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

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NELS | Network for End of Life Studies |CE | Interdisciplinary Capacity Enchancement

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 **renal disease** and is one of a series of reports from NELS ICE describing persons dying from specific chronic diseases in Nova Scotia.

Subsequent work will hopefully involve the linkage of NSVS data to administrative data from disease registries, palliative care program (PCP) databases, the Canadian Institute for Health Information (CIHI) hospital discharge abstract database, SEAscape (single entry access - continuing care), medication databases (e.g. Pharmacare) and physician billings (Appendix A).

Purpose

The purposes of this report are to:

- share a synthesis of renal disease findings from an analysis of NSVS death certificate data;
- dialogue with persons interested in further building research and surveillance to improve care available to people at end of life with renal disease; and,
- examine disparities in health service use for 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. 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.

Methods

Study Subjects: The study population is Nova Scotia residents of all ages who died from January 1, 1998 to December 31, 2005 (N = 63,431). These decedents were identified from the NSVS death certificate database maintained by the Population Health Research Unit (PHRU) at Dalhousie University. While all deaths were included, the International Classification of Disease (ICD) codes for injuries, poisonings and other external causes of death were provided as XXX.

Classification of Renal Disease 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). Table 1 lists the ICD codes used in renal disease that were selected for this report. These codes were identified from a description of chronic kidney disease by the West Virginia Bureau for Public Health, (2006). Renal disease death counts by disease type are provided in Appendix B.

| Type of renal disease | ICD-9 codes ^a | ICD-10 codes ^b |
|--------------------------------------|--------------------------|---------------------------|
| | (1979-1999) | (2000-present) |
| Glomerular diseases | 580-583 | N00-N07 |
| Renal failure | 584-586 | N17-N19 |
| Other disorders of kidney and ureter | 587-589 | N25-N27 |
| Diabetic nephropathy | 250.4 | E10.2, E11.2, E14.2 |
| Hypertensive renal disease | 403-404 | 112-113 |

 Table 1: International Classification of Diseases (ICD) codes for renal disease.

^a There were no recorded deaths from ICD-9 codes 250.4, 588 or 589.

^b There were no recorded deaths from ICD-10 codes N00, N01, N06, N07 or N27.

There is disagreement in the literature as to how to identify renal disease deaths using the ICD cause of death codes. In addition to the West Virginia approach, Australia has its own definition of chronic kidney disease (Australian Institute of Health and Welfare, 2005). Statistics Canada (2005) uses a list of 113 selected causes of death developed by the National Center for Health Statistics in the United States; one of these selected causes of death categories includes nephritis, nephrotic syndrome and nephrosis. A comparison of the various renal disease ICD groupings and the number of deaths within each of these groupings is in Appendix C.

Another renal disease classification is a list of primary renal diagnoses within the Canadian Organ Replacement Register (CORR). CORR, available from the Canadian Institute for Health Information (CIHI), is the national information system for organ failure, transplantation, organ donation and renal dialysis, with a mandate to record and analyze the level of activity and outcome of vital organ transplantation and dialysis activities. It is a longitudinal database that follows individuals with end-stage organ failure from their first treatment to their death (Canadian Institute for Health Information, 2008). On May 28th, the author met with Dr. Grace Paterson, Medical Informatics, whose PhD work examined the classification of chronic kidney disease. Dr. Paterson provided a 2004 list of the CORR primary renal diagnoses mapped to ICD-10. The author attempted to tabulate the number of deaths for each of the primary renal diagnoses but unfortunately the cause of death data is not detailed enough to group deaths using the primary renal diagnoses.

Multiple Causes of Death: 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." To gain a more complete understanding of the burden of renal disease, all records for which renal disease was mentioned as a cause of death on the death certificate were examined. This report uses methods similar to those in a report by Gorina and Lentzer (2008) who investigated multiple cause-of-death data for decedents over age 65.

Results

Deaths with Renal Disease Mentioned or Selected as the Underlying Cause: A total of 1,295 persons died with renal disease as their underlying cause of death¹ from 1998 to 2005 in Nova Scotia. A further 4,377 persons had renal disease as a cause of death which was not selected as the underlying cause. Thus, a total of 5,672 persons had any mention of renal disease on their death certificate which is 8.9% of all deaths from 1998 to 2005.

The percentage of total deaths from renal disease increased from 1998 to 2005 (Table 2). The rise in deaths from 554 and 634 in 1998 and 1999 respectively and more than 700 deaths in 2000 and onward may be due to changes in coding practices with the introduction of ICD-10 in 2000.

Table 2: Number of deaths with renal disease as the underlying or other mentioned cause, by year of death, NovaScotia, 1998-2005.

| | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | Total |
|--|--------------|--------------|--------------|--------------|--------------|--------------|--------------|--------------|----------------|
| Renal disease selected as the underlying cause | 129 | 147 | 161 | 145 | 174 | 161 | 193 | 185 | 1,295 |
| Renal disease mentioned but not the underlying cause | 425 | 487 | 546 | 575 | 575 | 573 | 613 | 583 | 4,377 |
| Total Mentions (% of total deaths) | 554 (7.0) | 634 (8.4) | 707 (9.0) | 720 (9.2) | 749 (9.5) | 734 (9.2) | 806 (9.9) | 768 (9.4) | 5,672 (8.9) |

The majority of renal disease deaths appear amoung those aged 65 or older (Figure 1 and Table 3). The mean age of decedents with an underlying cause of renal disease is 81.2 years while the mean age of decedents with any mention of renal disease is 78.3 years. Renal disease is reported as a cause of death more often in males under age 85 but there are more deaths in females aged 85 and over.



Renal disease selected as the underlying cause



¹ It has been argued that renal disease should never be coded as the underlying cause of death and should only be listed as a comorbid condition that contributed to death (S. Soroka, personal communication, April 28, 2009). Renal disease is a consequence of other conditions including cardiovascular diseases, diabetes, autoimmune diseases, systemic infections, or urinary stones (Lewey et al., 2003; Levin et al., 2008).

| Age | Renal disease selected as the underlying cause | | | Renal but not t | disease mo the underly | entioned /ing cause | Total Mentions | | |
|-------|---|--------|-------|--------------------|---------------------------|------------------------|----------------|--------|-------|
| Group | Male | Female | Total | Male | Male Female Total | | | Female | Total |
| < 65 | 42 | 38 | 80 | 365 | 230 | 595 | 407 | 268 | 675 |
| 65-74 | 105 | 81 | 186 | 483 | 318 | 801 | 588 | 399 | 987 |
| 75-84 | 243 | 241 | 484 | 895 | 730 | 1,625 | 1,138 | 971 | 2,109 |
| 85 + | 222 | 323 | 545 | 592 | 764 | 1,356 | 814 | 1,087 | 1,901 |

Table 3: Number of deaths with renal disease as the underlying or other mentionedcause, by age and sex, Nova Scotia, 1998-2005.

Non-Renal Disease Causes of Death Mentioned for Persons with Renal Disease as the Underlying Cause: Among the 1,295 deaths with renal disease selected as the underlying cause, other non-renal disease causes of death included diseases such as heart disease, diabetes mellitus and pneumonia (Table 4). Since there could be up to 12 other causes of death beyond renal disease, an individual may be reported in more than one row of Table 4. For example, if a person had renal disease, pneumonia, and diabetes on their death certificate, this person would be one of the 109 pneumonia counts as well as one of the 169 diabetes mellitus counts. Refer to Appendix D for a listing of the ICD codes used.

The percentage of decedents having an underlying cause of renal disease and at least one non-renal disease cause of death mentioned was lowest for the 75-84 year age group (Table 4). Under age 75, 91.4% also had a non-renal disease cause of death mentioned. For age 85 and older, the proportion with non-renal disease causes was 87.3%.

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

| Non-Renal Disease | Aged < 75 (n = 266) | | Aged 75-84 (n = 484) | | Aged 85+ (n = 545) | | Overall (n = 1,295) | |
|---|------------------------|------|-------------------------|------|-----------------------|------|------------------------|------|
| | Ν | % | Ν | % | Ν | % | Ν | % |
| Congestive heart failure | 42 | 15.8 | 110 | 22.7 | 132 | 24.2 | 284 | 21.9 |
| Essential hypertension | 39 | 14.7 | 82 | 16.9 | 100 | 18.3 | 221 | 17.1 |
| Chronic ischemic heart disease | 49 | 18.4 | 89 | 18.4 | 59 | 10.8 | 197 | 15.2 |
| Diabetes mellitus | 56 | 21.1 | 65 | 13.4 | 48 | 8.8 | 169 | 13.1 |
| Pneumonia | 21 | 7.9 | 36 | 7.4 | 52 | 9.5 | 109 | 8.4 |
| Chronic obstructive pulmonary disease | 17 | 6.4 | 44 | 9.1 | 27 | 5.0 | 88 | 6.8 |
| Alzheimer's and dementia | 6 | 2.3 | 28 | 5.8 | 48 | 8.8 | 82 | 6.3 |
| Cardiovascular disease (stroke) | 20 | 7.5 | 31 | 6.4 | 29 | 5.3 | 80 | 6.2 |
| Total with ≥ 1 non-renal disease cause(s) [‡] | 243 | 91.4 | 414 | 85.5 | 474 | 87.0 | 1,131 | 87.3 |

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

Underlying Non-Renal Disease Causes when Renal Disease was Other Mentioned Cause: Among the 4,377 deaths where renal disease was mentioned but not given as the underlying cause, major non-renal disease underlying causes of death included cancer, heart disease and diabetes mellitus (Table 5).

| Non-Renal Disease | N | % |
|---|-------|------|
| Malignant neoplasms (cancer) | 723 | 16.5 |
| Chronic ischemic heart disease | 625 | 14.3 |
| Diabetes mellitus | 507 | 11.6 |
| Acute myocardial infarction | 387 | 8.8 |
| Congestive heart failure | 220 | 5.0 |
| Chronic obstructive pulmonary disease | 161 | 3.7 |
| Cardiovascular disease (stroke) | 156 | 3.6 |
| Pneumonia | 149 | 3.4 |
| Other non-renal disease underlying causes | 1,449 | 33.1 |
| Total | 4,377 | 100 |

Table 5: Number Number and percent of decedents with selected non-renal disease underlying causes of deathwhen renal disease was mentioned but not the underlying cause (n = 4,377), Nova Scotia, 1998-2005.

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 and nursing home.

Place of death has been used as an indicator of quality of care at 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). In Nova Scotia, using the PHRU NSVS data from 1998 to 2005, 62.6% of all adult deaths occurred 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.

For 1998 to 2005, 77.7% of all deaths where renal disease was mentioned on the death certificate occurred in hospital (Table 6). The percentage dying in hospital decreases as age increases with 85.3% dying in hospital among those under 75 years, and 67.5% dying in hospital among those 85 years and over.

| | Aged <75 | | Aged | 75-84 Age | | l 85+ | Overall | |
|--|----------|------|-------|-----------|-------|-------|---------|------|
| | N | % | Ν | % | Ν | % | Ν | % |
| Renal disease as the underlying cause | 225 | 84.6 | 363 | 75.0 | 322 | 59.1 | 910 | 70.3 |
| Renal disease mentioned but not the underlying cause | 1,192 | 85.4 | 1,343 | 82.7 | 962 | 70.9 | 3,497 | 79.9 |
| Total Mentions | 1,417 | 85.3 | 1,706 | 80.9 | 1,284 | 67.5 | 4,407 | 77.7 |

Table 5: Number and percent of hospital deaths with renal disease mentioned or selected as the underlying cause,by age, Nova Scotia, 1998-2005.

The percentages of in-hospital deaths for renal disease and seven other major chronic diseases were compared for adult decedents in Nova Scotia (Figure 2). Cancer has the highest percentage of in-hospital deaths at 70.9%² while Alzheimer's and dementia have the lowest percentage of in-hospital deaths at 27.6%.





Next Steps

The following are some proposed next steps:

1. Identify key study questions, data sources and linkages needed to answer questions and develop a data quality assessment and improvement plan. Appendix A is a diagram of data linkages proposed by NELS ICE that could be adapted to better reflect renal disease.

² Previous versions of Figure 2 only included renal failure, for which the proportion of in-hospital deaths was 71.5%.

- 2. NELS ICE has hired consultant Suha Masalmeh, an internationally trained physician and recent Master of Health Administration graduate, to conduct a literature review and obtain feedback from key informants on end of life care for persons with renal failure. The purpose of this project is to help identify gaps in research and services for persons suffering from renal failure in the last months of their life.
- 3. Investigate the feasibility of obtaining renal dialysis data from CORR and determine if data linkages are possible. By linking CORR data to palliative care program data, NELS ICE may be able to identify the number of people who stopped dialysis and were enrolled in a palliative care program.
- 4. Examine the potential of getting laboratory data to prospectively identify a renal disease cohort likely to benefit from palliative care. The ideal way to identify individuals with chronic kidney disease is to examine kidney function using lab data. Chronic kidney disease is defined as kidney damage or a glomerular filtration rate of less than 60 mL/min/1.73m² for three or more months (Levin et al., 2008). It was suggested that NELS ICE may want to track the degree of kidney function for individuals with chronic kidney disease at the time they are referred to a palliative care program (S. Soroka, personal communication, April 28, 2009). NELS ICE would be willing to work with the NSRP on planning such an initiative.
- 5. Discussion among areas stakeholders could lead to other ideas for next ssteps for research and operations to ensure equity in access to quality care at end of life.

Conclusion

The intent of NELS ICE is to increase capacity for interdisciplinary research development to improve care at the end of life for vulnerable populations. The development of an expanded end of life dataset and the dissemination of findings from the analyses of these data is one aspect of this capacity development. 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.

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Figure A1: Current and proposed NELS ICE data linkages.

Appendix A

Appendix B

Table B1: Number of deaths with renal disease as the underlying or other cause, by disease type, Nova Scotia, 1998-2005.

| | ICD-9 codes ^a | ICD-10 codes ^b | Underlying cause of | Mentioned as a cause but not the | Total | Ratio of mentioned to |
|---|-------------------------------|---|------------------------|----------------------------------|----------|-----------------------|
| Cause of death | (1999-1979) | (2000-present) | death | underlying cause | mentions | underlying |
| Nephritis, nephrotic syndrome and nephrosis | 580-589 | N00-N07, N17- N19, N25-N27 | 1,049 | 4,590 | 5,639 | 5.4 |
| Glomerular diseases | 580-583 | N00-N07 | 27 | 35 | 62 | 2.3 |
| Chronic nephritic syndrome | 582 | N03 | 9 | 20 | 29 | 3.2 |
| Unspecified nephritic syndrome | 583 | N05 | 11 | 4 | 15 | 1.4 |
| Renal failure ^c | 584-586 | N17-N19 | 1,021 | 4580 | 5601 | 5.5 |
| Acute | 584 | N17 | 129 | 775 | 904 | 7.0 |
| Chronic | 585 | N18 | 341 | 1,498 | 1,839 | 5.4 |
| Unspecified | 586 | N19 | 551 | 2,639 | 3,190 | 5.8 |
| Diabetic nephropathy ^d | 250.4 | E10.2, E11.2, E14.2 | 34 | 12 | 46 | 1.4 |
| Hypertensive renal disease or hypertensive heart and renal disease ^e | 403-404 | 112-113 | 212 | 30 | 242 | 1.1 |
| All renal disease ^f | 580-589, 250.4, 403-404 | N00-N07, N17- N19, N25-N27, E10.2, E11.2, E14.2, I12-113 | 1,295 | 4,377 | 5,672 | 4.4 |

^a There were no recorded deaths from ICD-10 codes N00, N01, N06, N07 or N27.

^b There were no recorded deaths from ICD-9 codes 250.4, 588 or 589.

^c 327 records had more than one type of renal failure mentioned.

^d Diabetic nephropathy only appeared in records from 2000-2005. There were 15 records with diabetic nephropathy as the underlying cause of death only. The presence of diabetics and renal disease mentioned on the death certificate resulted in the selection of diabetic nephropathy as the underlying cause of death.

^e Hypertensive renal disease includes any condition classifiable to 585 with any condition classifiable to 401 (ICD-9) and any condition in N00-N07, N18-N19 or N26 with any condition in I10 (ICD-10). Hypertensive heart and renal disease includes any condition classifiable to 402 with any condition classifiable to 403 (ICD-9) and any condition in I11 with any condition in I12 (ICD-10). 188 records had hypertensive renal disease or hypertensive heart and renal disease of death only. The presence of hypertension with heart and/or renal disease resulted in the selection of hypertensive renal disease or hypertensive heart and renal disease as the underlying cause of death.

^fTotals may not add up since a decedent can have more than one renal disease cause of death

Appendix C

Table C1: A comparison of three methods used to identify the total number of renal disease deaths, using NovaScotia data, 1998-2005.

| Method Source | ICD-9 codes (1979-1999) | ICD-10 codes (2000-present) | Number of deaths with any mention of renal disease |
|--|--|---|--|
| Australian Institute of Health and Wellness Chronic kidney disease Includes: • Glomerular diseases • Renal tubulo-interstitial diseases • Chronic renal failure • Unspecified renal failure • Other disorders of kidney and ureter • Proteinuria • Mechanical complication of vascular dialysis catheter* • Kidney transplant failure and rejection* • Diabetic nephropathy • Hypertensive renal disease | 580-583, 590.0, 590.2-590.9, 585, 586, 753.0-753.4, 587-589, 593.0- 593.2, 593.8, 593.9, 790.1, 593.6, 996.1*, 996.8*, 250.4, 403-405 | N00-N07, N11-N12, N14-N15, N18, N19, Q60-Q63, N25-N28, N39.1, N39.2, T82.4*, T86.1*, E10.2, E11.2, E14.2, I12-I13, I15.0, I15.1 | 5,189 |
| National Center for Health Statistics, United States and Statistics Canada 113 selected causes of death – Nephritis, nephrotic syndrome and nephrosis Includes: • Glomerular diseases • Renal failure (including acute) • Other disorders of kidney and ureter | 580-589 | N00-N07, N17-N19, N25-N27 | 5,639 |
| West Virginia Bureau for Public Health Includes: • Glomerular diseases • Renal failure (including acute) • Other disorders of kidney and ureter • Diabetic nephropathy • Hypertensive renal disease | 580-589, 250.4, 403-404 | N00-N07, N17-N19, N25-N27, E10.2, E11.2, E14.2, I12-113 | 5,672 |

Appendix D

 Table D1: 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 | 110 |
| Chronic ischemic heart disease (excluding acute myocardial infarction) | 412-414, 429.2 | 120, 125 |
| Acute myocardial infarction | 410 | 121-122 |
| Diabetes mellitus | 250 | E10-E14 |
| Cerebrovascular disease (stroke) | 430-434, 436-438 | 160-169 |
| Congestive heart failure | 428 | 150 |
| Alzheimer's disease and dementia | 290, 331.0 | F00-F03, G30 |