# EVALUATION OF END OF LIFE CARE FOR PERSONS DYING OF CHRONIC DISEASES IN NOVA SCOTIA, PHASE 1

Chronic Obstructive Pulmonary Disease (COPD)

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#### 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 moving beyond cancer to investigate end of life care for other chronic diseases. Phase One is an analysis of death certificate data from Nova Scotia Vital Statistics.

This report focuses on **chronic obstructive pulmonary disease (COPD)**. It 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;
- to 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 COPD; and,
- to 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.

# **Study Subjects**

The study population is all Nova Scotia residents who died from January 1, 1998 to December 31, 2005 (N = 63,431). These decedents have been identified from the Nova Scotia Vital Statistics death certificate database maintained by the Population Health Research Unit (PHRU) at Dalhousie University. Among these 63,431 persons of all ages, 3038 (4.8%) had COPD as their underlying cause of death, and 7359 (11.6%) had COPD as one of their causes of death.

# **Death Analysis**

Descriptive findings were prepared using data recorded on the provincial death certificates, and are reported in the following sections:

- COPD as underlying or other cause of death
- Trends over time and projections
- Associated causes of death
- Factors associated with dying in-hospital

These figures are limited but provide an indication of what is possible in more extensive future analyses.

Multivariate analyses are planned but are not as yet available. In Phases Two and Three, further databases will be included for analysis.

## **COPD** as Underlying or Other Cause of Death

Table 1 lists the International Classification of Diseases (ICD) codes for chronic obstructive pulmonary disease (COPD). From 1979 to 1999, causes of death were coded using the ninth revision of ICD (ICD-9). Since January 1, 2000, causes of death have been coded using the tenth revision of ICD (ICD-10).

Table 1: International Classification of Diseases (ICD) codes for COPD

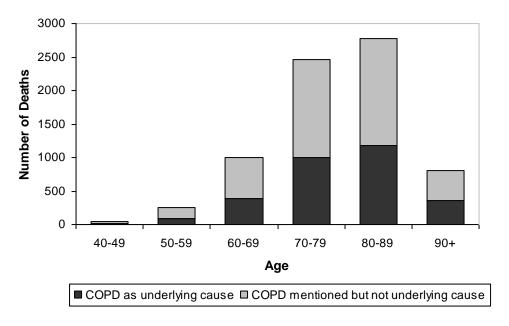
	ICD-9 (1979-1999) Chronic obstructive pulmonary disease and allied conditions				
490	Bronchitis, not specified as acute or chronic				
491	Chronic bronchitis				
492	Emphysema				
496	Chronic airway obstruction, not elsewhere classified				
ICD-10 (2000-present)					
Chronic lower respiratory diseases					
J40	Bronchitis, not specified as acute or chronic				
J41	Simple and mucopurulent chronic bronchitis				
J42	Unspecified chronic bronchitis				
J43	Emphysema				
J44	Other chronic obstructive pulmonary disease				

There are 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 COPD, all records for which COPD was mentioned as a cause of death on the death certificate were examined.

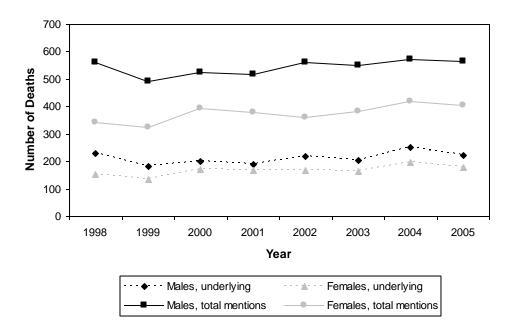
A total of 3038 persons died with COPD as their underlying cause of death from 1998 to 2005 in Nova Scotia. This is 4.8% of all Nova Scotia deaths. A further 4321 persons had COPD as a cause which was not selected as the underlying cause, for a total of 7359 with COPD mentioned on their death certificate, which is 11.6% of all Nova Scotia deaths. COPD was listed as the underlying cause for only 41.3% of all deaths where COPD was mentioned.

COPD typically appears as a cause of death after age  $40^{\circ}$  (Figure 1) and is reported more often in males than females (Figure 2). The mentioned-to-underlying-cause ratios decrease slightly with age (Table 2) which is not unexpected given that the number of causes of death recorded on the death certificate tends to increase with age (Figure 3).

<sup>&</sup>lt;sup>1</sup> Among those with COPD mentioned as a cause of death anywhere on the death certificate, 8 persons (0.12% of all total mentions) are under age 40. These decedents were excluded from the analysis.



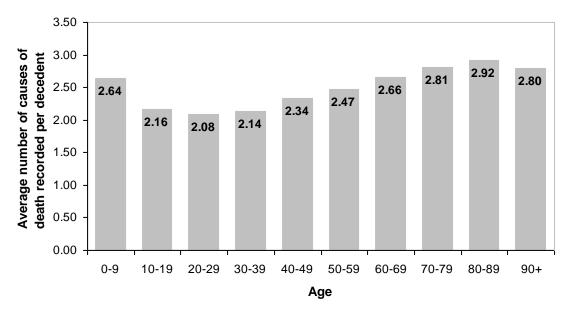
**Figure 2:** Number of death records with COPD as underlying cause and COPD mentioned but not underlying cause, by age, age 40+, Nova Scotia, 1998-2005.



**Figure 1:** Number of death records with COPD as underlying cause and total mentions of COPD, by year and sex, age 40+, Nova Scotia, 1998-2005.

**Table 2:** Number and percentage of deaths with COPD selected as underlying cause or mentioned anywhere on the death certificate, by age group, ages 40+, Nova Scotia, 1998-2005.

Age group	Total deaths	Deaths with COPD as underlying cause (%)	Deaths with COPD mentioned (%)	Ratio of mentioned to underlying causes
40-49	2,344	16 (0.7%)	51 (2.2%)	3.2
50-59	4,794	93 (1.9%)	253 (5.3%)	2.7
60-69	8,541	386 (4.5%)	997 (11.7%)	2.6
70-79	15,913	1005 (6.3%)	2470 (15.5%)	2.5
80-89	20,454	1178 (5.8%)	2781 (13.6%)	2.4
90+	9,163	358 (3.9%)	799 (8.7%)	2.2
Total	61,209	3036 (5.0%)	7351 (12.0%)	2.4



**Figure 3:** Average number of causes of death recorded per decedent, by age, Nova Scotia, 1998-2005.

# **Trends over Time and Projections**

To forecast the number of deaths up to the year 2020 in Nova Scotia from COPD in the NELS ICE Surveillance Report (NELS ICE, 2008), death counts were available for 1999 to 2004 only. Figure 2 shows that there was a slight increase in deaths each year from 1999 to 2004. To compute these projections, it was assumed that future trends in age-specific death rates would be similar to past trends. The Table 3 projections below are based on Nova Scotia population data and projections

using the methods described in Saint-Jacques et al. (2006). A substantial increase of over 70% in the total number of COPD deaths from 2004 to 2020 was predicted<sup>2</sup>.

A growing COPD burden was also reported in the literature. From Lacasse, Brooks, & Goldstein (1999), it is anticipated that there will be large increases in the number of COPD deaths over the next decade in Canada, particularly among women. The WHO Global Burden of Disease Project estimated that COPD was the fifth leading cause of death worldwide in 2001 and is expected to be the third leading cause by 2020 (Buist et al., 2007). From these projections, it is believed that COPD will be an increasing health issue globally, across Canada and in Nova Scotia.

		Death Counts					
		Male	Female	Total			
Actual	2004	250	197	447			
Projected	2010	270 240		510			
	2015	320	300	620			
	2020	400	370	770			

**Table 3:** Actual and projected annual deaths due to COPD, Nova Scotia.

The Table 3 projections were based on historical data for only six years, and the numbers of deaths in the various age-sex groups are limited. From Figure 2, there is no clear increase in the change in the number of deaths from 1998 to 2005. If we compute projections based on the eight years in Figure 2, we will not show as large an increase in COPD deaths for future years.

We have not made this computation at this time since we have concerns with both the 1998 and 2005 data. The 1998 data was based on ICD-9 coding while data from 2000 onward uses ICD-10 coding. For COPD, this may have meant that fewer deaths are classified as COPD under the new ICD 10 coding and thus the higher 1998 counts may be an artefact of coding rather than an appropriate first year of counts to include in a time trend analysis. Some death certificate records are received each year after the closing of a file for recording purposes. Therefore, the 2005 counts may be slightly lower than the total number of deaths that will be known at a later date when a more up-to-date file is received from Nova Scotia Vital Statistics.

For this report, we have decided it is best to simply fully report the current state of knowledge, and note that more analysis will be needed in the future when we have longer term and more stable trend data. There will be an ongoing need to review Nova Scotia trends in light of trends across Canada and internationally.

### **Associated Causes of Death**

Individuals with COPD often die of other chronic diseases such as cancer or cardiovascular disease. Table 4 reports the underlying cause of death for the 7351 deaths in those over age 40 where COPD was mentioned as a cause of death.

<sup>&</sup>lt;sup>2</sup> These COPD projections are from End of Life Care in Nova Scotia Surveillance Report (NELS ICE, 2008). The 1999-2004 death counts were obtained from Vital Statistics, Service Nova Scotia and Municipal Relations.

**Table 4:** Top ten underlying causes with any mention of COPD on the death certificate (n = 7351), age 40+, Nova Scotia, 1998-2005.

Disease	Number of Deaths		
	N	%	
COPD	3036	41.3	
Cancer	1263	17.2	
Chronic ischemic heart disease	786	10.7	
Acute myocardial infarction	383	5.2	
Stroke	220	3.0	
Congestive heart failure	200	2.7	
Diabetes mellitus	137	1.9	
Accidents, injuries and poisonings	105	1.4	
Alzheimer's disease and dementia	96	1.3	
Renal failure	67	0.9	

Among the 3036 deaths in those over age 40 with COPD selected as the underlying cause, the other causes of death included pneumonia, respiratory failure and cardiovascular disease (Table 5). Since there could be up to 12 other causes beyond COPD, an individual may be reported in more than one row of this table. For example if a person had COPD, pneumonia, and diabetes on their death certificate, this person would be one of the 916 pneumonia counts as well as one of the 266 diabetes counts.

**Table 5:** Top ten other causes with COPD as the underlying cause of death (n = 3036), age 40+, Nova Scotia, 1998-2005.

Disease	Number of Deaths			
Disease	N	%		
Pneumonia	916	30.2		
Cardiac or respiratory arrest	669	22.3		
Respiratory failure	590	19.4		
Congestive heart failure	469	15.4		
Chronic ischemic heart disease	368	12.1		
Diabetes mellitus	266	8.8		
Alzheimer's disease and dementia	224	7.4		
Cancer	214	7.0		
Essential (primary) hypertension	185	6.1		
Renal failure	160	5.3		

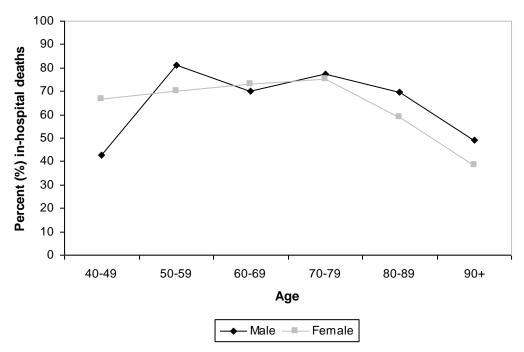
# **Factors Associated with Dying In-Hospital**

These vital statistics data, which were obtained from the Population Health Research Unit (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.

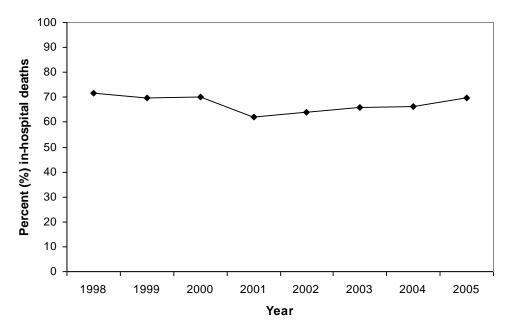
From 1998 to 2005, 67.4% of all deaths with COPD as the underlying cause among people over age 40 in Nova Scotia occurred in hospital (Table 6). The percentage of in-hospital deaths tends to increase from ages 40-49 to ages 70-79 for both males and females. After age 80, the percentage of in-hospital deaths decreases (Figure 4). Rates of in-hospital deaths remained fairly constant over the eight years of data (Figure 5).

**Table 6:** Location of death where COPD was selected as the underlying cause of death, by sex and age, age 40+, Nova Scotia, 1998-2005.

	Sex	Aged 40-59		Aged 60-79		Aged 80+		Total Aged 40+	
Location		N	%	N	%	N	%	N	%
In hospital	Male	38	76.0	601	75.3	558	65.6	1197	70.4
	Female	41	69.5	443	74.7	366	53.4	850	63.6
	Total	<i>7</i> 9	72.5	1044	<i>75.1</i>	924	60.2	2047	67.4
Out of hospital	Male	12	24.0	197	24.7	293	34.4	502	29.6
	Female	18	30.5	150	25.3	319	46.6	487	36.4
	Total	30	27.5	347	24.9	612	39.8	989	32.6

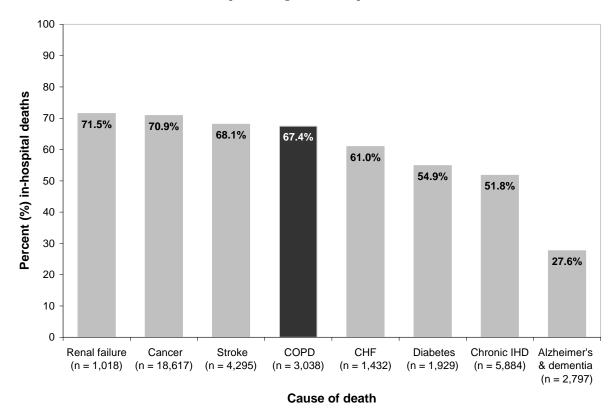


**Figure 4:** Percentage of in-hospital deaths where COPD was selected as the underlying cause of death, by age and sex, age 40+, Nova Scotia, 1998-2005.



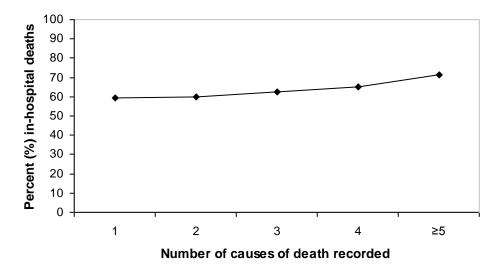
**Figure 5:** Percentage of in-hospital deaths where COPD was selected as the underlying cause of death, by year of death, age 40+, Nova Scotia, 1998-2005.

The percentages of in-hospital deaths for COPD and seven other major chronic diseases were compared (Figure 6). Renal failure has the highest percentage of in-hospital deaths at 71.5% while Alzheimer's and dementia have the lowest percentage of in-hospital deaths at 27.6%.



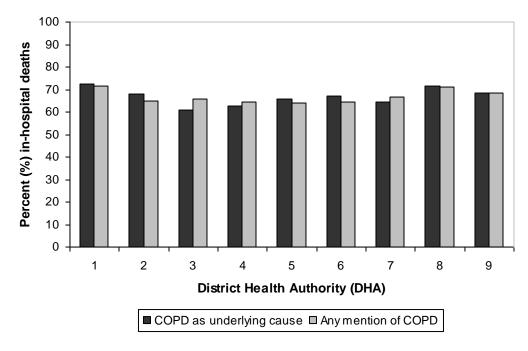
**Figure 6:** Percentage of in-hospital deaths for major underlying chronic disease causes of death, age 20+, Nova Scotia, 1998-2005.

Rates of in-hospital deaths increase as the number of causes recorded on the death certificate increases (Figure 7).



**Figure 7:** Percentage of in-hospital deaths by number of causes of death recorded, age 20+, Nova Scotia, 1998-2005.

The percentage of in-hospital deaths for COPD was between 61 to 73% across each of the nine district health authorities (DHAs) in Nova Scotia (Figure 8). Residence information in the Vital Statistics data set is limited, so county of death was used to identify the DHA. The DHA boundaries do not exactly match the county boundaries. Hants County was included in Colchester East Hants Health Authority while Inverness County was included in Cape Breton District Health Authority to prepare the Figure below.



**Figure 8:** Percent of in-hospital deaths where COPD selected as underlying cause or mentioned anywhere on death certificate, by DHA, Nova Scotia, 1998-2005.

# **Next Steps and Caveats**

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, 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<sup>3</sup> in the delivery of end of life care with the aim of improving care for persons who may have inadequate access to quality care (i.e., **overcoming disparities**).

Conclusions cannot be reached from the data reported herein. Many hypotheses can be presented for the findings reported. An adequate literature review has not been carried out as yet to provide a context for these observations. These data are being shared because they have not been previously available, and the goal of NELS ICE is to build research and surveillance capacity to help improve care for vulnerable populations. The provision and discussion of these data provide a forum for this 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. The development and dissemination of these data is one aspect of this capacity development. NELS ICE funding is limited. Therefore, other partners and resources are needed to be able to build upon this initial base of progress being made by the NELS ICE team. 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.

<sup>&</sup>lt;sup>3</sup> Inequities are differences between subpopulations that may not be justifiable on the basis of need for quality care.

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