Chronic Disease and Palliative Care Program Data Linkage and Analysis Project: *The 3x3 Network for End of Life Study (NELS)*

Palliative Care Programs

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Background

• It is increasingly being recognized that end of life (EOL) care requires greater attention
• Evidenced-based decision making requires reliable data
• Much of the research on EOL care has focused on cancer
  • Other diseases have a terminal phase
  • The occurrence of co-morbidities can affect service requirements
• Linked administrative datasets are a valuable tool to study EOL care issues
Data Sources

- Link data from 3 disease registries and 3 Palliative Care Programs to Vital Statistics Death Certificate data
- Registry data:
  - Cancer
  - Diabetes
  - Cardiovascular
- Palliative Care Program (PCP) data
  - Capital Health
  - Cape Breton
  - Colchester
- Probabilistic data linkage
Study Subjects

- All deaths in Nova Scotia as defined by NS Vital Statistics 1995-2009
- Total number of deaths: 121,458
- Since we only have PC data from 3 DHAs, many of the statistics are based on the population in those DHAs only
  - e.g. percentage enrolled in a palliative care program is based on the population in corresponding DHA
- To determine DHA, a residential postal code is required
  - 6,178 (5.1%) in total have a missing postal code
Vital Statistics

All Deaths in NS
N=121,458

Year of Death

Year of Death – Capital Health PCP

Capital Health PCP Enrollees Linked to VS
N=12,976
Year of Death – Colchester PCP

Colchester East Hants PCP Enrollees Linked to VS
N=1,569

Year of Death
Year of Death – Cape Breton PCP

Cape Breton PCP Enrollees Linked to VS
N=5,631

Year of Death
Age and Sex Distribution
All Deaths and PCP Enrollees

Sex Distribution

All Deaths
- Female: 49.5%
- Male: 50.5%

PCP
- Female: 49.3%
- Male: 50.7%

Age Distribution

Mean age
- All: 74.5
- PCP: 70.4
Sex Distribution by PCP

- Capital Health: 48.8% female, 51.2% male
- Colchester: 52.6% female, 47.4% male
- Cape Breton: 49.9% female, 50.2% male
Age Distribution by PCP

Age at Death

mean age at death
CH: 69.3
CEH: 74.8
CB: 71.7

Capital Health
Colchester
Cape Breton

age group
0-9 10-19 20-29 30-39 40-49 50-59 60-69 70-79 80-89 90-99 100+
Where Do PCP Enrollees Reside?

• Residential Postal Code information used to determine resident DHA

• Postal Code information obtained from VS
  • If missing, other data sources used where available

• Missing/Invalid Postal Code information
  • 1.6% of all PCP Enrollees
## Residential DHA by PCP

<table>
<thead>
<tr>
<th>Area</th>
<th>Capital Health</th>
<th>Colchester</th>
<th>Cape Breton</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Shore</td>
<td>3.45%</td>
<td>0.13%</td>
<td>0.05%</td>
</tr>
<tr>
<td>South West</td>
<td>2.27%</td>
<td>0.19%</td>
<td>0.02%</td>
</tr>
<tr>
<td>Annapolis Valley</td>
<td>2.79%</td>
<td>0.45%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Colchester East Hants</td>
<td>4.62%</td>
<td>90.70%</td>
<td>0.04%</td>
</tr>
<tr>
<td>Cumberland</td>
<td>1.20%</td>
<td>2.82%</td>
<td>0.02%</td>
</tr>
<tr>
<td>Pictou</td>
<td>1.55%</td>
<td>1.28%</td>
<td>0.05%</td>
</tr>
<tr>
<td>Guysborough/Antigonish</td>
<td>1.64%</td>
<td>0.26%</td>
<td>2.21%</td>
</tr>
<tr>
<td>Cape Breton</td>
<td>1.62%</td>
<td>0.13%</td>
<td>97.35%</td>
</tr>
<tr>
<td>Capital</td>
<td><strong>80.86%</strong></td>
<td>4.04%</td>
<td>0.27%</td>
</tr>
</tbody>
</table>
PCP Enrollment

- Percentage of deaths enrolled in PCPs
- District Health Authority population
  - All deaths
  - Conditions which could potentially benefit from PCP (Rosenwax et al*)
    - Maximal Estimate: all deaths except pregnancy-related and sudden deaths
    - Minimal Estimate: 10 conditions
- Limited years
  - Capital Health: 1996-2009
  - Colchester East Hants: 2003-2009
  - Cape Breton: 1996-2009

PCP Enrollment

- Capital Health (1996+)
- Colchester (2003+)
- Cape Breton (1996+)

- All deaths:
  - Minimal: 27.8%
  - Maximal: 30.4%
  - All deaths: 28.8%

- Maximal:
  - Minimal: 29.3%
  - Maximal: 32.5%
  - All deaths: 30.2%

- Minimal:
  - Minimal: 45.3%
  - Maximal: 48.9%
  - All deaths: 46.4%
PCP Enrollment for those in Disease Registries

Percentage in PCP by Registry Enrollment

Denominator includes those in Capital Health, Colchester East Hants or Cape Breton DHA who have the corresponding disease cause on death certificate.
Enrollment Days

- Days enrolled in PCP
  - Used as a quality care indicator

- First referral date until death used for Colchester and Cape Breton

- First PCP visit until death used for Capital Health
  - 1996-2004 > 90% have missing value for referral date
  - Mean days between first referral and first visit for Capital Health where both dates are non-missing (2005-2009):
    - 4.39 days when referral date is not the same as the first visit date
    - 40.5% had the same referral and first visit date
Enrollment Days Over Time

Days Between First Referral/Visit and Death by Year

- Capital Health
- Colchester
- Cape Breton

Note: days from first visit to death used for CH while first referral used for CEH and CB
Enrollment Days Over Time – With Cancer

Days Between First Referral/Visit and Death
by Year
With a Cancer Cause of Death

Mean all years
CH:
cancer 138.9
noncancer 184.0
CEH:
cancer 133.6
noncancer 171.4
CB:
cancer 154.7
noncancer 190.6

note: days from first visit to death used for CH while first referral used for CEH and CB
## Time from Palliative Care Enrollment to Death

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>first referral</td>
<td>first referral</td>
<td>first referral</td>
</tr>
<tr>
<td>≤7 days</td>
<td>19.2%</td>
<td>22.6%</td>
<td>20.4%</td>
</tr>
<tr>
<td></td>
<td>20.7%</td>
<td>23.5%</td>
<td></td>
</tr>
<tr>
<td>≤14 days</td>
<td>28.7%</td>
<td>31.2%</td>
<td>28.8%</td>
</tr>
<tr>
<td></td>
<td>30.2%</td>
<td>32.5%</td>
<td></td>
</tr>
</tbody>
</table>
Causes of Death

• All causes of death from death certificate utilized

• Can be up to 13 causes of death listed

• Disease types were identified through ICD coding used on the death certificate
Number of Death Causes

Mean Causes
All Decedents and PCPs

- All deaths: 2.85
- Capital Health: 2.27
- Colchester: 2.60
- Cape Breton: 2.44
Number of Death Causes – without Cancer Cause

Mean Causes All Deaths and PCPs
Decedents Without a Cancer Cause

<table>
<thead>
<tr>
<th>Causes</th>
<th>All deaths</th>
<th>Capital Health</th>
<th>Colchester</th>
<th>Cape Breton</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3.03</td>
<td>3.02</td>
<td>3.12</td>
<td>3.04</td>
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</table>
Cause of Death Frequencies

<table>
<thead>
<tr>
<th>Program</th>
<th>All Deaths</th>
<th>CH</th>
<th>CEH</th>
<th>CB</th>
<th>All PCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>32.2%</td>
<td>83.6%</td>
<td>70.9%</td>
<td>76.5%</td>
<td>80.5%</td>
</tr>
<tr>
<td>Cardiovascular Disease</td>
<td>31.6%</td>
<td>10.1%</td>
<td>16.4%</td>
<td>14.0%</td>
<td>11.8%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>10.6%</td>
<td>4.9%</td>
<td>8.6%</td>
<td>7.5%</td>
<td>5.9%</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>11.7%</td>
<td>6.2%</td>
<td>8.2%</td>
<td>6.2%</td>
<td>6.3%</td>
</tr>
<tr>
<td>COPD</td>
<td>11.5%</td>
<td>6.3%</td>
<td>11.9%</td>
<td>10.4%</td>
<td>7.9%</td>
</tr>
<tr>
<td>Dementia/Alzheimer’s</td>
<td>10.2%</td>
<td>2.6%</td>
<td>7.6%</td>
<td>4.4%</td>
<td>3.5%</td>
</tr>
<tr>
<td>Renal</td>
<td>8.8%</td>
<td>6.6%</td>
<td>6.7%</td>
<td>6.5%</td>
<td>6.5%</td>
</tr>
<tr>
<td>observations</td>
<td>121,458</td>
<td>12,976</td>
<td>1569</td>
<td>5631</td>
<td>19,835</td>
</tr>
</tbody>
</table>

* Categories are not mutually exclusive.
Cancer Cause of Death Trends

With Cancer Cause of Death

- all deaths
- 3 DHAs-all deaths
- Capital Health PCP
- Colchester PCP
- Cape Breton PCP
Non-Cancer Causes

**Percent of Enrollees with Disease Cause**

*All PCPs*

- CV
- Diabetes
- Pneumonia
- COPD
- Dementia
- Renal

Year:
- 1995
- 1996
- 1997
- 1998
- 1999
- 2000
- 2001
- 2002
- 2003
- 2004
- 2005
- 2006
- 2007
- 2008
- 2009
## Trends

<table>
<thead>
<tr>
<th>Disease Cause</th>
<th>Average Annual Change in Percent of Enrollees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>-1.57%</td>
</tr>
<tr>
<td>Cardiovascular Disease</td>
<td>0.58%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>0.36%</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>0.07%</td>
</tr>
<tr>
<td>COPD</td>
<td>0.41%</td>
</tr>
<tr>
<td>Dementia/Alzheimer’s</td>
<td>0.45%</td>
</tr>
<tr>
<td>Renal</td>
<td>0.37%</td>
</tr>
</tbody>
</table>
Percentage of Cancer Decedents Seen by Palliative Care Program in Nova Scotia

Percentage of Deaths with Cancer as a Cause Enrolled in PCP by Year

Capital Health
Colchester
Cape Breton
Nursing Home Residents Dying of Cancer seen by a Palliative Care Program

Percentage of Deaths with Cancer as a Cause Enrolled in PCP by Year

Capital Health
Colchester
Cape Breton
Palliative Care Programs Diagnosis Data

• Capital Health PCP uses ICD-9 codings (as is used on the death certificates)
  • Two variables available to indicate health condition
    • Primary Diagnosis
    • Comorbidity

• Colchester East Hants and Cape Breton PCPs utilize free text to indicate diagnosis
  • The program searches the diagnoses variables for a list of words and phrases to indicate the various diseases.
  • There could be multiple conditions listed
# PCP Diagnoses Frequencies

<table>
<thead>
<tr>
<th>Program</th>
<th>CH Primary Diagnosis or co-morbidity</th>
<th>CH Primary diagnosis</th>
<th>CEH Diagnosis</th>
<th>CB Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>85.9%</td>
<td>84.3%</td>
<td>63.9%</td>
<td>78.2%</td>
</tr>
<tr>
<td>Cardiovascular Disease</td>
<td>6.8%</td>
<td>2.5%</td>
<td>2.5%</td>
<td>3.5%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>5.1%</td>
<td>2.5%</td>
<td>0.13%</td>
<td>0.23%</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>0.90%</td>
<td>0.47%</td>
<td>1.2%</td>
<td>0.60%</td>
</tr>
<tr>
<td>COPD</td>
<td>5.3%</td>
<td>1.6%</td>
<td>4.1%</td>
<td>4.6%</td>
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<td>0.82%</td>
<td>2.4%</td>
<td>2.1%</td>
</tr>
<tr>
<td>Renal</td>
<td>3.3%</td>
<td>1.8%</td>
<td>4.9%</td>
<td>4.6%</td>
</tr>
<tr>
<td>observations</td>
<td>12,976</td>
<td>12,976</td>
<td>1,569</td>
<td>5,631</td>
</tr>
</tbody>
</table>

Note: Categories are not mutually exclusive
Other conditions not listed due to small numbers
PCP Diagnosis and Cause of Death

For any of 7 conditions: cancer, CV, diabetes, renal, pneumonia, COPD, dementia

* CH-both indicates a match using either the primary diagnosis or co-morbidity variable
CH-Prim Diag indicates a match using the primary diagnosis variable only
PCP Diagnosis and Cause of Death

For any of 7 conditions: cancer, CV, diabetes, renal, pneumonia, COPD, dementia

* CH-both indicates a match using either the primary diagnosis or co-morbidity variable

CH-Prim Diag indicates a match using the primary diagnosis variable only
Nursing Home Residents and PCPs

- 9 indicators of residence in a nursing home in 3x3 data
  - 2 from VS data
  - 2 using CCNS algorithm using address information
  - 2 from cardiovascular registry
  - 2 from Cape Breton PCP data
  - 1 from Colchester PCP data

- The time period and populations covered varies across indicators

- The 2 CCNS variables cover the entire study period and population
Nursing Home Residents

Percent in a Nursing Home

- All Deaths: 23.04%
- in 3 PC DHAs: 21.14%
- in any PCP: 7.37%
Nursing Home Residents by PCP

Percent in Nursing Home by Individual PCP

- Capital Health: 6.29%
- Colchester: 10.14%
- Cape Breton: 8.67%
NH Residents in a PCP

Percent of Nursing Residents in a PCP

- 9.33% for any PCP
- 7.73% for CH
- 9.12% for CEH
- 12.32% for CB
Place of Death

• Location of death is an indicator of quality care near the end of life
• Most patients prefer to die at home
• An algorithm developed by CCNS is used to determine place of death
• Variable constructed indicates if the death occurred in hospital, nursing home or “other”
Place of Death

- “place of death” is distinguished from “location of care” in the last weeks of life
- Decedents may be admitted to the hospital in the last few days of life
- In recent work, researchers have measured the location of care in the last weeks of life
- Further data linkages to the 3x3 NELS data are required to explore location of care during end of life
  - e.g. hospital admission/discharge data
Place of Death

All Deaths and PCP Enrollees

- Hospital
- Nursing Home
- Others

- All Deaths
- CH
- CEH
- CB
Thank you for your attention!