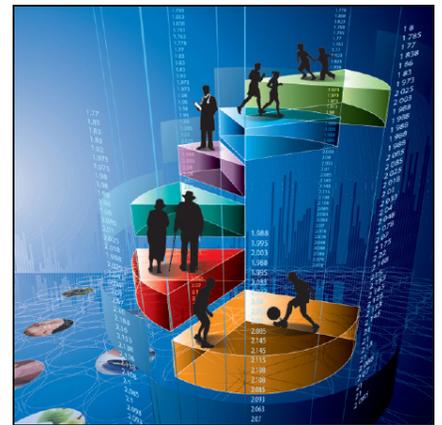


## Health Reports

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# Prevalence of chronic pain among individuals with neurological conditions

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## Abstract

**Background:** The prevalence of pain among people with a variety of individual neurological conditions has been estimated. However, information is limited about chronic pain among people with neurological conditions overall, and about the conditions for which chronic pain is most prevalent. To fill these information gaps, a common method of pain assessment is required.

**Data and methods:** The data are from the Survey on Living with Neurological Conditions in Canada, a cross-sectional national survey. Based on self-reports, chronic pain was assessed for 16 neurological conditions. Multivariable logistic regression was used to produce odds ratios and 95% confidence intervals (CIs).

**Results:** Close to 1.5 million individuals aged 15 or older who lived in private households reported having been diagnosed with a neurological condition. The overall prevalence of chronic pain for the 16 neurological conditions combined was 36% (95% CI: 31% to 42%). The odds of chronic pain were significantly elevated among individuals with spinal cord trauma.

**Interpretation:** Chronic pain is highly prevalent among people with neurological conditions, particularly those with spinal cord trauma. These results suggest a need to target health services and direct research to improved pain management, and thereby reduce the burden of neurological disease.

**Keywords:** Migraine, pain assessment, pain measurement, spinal cord diseases, spinal cord injuries

According to recent estimates, 6 million people in Canada (19% of the population)<sup>1</sup> and 25 million in the United States (11%)<sup>2</sup> report a form of chronic pain. Debilitating in the general population,<sup>3</sup> chronic pain among people with neurological conditions further reduces quality of life and increases the burden on the health care system.<sup>4-6</sup>

The prevalence of pain has been estimated separately for individuals with various neurological conditions, including spinal cord injury,<sup>7-9</sup> stroke,<sup>10-12</sup> multiple sclerosis,<sup>13-15</sup> and Parkinson's disease.<sup>16-18</sup> Pooling prevalence estimates *across studies*, which is necessary to accurately depict the overall burden of chronic pain in neurological conditions, is hampered by a lack of a unifying definition of pain. As well, the prevalence of chronic pain *across neurological conditions* is difficult to estimate without applying the same definition across studies. Both factors are important for planning health care services and training health care professionals to better manage chronic pain.

Based on a common definition of pain, this analysis estimates and compares the prevalence of chronic pain among household residents aged 15 or older within and between 16 neurological conditions.

## Data and methods

### Data source

The data are from the 2011/2012 Survey on Living with Neurological Conditions in Canada (SLNCC).<sup>19-21</sup> Ethics approval for the use of SLNCC data was obtained via the publicly available data clause from the University of British Columbia, in accordance with the Tri-Council Policy Statement.<sup>22</sup>

SLNCC participants were identified from the 2010/2011 Canadian Community Health Survey (CCHS),<sup>23</sup> a cross-sectional general population survey conducted by Statistics Canada. The CCHS included questions about neurological conditions; respondents who reported having been diagnosed with such conditions were selected for the SLNCC. These CCHS respondents were asked if members of their household had one or more of the same conditions; those identified were also selected to participate in the SLNCC.<sup>23</sup>

The estimated response rate for the 2010/2011 CCHS was 72%.<sup>24</sup> Among individuals reporting a neurological condition on the CCHS, the estimated response rate for completing a subsequent diagnosis module on the SLNCC was 82%.<sup>23</sup>

Trained interviewers obtained data from the community-dwelling population aged 15 or older in the 10 provinces. The interviews were conducted from September 2011 through March 2012. The SLNCC excluded people living in the territories, institutions, and reserves, and full-time members of the Canadian Forces. These exclusions represent less than 3% of the Canadian population.<sup>23</sup>

### Selected neurological conditions and pain assessment

Neurological conditions were derived from self-reports (Text table 1). In addition to questions about diagnosed neurological conditions, three SLNCC questions pertained to pain,<sup>25</sup> one of which was chosen for this analysis: "Are you usually free of pain or discomfort?"

For this study, several exclusions from the SLNCC cohort (weighted estimate = 1,737,888) were necessary. To achieve mutually exclusive categories, respondents who reported a

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**Text table 1****Interview questions for Survey on Living with Neurological Conditions in Canada (SLNCC)**

Before beginning the questions about neurological conditions, respondents were told: "Now, I'd like to ask some questions about neurological conditions, which are conditions that affect the brain, spinal cord, nerves or muscles. We are interested in conditions which are expected to last or have already lasted six months or more and have been diagnosed by a doctor or other health professional."

<b>Condition</b>	<b>SLNCC question</b>	<b>Variable name(s)</b>	<b>Interviewer notes</b>
<b>Pain</b>	Are you usually free of pain or discomfort?	HUNX_29	
<b>Spinal cord trauma</b>	Do you have a neurological condition caused by a spinal cord injury? AND: Was the spinal cord injury caused by trauma? A traumatic spinal cord injury is damage to the spinal cord caused by physical impact, for example, a car crash or a fall that results in paralysis, loss of strength, loss of sensation, or difficulty controlling the bowel or bladder.	DINX_16A and DINX_16B	A neurological condition is a disorder of the brain, spinal cord, nerves or muscles that can result in symptoms such as paralysis, weakness, poor coordination, loss of sensation, seizures, confusion, pain and altered levels of consciousness. A spinal cord injury is damage to the spinal cord that results in paralysis, loss of strength, loss of sensation, or difficulty controlling the bladder or bowel. Do not include back pain if this is the only symptom of spinal cord injury. If the respondent says they have been diagnosed with a spinal cord injury, but are not currently experiencing symptoms, classify their response as "No."
<b>Dystonia</b>	Do you have dystonia?	DINX_08A	If the respondent says they have been diagnosed with dystonia, but are not currently experiencing symptoms, classify their response as "Yes."
<b>Muscular dystrophy</b>	Do you have muscular dystrophy?	DINX_07A	If the respondent says they have been diagnosed with muscular dystrophy, but are not currently experiencing symptoms, classify their response as "Yes."
<b>Brain tumour</b>	Do you have a neurological condition caused by a brain or spinal cord tumour? Is this a brain tumour?	DINX15BA	Include both malignant and benign tumours. Include tumours that start in the brain or spinal cord and cancer from elsewhere in the body that has spread to the brain or spinal cord. If the respondent says they have been diagnosed with a brain or spinal cord tumour, but are not currently experiencing symptoms, classify their response as "No."
<b>Spina bifida</b>	Do you have spina bifida?	DINX_05A	If the respondent says they have been diagnosed with spina bifida, but are not currently experiencing symptoms, classify their response as "Yes."
<b>Multiple sclerosis</b>	Do you have multiple sclerosis?	DINX_02A	If the respondent says they have been diagnosed with multiple sclerosis, but are not currently experiencing symptoms, classify their response as "Yes."
<b>Cerebral palsy</b>	Do you have cerebral palsy?	DINX_04A	If the respondent says they have been diagnosed with cerebral palsy, but are not currently experiencing symptoms, classify their response as "Yes."
<b>Migraine headaches</b>	To begin, do you have migraine headaches that have been diagnosed by a health professional?	DINX_01A	If the respondent says they have been diagnosed with migraine headaches, but are not currently experiencing symptoms, classify their response as "Yes."
<b>Stroke</b>	Do you suffer from the effects of a stroke? Have you ever had a stroke (that has been diagnosed by a health professional)?	DINX_14A	A stroke is a sudden loss of brain function that occurs when the blood flow supplying oxygen to a part of the brain is interrupted. Damage to the brain caused by a stroke can result in difficulties with movement, vision, speech, language, and cognition. If the respondent says they have been diagnosed with a stroke, but are not currently experiencing symptoms, classify their response as "No."
<b>Epilepsy</b>	Do you have epilepsy?	DINX_03A	If the respondent says they have been diagnosed with epilepsy, but are not currently experiencing symptoms, classify their response as "Yes."
<b>Parkinson's disease</b>	Do you have Parkinson's disease?	DINX_10A	If the respondent says they have been diagnosed with Parkinson's disease, but are not currently experiencing symptoms, classify their response as "Yes."
<b>Amyotrophic lateral sclerosis (other conditions)</b>	Do you have ALS (Lou Gehrig's disease/amyotrophic lateral sclerosis)?	DINX_11A	If the respondent says they have been diagnosed with ALS, but are not currently experiencing symptoms, classify their response as "Yes."

**Text table 1**

**Interview questions for Survey on Living with Neurological Conditions in Canada (SLNCC)**

Before beginning the questions about neurological conditions, respondents were told: “Now, I’d like to ask some questions about neurological conditions, which are conditions that affect the brain, spinal cord, nerves or muscles. We are interested in conditions which are expected to last or have already lasted six months or more and have been diagnosed by a doctor or other health professional.”

Condition	SLNCC question	Variable name(s)	Interviewer notes
<b>Huntington’s disease (other conditions)</b>	Do you have Huntington’s disease?	DINX_12A	If the respondent says they have been diagnosed with Huntington’s disease but are not currently experiencing symptoms, classify their response as “Yes.”
<b>Tourette’s syndrome (other conditions)</b>	Do you have Tourette’s syndrome?	DINX_09A	If the respondent says they have been diagnosed with Tourette’s syndrome, but are not currently experiencing symptoms, classify their response as “Yes.”
<b>Hydrocephalus</b>	Do you have hydrocephalus?	DINX_06A	If the respondent says they have been diagnosed with hydrocephalus, but are not currently experiencing symptoms, classify their response as “Yes.”
<b>Dementia</b>	Do you have Alzheimer’s disease or any other dementia?	DINX_13A	If the respondent says they have been diagnosed with Alzheimer’s disease or other dementia, but are not currently experiencing symptoms, classify their response as “Yes.”
<b>Excluded conditions</b>			
<b>Brain trauma</b>	Do you have a neurological condition caused by a brain injury? AND: Was the brain injury caused by trauma? A traumatic brain injury is damage to the brain caused by physical impact, for example, a hit to the head, a car crash or a fall that results in difficulties with attention, cognition, language, memory, behaviour or movement.	DINX_17A and DINX_17C	A brain injury is damage to the brain that results in difficulties with attention, cognition, language, memory, behaviour or movement. If the respondent says they have been diagnosed with a brain injury, but are not currently experiencing symptoms, classify their response as “No.”
<b>Brain injury (non-traumatic)</b>	Do you have a neurological condition caused by a brain injury? AND NOT: Was the brain injury caused by trauma? A traumatic brain injury is damage to the brain caused by physical impact, for example, a hit to the head, a car crash or a fall that results in difficulties with attention, cognition, language, memory, behaviour or movement.	DINX_17A and NOT DINX_17C	A brain injury is damage to the brain that results in difficulties with attention, cognition, language, memory, behaviour or movement. If the respondent says they have been diagnosed with a brain injury, but are not currently experiencing symptoms, classify their response as “No.”
<b>Spinal cord tumour</b>	Do you have a neurological condition caused by a brain or spinal cord tumour? Is this a spinal cord tumour?	DINX15BB	Include both malignant and benign tumours. Include tumours that start in the brain or spinal cord and cancer from elsewhere in the body that has spread to the brain or spinal cord. If the respondent says they have been diagnosed with a brain or spinal cord tumour, but are not currently experiencing symptoms, classify their response as “No.”
<b>Spinal cord injury (non-traumatic)</b>	Do you have a neurological condition caused by a spinal cord injury? AND NOT: Was the spinal cord injury caused by trauma? A traumatic spinal cord injury is damage to the spinal cord caused by physical impact, for example, a car crash or a fall that results in paralysis, loss of strength, loss of sensation, or difficulty controlling the bowel or bladder.	DINX_16A and NOT DINX_16B	A neurological condition is a disorder of the brain, spinal cord, nerves or muscles that can result in symptoms such as paralysis, weakness, poor coordination, loss of sensation, seizures, confusion, pain, and altered levels of consciousness. A spinal cord injury is damage to the spinal cord that results in paralysis, loss of strength, loss of sensation, or difficulty controlling the bladder or bowel. Do not include back pain if this is the only symptom of spinal cord injury. If the respondent says they have been diagnosed with a spinal cord injury, but are not currently experiencing symptoms, classify their response as “No.”

diagnosis of more than one neurological condition were omitted (220,995), as were those with missing values (“don’t know,” “refused to answer,” or “not stated”) for the pain question (43,493), and those with conditions with a sample size insufficient for logistic regression analyses (6,289). The final weighted study sample totalled 1,467,165.

**Statistical analysis**

Descriptive statistics (percentages and means) were used to present the prevalence of neurological conditions and demographic characteristics of respondents who reported having been diagnosed. Multivariable logistic regression was used to compare the odds of chronic pain (adjusting for age and sex) between neurological conditions.

Probability weighting accounted for the SLNCC survey sampling design. Survey weights were obtained by dividing the frequency weights provided by Statistics Canada (the number of people represented by the individual) by the average frequency weight for the given sample. Thus, the values are representative of sex and age groups in each health region. SAS statistical software (SAS

Institute, Cary, NC, USA, Version 9.3) was used for all statistical analyses.

## Results

In 2011/2012, close to 1.5 million household residents aged 15 or older reported having been diagnosed with a neurological condition. Their median age ranged from 25 among those with cerebral palsy to 80 among those with dementia (Table 1). Females made up 84% of people reporting migraine headaches. The lowest percentage of females—23%—was among those in the “other” category, which comprised amyotrophic lateral sclerosis, Tourette’s syndrome, and Huntington’s disease.

The prevalence of chronic pain among people with neurological conditions overall was 36% (95% CI: 31% to 42%) (Figure 1). The percentage reporting that they were *not* usually free of pain peaked at 84% among those with spinal cord trauma. As well, more than half of those with a brain tumour or dystonia reported chronic pain. Pain was least prevalent among people with epilepsy (25%).

The unadjusted odds of reporting chronic pain, relative to all the other neurological conditions combined, were significantly higher only among individuals with spinal cord trauma (10.7; CI = 3.4 to 30.4) (Table 2). When age

and sex were taken into account, the odds were reduced, but remained significantly high (8.3; CI = 1.5 to 46.2).

## Discussion

Pain has been extensively examined among people with various neurological conditions.<sup>8-12,16-18,20,26-30</sup> However, owing to differences in assessment and study methodology, pooled estimates and comparisons across conditions are nearly impossible. This is the first study to use a single pain question in a large sample with various neurological conditions, thereby permitting such an analysis. In response to a comprehensive and representative national survey, more than a third (36%) of people with neurological conditions reported that they were *not* usually free of pain.

The prevalence of pain reported by people with neurological conditions is about twice estimates for the general population (figures based on the same pain question range from 15% to 19%).<sup>31</sup> Although the SLNCC sample is older and contains a larger percentage of females, age and sex likely do not entirely account

for this discrepancy. Contributing factors may include spasms (for example, cervical dystonia),<sup>32</sup> cancer (for example, brain tumours),<sup>33</sup> and paralysis (for example, post-stroke shoulder pain).<sup>11</sup> Depression associated with neurological conditions may also be associated with greater pain prevalence.<sup>34</sup>

The prevalence of chronic pain was highest—84%—among those with traumatic spinal cord damage. A defining feature of spinal cord trauma is central and peripheral neuropathic pain symptoms (42%),<sup>30,35</sup> as well as nociceptive musculoskeletal pain (71%).<sup>35</sup> Pain often emerges in the initial days after injury, increases in severity over time, and is problematic to manage.<sup>35</sup> Reliance on mobility devices such as wheelchairs and/or crutches can also result in musculoskeletal pain (for instance, shoulders).<sup>9</sup>

## Strengths and limitations

A strength of this study is that pain prevalence is based on a single question answered by a large number of survey respondents with neurological conditions. Even so, the prevalence of pain

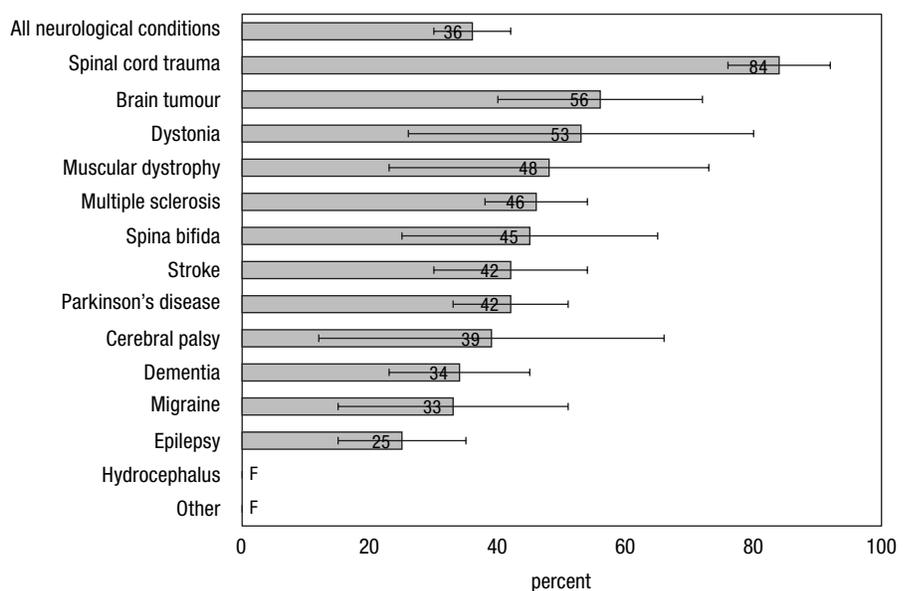
**Table 1**  
Median age and percentage female, by neurological condition, household population aged 15 or older reporting one neurological condition, Canada excluding territories, 2011/2012

Condition	Median age	% female
Spinal cord trauma	55	30
Dystonia	60	50
Muscular dystrophy	34	27
Brain tumour	57	57
Spina bifida	33	64
Multiple sclerosis	51	74
Cerebral palsy	25	55
Migraine headaches	41	84
Stroke	68	48
Epilepsy	44	59
Parkinson’s disease	72	36
Other <sup>†</sup>	26	23
Hydrocephalus	27	39
Dementia	80	60

<sup>†</sup> amyotrophic lateral sclerosis, Huntington’s disease, Tourette’s syndrome

Source: 2011/2012 Survey on Living with Neurological Conditions in Canada.

**Figure 1**  
Prevalence of chronic pain, by neurological condition, household population aged 15 or older reporting one neurological condition, Canada excluding territories, 2011/2012



F too unreliable to be published

I = 95% confidence interval

Note: "Other" comprises amyotrophic lateral sclerosis, Huntington's disease, and Tourette's syndrome.

Source: 2011/2012 Survey on Living with Neurological Conditions in Canada.

among individuals with neurological conditions may be an underestimate, as the sample is community-based and does not include residents of institutions.

Another limitation is that the data were self-reported. Although self-report has been shown to be appropriate for the measurement of pain,<sup>36</sup> it has not been validated for the majority of neurological conditions (exceptions include stroke and migraine<sup>37,38</sup>). Self-report may be less valid in situations where proxy assessment is required and in conditions such as dementia that affect cognitive function.<sup>39</sup> Research suggests that self-reported diagnosis tends to be more

### *What is already known on this subject?*

- The prevalence of chronic pain has been estimated for various neurological conditions.
- To determine the prevalence of pain among people with neurological conditions overall and the neurological conditions for which pain is most prevalent, a common method of pain assessment is required.

### *What does this study add?*

- The 2011/2012 Survey on Living with Neurological Conditions in Canada (SLNCC) asked respondents: “Are you usually free of pain or discomfort?”
- With SLNCC data, it is possible to estimate and compare the prevalence of chronic pain among people with neurological conditions.
- More than a third of individuals aged 15 or older with neurological conditions reported that they were *not* usually free of pain.
- Among people with spinal cord trauma, the prevalence of chronic pain was particularly high, at 84%.

**Table 2**

**Unadjusted and adjusted odds ratios for presence of chronic pain, by neurological condition, relative to odds of chronic pain in other neurological conditions combined, household population aged 15 or older reporting one neurological condition, Canada excluding territories, 2011/2012**

Condition	Unadjusted			Adjusted for age and sex		
	Odds ratio	95% confidence interval		Odds ratio	95% confidence interval	
		from	to		from	to
Spinal cord trauma	10.7*	3.4	30.4	8.3*	1.5	46.2
Dystonia	2.2	0.4	12.9	1.7	0.3	10.4
Muscular dystrophy	1.9	0.6	6.6	2.0	0.6	6.5
Brain tumour	2.4	0.6	9.9	2.0	0.6	6.7
Spina bifida	1.5	0.4	5.3	1.8	0.6	5.6
Multiple sclerosis	1.6	0.5	5.1	1.5	0.4	4.8
Cerebral palsy	1.3	0.1	13.7	1.8	0.2	18.8
Migraine headaches	0.7	0.2	2.5	1.0	0.3	2.7
Stroke	1.3	0.4	4.3	0.7	0.4	1.4
Epilepsy	0.6	0.1	5.4	0.6	0.1	3.6
Parkinson’s disease	1.2	0.5	3.1	0.6	0.2	1.7
Other†	0.4	0.0	6.5	0.5	0.0	4.8
Hydrocephalus	0.4	0.1	1.7	0.5	0.1	2.5
Dementia	1.0	0.4	2.3	0.4	0.2	1.0

\* significantly different from reference category (p < 0.05)

† amyotrophic lateral sclerosis, Huntington’s disease, Tourette’s syndrome

Note: Reference category is prevalence of chronic pain in all other neurological conditions combined.

Source: 2011/2012 Survey on Living with Neurological Conditions in Canada.

valid for conditions with clear symptomatology and event history.<sup>40</sup> Therefore, several neurological conditions may have adequate validity (for example, spinal cord trauma). As well, the SLNCC interviewer notes attempted to clarify responses (for instance, “Do not include back pain if this is the only symptom of spinal cord injury”). Moreover, the age and sex distributions of the conditions generally match published literature (large percentage of females among those with migraine<sup>20</sup>; large percentage of males among those with traumatic spinal cord injury<sup>7,35</sup>).

A final limitation is that the SLNCC does not specify the source and duration of pain, so it is not possible to determine if pain was present before the onset of the neurological condition and/or a result of other non-neurological chronic conditions.

### **Conclusion**

Overall, more than a third of people with neurological conditions reported chronic pain. The high prevalence of chronic

pain among individuals with spinal cord trauma indicates a need for targeted health services and for research to identify effective treatments options.

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