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

COPD

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Introduction

• The 3x3 NELS study utilizes linked administrative data to study End of Life (EOL) issues

• NS Vital Statistics death certificate data was linked to registry data from 3 provincial disease programs:
  • Cancer
  • Diabetes
  • Cardiovascular

• Data from 3 palliative programs were also linked:
  • Capital Health
  • Colchester East Hants
  • Cape Breton
End of Life Research

• Much of the EOL/palliative care research has focused on cancer
• Other diseases have a terminal phase
• Co-morbidities play a large role
  • e.g. evidence of COPD linked to CV disease
• Administrative data can be a valuable tool
  • Ethical and other sensitivities surrounding EOL data collection
  • Helps provide a more complete picture of health conditions near the EOL
Data

• All deaths in Nova Scotia 1995-2009
  • 121,458
• Linked to other data using probabilistic linkage
• For registry data, identifying information stripped before health service information attached and transferred to NELS ICE analysts
Causes of Death

- Focus on all causes of death from death certificate
- Can be up to 13 causes of death listed
- We also present some statistics using underlying cause for comparison
- Disease types were identified through ICD coding used on the death certificate
COPD Cause of Death

All years:
COPD Any cause: 13,984
COPD Underlying cause: 1550

All years:
COPD Any cause: 11.5%
COPD Underlying cause: 1.3%
Sex and Age Distribution
All Deaths, Any COPD Cause, Underlying Cause COPD

Mean age at death:
All deaths: 74.5
COPD any cause: 78.3
COPD underlying cause: 77.7
DHA Distribution
All Deaths, Any COPD Cause, Underlying Cause COPD
Number of Death Causes

Means:
All deaths: 2.85
Any COPD: 3.70
Underlying: 2.06
## COPD Diagnosis Codes Used For Analysis

<table>
<thead>
<tr>
<th>ICD-9 &lt; 2000</th>
<th>ICD-10 &gt;=2000</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>490</td>
<td>J40</td>
<td>Bronchitis, not specified as acute or chronic</td>
</tr>
<tr>
<td>491.0-491.9</td>
<td>J41.0 – J42</td>
<td>Bronchitis</td>
</tr>
<tr>
<td>492.0-492.8</td>
<td>J43.0 - J43.9</td>
<td>Emphysema</td>
</tr>
<tr>
<td>na</td>
<td>J44.0 – J44.9</td>
<td>Other chronic obstructive pulmonary disease</td>
</tr>
<tr>
<td>496.0</td>
<td>na</td>
<td>Chronic airway obstruction, not elsewhere classified</td>
</tr>
<tr>
<td>Disease (any cause indicates)</td>
<td>All Deaths</td>
<td>Any COPD Cause</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>------------</td>
<td>----------------</td>
</tr>
<tr>
<td>COPD</td>
<td>11.5%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Cancer</td>
<td>32.2%</td>
<td>22.1%</td>
</tr>
<tr>
<td>Cardiovascular Disease</td>
<td>32.2%</td>
<td>41.4%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>10.6%</td>
<td>11.5%</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>11.7%</td>
<td>19.8%</td>
</tr>
<tr>
<td>Dementia/Alzheimer’s</td>
<td>10.2%</td>
<td>7.4%</td>
</tr>
<tr>
<td>Renal</td>
<td>8.8%</td>
<td>8.2%</td>
</tr>
<tr>
<td>Sudden Death</td>
<td>5.5%</td>
<td>1.4%</td>
</tr>
<tr>
<td>observations</td>
<td>121,458</td>
<td>13,984</td>
</tr>
</tbody>
</table>

* Categories are not mutually exclusive.
Enrollment in Disease Registries

Note: individuals can be in more than one registry
Palliative Care Programs

- Have data from 3 District Health Authorities
  - Capital Health (CH) 1995-2009
  - Colchester East Hants (CEH) 2002-2009
  - Cape Breton (CB) 1995-2009
- CH uses ICD-9 coding for
  - Primary diagnosis
  - Co-morbidities
- CEH and CB – free text
  - Mostly primary diagnosis
# Percent with COPD for Individuals in a PCP

<table>
<thead>
<tr>
<th></th>
<th>CH (%)</th>
<th>CEH (%)</th>
<th>CB (%)</th>
<th>Any of the 3 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any COPD Cause</td>
<td>6.3%</td>
<td>11.9%</td>
<td>10.4%</td>
<td>7.9%</td>
</tr>
<tr>
<td>COPD Underlying Cause</td>
<td>0.47%</td>
<td>1.1%</td>
<td>0.85%</td>
<td>0.63%</td>
</tr>
<tr>
<td>COPD Diagnosis in PCP</td>
<td>5.2%</td>
<td>4.1%</td>
<td>4.6%</td>
<td>5.1%</td>
</tr>
<tr>
<td>Either source</td>
<td>9.2%</td>
<td>12.8%</td>
<td>11.9%</td>
<td>10.3%</td>
</tr>
<tr>
<td>observations</td>
<td>12,976</td>
<td>1569</td>
<td>5631</td>
<td>19,835</td>
</tr>
</tbody>
</table>

Note: Both primary and co-morbidity variables were used to calculate the Capital Health percentage.

A small number of individuals were enrolled in more than one PCP.
Individuals with COPD in PCPs Over Time

All Years: 10.2%
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
- The variable constructed indicates if the death occurred in the hospital, a nursing home or “other”
Place of Death vs Location of Care

- “place of death” is distinguished from “location of care” in the last weeks of life
- Decedents may have been 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

- Hospital: 70%
- Nursing Home: 10%
- Other: 20%

- All deaths
- COPD any cause
- COPD underlying cause