Reaping the Benefits of Cancer Registries: Examples from End of Life Studies

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Outline

Beginnings
  Cancer Registry
  Context

Growth
  Linkage to Population Administrative Databases
  Data Quality Assessment
  Expertise and Experiences

Harvest
  Publications
  Research Grants
  New Collegial Relationships
Beginning: Cancer Registry

Cancer Registry data back to 1960’s

Death Clearance
Mortality Rates, and Survival Statistics

Death Certificate Only Rates, and Mortality to Incidence Ratios

50% of people diagnosed with cancer die of cancer
Context

Canadian Health Care System
  Provincial administered; publicly funded
  Hospital care
  Fee for service Physician visits

Senate Reports on Care of the Dying, 1995 ...
  Limited tertiary hospital based palliative medicine
  Virtually no hospice or other community care

Record Linkage
  Statistics Canada Mortality Database
  Provincial Population Health Research Units
  Halifax Palliative Care Program - 1988
Growth

Linkage to Population Administrative Databases

Data Quality Assessment Experiences
Linkage of Cancer Registry Data to Population Based Administrative Databases

Data Sources
- Death Certificates
- Hospital Admissions
- Palliative Programs
- Palliative Radiation
- Medical Oncology
- Physician Services
- Cancer Registry
- Home Care
- Nursing Home
- Narcotic Analgesics

Postal code -> Enumeration Area -> Census -> SES, culture
Data Quality Framework to assess Administrative Databases being added

Value
Provide checklist for data quality monitoring
Identify time periods and data fields of sufficient quality for reporting
Assist in reconciling data quality problems
Provide a structure for data quality reports
Aid in establishing data quality standards

Concepts
<table>
<thead>
<tr>
<th>coding constancy</th>
<th>data fields complete</th>
</tr>
</thead>
<tbody>
<tr>
<td>accuracy, reliability</td>
<td>includes all persons</td>
</tr>
<tr>
<td>validity, interpreting</td>
<td>includes all services</td>
</tr>
<tr>
<td>timely data transfer</td>
<td>reporting constancy</td>
</tr>
</tbody>
</table>

Expertise

For Record Linkage,
Data Quality Assessment,
Statistical Analysis, and
Ongoing Database Updating

R Dewar, B Lawson, C Boyd, N St Jacques,
J Gao, M O'Brien
Expertise

For Interpretation and Knowledge Translation:

Clinicians from Family Medicine, Palliative Care, Palliative Radiation, Medical Oncology, and Pharmacy

F Burge, I Cummings, P McIntyre, D Orychock, P Joseph, D Rheaume, D Rayson, L Broadbent, E Grunfeld
Personal experiences

Health Services Administration

Family and Friends

Breast Cancer Survivor, and
Dragon Boat Team Member
Harvest

Publications

Research Grants

New Collegial Relationships
Initial publications

Palliative Care Program Referral by Age, Halifax


Hospital Days in Last Six Months of Life, 1992-1998

Percent of Patients (%) vs. Total days in hospital
Family Physician Visits in last six months of life, 1995

- Home: 19%
- Office: 30%
- Hospital: 31%
- Emergency: 11%
- Long term care: 9%
CIHR Grant
New Emerging Team (NET)
British Columbia, Saskatchewan, and Nova Scotia
Cultural indicators

Referral to Palliative Care Program, Halifax and Cape Breton 1998-2003

- Patients from African Nova Scotian Communities: 79%
- All Patients: 74%

 Postal code at Death > Census Area > Census > Culture
CIHR Interdisciplinary Capacity Enhancement (ICE) Grant for Equity in Access to End of Life Care for Vulnerable Populations

1. Surveillance System and Report of inequity in quality care
2. Defining vulnerable populations at end of life: Ethical Analysis
3. Quality pediatric terminal care and vulnerabilities
4. African Canadians and End-of-Life Care
5. Attaining a better understanding of gender and age at end of life
6. Quality end of life cancer care for vulnerable elderly
7. Community based quality care at end of life with COPD
8. Canadian Compassionate Care Benefit: Is it working?
Interactions with other Canadian Colleagues

Study Subjects

Definitions of EOL study subjects vary. Further dialogue on inclusion, uncertain and exclusion criteria is required.

- Persons with cancer as primary cause of death
- Persons with cancer as another cause of death
- Persons who had a cancer diagnosis but not cause of death

Grunfeld 2004

- All persons dying of cancer who could benefit by receiving palliative care

- Persons dying of cancer
  - Persons with cancer who died of other chronic disease e.g. Alzheimer’s COPD, stroke,
  - Died of cancer treatment

Gagnon 2005

- Cancer diagnosis in Cancer Registry prior to death certificate (DC) linkage
  - Burge 2002, 2003

- DC follow back identified (DCI) new cancer case, eg clinical diagnoses in long term care facilities. Majority >80 years

- Death Certificate Only (DCO) case: date of diagnosis is date of death
## Quality Care Indicators

### Place of Death for women dying of breast cancer, 1998-2002,
E Grunfeld et al, 2006

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Statistic description</th>
<th>Nova Scotia</th>
<th>Ontario</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place of death</td>
<td>In hospital</td>
<td>63.4%</td>
<td>52.9%</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>DEMOGRAPHIC FACTORS</th>
<th>Odds Ratios (95% Confidence Intervals)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (20-44 years)</strong></td>
<td></td>
</tr>
<tr>
<td>45-64</td>
<td>1.0 (0.8-1.2)</td>
</tr>
<tr>
<td>65-74</td>
<td>1.0 (0.8-1.2)</td>
</tr>
<tr>
<td>75-84</td>
<td>1.3 (1.1-1.5)</td>
</tr>
<tr>
<td>85+</td>
<td>2.1 (1.7-2.5)</td>
</tr>
<tr>
<td><strong>Sex (Male)</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1.4 (1.3-1.4)</td>
</tr>
<tr>
<td><strong>CLINICAL SITUATION</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Time lived after cancer diagnosis (&lt;61 days)</strong></td>
<td></td>
</tr>
<tr>
<td>61-120</td>
<td>2.0 (1.8-2.3)</td>
</tr>
<tr>
<td>121+</td>
<td>2.6 (2.4-2.8)</td>
</tr>
<tr>
<td><strong>Tumor group (Lung)</strong></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>1.9 (1.7-2.1)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>1.6 (1.4-1.7)</td>
</tr>
<tr>
<td>Prostate</td>
<td>1.6 (1.4-1.8)</td>
</tr>
<tr>
<td>Other</td>
<td>1.2 (1.1-1.3)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>COMMUNITY OF RESIDENCE</th>
<th>Odds Ratios (95% Confidence Intervals)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Region</strong> (Halifax County)</td>
<td>Crude</td>
</tr>
<tr>
<td>Cape Breton County</td>
<td>0.6 (0.6-0.7)</td>
</tr>
<tr>
<td>All other counties</td>
<td>0.7 (0.6-0.7)</td>
</tr>
<tr>
<td><strong>Immigrant</strong> (No)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.5 (1.3-1.6)</td>
</tr>
<tr>
<td><strong>Median Income</strong> ($0-25,499)</td>
<td></td>
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<tr>
<td>25,500-31,999</td>
<td>0.9 (0.8-1.0)</td>
</tr>
<tr>
<td>32,000-37,499</td>
<td>0.9 (0.8-1.0)</td>
</tr>
<tr>
<td>37,500-45,999</td>
<td>0.9 (0.8-1.0)</td>
</tr>
<tr>
<td>46,000+</td>
<td>1.2 (1.1-1.3)</td>
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<tr>
<td><strong>HEALTH SERVICES</strong></td>
<td></td>
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<tr>
<td>Nursing Home Resident$^1$ (No)</td>
<td></td>
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<tr>
<td>Yes</td>
<td>22.8 (18.1-28.7)</td>
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<tr>
<td>Palliative Radiation (No)</td>
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<tr>
<td>Yes</td>
<td>0.9 (0.8-0.9)</td>
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<tr>
<td>Medical Oncology Consultation (No)</td>
<td></td>
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<tr>
<td>Yes</td>
<td>0.8 (0.8-0.9)</td>
</tr>
</tbody>
</table>
Research with other Canadian Colleagues

Costing Palliative Care in Five Canadian Cities,
S Dumont et al

Investigating Bias in Study Sample Selection,

Compare Study Decedents to Persons dying of cancer in same time period
Products

Assess Palliative Care Policy and Program

Surveillance Report Card

Research Program

Increased Access to Quality End of life Care
Network for End of Life Studies

Questions?