
Access to Multiple Sclerosis Diagnosis for Canadian Neurologists

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ABSTRACT: Background: Access to multiple sclerosis (MS) diagnosis in Canada has never been assessed. This study was designed to examine the pattern of MS diagnosis in Canada, including neurologists' diagnostic approach and waiting times for investigations. **Methods:** A mail survey was forwarded to every registered neurologist in Canada (n = 479) in late 1996. Questions included their diagnostic approach to MS including perceived waiting times for various investigations including MRI. Actual MRI waiting periods were separately obtained from booking clerks or neuroradiologists from every MRI unit in Canada. **Results:** 153 responses were received. Neurological assessment is obtained, on average, 1 month after referral. MRI is routinely ordered by 92% of neurologists for suspected MS followed by evoked potentials (EP) (36%) and lumbar puncture (LP) (17%). The perceived waiting period for EP and LP is less than one month but 3 months for MRI. This is very similar to the actual waiting periods obtained from the MRI units surveyed (mean of 101 days). There is a trend for longer waiting periods as one moved east to west (Eastern provinces – mean of 62 days, Ontario – 95 days, Quebec – 102 days and 122 days in the Western provinces). Private MRI units have appeared in the Western provinces and have the shortest waiting periods (2 weeks maximum). The current MRI/million population ratio in Canada is 1.8, far below the ratios of other developed nations. **Conclusions:** Canadian neurologists prefer MRI of the brain to confirm an MS diagnosis and desire greater access to it. Access to neurological assessment, EP and LP is probably adequate but the average wait for MRI of 3 months is relatively long. The perceived average waiting period for MRI is similar to the actual waiting times of 3 months, with the Western provinces of Canada having the longest waits. Canada continues to have one of the lowest MRI/population ratios in the developed world.

RÉSUMÉ: Accès des neurologues canadiens au diagnostic de sclérose en plaques. Introduction: L'accès au diagnostic de la sclérose en plaques (SEP) n'a jamais été évalué au Canada. Cette étude a été élaborée dans le but d'examiner le profil diagnostique de la SEP au Canada, incluant l'approche diagnostique des neurologues et le temps d'attente pour l'investigation. **Méthodes:** Un questionnaire a été envoyé par la poste à chaque neurologue enregistré au Canada (n = 479) à la fin de 1996. Les questions touchaient à leur approche diagnostique de la SEP, incluant le temps d'attente qu'ils estimaient pour différentes modalités d'investigation, dont la RMN. Le temps d'attente réel pour la RMN a été fourni séparément par des réceptionnistes et/ou par des neuroradiologues de chaque unité de RMN au Canada. **Résultats:** Nous avons reçu 153 réponses. L'évaluation neurologique est obtenue en moyenne 1 mois après que le patient soit référé. La RMN est demandée de routine par 92% des neurologues lorsqu'une SEP est soupçonnée, suivie par les potentiels évoqués (PÉ)(36%) et la ponction lombaire (PL)(17%). Le temps d'attente estimé pour les PÉ et la PL est de moins de 1 mois, mais il est de 3 mois pour la RMN. Ces estimés sont très semblables au temps d'attente réel obtenu pour les unités de RMN étudiées (moyenne de 101 jours). Il existe une tendance vers une période d'attente plus longue d'est en ouest (provinces de l'est - moyenne de 62 jours, Ontario - 95 jours, Québec - 102 jours et 122 jours dans les provinces de l'ouest). Des unités privées de RMN ont surgi dans les provinces de l'ouest et elles ont le temps d'attente le plus court (2 semaines au maximum). Le rapport actuel de RMN/million de population au Canada est de 1.8, ce qui est bien en deça de celui d'autres pays industrialisés. **Conclusions:** Les neurologues canadiens préfèrent confirmer un diagnostic de SEP par la RMN et désirent une plus grande accessibilité à cet examen. L'accès à l'évaluation neurologique, aux PÉ et à la PL est probablement adéquat, mais le temps d'attente moyen de 3 mois pour la RMN est relativement long. Le temps d'attente moyen perçu pour la RMN est semblable au temps d'attente réel de 3 mois, les provinces de l'Ouest ayant les plus longues attentes. Le Canada continue d'avoir le rapport RMN/population le plus bas parmi les pays industrialisés.

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Access to multiple sclerosis (MS) diagnosis in Canada has never been assessed. Waiting times for procedures such as coronary artery surgery are well documented,¹ whereas the same cannot be said for any neurological disorder including MS. There exists the perception, at least in many physicians' minds that health care access including neurological access is relatively difficult in Canada, particularly when compared to other countries in the developed world. In addition, the recent development of new therapies in MS such as beta-interferon and glatiramer acetate, can be expected to increase the demand for access to MS diagnosis and subsequent treatment. Our study was designed to

examine the pattern of MS diagnosis in Canada, including neurologists' diagnostic approach and waiting times for tests.

METHODS

A survey was forwarded by mail to every registered neurologist in Canada (n = 479) in late 1996. It required 10-15 minutes

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for completion. No honorarium was provided. A stamped addressed envelope was enclosed with the survey. A survey in French was provided for all the mailings to neurologists in the province of Quebec. Repeat mailings were not performed for budgetary reasons. The respondents provided their opinions on various aspects of the process of MS diagnosis and their perceived waiting periods for subsequent investigations, including MRI. Actual MRI waiting times were then directly assessed by telephoning every MRI unit in Canada and enquiring of the booking clerk and/or the neuroradiologist as to the average waiting time for a non-contrast cerebral MRI in a case of suspected MS. This aspect of the survey was completed in 1997.

RESULTS

Four hundred and seventy-nine surveys were sent out and 153 responses were returned. Ten were returned without being filled out. Sixty-seven neurologists volunteered their address including province of practice. There were a total of 9 respondents from the Eastern provinces (including Newfoundland, New Brunswick, Nova Scotia and Prince Edward Island) and 12 from Quebec. Thirty-four respondents were from Ontario while 12 responses were obtained from Central and Western Canada (including Manitoba, Saskatchewan, Alberta and British Columbia).

The average survey respondent was 45.8 years old (range of 29 - 68). One hundred and twelve respondents were male, twenty-five were female and six did not indicate their gender. Seventy-two percent worked in an office or clinic setting, and 88% were affiliated in some manner with a teaching hospital. Respondents could have an affiliation with more than one type of practice setting and hospital.

Waiting Times

The average waiting period between referral to the respondent and actual assessment for MS diagnosis was 30.5 days or 1 month. Approximately one-half of the patients were reported to wait between 1 week and 1 month to be seen although 33% waited 2-3 months or longer for assessment.

In cases of suspected MS, MRI scan is routinely ordered by 92% of neurologists followed by evoked potentials (36%), lumbar puncture (17%) and CT scan of the brain (12%). Respondents could choose any number of confirmatory diagnostic tests. Asked to list a "second-choice" test, lumbar puncture was mentioned by 72% and evoked potentials by 53% of survey respondents.

The average reported waiting time for MS diagnostic tests (including evoked potentials, CT scan and MRI of the head) varied considerably and is indicated in Table 1. For non-urgent outpatient MRI of the brain, 9% of neurologists must wait 1 week to 1 month for patients to receive the test. Thirty-four percent must wait 1-3 months, while 41% wait 3-6 months. Fourteen percent of neurologists listed a waiting time of longer than 6 months. The average waiting time from neurologists' perceptions is 103 days or a little over 3 months. The average reported wait for lumbar puncture, evoked potentials and CT scan is under one month in each instance.

The data in Table 2 summarize information on waiting times obtained from the booking clerks and/or neuro-radiologists from MRI units across the country. The average waiting period for an outpatient MRI of the brain for suspected MS in Canada (with the public health system) is 101 days (standard deviation of 62

Table 1: Waiting Time for Access to Diagnostic Tests in Suspected MS (Neurologists' Estimates).

	1 week to 1 month	1 to 3 months	3 to 6 months	> 6 months	not available
MRI of Brain for MS	9%	34%	41%	14%	2%
Lumbar Puncture	91%	2%	—	—	7%
Evoked Potentials	73%	22%	1%	—	4%
CT Scan of Head	57%	29%	1%	—	13%

days). The waiting list is shortest in the Eastern Provinces, averaging 62 days or 2 months (standard deviation of 19 days). Ontario's waiting list is 95 days (standard deviation of 74 days) which is similar to patients in Quebec who wait on average 102 days (standard deviation of 52 days). The wait at private MRI units ranges from 1 day to 2 weeks in Western Canada whereas that in the public sector in this region is the country's longest at 122 days (or 4 months) (standard deviation of 54 days). Table 2 also lists the number of MRI units, the MRI/million ratios, the neurologist per million ratio and the ratio of full-time neurologist equivalents to MRI units in each province. Excluding Quebec (13.4), the neurologist/MRI ratio is approximately 7.5 in all regions of the country, whereas the MRI/million ratio in all parts of the country hovers around 2. Quebec has the lowest MRI/million ratio at 1.4 and the highest neurologist/million ratio in the country at 18.8.

The actual diagnostic utility to the clinician of these tests in suspected MS was variable. MRI scan of the brain was characterized as "very useful" by 93% of neurologists while lumbar puncture, evoked potentials and CT scan of the brain received the same evaluation by 19%, 15% and 2% of respondents respectively. Lumbar puncture and evoked potentials were considered as "moderately useful" by 57% and 47% of neurologists respectively. Three percent of respondents "never order" MRI, 4% never ordered lumbar puncture while 8% never ordered evoked potentials.

Seventy-two percent of respondents requested greater access to MRI of the brain whereas enhanced access to lumbar puncture, CT scan of the brain and evoked potentials were requested by 1%, 1% and 6% of the respondents respectively.

DISCUSSION

The attitudes of Canadian neurologists regarding access by their patients to MS diagnosis have never been assessed. There are no reports from the American or European literature on this subject either. However, the issues are important as a measure of how the health-care system functions in the real world and the data obtained are usable in health-care planning. In this survey of all Canadian neurologists, the response rate was 30%, which is typical for an instrument of this type completed with a single mailing on an entirely voluntary basis.

Most neurologists (88.2%) have at least a partial affiliation with a teaching hospital centre reflecting the technology intensive

Table 2: Number of MRI Units Across Canada and Average Waiting Times.

Province	Population (Millions)*	Public MRI Units	Private MRI Units	Average MRI Waiting Time (Days)	MRI/ Million Population Ratio	Full Time Neurologist Equivalent (FTNE)**	FTNE/ MRI Ratio	FTNE/ Million Ratio
Newfoundland	0.55	1	–	90	1.8	5.9	5.9	10.7
New Brunswick	0.74	1	–	60	1.4	9.6	9.6	13.0
Nova Scotia	0.91	2	–	49	2.2	13.2	6.6	14.5
PEI	0.13	–	–					
Eastern Provinces	2.33	4	–	62 +/- 19.37	1.7	28.7	7.2	12.3
Quebec	7.14	10	–	102 +/- 52.24	1.4	134.2	13.4	18.8
Ontario	10.75	21***	–	95 +/- 74.28	2.0	157	7.5	14.6
Manitoba	1.11	1	–	60	0.9	15.9	15.9	14.3
Saskatchewan	0.99	1	–	150	1.0	8.8	8.8	8.9
Alberta	2.7	4****	2	110	2.7	31.1	8.8	11.5
British Columbia	3.72	8	2	131	2.7	51.1	6.4	13.7
Western Provinces	8.52	14	4	122 +/- 54.10	2.1	106.9	7.6	12.5
All of Canada	28.85	49	4	101 +/- 62.28	1.8	427	8.06	14.8

* Taken from Statistics Canada, Canadian Census – 1996.

** FTNE – Full Time Neurologist Equivalent; Taken from Guberman A. (Canadian Neurology Manpower Survey – 1994).

*** One of these units is purely for research and not available for clinical use.

**** One of these units only for clinical oncology and not used for MS diagnosis.

nature of this specialty. The survey revealed that 62% of neurologists see patients with suspected MS for consultation within 1 month and a full 33% report a wait of 2 or more months for evaluation.

MRI scan of the brain is routinely ordered in an MS work-up by 92% of neurologists confirming its pre-eminent role in MS diagnosis. No other test approaches this frequency with evoked potentials and lumbar puncture routinely ordered by 36% and 17% of neurologists respectively. However, lumbar puncture and evoked potentials have an important supplementary role in MS diagnosis, used by at least one-half of the neurologists as second choice tests. They are presumably used in those instances where the findings on the MRI scan of the brain are unexpectedly negative, equivocal, non-specific or not promptly available. Because the sensitivity of MRI in MS diagnosis varies with the clinical certainty of the diagnosis,² the use of second choice tests on occasion is inevitable. CT scan of the brain is used on a routine basis by only a small minority (12%), and probably because of a lack of access to MRI.

As 91% of neurologists in this survey reported having to wait 1 month or longer to obtain an MRI of the brain, the other tests such as evoked potentials and CSF exam are likely to be used more widely than they otherwise would be. The information such investigations provide can be useful but is limited and still does not preclude the need for an imaging procedure of the nervous system, at additional expense to the health care system. Access to the diagnostically less useful evoked potentials is adequate (73% of neurologists can obtain this test within 1 month), and there are no barriers to access to CSF exam (93% within 1 month).

The relative preference of test ordering is reflected by neuro-

logists impressions of the utility of these tests. Ninety-three percent felt that MRI was "very useful" as compared to 19% for lumbar puncture and 15% for evoked potentials.

The neurologists' perceptions with respect to the MRI waiting times closely mirror reality as demonstrated by the similar figures obtained in the independent survey of MRI units (103 days for average perceived waiting time versus 101 days for the actual average waiting time). Regional differences in MRI waiting times showed a clear trend towards increase as one moves from east to west in Canada (Eastern provinces – 62 days; Ontario – 99 days; Quebec – 102 days; Western provinces – 122 days).

A recent survey in 1994 of the number of clinically active neurologists in Canada by Guberman (Canadian Neurology Manpower Survey – 1994, presented at the 31st meeting of the Canadian Congress of Neurological Sciences, 1996), (Personal Communication, 1997) suggested that the neurologist per million population ratio was the lowest in the Eastern provinces (12.3), followed by Western Canada (12.5), Ontario (14.6) and then Quebec (18.8) (see Table 2). The full-time neurologist equivalent (FTNE) per MRI ratio in Table 2 is remarkably constant at about 7.5 across regions of the country excluding Quebec (13.4). This suggests that the number of neurologists alone or even number per MRI unit does not directly influence MRI waiting times. It is also interesting to note that the waiting times did not correlate consistently with the number of MRI units per million either. For instance, Alberta (2.2) and British Columbia (2.7) had slightly higher MRI/population ratios than the national average (1.8), yet had the longer waiting lists (110 and 131 days versus 103 days). The Eastern provinces had slightly lower MRI/population ratios (1.7) and yet, had the shorter waiting lists (62 days).

It is probable that other factors play a role in determining waiting times. For instance, enquiries at one site, revealed a relatively long waiting time because of a shortage of neuroradiologists at that centre. The prioritization by neuroradiologists of the importance of promptly diagnosing MS is another potential factor. We noticed that hospitals with a particular interest in MS research and patient care also tended to have longer waiting times, presumably because of increased MRI demand. Lastly, the epidemiology of the disease may vary across the country and several studies have suggested an increase in the prevalence of MS as one moves from east to west in Canada.³⁻⁶

Previous studies have indicated typically a substantial delay between symptom onset and MS diagnosis.⁷⁻⁹ Patients who present for neurologic investigation generally report dissatisfaction with the wait associated with the provision of an MS diagnosis^{8,9} and this period of uncertainty and anxiety is exacerbated by the time spent waiting for evaluation. In three studies,⁸⁻¹¹ patients with suspected MS reported generally favourable psychological changes at the conclusion of work-up. They experienced relief over the fact that the diagnosis was not something even worse (e.g., malignant tumor) as well as a sense of vindication over the organicity of their symptoms, in contrast to what they have often been told by other physicians earlier in their disease. Nonetheless, communicating the diagnosis can at the same time worsen a patient's sense of well-being and increase worries about future health.^{9,10}

A systematic study of the cost-benefit ratio of faster MRI access was not performed although we expect that a shorter waiting period would eliminate medically unnecessary admissions to hospital that currently occur simply to allow the patient to go to the head of the MRI waiting list. One potentially negative aspect of increased MRI access is the possibility of an increase in MS diagnosis based on false-positive MRI findings, especially in older patients. This situation can be avoided by rigorously using MRI as an adjunct to clinical diagnosis rather than as the gold standard test for MS.

Canadian neurologists do not feel that they have adequate access to MRI scanning and 72% requested faster access to this test. This concern is a reflection of Canada's relative lack of such machines and their preponderant presence in teaching hospitals of large cities. There are currently 53 MRI units across Canada in both research and clinical use, or a ratio of 1.8 units per million population. For the public sector however, there are 47 units available for clinical use in the diagnosis of MS with an average waiting time of about 3 months. There is a striking difference in the availability of such imaging in the private sector in which the scans can be obtained after a maximum wait of 2 weeks.

The Canadian MRI per million population ratio as a whole in 1997 of 1.8 was lower than the 1997 ratio of all other developed western nations (France 3.5, Great Britain 3.9, Korea 4.2, Italy 6.3, Sweden 9.0, Germany 9.6, Austria 10.6, Switzerland 13.9, U.S.A. 20.2 and Japan 25.6 MRI units per million population) (Siemens, Personal Communication, 1997). Provincial MRI per million population ratios in 1996 ranged from a low 0.9 per million in Manitoba to a high of 2.7 in British Columbia (see Table 2). In 1996, the government of Ontario committed itself to funding an additional 23 MRI units in Ontario, mostly in community

hospitals (Foley, R., Ontario Association of Radiologists, Personal Communication, 1997). As of December, 1997, 10 new units had been installed and were operational (Walker, D., Ontario Ministry of Health, Personal Communication, 1997). Even if all 23 of these new units were currently operational, the ratio in Ontario would be 3.3 units per million which represents a substantial increase over current levels but still leaves the province with ratios below 1997 values of other developed countries. In Canada as a whole, we would have 66 MRI units with a population of 28.85 million¹² or a ratio of 2.3, a ratio slightly above that of Latvia (1.8) and Turkey (1.6).

In summary, Canadian neurologists rely on MRI of the brain to confirm an MS diagnosis but have difficulties with access to this test. Patients with suspected MS must wait about one month before receiving neurologic consultation followed by a further wait of more than 3 months for an MRI scan of the brain. Access to other less useful tests such as evoked potentials and cerebrospinal fluid exam is available within one month in the vast majority of cases. Canada has fewer MRI units than any other country in the developed world.

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