Medical Tourism for the Treatment of Chronic Cerebrospinal Venous Insufficiency in Multiple Sclerosis

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BACKGROUND

- Medical tourism involves patient travel to another country to obtain medical care.[1]
- Motivations include lower out-of-pocket costs for uninsured procedures, avoiding long wait times and gaining access to procedures that are not available in the home country.[2]
- Concerns include patient safety, quality of care, and continuity of care for long-term monitoring.[1]
- The chronic cerebrospinal venous insufficiency (CCSVI) hypothesis has been of great interest to multiple sclerosis (MS) patients; however, procedures for CCSVI are not available in Canada.
- Many Albertans have travelled out-of-country and paid to have these interventions.

OBJECTIVES

- To describe the sources of information utilized by patients to learn about and choose the facility for CCSVI treatment.
- To examine differences in clinical practices at these out-of-country facilities and patient-reported outcomes across the countries where CCSVI treatment was obtained.

METHODS

Data Source:

- The Alberta Multiple Sclerosis Initiative (TAMSI) is a longitudinal observational study that uses online questionnaires to collect patient-reported information about the safety, experiences, and outcomes following CCSVI treatment.
- All Albertans with MS were encouraged to participate, irrespective of treatment status. In total, 866 patients enrolled between July 2011 and June 2013. Based on data at Alberta health there were 11,721 Alberta residents with MS as of March 2012.
- The study was approved by Research Ethics Boards at the University of Calgary and the University of Alberta.

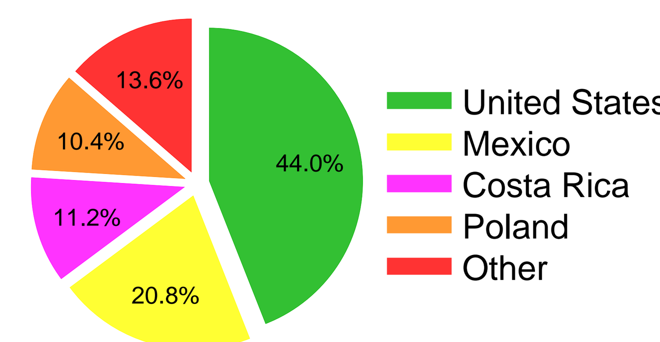
Statistical Analyses:

- Categorical variables were described as frequency (percent) and compared between groups using the Fischer's exact test.
- Continuous variables were described as mean (standard deviation [SD]) or median (interquartile range [IQR]) and compared between groups using one-way analysis of variance or the Kruskal-Wallis test, for normal or skewed distributed variables, respectively.

RESULTS

- 124 patients obtained treatment for CCSVI between April 2010 and September 2013, with one patient going twice.
- 55 patients travelled to the United States, 26 to Mexico, 14 to Costa Rica, 13 to Poland, 6 to India, 5 to Bulgaria, 4 to Germany, and 1 each to Jordan and Scotland.
- CCSVI treatment was obtained at 22 facilities: 7 in the United States, 4 in Mexico, 1 in Costa Rica, 3 in Poland, 2 in India, and 1 each in Bulgaria, Germany, Scotland and Jordan.

RESULTS



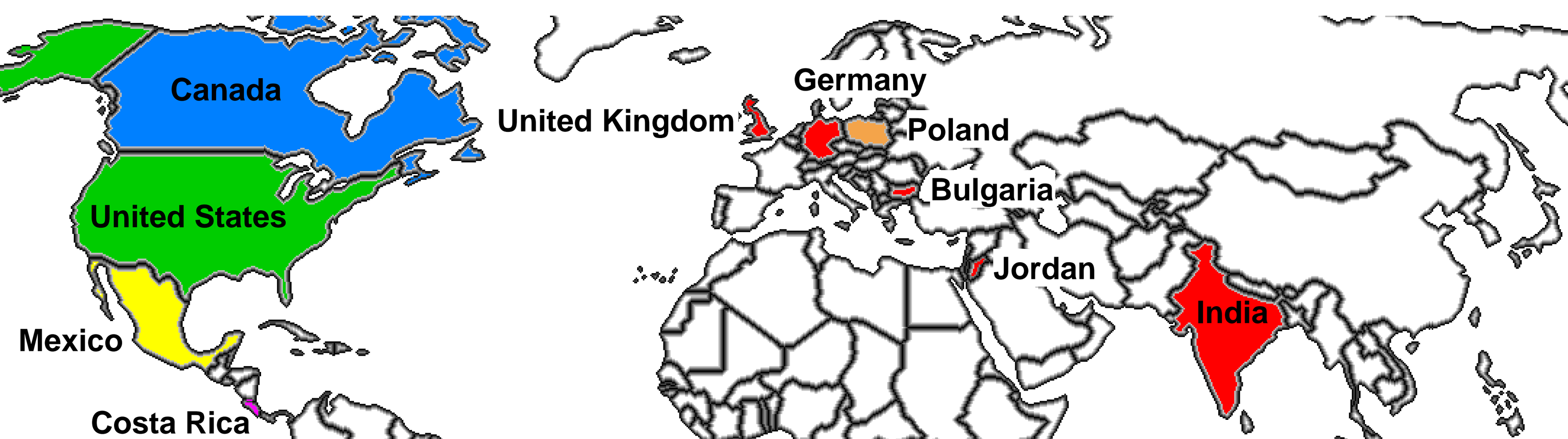


Figure 1. Countries were CCSVI treatment was obtained

Table 1. Characteristics of the study patients

	n	%
Women	81	65.3
Mean age (years, SD)	49.7	11.6
Clinical Course		
RRMS	53	44.2
SPMS or PRMS	37	30.8
PPMS	17	14.2
Uncertain, Possible MS or Not MS	13	10.8
Mean age at MS onset (years, SD)	33.1	11.1
Median disease duration (years, IQR)	15	19-21
Disability †		
Normal	10	8.5
Mild or moderate disability	22	18.6
Gait disability or use of cane	40	33.9
Bilateral support or wheelchair	46	39.0

† Estimated EDSS using the Patient Determined Disease Steps (PDDS)

Table 2. Sources of information utilized to learn about and choose the treatment centre

	n	%
Learned about the facility		
Internet search	70	56.0
Friend or relative	58	46.4
Information from organized groups	27	21.6
Online chat groups	20	16.0
Other *	11	8.8
Chose the facility		
Reputation of physicians	81	64.8
Recommended by an acquaintance	56	44.8
Distance	52	41.6
Cost	41	32.8
Recommended on the internet	21	16.8
Weather	16	12.8
Other †	26	20.8

* Media (n=6), physician (n=4) and dentist; † Availability (n=13), quality of care/health care system (n=7), ease of travel (n=5), and Canadian medical tourism company

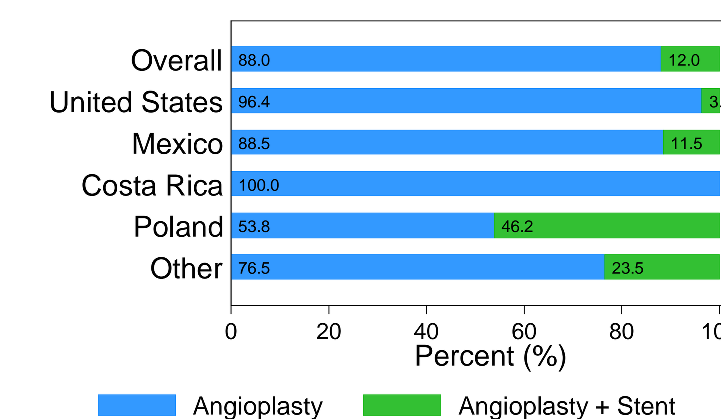
Table 3. Clinical practices at the facility.

	n	%
Informed patient of risks		
Thrombosis or restenosis	107	87.7
Bleeding due to medication	77	63.1
Neck pain	76	62.3
Allergic reaction to dye	69	56.6
Injury to vein in the groin	61	50.0
Fatal bleeding	53	43.4
Kidney injury from the dye	36	29.5
Stent movement	32	26.2
Cancer from the radiation	14	11.5
Other *	6	4.9
Not informed of any risks	5	4.1
Informed there were no risks	2	1.6
Follow-up treatments		
None	54	43.2
Anticoagulant	42	33.6
Aspirin	30	24.0
Plavix	17	13.6
Physiotherapy	14	11.2
Relation techniques	6	4.8
Occupational therapy	1	0.8
Other †	1	0.8
Follow-up investigations		
None	73	59.3
Ultrasound	41	33.3
MRI	21	17.1
CT scan	6	4.9
Catheter venography	6	4.9
Other ‡	3	2.4
Report provided to patient	103	82.4
Report sent to physician	30	24.0

Anticoagulant = Pradax, LMW Heparin or Coumadin
* Death (n=3), not specified (n=2), and heart attack, stroke and death; † Omega 3 supplement; ‡ Disability scales, EEG and EEG, and auditory, physical and mental exams

Table 4. Patient-reported outcomes

	n	%
Patient informed neurologist	97	78.9
Outcome		
Successful without difficulty	99	79.2
Successful with some trouble	24	19.2
Unsuccessful	2	1.6
Experience		
Easier than expected	60	48.0
As easy as expected	53	42.4
Harder than expected	12	9.6
Median satisfaction (1 = worst, 10 = best, IQR)	7	5-9



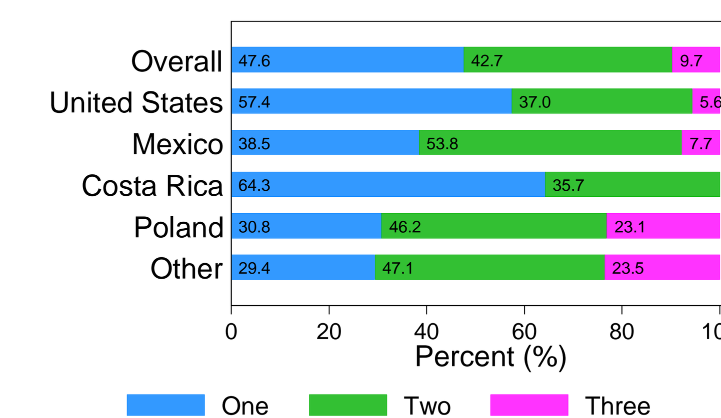


Figure 2. Type of intervention and the number of veins treated

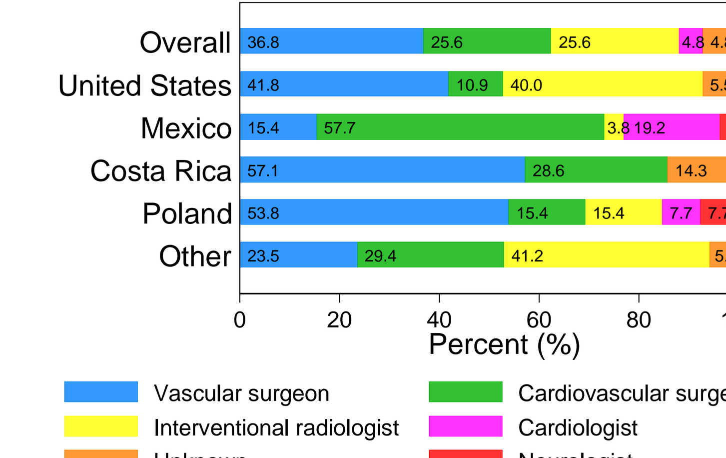
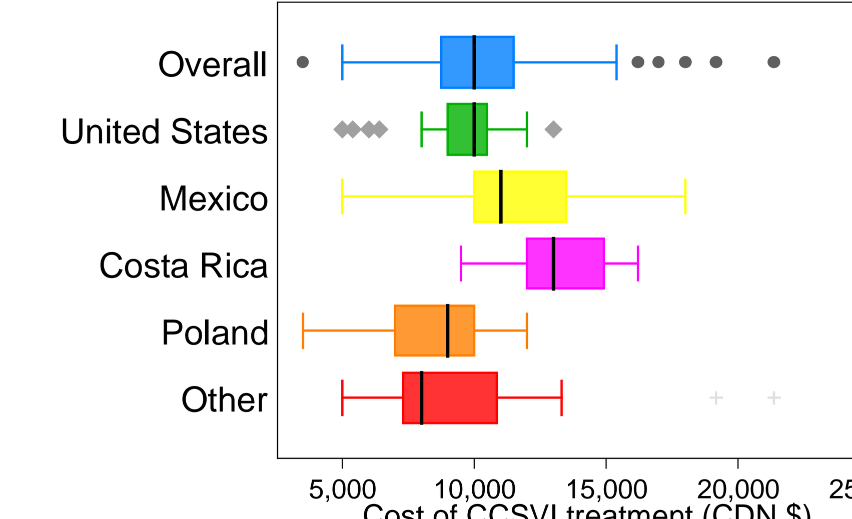


Figure 3. Specialty of the treating physician



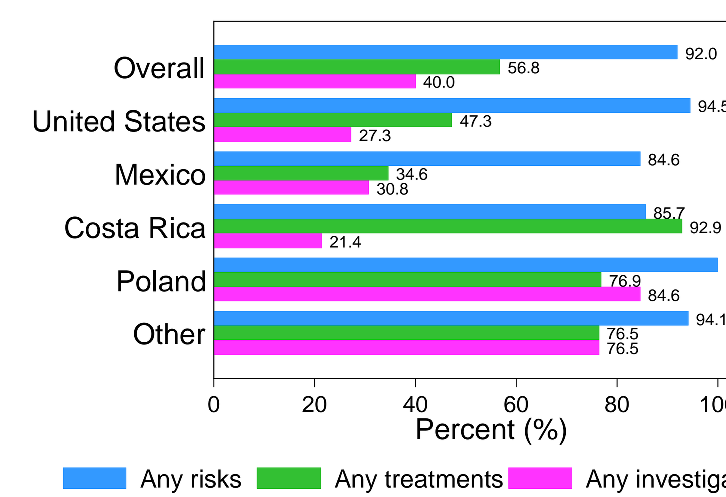


Figure 4. Risk communication and follow-up care provided at the treatment centre

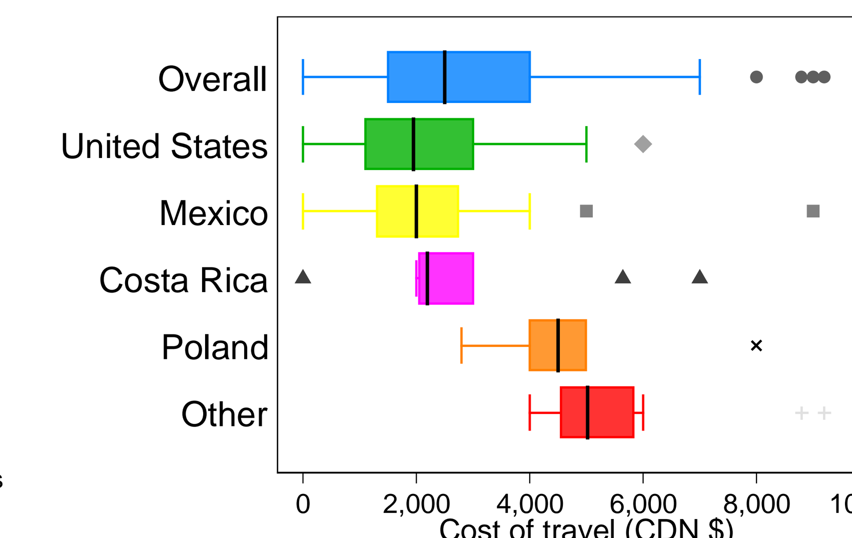


Figure 5. Cost of CCSVI treatment and travel

- The specialty of the treating physician ($p<0.0001$), type of intervention ($p=0.0004$), cost of treatment ($p=0.0001$) and travel ($p=0.0001$), and any follow-up treatments ($p=0.0004$) and investigations ($p<0.0001$) were each significantly associated with the country where CCSVI treatment was obtained.
- There were no significant differences in the number of veins treated, risk communication, continuity of care, or patient-reported outcomes between countries ($p>0.05$).

CONCLUSION

- Because CCSVI treatment is an unproven experimental therapy there are currently no standardized clinical practice guidelines for these procedures. MS patients who travelled abroad for CCSVI treatment reported significant variability in the clinical practices of the treating facilities.
- Variability in care, as seen here, is known to vary geographically and between specialties and indicates many patients are receiving less than optimal care.

DISCLOSURES & REFERENCES

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1. Crooks VA, Snyder J. Medical tourim: What Canadian family physicians need to know. Can Fam Physician 2011;57:527-529. 2. Synder J, Crooks VA, Johnston R, Kinsbury P. What do we know about Canadian involvement in medical tourism? A scoping review. Open Medicine 2011;5(3)E139-148.