End of Life Care in Nova Scotia: Surveillance Report

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What is the Network for End of Life Studies (NELS)?

- Research group based at Dalhousie University, Capital Health, Cancer Care Nova Scotia and the IWK Health Centre
- Members have a range of research and clinical expertise.
- Goal: To improve end of life care for persons with terminal illness by enhancing interdisciplinary research capacity.
NELS Research Framework

Equity in Quality End of Life Care for Vulnerable Populations

- Surveillance
- Knowledge Translation
- Explanatory Research
- Intervention Research

Age
Gender
Rural Populations
Socio-economically disadvantaged African Canadians

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

- Canadian Institutes for Health Research (CIHR) strategic initiative grant: “Reducing Health Disparities and Promoting Equity for Vulnerable Populations” (2006-2011)

- Objectives of this research development grant:
  - Investigate factors associated with vulnerability at end of life
  - Identify inequities in end of life care.
- By building research capacity
- Six projects
Development of a surveillance report of indicators of *access* to quality care at end of life

Purpose of surveillance report:
- Offer recommendations to build surveillance and research capacity
- Provide evidence needed by decision-makers to identify and address inequities in *access* to quality end of life care
Chapter 1

- The problem
- The Context
- Our Approach
- Our Conceptual Framework

End of life care
- Availability
- Uptake
- Quality
(Hausman)
Chapter 1: Introduction

Surveillance Report in Relation to Contributors and Audiences:
- Persons dying of chronic disease and their caregivers
- Champions of public and professional education, awareness, and advocacy
Chapter 1 Recommendations

- **Recommendation 1:** Refine and develop comprehensive conceptual frameworks that help elucidate dimensions of vulnerability, disparities, and inequities in access to end of life care.

- **Recommendation 2:** Produce further reports that openly share and critique ideas and examples from research.

- **Recommendation 3:** Work with others so that end of life care surveillance, quality indicator reporting, knowledge exchange, and improved access to quality end of life care for vulnerable populations become sustainable.
Chapter 2: Vulnerable Populations

Distribution of income by district health authority, Nova Scotia, 2001

Median Individual Income

- $15,000 - $16,000
- $16,000 - $17,500
- $17,500 - $18,500
- $18,500 - $22,000

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Chapter 2 Recommendations

- **Recommendation 4:** Conduct population-based studies to better understand the needs of children and youth and the elderly as well as factors associated with sex and gender.

- **Recommendation 5:** Improve our ability to identify factors associated with race, ethnicity, language, and culture that may adversely influence end of life care provision.

- **Recommendation 6:** Gain a better understanding of the costs associated with end of life care in rural and urban areas.
Chapter 3: Burden of Death and Dying

Deaths from selected chronic diseases, by year, Nova Scotia, 1999-2004
Chapter 3 Recommendation

- **Recommendation 7:** Expand the clinical breadth of the research team so that we can gain a better understanding of end of life care issues for persons dying of chronic diseases other than cancer and including co-morbidities.
Chapter 4: Health Service Utilization

Trends in palliative care program enrollment rates for adults dying of cancer, Halifax and Cape Breton counties, 1996-2005

Trends in palliative care program enrollment rates for adults dying of cancer, Halifax and Cape Breton counties, 1996-2005
## Chapter 4: Health Service Utilization

Mean number of family physician visits in the last 12 months of life for adults dying of congestive heart failure, Nova Scotia, 1998-2001

<table>
<thead>
<tr>
<th>Location</th>
<th>Months Prior to Death</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Hospital</td>
<td>11.8</td>
</tr>
<tr>
<td>Office</td>
<td>0.7</td>
</tr>
<tr>
<td>Home</td>
<td>0.7</td>
</tr>
<tr>
<td>Emergency</td>
<td>1</td>
</tr>
<tr>
<td>Long term care</td>
<td>1.7</td>
</tr>
</tbody>
</table>
Chapter 4 Recommendations

- **Recommendation 8:** In partnership with end-of-life care providers, improve the classification of end of life and palliative care.

- **Recommendation 9:** Provide a broader understanding of the role of the hospital for end of life care.

- **Recommendation 10:** Continue to explore the use of the SEA (single entry access) MDS (minimum data set) for home and long-term care.
Chapter 4 Recommendations

- **Recommendation 11:** Encourage development of palliative care service databases across the province with common data fields and definitions.

- **Recommendation 12:** Further examine the role of long-term care facilities in the provision of end of life care.

- **Recommendation 13:** Carry out multivariate statistical analyses to test hypotheses and control for confounding and interaction among variables to provide a more rigorous understanding of resources used to provide end of life care.
Chapter 5: Indicators of Quality Care

Trend in the mean number of days between enrollment in a palliative care program and death for adults dying of cancer, Halifax and Cape Breton counties, 2000-2005

![Graph showing trend in the mean number of days between enrollment in a palliative care program and death for adults dying of cancer, Halifax and Cape Breton counties, 2000-2005. The graph compares rural and urban areas, with a peak in the mid-2000s.](image-url)
Chapter 5 Recommendations

- **Recommendation 14:** While gaining insights from other countries and Canadian provinces, continue to contribute to the further development of population-based surveillance of quality care at end of life.

- **Recommendation 15:** Use both prospective and retrospective study designs to examine the optimal sequences and combinations of end of life care provision.

- **Recommendation 16:** Promote the development of a sustainable province-wide end of life care surveillance system.
Chapter 6: Public Policies to Support Caregiving

Human Resources and Social Development Canada Employment Insurance
Compassionate Care Benefits Eligibility Criteria

Applicant

- Meets definition of “family member”
- Has family member at risk of dying in 26 weeks
- Medical certificate obtained

In workforce

- 600 hours work/EI contributions in past 52 weeks
- Weekly earnings have decreased by 40%

Exclusions

- Does not meet definition of family member
- Does not meet EI criteria for work eligibility
- Family member not dying, could not get certificate

Network for End of Life Studies
Interdisciplinary Capacity Enhancement
Chapter 7: Education and Awareness

Inclusion of palliative care education at Nova Scotia universities and community colleges

<table>
<thead>
<tr>
<th>Institution</th>
<th>Profession</th>
<th>Undergraduate</th>
<th>Graduate</th>
</tr>
</thead>
<tbody>
<tr>
<td>St. Francis Xavier University</td>
<td>Nursing</td>
<td></td>
<td>RN Certificate in Continuing Care via distance delivery</td>
</tr>
<tr>
<td>Cape Breton University</td>
<td>Nursing</td>
<td>Information unavailable at this time</td>
<td></td>
</tr>
<tr>
<td>Nova Scotia Community College</td>
<td>Licensed Practical</td>
<td>Oncology Nursing/Palliative Care is a required course</td>
<td>Continuing care is a required course</td>
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<tr>
<td></td>
<td>Nursing</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Continuing Care Worker</td>
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# Chapter 7: Education and Awareness

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</table>
| Dalhousie University | Medicine   | Four week medicine subspecialty clinical rotation in palliative medicine      | □ Palliative Care in first 2 yrs Family Medicine curriculum  
□ Other palliative care education available (e.g. videoconference, refresher courses) |
| Nursing       |            | □ Palliative care elective  
□ May elect mandatory community placement at a site offering end of life care | Elective course on death and dying/palliative care and oncology nursing for Master of Nursing students |
| Pharmacy      |            | □ Senior seminar deals with cancer and addresses some end of life care issues  
□ May opt for compulsory Community Experience Program at a site offering end of life care |                                                                                                                                        |
| Social Work   |            | Palliative Care education integrated in course on Aging                        | Palliative Care education integrated in course on Aging plus and elective on HIV/AIDS for Master of Social Work students |
| All health care professions | Students from 22 independent health care profession programs participate in 2-hour inter-professional learning module on Palliative Care |                                                                                                                                        |
Chapter 7 Recommendation

- **Recommendation 17**: Assist providers of professional and public education to help ensure equity in access to quality end of life care research is accessible and translates into evidence-based practice.
Chapter 8: African Canadian Population

- A potentially specific “vulnerable” population
- Highlight in each report
- Although no specific recommendation made, development of cultural competence in end of life care is the theme under development
Conclusion

- Remind ourselves that surveillance report is to be a “tool” to aid our understanding of access to end-of-life care
- We have more conceptual and definitional work to do
- We have more data development work to do
Thank you