

# PERSONS DYING OF MULTIPLE SCLEROSIS IN NOVA SCOTIA FROM 1998 TO 2005

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December 2008

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**NELS** | Network for End of Life Studies  
**ICE** | Interdisciplinary Capacity Enhancement

## Introduction

With support from a Canadian Institutes of Health Research (CIHR) Interdisciplinary Capacity Enhancement (ICE) grant (#HOA-80067), the Network for End of Life Studies (NELS) is investigating end of life care for chronic diseases. Phase One is an analysis of death certificate data from Nova Scotia Vital Statistics. This report focuses on **multiple sclerosis (MS)** and is one of a series of reports from NELS ICE describing persons dying from specific chronic diseases in Nova Scotia.

## Purpose

The purposes of this report are to:

- share a synthesis of findings from a descriptive analysis of Vital Statistics data;
- enter into dialogues with persons interested in building research and surveillance to review and improve the care available to people at end of life with MS; and,
- begin to identify and examine disparities in health service use at end of life for vulnerable populations at risk for reduced access to quality end of life care.

This report is being shared with you to explore ways to build research and surveillance capacity to help improve care for vulnerable populations. One of our NELS ICE definitions of vulnerable populations is groups of people who have a limited number of deaths each year but may have specific needs at end of life. Historically, palliative care programs have been developed for the many numbers of persons dying relatively quickly of cancer each year. In recent years, there has been increasing interest in examining palliative and end of life care issues for persons dying of chronic conditions other than cancer.

## Study Subjects, Data Analysis, and Definitions

The study population is all Nova Scotia residents who died from January 1, 1998 to December 31, 2005 (N = 63,431). These decedents were identified from the Nova Scotia Vital Statistics death certificate database maintained by the Population Health Research Unit (PHRU) at Dalhousie University. Descriptive findings were prepared using data recorded on the provincial death certificates. These data are limited but provide a basis for future studies.

From 1979 to 1999, causes of death were coded using the ninth revision of the International Classification of Diseases (ICD-9). Since January 1, 2000, causes of death have been coded using the tenth revision of ICD (ICD-10). The ICD-9 code for MS is 340 while the ICD-10 code is G35.

There can be up to 13 causes of death listed on the death certificate. When only one cause of death is recorded, this cause of death is selected as the underlying cause. When more than one cause of death is recorded, the underlying cause is identified using a set of rules developed by the World Health Organization (Statistics Canada, 2005). The underlying cause of death is defined by Statistics Canada (2007) as “(a) the disease or injury which initiated the train of morbid events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury.” In order to gain a more complete understanding of the burden of MS, all records for which MS was mentioned as a cause of death on the death certificate were examined.

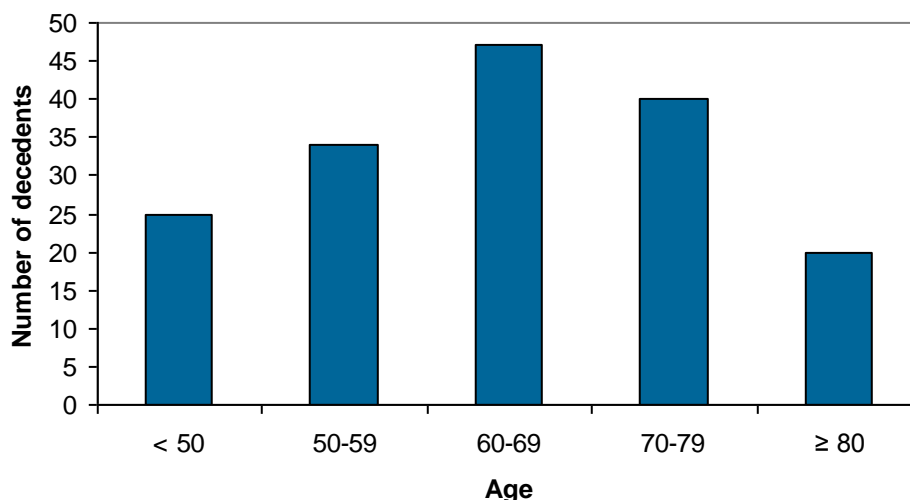
## Death counts

Among the 63,431 persons who died in Nova Scotia from 1998 to 2005, 166 (0.3%) had MS mentioned on the death certificate as one of their causes of death. MS was listed as the underlying cause for 96<sup>1</sup> (57.8%) of these deaths. Other underlying causes where MS was mentioned as a cause of death included: cancer (15.1%); diseases of the circulatory system including stroke, heart failure, myocardial infarction and chronic ischemic heart disease (14.5%); and, diseases of the respiratory system including chronic obstructive pulmonary disease and pneumonia (6.6%).

MS is reported more often in females than males. The number of deaths each year from MS remained fairly constant from 1998 to 2005 (Table 1). MS typically appears as a cause of death between age 50 and 79 (Figure 1). The mean age of MS decedents is 64.2.

**Table 1:** MS mentioned as a cause of death, by sex and year, Nova Scotia, 1998-2005.

	1998	1999	2000	2001	2002	2003	2004	2005	TOTAL
<b>Male</b>	4	8	7	10	8	9	11	7	<b>64</b>
<b>Female</b>	11	7	7	19	10	18	11	19	<b>102</b>
<b>Total</b>	15	15	14	29	18	27	22	26	<b>166</b>



**Figure 1:** MS mentioned as a cause of death, by age, Nova Scotia, 1998-2005.

## Location of Death

Place of death has been used as a crude indicator of quality of care at end of life. Surveys have shown that the majority of persons would like to die in their own home or community based care rather than in hospital if adequate home and community care is available. In Nova Scotia using data

<sup>1</sup> There were 4 records where MS was not listed as one of the up to 13 causes of death but was selected as the underlying cause of death. Further investigation is required to determine why MS was selected as the underlying cause for these records.

from 1998 to 2005, 62.7% of persons died in hospital. This rate of hospital death is considered relatively high compared to rates in other countries such as the US, UK and some other European countries.

The NS vital statistics data from PHRU only report location of death as in hospital or out of hospital. Using a more complete data set obtained directly from Nova Scotia Vital Statistics, out of hospital can be subdivided into private residence or nursing home, which is important to discern in these types of analyses.

From the limited data we now have available for 1998 to 2005, 51.2% of all deaths where MS was mentioned on the death certificate occurred in hospital (Table 2). The percentage dying in hospital tends to decrease as age increases with more than 50% dying in hospital among those under 75 years, and 40% dying in hospital among those 75 years and over.

**Table 2:** Number and percent of hospital deaths with MS as the underlying versus other cause of death, by age group, Nova Scotia, 1998-2005.

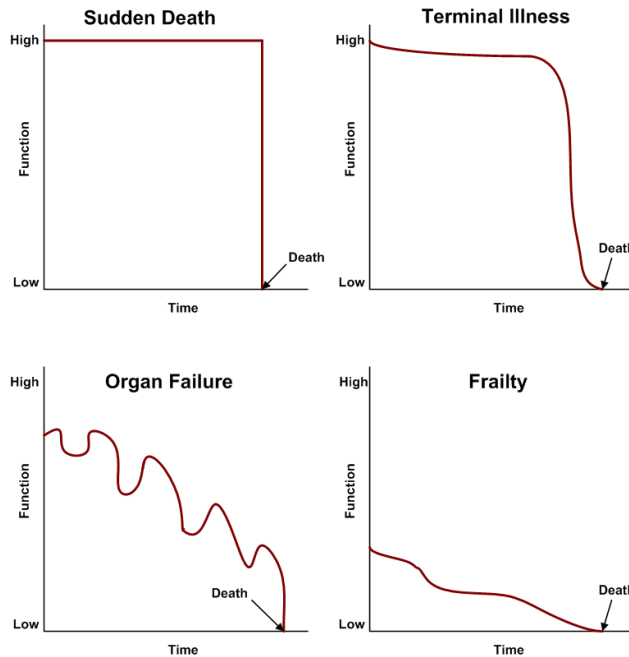
	Aged <55		Aged 55-74		Aged 75+		TOTAL	
	N	%	N	%	N	%	N	%
MS as underlying cause	15	51.7	22	43.1	7	43.8	44	45.8
MS mentioned as other cause but not underlying cause	8	66.7	26	66.7	7	36.8	41	58.6
<b>Any mention of MS</b>	<b>23</b>	<b>56.1</b>	<b>48</b>	<b>53.3</b>	<b>14</b>	<b>40.0</b>	<b>85</b>	<b>51.2</b>

There is a trend toward those dying with MS as the underlying versus other cause of death having a lower percentage dying in hospital (45.8% versus 58.6%), but this trend is not statistically significant. Among the persons dying with MS as the underlying cause of death there is little variation by age group in the percentage dying in hospital (range from 43.1% to 51.7% across age groups). Among those with MS mentioned but not as the underlying cause of death, higher hospital death rates occur at younger ages and lower rates among the elderly, which is similar to the age trend for all adult chronic disease deaths.

## Disease Trajectories

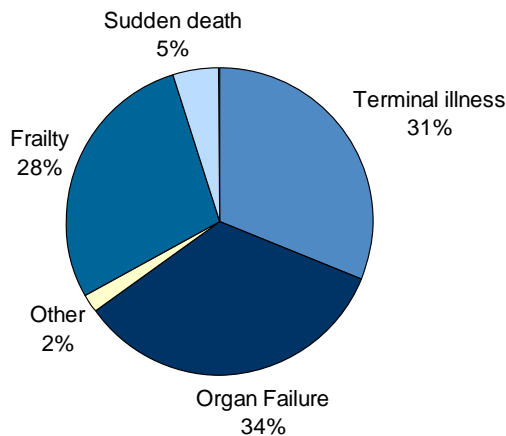
The following overview of disease trajectories as death approaches and grouping of causes of death may be of interest to you. MS as well as a number of other chronic conditions have relatively small numbers of deaths each year. One question that we have at NELS ICE is whether there may be other chronic conditions that could appropriately be grouped with MS to develop and assess the quality of palliative and end of life care for non-cancer patients.

Trajectories of dying were first described by Glaser and Strauss in 1968 (Lunney et al., 2002). Lunney et al. (2002 and 2003) refined this concept and have developed four trajectory groups (Figure 2). NELS ICE has assigned all NS decedents from 2000 to 2005 to one of the four trajectory groups based on methods by Fassbender et al. (2006) that used the underlying cause of death (Figure 3).



**Figure 2:** Trajectories of dying

This classification scheme helps foster dialogue on planning the end of life care needs for the majority of decedents. “Sudden Death” includes those who died as a result of an accident or other external cause of mortality. The “Terminal Illness” category includes those who declined over a short period of time due to cancer, HIV-related diseases, motor neuron disease or chronic renal failure. “Organ Failure” includes those individuals with conditions such as congestive heart failure or chronic obstructive pulmonary disease where functional status gradually declined but there were intermittent, serious exacerbations. *The “Frailty” category includes those who experienced prolonged dwindling due to Alzheimer’s disease, dementia, neurological conditions (e.g. MS), or late effects of stroke.*



**Figure 3:** Deaths by trajectory of dying, Nova Scotia, 2000-2005.

## Next Steps for NELS ICE Population-Based Chronic Disease End of Life Surveillance in Nova Scotia

The following next steps are planned or are in progress:

- 1) Multivariate modelling of predictors of dying in hospital (i.e., **further analysis**).
- 2) Production and sharing of comparable reports starting with cancer, chronic obstructive pulmonary disease, Parkinson's disease, congestive heart failure, renal disease, and deaths among children and youth (i.e., **networking**).
- 3) Discussion with researchers, graduate students, clinical residents, and others who may be interested in working with NELS ICE to use these data to submit manuscripts for peer review publication, and/or new research grant proposals (i.e., **building research capacity**).
- 4) Sharing these and other data as they emerge with persons involved in providing and planning palliative and end of life care (i.e., providing data for dialogue to help with **improving care**).
- 5) Identifying potential inequities in the delivery of end of life care with the aim of improving care for vulnerable persons who may have inadequate access to quality care (i.e., **overcoming disparities**).

## Conclusion

The provision and discussion of these data provide a forum for new research and surveillance development. The intent of NELS ICE is to provide capacity for interdisciplinary research development to improve care at the end of life for vulnerable populations. You are being provided with this report with the hope that you and your colleagues may find these data of use and that you will be part of this further building process.

Conclusions cannot be reached from the limited data reported herein. The number of deaths with MS on the death certificate in Nova Scotia (NS) is small. However, these NS data might begin to enable the exploration of "pilot" work for national or international study of palliative and end of life care for persons dying of MS. Alternatively, persons dying of MS might be grouped with persons dying of other conditions to further develop and evaluate palliative care in Nova Scotia.

## References

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