010:A1). These CCSVI therapeutic citizens feel that they have a moral obligation to fight for Liberation Therapy, maintaining the “hope” that it will work. This hope holds just as much, if not more, therapeutic currency as the scientific evidence itself. At times these competing regimes of value spark bitter confrontation and debate among politicians, CCSVI therapeutic citizens and the MS Society of Canada; at other times the value systems appear to be unintelligible to each other.

Both the mysterious, scientifically unexplained nature of the procedure, as well as the loaded term of liberation, have prompted a proliferation of metaphors and narratives around Liberation Therapy. These poetics serve as kindling for public debate and movement-building, which in turn are used as resources in the moral and therapeutic economies of Liberation Therapy. Conceptualizing these CCSVI patients as therapeutic citizens helps us to understand how militant patients can create new forms of citizenship—organized around therapy and a controversial medical identity—that not only exceed state citizenship, but effectively challenge it. In Canada, these therapeutic citizenship projects and movements create new subjectivities and languages that become vital resources in marshalling claims to “liberation”. In this case, the very name, “Liberation Therapy” helps to politicize CCSVI patients, making explicit the link between the biological and the political. Framing this therapy metaphorically in terms of “liberation,” rather than simply “a cure,” draws from well-established social and political narratives related to emancipation and empowerment. As this rhetoric establishes Liberation Therapy as a biopolitical and bioethical imperative, it becomes a crucial resource in making the treatment not only visible and understandable, but its delivery nonnegotiable.

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