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Multiple sclerosis: Prevalence and impact

by Heather Gilmour, Pamela L. Ramage-Morin and Suzy L. Wong

Abstract

This article provides new information about multiple sclerosis (MS) using the 2010/2011 Neurological Conditions Prevalence File, the 2011/2012 Survey of Neurological Conditions in Institutions in Canada, and the 2011 Survey on Living with Neurological Conditions in Canada. An estimated 93,500 Canadians living in private households and 3,800 residents of long-term care institutions had been diagnosed with MS. Prevalence estimates were 159 and 418 cases per 100,000 population for men and women, respectively; 2.6 women reported MS for every man with the condition. Among the household population, MS was generally diagnosed between the ages of 20 and 49 (82%). For the majority (68%), MS was their only neurological condition. The impact of MS included pain that prevented activities, impairments in mobility, cognition or sleep, and limitations in social functioning. Almost two-thirds (64%) stated that MS affected their lives at least moderately.

Keywords: Cognition, mortality, myelitis, neurological disease

Estimates from individual provinces suggest that the prevalence of multiple sclerosis (MS) among Canadians may be one of the highest in the world. MS is a progressive, potentially disabling disease of the central nervous system that damages myelin, the protective layer surrounding nerves. This disrupts communication to and from the brain, producing symptoms such as vision impairment, loss of coordination and balance, extreme fatigue, pain, bladder dysfunction, cognitive impairment, numbness, weakness, and mood changes. The nature and severity of symptoms vary and may be characterized by periods of relapse and remission.

While the cause of MS is unknown, differences by region, sex, and ethnicity have led researchers to investigate sex hormones, diet, genetic factors, and environmental conditions, such as exposure to ultraviolet radiation. ⁶⁻⁹ Results have been inconclusive and are complicated by different data sources—from self-reports to clinical assessment—and by factors including changes in population composition through natural increase and migration. ^{2,8}

This study examines the prevalence of MS and its impact on those diagnosed. MS among Canadians in private households is based on self-reported data from two nationally representative surveys: the 2010/2011 Neurological Conditions Prevalence File and the 2011 Survey on Living with Neurological Conditions in Canada. In-depth information from the latter is presented for household residents aged 15 or older, including age at diagnosis, comorbidity, treatment, and impact. Based on the 2011/2012 Survey of Neurological Conditions in Institutions in Canada, for the first time, the prevalence of MS among people in long-term care facilities is reported. Deaths due to MS are from the Canadian Vital Statistics, Death Database (see *The data*).

Prevalence

In 2010/2011, based on the most recent nationally representative data, an estimated 93,500 Canadians reported a diagnosis of MS. At 290 cases per 100,000 population (Table 1), prevalence exceeded that in many other countries and was higher than

Table 1
Prevalence of multiple sclerosis per 100,000 population, by selected characteristics, household population (2010/2011) and residents of long-term care institutions (2011/2012), Canada

	Prevalence per 100,000	95% confidence interval	
Characterisitc	population	from	to
Households			
Total	290	258	325
Multiple sclerosis and other neurological conditions [†]	92	71	119
Multiple sclerosis without other neurological conditions	197	175	223
Sex			
Males [‡]	159	125	201
Females	418*	367	477
Age group			
0 to 17	F	F	F
18 to 44	233*	188	290
45 to 64 [‡]	478	417	548
65 to 79	470 ^E	333	663
65 or older	267 ^{E*}	149	479
Institutions			
Total	1,460	1,380	1,540
Sex			
Males [‡]	1,300	1,200	1,400
Females	1,540*	1,450	1,620
Age group			
0 to 17	F	F	F
18 to 44	2,130*	1,820	2,440
45 to 64 [‡]	6,910	6,450	7,380
65 to 79	2,540*	2,380	2,700
65 or older	300*	270	330

^E use with caution

Sources: 2010/2011 Canadian Community Health Survey - Neurological Conditions Prevalence File; 2011/2012 Survey of Neurological Conditions in Institutions in Canada (CANSIM Table 105-1305).

F too unreliable to be published

^{*} signficantly different from reference group (p < 0.05)

[†] ALS (Lou Gehrig's disease/amyotrophic lateral sclerosis), Alzheimer's disease or any other dementia, brain injury, brain tumour, cerebral palsy, dystonia, effects of a stroke, epilepsy, Huntington's disease, hydrocephalus, migraine, muscular dystrophy, Parkinson's disease, spina bifida, spinal cord injury, spinal cord tumour, Tourette's syndrome

[‡] reference group

reported in earlier Canadian studies.^{2,10} Global estimates vary widely, and differing methodologies make direct comparisons between studies difficult. The United Kingdom, for example, reports a rate per 100,000 of 203; Sweden, 189; and Ecuador, 3.2.^{6,11,12} Increased prevalence in recent years is thought to be attributable to longer survival time and advances in diagnosis rather than to changes in disease risk.^{13,14}

Women are two to three times more likely than men to have MS. The imbalance in the sex ratio is thought to be increasing in several countries, including Canada, ¹³ where 2.6 women reported MS for every man with the condition. This disparity is reflected in prevalence estimates of 418 cases per 100,000 women and 159 cases per 100,000 men.

MS is much more common among people in long-term care facilities. In 2011/2012, an estimated 3,800 long-term care residents were reported to have MS, which equates to 1,460 cases per 100,000 (95% CI: 1,380 to 1,540). As in the household population, women were significantly more likely than men to have MS. Prevalence peaked in the 45-to-64 age range.

Age at diagnosis

In Canada and other countries, 11,15 MS is usually diagnosed before age 50—82% of household residents aged 15 or older reporting MS had been diagnosed at ages 20 to 49 (95% CI: 75.9 to 86.5). The average age at which people first experienced symptoms was 32, with a diagnosis about five years later at age 37.

Consistent with previous work, ^{16,17} the time between the onset of symptoms and diagnosis was longer for women than for men and for those whose symptoms appeared at earlier ages (Table 2). The gap between the appearance of symptoms and diagnosis was 5.4 years for women, compared with 2.6 years for men (p < 0.01). The gap was longer for people whose symptoms began before age 20, and shorter for those whose symptoms appeared at age 40 or later, compared with those whose symptoms appeared at ages 30 to 39. People with MS had lived with the condition for an average of

Table 2
Mean age at symptom onset and at diagnosis of multiple sclerosis, by age group at symptom onset, household population aged 15 or older with multiple sclerosis, Canada excluding territories, 2011

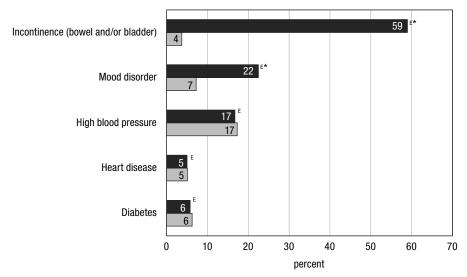
		Age group at symptom onset			
	15 to 19	20 to 29	30 to 39†	40 to 49	50 or older
Mean age at symptom onset	15.6	24.7	34.2	43.3	56.0
Mean age at diagnosis	26.0**	28.9**	38.7**	45.9**	58.0**
Mean years between symptom onset and diagnosis	10.5*	4.3	4.5	2.6*	2.0*

^{*} signficantly different from reference age group (p < 0.05)

Source: 2011 Survey of Living with Neurological Conditions in Canada.

Figure 1
Percentage reporting selected chronic conditions, by multiple sclerosis status, household population aged 15 or older, Canada excluding territories, 2011

Chronic condition



■ Population with multiple sclerosis

* significantly different from general household population (p < 0.05)

Sources: 2011 Survey of Living with Neurological Conditions in Canada (population with multiple sclerosis) and 2011 Canadian Community Health Survey (general household population).

15 years, although for some, the period extended beyond 50 years.

Non-neurological comorbidity

Research has shown that comorbidities in MS affect disability progression, quality of life, need for health care, and mortality risk. ¹⁸⁻²⁰ In this study, people aged 15 or older with MS were about 15 times more likely than the general population to report urinary or bowel incontinence (59% versus 4%), which may be due, in part, to damage to the nerve path-

ways from the brain to the bladder and the bowels^{21,22} (Figure 1). They were more than three times as likely to have a mood disorder (22% versus 7%). A combination of biological, behavioural, psychological, and disease-related factors are thought to contribute to this pattern.²³ On the other hand, the prevalence of diabetes, heart disease, and high blood pressure among people with MS did not differ significantly from the general population, and other research has found a reduced risk of cancer among MS patients.24

^{**} significantly different from mean age at symptom onset (p < 0.01)

[†] reference group

[■] General household population

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Impact

For survey respondents with MS and other neurological conditions, it is not possible to separate impacts that may be due to MS from those due to the other disorders. Consequently, analysis of the impact of MS was restricted to individuals whose only neurological condition was MS (68%; 95% CI: 62 to 74). This may introduce a bias if those with multiple neurological conditions experience greater impacts overall.

About two-thirds of these people reported that MS affected their lives moderately, quite a bit, or extremely (Table 3). The remaining third stated that their lives were affected only a little bit or not at all.

It is difficult to generalize about the impact of MS because it can manifest in many ways and affect different parts of the body to varying degrees. Although 57% of people with MS could walk without aid, almost a third (31%) required a wheelchair, a mechanical aid such as a cane or walker, or the help of another person; 12% could not walk at all. Just over half (53%) were usually pain-free, with the rest reporting pain that prevented a few activities (21%) or some/most activities (25%). Nearly two-thirds (62%) experienced difficulty getting a good night's sleep.

In addition to physical effects, MS may have cognitive impacts at any stage. Half (50%) of people whose only neurological condition was MS had difficulty remembering most things and/or thinking and solving problems.

MS was limiting in other ways. About a third reported that it had prevented them from driving (30%), or compromised their educational opportunities (32%). More than half (58%) experienced at least some limitations in job opportunities; 44% characterized these limitations as "quite a bit" or "extreme." As well, 43% reported that MS had a negative impact on their social interactions; for instance, they felt left out, embarrassed, or perceived that others felt uncomfortable around them or avoided them.

Table 3
Percentage reporting impacts on life and limitations, household population with multiple sclerosis[†] aged 15 or older, Canada excluding territories, 2011

		95° confid inter	ence
Impact on life/Limitation	%	from	to
Overall, how much multiple sclerosis affects life			
Not at all	14.4 ^E	9.1	22.1
A little bit	21.7		29.2
Moderately Quite a bit	24.0 20.3		31.2 26.6
Extremely	20.3 19.5 ^E		27.8
Functional impact	13.3	10.2	21.0
•			
Mobility Able to walk without aid	57.0	48 1	65.5
Able to walk with aid	31.2	24.1	
Unable to walk	11.8 ^E		18.8
Pain			
Usually free of pain	53.5	43.8	62.9
Pain prevents none/a few activities	21.1	15.6	
Pain prevents some/most activities	25.5 ^E	18.0	34.6
Limited getting a good night's sleep			
Not at all	37.8	31.0	45.1
A little bit/Moderately	35.5	28.0	43.8
Quite a bit/Extremely	26.7	19.9	34.9
Cognition			
Able to remember and think	49.9	42.5	57.4
At least some difficulty remembering and thinking	50.1	42.6	57.5
Social impact			
Prevented from driving [‡]			
Yes	29.8	23.4	37.0
No	70.2	63.0	76.6
Limited educational opportunities			
Not at all	67.8		74.3
A little bit/Moderately	17.6 ^E	12.4	
Quite a bit/Extremely	14.6 ^E	10.4	20.2
Limited job opportunities			
Not at all	41.8		49.8
A little bit/Moderately	13.9 ^E		19.9
Quite a bit/Extremely	44.2	36.0	52.8
Social interactions			
Negative feelings about social interactions	40.4	047	50.0
Sometimes/Often/Always	43.1 56.9	34.7 48.0	
Rarely/Never	50.9	40.0	00.5
Embarrassed Compating of Other (Alueus)	07.5	00.0	05.0
Sometimes/Often/Always Rarely/Never	27.5		35.8 79.4
•	72.5	64.2	79.4
People felt uncomfortable around me Sometimes/Often/Always	10.5	13.5	24.8
Rarely/Never	18.5 81.5	75.2	86.5
Felt left out	01.0	13.2	00.5
Sometimes/Often/Always	31.1	23.6	39.8
Rarely/Never	68.9	60.2	76.4
Some people avoided me	00.0	00.2	10.7
Sometimes/Often/Always	13.9 ^E	8.4	21.9
Rarely/Never	86.1	78.1	91.6
E use with caution			

^E use with caution

Source: 2011 Survey of Living with Neurological Conditions in Canada.

 $^{^{\}scriptscriptstyle \dagger}$ no other selected neurological conditions

[‡] population aged 16 or older with valid driver's license

Treatment

There is no cure for MS, although treatments are available to help manage the disorder, ¹⁴ including pharmaceuticals, physiotherapy, occupational therapy, cognitive rehabilitation, and complementary and alternative therapies. ⁷ The use of "liberation therapy," a controversial treatment that dilates narrowed neck veins, ²⁵ is unsupported for the management of MS patients, based on recent results from a large clinical trial in Canada. ²⁶

A majority (83%) of Canadians aged 15 or older with MS reported using one or more treatments (Table 4). Of those, 84% took medications, and 49% had rehabilitation therapy. Counselling and complementary medicine were used

by 27% and 25%, respectively. Smaller percentages reported urinary catheterization and liberation therapy. Of those who received treatment, 39% reported one type, and the remaining 61% had multiple treatment strategies.

Deaths

Life expectancy is shorter for people with MS,^{20,27} the most common cause of death being MS itself or related complications such as infections. In 2013, of the total 252,338 deaths that occurred in Canada, MS was the underlying cause for 521 (1.5 per 100,000 population). It was a less common cause of death than Parkinson's disease (2,354 deaths; 6.7 per 100,000) and Alzheimer's disease (6,345 deaths; 17.9 per 100,000), but

Table 4 Number and percentage who received selected treatments, by type and number of treatments, household population with multiple sclerosis aged 15 or older, Canada, 2011

		95% confidence interval	
Treatment	%		to
Received treatment			
Yes	82.5	76.6	87.2
No	17.5	12.8	23.4
Type of treatment ^{†‡}			
Medication (injections/infusions/pills)	83.7	74.1	90.2
Rehabilitation therapy	48.5	40.7	56.4
Counselling/Psychotherapy	27.0	20.2	35.1
Complementary/Alternative medicine	25.3	19.1	32.8
Urinary catheterization	15.6 ^E	10.8	22.0
Venous angioplasty/Liberation therapy	10.3 ^E	5.8	17.6
Number of different types of treatment [†]			
1	38.9	31.4	47.0
2	30.0	23.2	37.9
3	15.9 [₌]	11.3	21.9
4 or more	15.2 ^E	10.2	22.1

E use with caution

Source: 2011 Survey of Living with Neurological Conditions in Canada.

more common than epilepsy (240 deaths; 0.7 per 100,000) and cerebral palsy (160 deaths; 0.5 per 100,000).

Conclusion

This study presents up-to-date national estimates of the prevalence of MS and highlights many condition-specific impacts on the lives of those with MS. The prevalence of MS in Canada is among the highest reported in the world. An estimated 93,500 Canadians in private households, and 3,800 in long-term care facilities, have MS. It is most frequently diagnosed between the ages of 20 and 49.

Unlike neurological disorders such as dementia²⁸ and Parkinson's disease²⁹ that tend to develop at older ages, MS is more prevalent in younger adults. Longer duration and the potential early loss of productivity due to physical disability, fatigue, comorbidity, and need for assistance affect the societal cost of MS.¹² ■

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[†] among those who received one or more selected treatments

 $[\]ensuremath{^{\ddagger}}$ because multiple treatments could be indicated, detail sums to more than 100%

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The data

Data source

This study is based on cross-sectional, nationally representative data from the 2011 Canadian Community Health Survey (CCHS) (63,542 respondents; response rate 69.8%); the Neurological Conditions Prevalence File (285,971 respondents; response rate 70.6%) derived from the 2010 and 2011 Canadian Community Health Surveys (CCHS); the 2011 Survey on Living with Neurological Conditions in Canada (SLNCC) (4,569 respondents; response rate 81.6%); and the 2011/2012 Survey of Neurological Conditions in Institutions in Canada (4,245 institutions; response rate 63.5%) accessed through CANSIM table 105-1305. These surveys are described in previous studies. Peath data are from the Canadian Vital Statistics Death Database accessed through CANSIM tables 102-0526 and 102-0551. Documentation is available at www.statcan.gc.ca. The analysis of people aged 15 or older in the household population whose only neurological condition was MS was based on a sample of 525 respondents (122 men, 403 women) from the SLNCC.

Definitions

Respondents were asked about specific neurological conditions (including multiple sclerosis) that had lasted or were expected to last six months or more and had been diagnosed by a health professional. Non-neurological chronic conditions were: bladder and/or bowel incontinence, high blood pressure (with related medication in the past month), heart disease, diabetes (except during pregnancy), and mood disorder.

The response categories to the question, "Overall, how much do you feel that your neurological condition(s) affects your life?" were "not at all," "a little bit," "moderately," "quite a bit" or "extremely." The mobility, pain and cognition components of the Health Utilities Index-Mark 3³² provide descriptions of functional health and were adapted for use on the CCHS and SLNCC.

Answers to the question, "How much do you feel that your condition has limited you in getting a good night's sleep?" were grouped as "not at all" versus "a little bit/moderately" or "quite a bit/extremely."

Respondents older than 16 with a valid driver's licence were asked if their neurological condition had prevented them from driving. Separate questions addressed the extent to which the condition limited educational and job opportunities. Responses were grouped as "not at all," "a little bit/moderately," or "quite a bit/extremely."

Respondents with neurological conditions were asked four questions about social interactions. Those who responded "always" or "often" rather than "sometimes," "rarely," or "never" were considered to have interactions that had been affected by the condition.

Analysis

Weighted frequencies, cross-tabulations, and means were calculated to examine the prevalence of MS and its impact. To account for survey design effects, standard errors and coefficients of variation were estimated using the bootstrap technique.^{33,34}

Limitations

The prevalence of diagnosed neurological conditions was based on self-reports by individuals or proxy respondents for the household surveys, and by administrative staff for institutions; they were not verified by any other source. It is not known if this under- or overestimated prevalence; either way, it limits comparability with studies that used administrative data or ascertained cases with clinical assessment or chart review. For residents of institutions, only prevalence data were available; therefore, most analyses focus on the household population and do not represent people in long-term care. Detailed analysis of people with MS in the household population (based on the SLNCC) is restricted to those aged 15 or older. Inconsistencies emerged between the CCHS and the SLNCC in respondents identified as having MS: 119 respondents who had MS in the CCHS did not in the SLNCC; 21 who had MS in the SLNCC did not in the CCHS. This may have been due to differences in how people responded in each survey or eligibility for the surveys based on screening questions. Details are available elsewhere.³⁵

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