

**CONGESTIVE HEART FAILURE DISEASE MORTALITY IN NOVA SCOTIA FROM
1998 TO 2005:
A DESCRIPTIVE ANALYSIS USING BOTH UNDERLYING AND
MULTIPLE CAUSES OF DEATH**

Lynn Lethbridge
Analyst
Network for End of Life Studies*
Lynn.Lethbridge@dal.ca

July 2010

Network for End of Life Studies
Interdisciplinary Capacity Enhancement
1276 South Park Street
Room 568 Bethune Building
Halifax, NS, Canada B3H 2Y9
Phone: (902) 473-2216
Fax: (902) 473-4425
Email: nels@dal.ca
Web site: <http://www.nels.dal.ca>

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

*We would like acknowledge and thank Alison Zwaagstra whose previous work on disease profiles are the basis for this report.

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 persons dying of chronic diseases. Phase One is an analysis of death certificate data from Nova Scotia Vital Statistics (NSVS). This report focuses on congestive heart failure (CHF) and is one of a series of reports from NELS ICE describing persons dying from specific chronic diseases in Nova Scotia. Reports produced in 2008 and 2009 were prepared by Alison Zwaagstra. This report uses and builds further on her work

The number of CHF deaths in Canada has increased steadily since 1980 for both males and females with the projected number expected to double over the next 20 years (Canadian Heart Failure Network, 2010). Despite the rising number of cases, palliative care for CHF patients is less-widespread than for those with cancer with many patients receiving aggressive care right up until death (Formiga et al, 2004). There are considerable opportunities to improve end-of-life care through solid, evidence-based research (Casarett and Karlawish, 2000). A retrospective profile of CHF deaths in Nova Scotia can help inform decision-makers and further our understanding of treatment near the end-of-life.

Purpose

The purposes of this report are to:

- share a synthesis of CHF findings from an analysis of NSVS death certificate data, and
- dialogue with persons interested in further building research and surveillance to improve care available to people at end of life with CHF.

This report is being shared with you to explore ways to build research and surveillance capacity to help improve care for vulnerable populations. 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.

Data and Methods

Study Subjects: The study population is Nova Scotia (NS) residents of all ages who died from January 1, 1998 to December 31, 2005 (N = 63,431). Decedents were identified from the NSVS death certificate database maintained by the Population Health Research Unit (PHRU) at Dalhousie University. All deaths are included in the file with the International Classification of Disease (ICD) codes used to identify the cause of death for each individual “The ICD is the international standard diagnostic classification for all general epidemiological, many health management purposes and clinical use” (WHO, 2010).

Classification of CHF Deaths: 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). In a report on ICD-9 and ICD-10 coding in Alberta, the Health and Wellness division has developed guidelines to establish consistent classification schemes of morbidity and mortality (Alberta Health and Wellness, 2006). The report incorporates information on disease coding from Statistics Canada, WHO, CDC (US) and National Statistics in the UK. To identify CHF, the

study recommends using cause of death ICD-9 code '428' and ICD-10 code 'I50'. This analysis follows this coding guideline.

Multiple Causes of Death: A death certificate can list up to 13 causes of death. For surveillance, resource allocation and research purposes, a single, primary cause is identified drawn from all conditions on the certificate. Pathologists refer to this as the “underlying cause of death” which 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.” When only one cause of death is recorded, this is the underlying cause. When more than one cause of death is recorded, the underlying cause is identified using a comprehensive set of rules developed by the World Health Organization (Statistics Canada, 2005). The PHRU NSVS data file includes the underlying cause as well as any other recorded causes of death. This report profiles those individuals where CHF is listed as the underlying cause of death as well as those for whom CHF was given any mention as a cause of death.

It is important to analyse cause-of-death information beyond the underlying cause for several reasons. Often death has more than one cause. Monitoring multiple conditions enables researchers to more comprehensively track the presence and interaction of conditions leading to death (Redelings et al, 2006, Wall et al 2005). There can be disagreements and process problems when assigning a single cause on death certificate, particularly for older adults (Gorina and Lentzner, 2008; Smith Sehdev and Hutchins, 2001). As well, demographic trends in CHF could be underestimated as research suggests CHF may be mentioned as a cause 1-6 times more frequently beyond the underlying cause (Rodriguez-Artalejo et al, 1997). A better understanding of the complexities of morbidity can help offer insight into important health issues, including end-of-life care.

Quality Care Indicator: Administrative data, including vital statistics, can be utilized to gauge quality health care. In previous studies, place of death has been used as a quality care indicator for individuals near the end-of-life (Burge et al., 2003; Grunfeld et al., 2006; NELS ICE, 2008). Most 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 (Grunfeld et al., 2008). As such, a higher proportion of deaths occurring in acute care facilities may be an indication of inadequate end-of-life care.

Trajectories: In addition to place of death, the events prior to death could also benefit from greater investigation. The trajectory from highly functioning to death can take a very different path depending on the cause. A classification of trajectories of dying helps foster dialogue on planning the end of life care needs for the majority of decedents. Trajectories were first described by Glaser and Strauss in 1968 (Lunney et al., 2002). Lunney et al. (2002 and 2003) refined this concept and developed four trajectory groups (Figure 1). “Sudden Death” includes those who died as a result of an accident or other external cause of mortality. Those who declined over a short period of time due to cancer, HIV-related diseases, motor neuron disease or chronic renal failure are classified under “Terminal Illness”. The “Organ Failure” grouping is comprised of those individuals with conditions such as diabetes, CHF or COPD where functional status gradually declined with intermittent, serious exacerbations. Finally, the “Frailty” category includes those who experienced prolonged dwindling due to Alzheimer’s disease, neurological conditions or late effects of stroke.

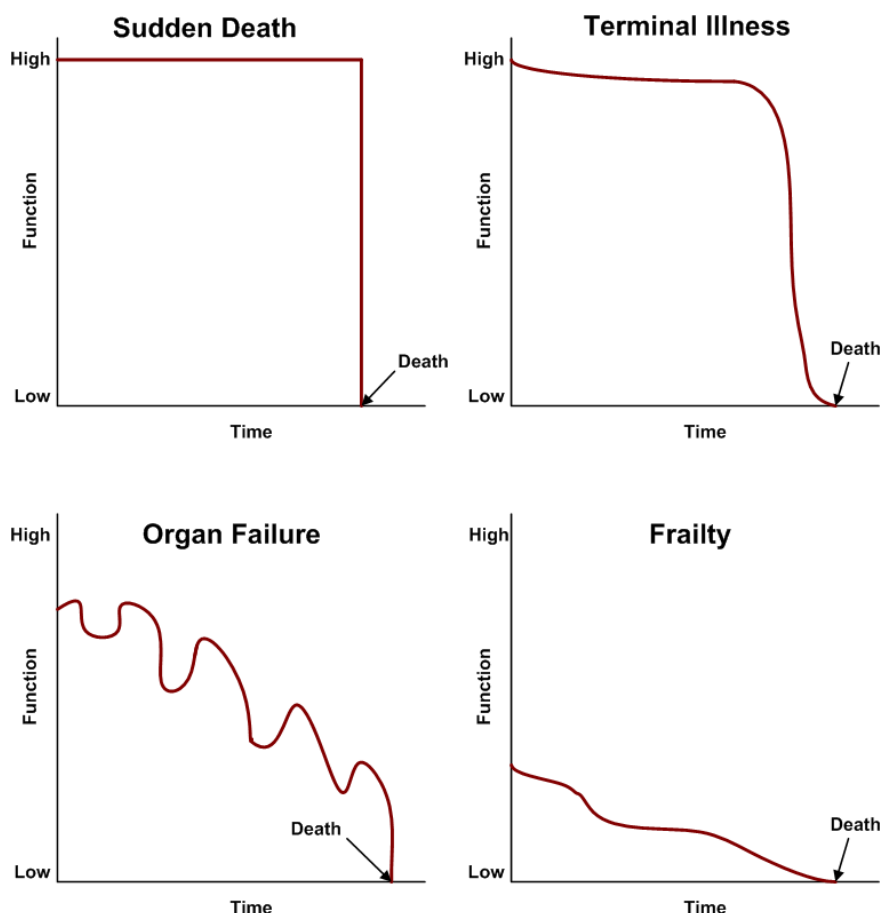


Figure 1: Trajectories of dying.

Associations Between Causes of Death:

Following Gorina and Lentzner (2008)¹, the strength of association between causes of death is calculated as: $\frac{\text{Observed number of deaths with both causes A\&B}}{\text{Expected number of deaths with both causes A\&B}}$

Where expected number of deaths based on the assumption of independence is:

$\frac{(\text{deaths with cause A}) \times (\text{deaths with cause B})}{\text{Total deaths (all causes)}}$

If the ratio of observed to expected is greater than 1, the association is stronger than expected while a value less than 1 indicates an association which is less than expected. The chi-squared statistic is calculated to test if the causes are independent using a 95% confidence level. The null hypothesis that the causes are independent is rejected if the test result is significant.

¹ Gorina Y and Lentzner h (2008) Multiple Causes of Death in Old Age *Aging Trends* No. 9 Hyattsville, MD National Center for Health Statistics

Results

Deaths with CHF Selected as the Underlying Cause: From 1998 to 2005, a total of 1,432 persons died in Nova Scotia with CHF listed as the underlying cause of death. This is 2.3% of all deaths over that period (see Table 1). For the years 2000-2005, the province accounted for 5.3%-6.2% of the CHF deaths in Canada (Statistics Canada, 2010). Over the same period, the population was only about 3% of the national population suggesting NS is over-represented in terms of CHF deaths (Figure 2)².

Table 1: Number of deaths with CHF mentioned or selected as the underlying cause, by year of death, Nova Scotia, 1998-2005.

	1998	1999	2000	2001	2002	2003	2004	2005	Total
CHF selected as the underlying cause	172	174	199	169	194	171	176	177	1432
CHF mentioned but not the underlying cause	714	678	688	698	715	719	744	750	5706
Total Mentions	886	852	887	867	909	890	920	927	7138
Deaths in NS (all causes)	7969	7554	7819	7803	7920	7997	8168	8201	63,431
Total CHF Mentions as a % of All Deaths	11.1%	11.3%	11.3%	11.1%	11.5%	11.1%	11.3%	11.3%	11.3%

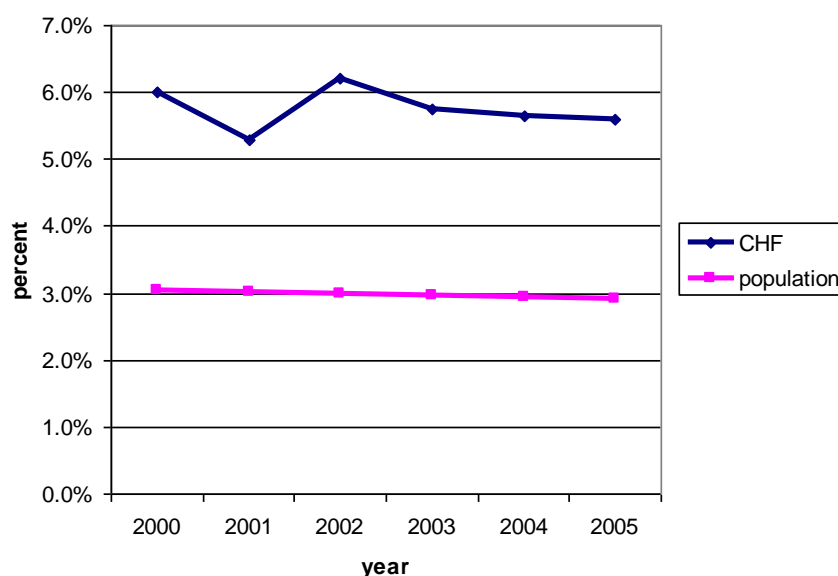


Figure 2: CHF Deaths and Population in Nova Scotia as a Percentage of Canadian Totals 2000 – 2005.

² It should be noted, however, Nova Scotia has an older population than Canada. In 2005, for example 14.4% of the Nova Scotian population was 65 or older compared with 13.1% for Canada.

Table 2 compares the percentage of all deaths which list CHF as the underlying cause in Nova Scotia with that of Canada for 2000-2005. For each year, a higher percentage of deaths in the province are attributed to CHF than in the country as a whole. As well, there is a slight downward trend in both jurisdictions over the period. As mentioned, determining the cause of death is not always straightforward. As a result, there can be difficulties for coders when completing cause of death information on the death certificate. As table 2 indicates, however, there appears to be some consistency as CHF death rates remain fairly stable over time and move in the same general direction both in the province and the country.

Table 2: Percentage of All Deaths with CHF as the Underlying Cause, Nova Scotia and Canada, 2000-2005.

	Nova Scotia	Canada
2000	2.5%	1.5%
2001	2.2%	1.4%
2002	2.4%	1.4%
2003	2.1%	1.3%
2004	2.2%	1.4%
2005	2.2%	1.4%

Deaths with CHF Mentioned But Not Selected as the Underlying Cause: CHF was listed as a cause of death but not selected as the underlying cause for 5,706 individuals from 1998-2005. Thus, a total of 7,138 persons had any mention of CHF on their death certificate which is 11.3% of all deaths. As Table 1 indicates, CHF mentions as a percentage of all deaths have remained steady from in terms of a year-to-year comparison.

Age and Sex Patterns: Of those dying of CHF in NS, about 63% were female. A comparison with national statistics shows the female percentage was higher in NS compared with the country as a whole. Over the 2000-2005 period, only 60% CHF deaths in Canada were female (Statistics Canada, 2010). The number of deaths due to CHF increases with age with a sharp increase from the 65-74 to the 75-84 categories (Table 3 and Figure 3).

Table 3: Number of deaths with CHF mentioned or selected as the underlying cause, by age and sex, Nova Scotia, 1998-2005

Age Group	CHF selected as the underlying cause			CHF mentioned but not the underlying cause			Total Mentions		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
< 45	nr	nr	nr	nr	nr	nr	14	11	25
45-64	20	18	38	178	87	265	198	105	303
65-74	55	50	105	424	298	722	479	348	827
75-84	205	232	437	1075	1038	2113	1280	1270	2550
85 +	255	596	851	890	1692	2582	1145	2288	3433

nr – not reported due to small cell sizes

Approximately 90% of those who died with CHF as the underlying cause were aged 75 or older with an age range of 42 to 107 years. The age distribution differs by sex, however, as 92% of females CHF decedents were 75 years or older while only 86% of males were in the oldest age category. Males dying with CHF tended to be younger than females. The mean age of decedents with CHF is listed as the underlying cause is 85.5 years while the mean age of decedents with any mention is 82.9 years. Males with any mention of a CHF cause averaged 80.4 years at death with females 84.8 years of age.

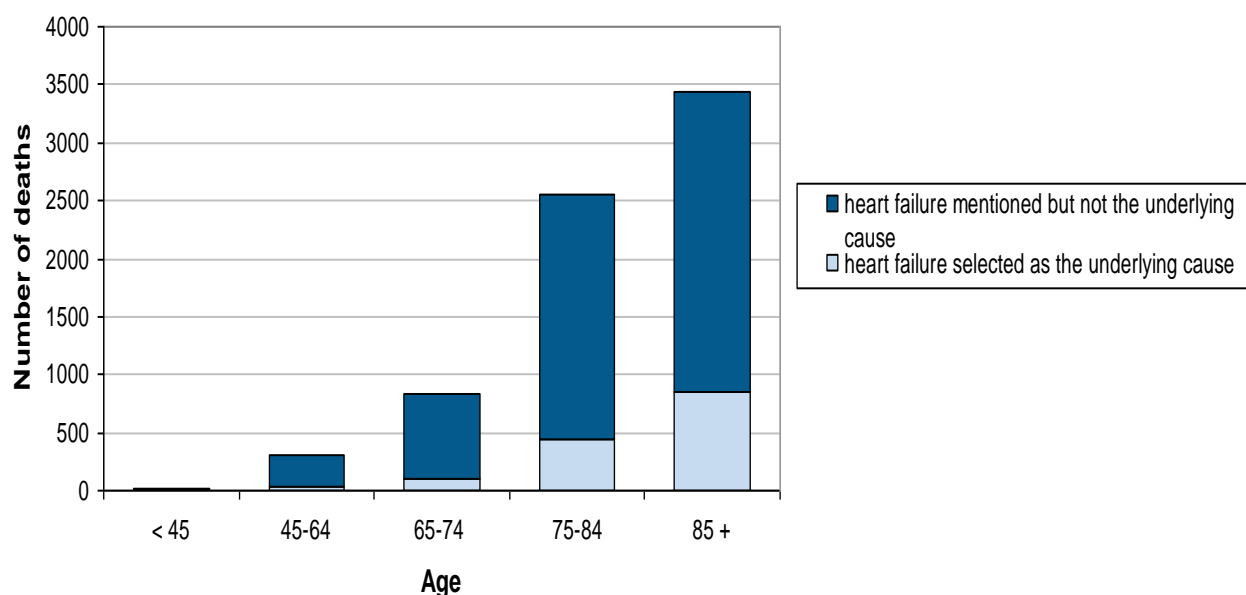


Figure 3: Number of deaths with CHF mentioned 1998-2005.

Other Causes of Death Mentioned for Persons with Heart Disease as the Underlying Cause: The occurrence of other diseases mentioned as a cause of death is outlined in Table 4. Among the 1,432 deaths with CHF listed as the underlying cause, 84.8% had at least one other cause of death. For all ages, renal failure was the most frequently-listed co-morbidity disease at 15.3%. Note that since there could be up to 12 other causes of death, an individual may be reported in more than one row. For example, if an individual had CHF, diabetes, and cancer on their death certificate, this person would be one of the 147 diabetes counts as well as one of the 83 cancer counts. Refer to Appendix B for a listing of the ICD codes used to classify disease groupings.

The most frequently mentioned cause for those individuals who were under the age of 75 is diabetes while those 85 years and older were most likely to have pneumonia mentioned as another cause of death. The likelihood of having one or more causes mentioned on the death certificate beyond CHF decreases with age. For those less than 75 years, 88.2% had more than one cause listed while the rate for those 85 and older was 83.3%.

Table 4: Number and percent of decedents with selected non-CHF causes of death when CHF was the underlying cause (n = 1,295), by age group, Nova Scotia, 1998-2005.

Disease (other than CHF)	Aged < 75 (n =144)		Aged 75-84 (n =437)		Aged 85+ (n =851)		Overall (n = 1432)	
	N	%	N	%	N	%	N	%
Renal Failure	27	18.8%	93	21.3%	99	11.6%	219	15.3%
Pneumonia	15	10.4%	62	14.2%	140	16.5%	217	15.2%
Chronic obstructive pulmonary disease	29	20.1%	88	20.1%	83	9.8%	200	14.0%
Diabetes mellitus	30	20.8%	51	11.7%	66	7.8%	147	10.3%
Alzheimer's and dementia	6	4.2%	41	9.4%	90	10.6%	137	9.6%
Cerebrovascular disease (stroke)	9	6.3%	31	7.1%	62	7.3%	102	7.1%
Malignant neoplasms (cancer)	11	7.6%	27	6.2%	45	5.3%	83	5.8%
Essential hypertension	10	6.9%	18	4.1%	42	4.9%	70	4.9%
Peripheral vascular disease	4	2.8%	10	2.3%	15	1.8%	29	2.0%
Chronic ischemic heart disease	1	0.7%	0	0.0%	1	0.1%	2	0.1%
Other causes	87	60.4	251	57.4	485	57.0	823	57.5
Total with ≥ 1 non-congestive heart disease cause(s)[‡]	127	88.2	378	86.5	709	83.3	1214	84.8

[‡] Columns do not add up to the totals for this table because a CHF decedent may have more than one non-CHF disease cause of death mentioned. The total with ≥ 1 non-CHF cause(s) is the total number of decedents having an underlying cause of CHF and at least one non-CHF cause mentioned on their death certificate.

Underlying Non-CHF Causes when CHF Mentioned as a Cause: Among the 5,706 deaths where CHF was mentioned but not given as the underlying cause, chronic ischemic heart disease was most often the underlying cause followed by acute myocardial infarction (Table 5). It is likely not surprising that the most frequently mentioned underlying causes for decedents with CHF are other heart-related conditions.

Table 5: Number and percent of decedents with selected non-CHF underlying causes of death when CHF mentioned but not the underlying cause, Nova Scotia, 1998-2005.

Non-CHF Disease	N	%
Chronic ischemic heart disease	1627	28.5
Acute myocardial infarction	614	10.8
Malignant neoplasms (cancer)	476	8.3
Chronic obstructive pulmonary disease	469	8.2
Diabetes mellitus	292	5.1
Renal Failure	229	4.0
Pneumonia	214	3.8
Cerebrovascular disease (stroke)	179	3.1
Alzheimer's and dementia	108	1.9
Peripheral vascular disease	101	1.8
Essential hypertension	7	0.1
Other causes	1390	24.4
Total	5706	100.0

Hospital Deaths: In Nova Scotia, the PHRU NSVS data show that from 1998 to 2005, 62.6% of all adult deaths occurred in a hospital. A comparison across major underlying disease categories is shown in Figure 3. Cancer has the highest percentage of in-hospital deaths at 70.9%, closely followed by renal disease at 70.2%³ while Alzheimer's and dementia have the lowest percentage of in-hospital deaths at 27.6%. Sixty-one percent of the CHF group died in a hospital, placing it in the mid-range ranking among chronic conditions included in Figure 4.

³ Previous versions of Figure 3 in some of the 2008 and 2009 reports by Alison Zwaagstra only included renal failure, for which the proportion of in-hospital deaths was 71.5%. This is slightly higher than the 70.2% in-hospital death rate for all renal disease.

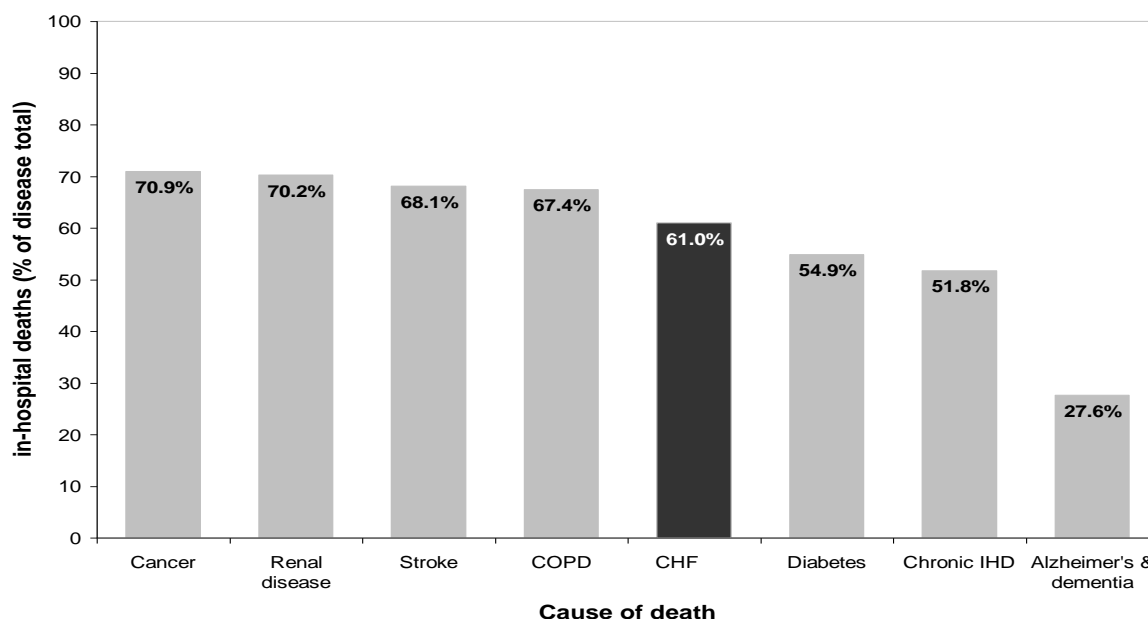


Figure 4: Percentage of in-hospital deaths for major underlying chronic disease causes of death, age 20+, Nova Scotia, 1998-2005.

For those with any mention of CHF on the death certificate, the in-hospital rate was 66.4%, higher than that for all deaths. As Table 6 indicates, rates were lower where heart disease is the underlying cause (61.0%) compared with those for whom it is mentioned but is not the underlying cause (67.7%). Also, older individuals were less likely to experience a hospital death at only 58.1% among those 85 years and older.

Table 6: Number and percent of hospital deaths with CHF mentioned or selected as the underlying cause, by age, Nova Scotia, 1998-2005.

	Aged <75		Aged 75-84		Aged 85+		Overall	
	N	%	N	%	N	%	N	%
CHF as the underlying cause	99	68.8	320	73.2	454	53.4	873	61.0
CHF mentioned but not the underlying cause	764	75.6	1558	73.7	1541	59.7	3863	67.7
Total Mentions	863	74.7	1878	73.7	1995	58.1	4736	66.4

Causes of Death by Place of Death: Cause of death analysis may help to indicate if the presence and interaction of particular diseases results in a higher proportion of individuals being sent to a hospital as death approaches. Table 7 shows the percentage of deaths where CHF was listed as the underlying cause, a secondary cause or had any mention, stratified by those who died in hospital and those who died out of hospital. There is a higher percentage of all hospital deaths which have CHF mentioned as a cause of death compared with the percentage of out of hospital deaths. Overall, 11.9% of in-hospital deaths mention CHF as a cause while 10.1% of non-hospital deaths mention it. In all years, CHF is more likely to be listed as a secondary cause among all hospital deaths (9.7% overall) compared with the percentage among non-hospital deaths (7.8% overall). Note, however,

in terms of underlying cause of death, the percentage of in-hospital deaths with CHF listed is lower than the non-hospital percentage (2.2% versus 2.4%, respectively). Note as well, there is variation across the individual years. There is a lower percentage of hospital deaths listing CHF as the underlying cause overall but in only four of the eight years included in the analysis.

Table 7: Percentage of CHF Deaths for Those Dying in and Out of Hospital, Nova Scotia, 1998-2005.

	1998	1999	2000	2001	2002	2003	2004	2005	Total
Individuals Dying In-Hospital									
Total CHF Underlying Cause of Deaths as a % of All Hospital Deaths	1.9%	2.2%	2.6%	2.0%	2.5%	2.2%	2.1%	2.2%	2.2%
Total CHF Secondary Cause of Death as a % of All Hospital Deaths	9.8%	9.8%	9.4%	9.8%	9.7%	9.9%	9.4%	10.0%	9.7%
Total CHF Mentions as a % of All Hospital Deaths	11.7%	12.0%	12.0%	11.7%	12.2%	12.1%	11.5%	12.2%	11.9%
Individuals Dying Out of Hospital									
Total CHF Underlying Cause of Deaths as a % of All Non-Hospital Deaths	2.6%	2.5%	2.5%	2.5%	2.4%	2.1%	2.3%	2.0%	2.4%
Total CHF Secondary Cause of Death as a % of All Non-Hospital Deaths	7.4%	7.6%	7.7%	7.6%	7.9%	7.5%	8.6%	7.9%	7.8%
Total CHF Mentions as a % of All Non-Hospital Deaths	10.1%	10.1%	10.2%	10.1%	10.3%	9.6%	11.0%	9.9%	10.1%

Table 8 indicates other causes of death are listed on the death certificate for individuals with CHF as the underlying cause for all, those who died in hospital and those who died out of hospital. Those who died in a hospital are more likely to have had at least one other cause of death listed as a secondary cause. Renal failure, pneumonia and COPD are listed most frequently for those in-hospital, consistent with all those with CHF as the underlying cause. For those who died out of hospital, Alzheimer's/dementia shows the highest probability of being mentioned. This is likely a function of age as older individuals are less likely to die in hospital and more likely to be diagnosed with dementia. Renal failure ranks fifth for those dying out of hospital at 9.8% of decedents. This may be an indication that CHF patients are more likely to be sent to hospital near the end of life when kidney failure occurs as well.

Table 8: Number and percent of decedents with selected non-CHF causes of death when CHF was the underlying cause, by place of death, Nova Scotia, 1998-2005.

Disease (other than CHF)	All (n = 1,432)		In-Hospital Deaths (n=873)		Out-of-Hospital Deaths (n=559)	
	N	%	N	%	N	%
Renal Failure	219	15.3%	164	18.8%	55	9.8%
Pneumonia	217	15.2%	154	17.6%	63	11.3%
Chronic obstructive pulmonary disease	200	14.0%	138	15.8%	62	11.1%
Diabetes mellitus	147	10.3%	87	10.0%	60	10.7%
Alzheimer's and dementia	137	9.6%	55	6.3%	82	14.7%
Cerebrovascular disease (stroke)	102	7.1%	60	6.9%	42	7.5%
Malignant neoplasms (cancer)	83	5.8%	62	7.1%	21	3.8%
Essential hypertension	70	4.9%	31	3.6%	39	7.0%
Peripheral vascular disease	29	2.0%	18	2.1%	11	2.0%
Chronic ischemic heart disease	2	0.1%	0	0.0%	2	0.4%
Other causes	823	57.5	520	59.6%	303	54.2%
Total with ≥ 1 non-congestive heart disease cause(s)[‡]	1214	84.8%	759	86.9%	455	81.4%

[‡] Columns do not add up to the totals for this table because a CHF decedent may have more than one non-CHF disease cause of death mentioned. The total with ≥ 1 non-CHF cause(s) is the total number of decedents having an underlying cause of CHF and at least one non-CHF cause mentioned on their death certificate.

Table 9 shows the number and percentage of other causes of death when CHF is mentioned but is not the underlying cause with a comparison of in and out-of-hospital deaths. Chronic ischemic heart disease (CIHD) is most likely to be mentioned on the death certificate for both groups although the percentage with CIHD is higher for the out-of-hospital deaths at 34.0% compared with 25.9% for those indicated as dying in a hospital. Over 25% of individuals with a hospital death show “other causes” (beyond those listed) recorded compared with 22.7% of those not in hospital.

Table 9: Number and percent of decedents with selected non-CHF underlying causes of death when CHF mentioned but not the underlying cause, Nova Scotia, by place of Death 1998-2005.

Non-CHF Disease	All		In-Hospital Deaths		Out-of-Hospital Deaths	
	N	%	N	%	N	%
Chronic ischemic heart disease	1627	28.5	1000	25.9%	627	34.0%
Acute myocardial infarction	614	10.8	447	11.6%	167	9.1%
Malignant neoplasms (cancer)	476	8.3	351	9.1%	125	6.8%
Chronic obstructive pulmonary disease	469	8.2	332	8.6%	137	7.4%
Diabetes mellitus	292	5.1	190	4.9%	102	5.5%
Renal Failure	229	4.0	169	4.4%	60	3.3%
Pneumonia	214	3.8	167	4.3%	47	2.6%
Cerebrovascular disease (stroke)	179	3.1	130	3.4%	49	2.7%
Alzheimer's and dementia	108	1.9	38	1.0%	70	3.8%
Peripheral vascular disease	101	1.8	63	1.6%	38	2.1%
Essential hypertension	7	0.1	4	0.1%	3	0.2%
Other causes	1390	24.4	972	25.2%	418	22.7%
Total	5706	100.0%	3863	100.0%	1843	100.0%

End-of-Life Trajectories: All deaths in Nova Scotia from 2000 to 2005 were assigned to functional decline categories based on methods used by Fassbender et al (2006) where disease are grouped by the underlying cause⁴. Figure 5a indicates that 31% died of a terminal illness, 34% organ failure, and 28% frailty. This suggests that end-of-life care could potentially be planned for at least 93% of all deaths in the province. By comparison, Figure 5b shows percentages for Alberta for comparable years. Overall, there is a similar distribution in both provinces. Sudden deaths, however, were slightly higher in Alberta at 7.1% likely reflecting a younger population.

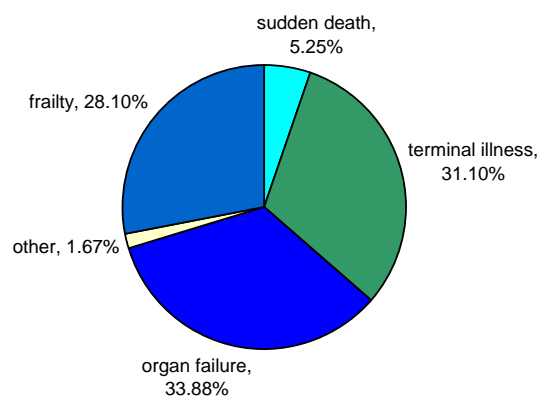


Figure 5a: NS deaths by trajectory of dying, All deaths 2000-2005.

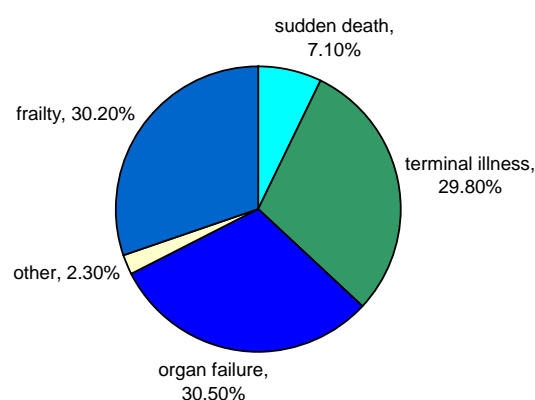


Figure 5b: Alberta deaths by trajectories of dying, All deaths 1999-2002. Source: Fassbender et al (2009)

⁴ Categories were not easily coded consistently between the ICD-10 and ICD-9 systems, therefore only deaths after 1999 (ie those using ICD-10 codes) were included.

Those with CHF listed as the underlying cause are categorized as dying of organ failure, using the Fassbender et al. methodology. Recall Figure 1 which suggests these individuals experience a gradual functional decline with periodic accelerated declines and recoveries back to the longer-period trend. As noted, there were also 5706 individuals where CHF was mentioned but was not the underlying cause. Where do these individuals fit in terms of trajectories of dying? As can be seen in Figure 6, 41% are categorized in the organ failure group but the plurality, 46%, follow the frailty trajectory. Over the same time period, these individuals begin at a lower level of functioning than those categorized with organ failure, and do not experience the exaggerated declines. As shown by Fassbender et al (2009), an understanding of the end-of-life experiences of those who have died can give valuable insight into both providing quality care and understanding the cost implications.

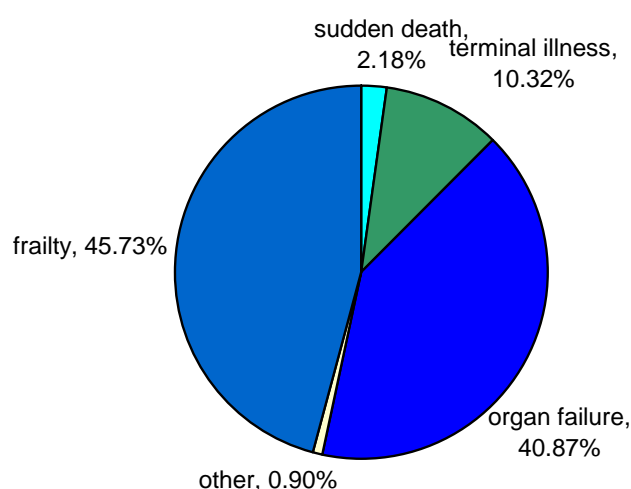


Figure 6: NS trajectories of death grouped by underlying cause where CHF is mentioned but is not the underlying cause, 2000-2005

Associations Between Causes of Death: Individuals with congestive heart failure appearing on the death certificate show a higher than expected probability of renal failure, CIHD, COPD, diabetes and hypertension being mentioned as well (Table 10).

The observed rate of occurrence of AMI and PVD with CHF did not differ from that expected. Causes of death that show a less than expected association include dementia, stroke, Parkinson's, cancer and Multiple Sclerosis.

Also included in Table 10 are associations by age group. Persons dying with congestive heart disease under age 65 demonstrate the strongest associations with other causes of death.

Table 10: Congestive Heart Failure – All Ages and Age Groups

Causes of Death Associated with Congestive Heart Failure	Ratio observed to expected deaths			
	All Ages	< 65	65-85	>85
Renal failure	2.09*	3.60*	2.11*	1.61*
Chronic ischemic heart disease	1.80*	2.45*	1.82*	1.51*
Chronic obstructive pulmonary disease	1.66*	3.53*	1.61*	1.37*
Diabetes	1.56*	3.45*	1.61*	1.25*
Essential hypertension	1.25*	2.23*	1.23*	0.97
Acute myocardial infarction	1.03	1.42*	1.09*	0.90
Peripheral vascular disease	0.96	1.64*	0.95	0.75*
Alzheimer's disease / dementia	0.81*	0.57	0.72*	0.57*
Cerebrovascular disease (stroke)	0.76*	0.64	0.73*	0.58*
Parkinson's	0.64*	6.44*	0.52*	0.54*
Malignant neoplasms (cancer)	0.34*	0.34*	0.35*	0.50*
Multiple Sclerosis	0.33*	0.53	0.43	1.09

* χ^2 test for independence significant at $p=.05$.

Next Steps

The following next steps are in progress or proposed:

1. Share this report with the provincial cardiac program and others for feedback and dialogue.
2. Identify key study questions, data sources and linkages needed to answer questions and develop a data quality assessment and further development plan. Appendix A is a diagram of data linkages proposed by NELS ICE that could be adapted for CHF and could include provincial cardiac data.
3. If time and resources permit, examine the potential of getting data to prospectively identify a CHF cohort likely to benefit from palliative care.

Conclusion

This report has profiled CHF deaths in Nova Scotia over the 1998-2005 period utilizing Vital Statistics data. It is hoped this will help enable researchers and decision-makers in this province to plan and provide for the best possible care near the end of life. There is potential for the development of an expanded end-of-life dataset through the linkages of existing sources to provide further insights and build capacity among the various stakeholders.

The intent of NELS ICE is to increase 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 the data development process for palliative and end of life care.

References

- Alberta Health and Wellness (2006) *Health Surveillance System Series ICD-9 to ICD-10 Coding with Reference to Causes of Death Grouping in Alberta*. Public Health Surveillance and Environmental Health.
- Burge, F., Lawson, B., & Johnston, G. (2003). Trends in the place of death of cancer patients, 1992-1997. *Canadian Medical Association Journal*, 168, 265-270.
- Canadian Heart Failure Network (2010) Facts about CHF in Canada. Available at: <http://www.chfn.ca/facts-about-chf-in-canada> (accessed January 2010).
- Casarett, D and Karlawish J (2000) Are special ethical guidelines needed for palliative care research? *Journal of Pain and Symptom Management* Vol 20 (2) 130-139.
- Fassbender K, Fainsinger R, Carson M, Finegan B (2009) Cost Trajectories at the End of Life: The Canadian Experience *Journal of Pain and Symptom Management* 38(1) 75-80.
- Fassbender, K. et al. (2006). Costs and utilization of health care services at end-of-life. Insitute for Public Economics Health Research Group, Edmonton, Alberta.
- Formiga F, Chivite D, Ortega C, Casas S, et al (2004) End-of-life preferences in elderly patients admitted for heart failure *Quarterly Journal of Medicine* 97, 803-808.
- Glaser B and Strauss (1968) *A Time for Dying*. Chicago: Aldine Publishing.
- Gorina, Y., & Lentzer, H. (2008). Multiple causes of death in old age. *Aging Trends*, No. 9. National Center for Health Statistics, Hyattsville, MD. Available at: <http://www.cdc.gov/nchs/data/ahcd/agingtrends/09causes.htm> (Accessed June 2009).
- Grunfeld, E., Lethbridge, L., Dewar, R., Lawson, B., Paszat, L. F., Johnston, G., et al. (2006). Towards using administrative databases to measure population-based indicators of quality of end-of-life care: testing the methodology. *Palliative Medicine*, 20, 769-777.
- Grunfeld, E., Urquhart, R., Mykhalovskiy, E., Folkes, A., Johnston, G., Burge, F. I., et al. (2008). Toward population-based indicators of quality end-of-life care: Testing stakeholder agreement. *Cancer*, 112, 2301-2308.
- Lunney J, Lynn J, Hogan C (2002) Profiles of Older Medicare Decedents *Journal of American Geriatrics Society*. 50, 1108-1112.
- Lunney J, Lynn J, Foley D, Lipson S, Guralnik J (2003) Patterns of functional decline at the end of life. *JAMA* 289 (18), 2387-2392.
- NELS ICE. (2008). End of Life Care in Nova Scotia Surveillance Report. Network for End of Life Studies (NELS) Interdisciplinary Capacity Enhancement (ICE), Dalhousie University, Halifax, Nova Scotia, Canada. Available at: <http://www.nels.dal.ca> (Accessed June 2009).
- Redelings M, Sorvillo F, Simon P (2006) A comparison of underlying cause and multiple cause of death US Vital Statistics, 2000-2001. *Epidemiology*, 17 (1) 100-103.

- Rodriguez-Artalejo F, Guallar-Castillon P, Banegas Banags J, Rey Calero J (1997) Trends in hospitalization and mortality for heart failure in Spain, 1980-1993. *European Heart Journal* 18, 1771-1779.
- Smith Schedev A and Hutchins G (2001) Problems with completion and accuracy of the cause-of-death certificate. *Archives of Internal Medicine*, 161 277-284.
- Statistics Canada. (2005). *Comparability of ICD-10 and ICD-9 for mortality statistics in Canada*. Available at: <http://www.statcan.ca/english/freepub/84-548-XIE/84-548-XIE2005001.pdf> (Accessed June 2009).
- Statistics Canada. (2007). *Causes of death: Definitions*. Available at: <http://www.statcan.gc.ca/pub/84-208-x/2007001/4067449-eng.htm> (Accessed June 2009).
- Statistics Canada (2010). Deaths by Cause, (Congestive Heart Failure) CANSIM II Table 1020529, various series.
- Wall M, Huang J, Oswald J, McCullen D (2005) Factors associated with reporting multiple causes of death. *BMC Medical Research Methodology* 5:4.
- World Health Organization (2010) International Classification of Diseases. Available at <http://www.who.int/classifications/icd/en/>. (Accessed January 2010)

Appendix A

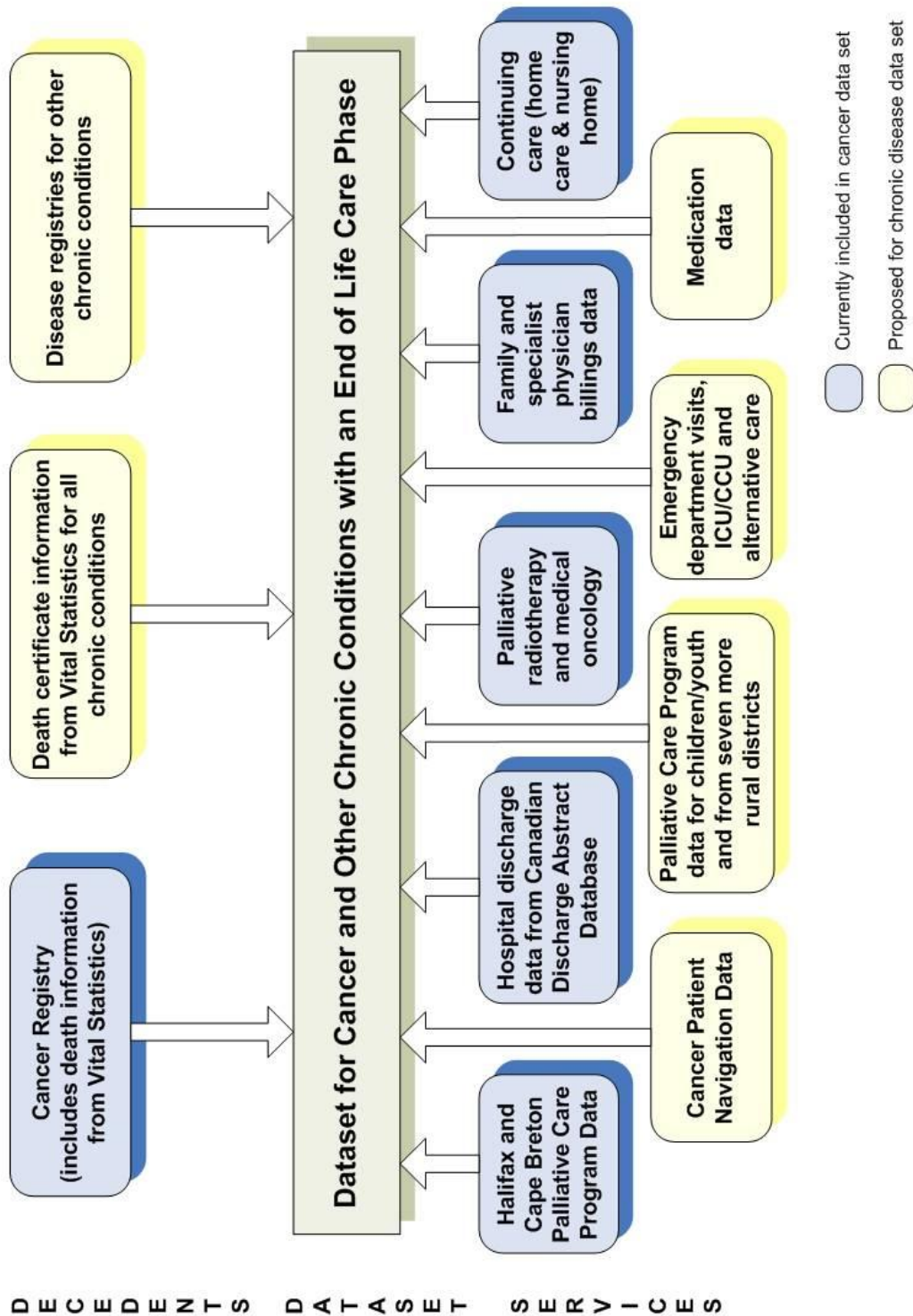


Figure A1: Current and proposed NELS ICE data linkages.

Appendix B

Table C1: Selected chronic diseases and their corresponding International Classification of Diseases (ICD) codes

Disease	ICD-9 (1979-1999)	ICD-10 (2000-present)
Renal disease	580-589, 250.4, 403-404	N00-N07, N17-N19, N25-N27, E10.2, E11.2, E14.2, I12-I13
Cancer	140-208	C00-C97
Chronic obstructive pulmonary disease (excluding asthma)	490-492, 496	J40-J44
Pneumonia	480-486	J12-J18
Essential hypertension	401	I10
Chronic ischemic heart disease (excluding acute myocardial infarction)	412-414, 429.2	I20, I25
Acute myocardial infarction	410	I21-I22
Diabetes mellitus	250	E10-E14
Cerebrovascular disease (stroke)	430-434, 436-438	I60-I69
CHF	428	I50
Alzheimer's disease and dementia	290, 331.0	F00-F03, G30