

Highlighting NELS ICE Successes

2006 - 2011

Grace Johnston, PI

Thursday, September 8, 2011

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

Network for End of Life Studies (NELS)

- Long term (10+ years) series of projects by **Halifax based researchers** to investigate **end of life care**
- Interdisciplinary team of researchers and clinicians from Dalhousie University, Capital Health District and IWK Health Centre in Halifax, Nova Scotia (NS)



Interdisciplinary Capacity Enhancement (ICE)

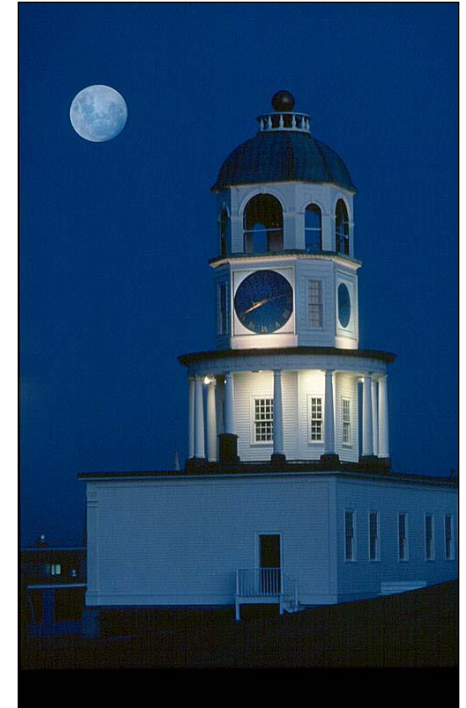
- 5-year (2006-2011)
- \$820,000
- Canadian Institutes for Health Research (CIHR) ICE grant: “Reducing Health Disparities and Promoting Equity for Vulnerable Populations”



Vision: To enhance interdisciplinary research capacity through collaborations aimed to identify disparities and inequities in quality end of life care; explicate end of life care vulnerabilities; and develop and test ways to overcome inadequacies in publicly funded end of life care for persons at end of life with chronic disease.

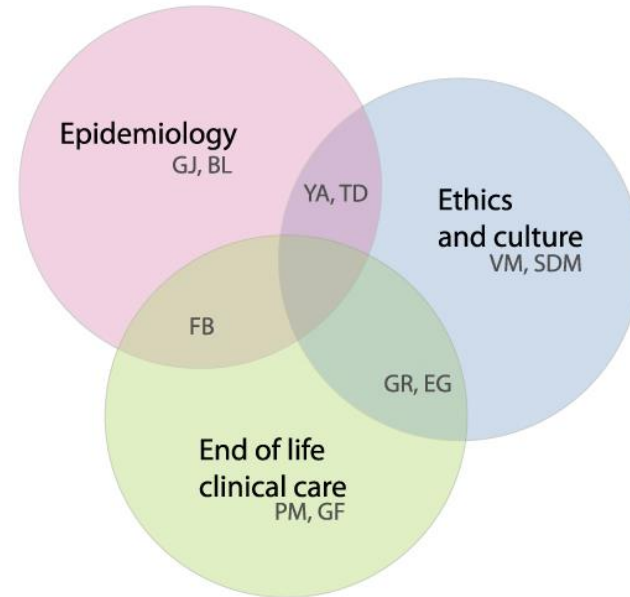
Goals of NELS ICE

1. Create an **interdisciplinary team**
2. Develop **surveillance** to identify **vulnerable populations**
3. Design and conduct **pilot studies**
4. Engage in **knowledge translation**



success: Interdisciplinary team

- **Grace Johnston**, PhD, Principal Investigator
- **Fred Burge**, MD FCFP MSc, Co-PI
- **Yukiko Asada**, PhD
- **Trevor Dummer**, PhD
- **Gerri Frager**, MD FRCPC
- **Eva Grunfield**, MD FCFP DPhil
- **Beverley Lawson**, MSc
- **Victor Maddalena**, BN MHSA PhD
- **Paul McIntyre**, MD FCFP
- **Graeme Rocker**, DM FRCP FRCPC MHSc



ICE Investigators - 2006

success: Expanded interdisciplinary team

Trainees	
New Investigators	14
Masters' & Recent Grads	17
PhD Students	4
Post Doctoral Fellows	2
Clinical/Admin	6

success: Expanded interdisciplinary team

New Investigators

- | | |
|------------------------------|--|
| Melissa Andrew | - ICE New Investigator recipient (NI), Project 6, LTC geriatric assessment |
| Yukiko Asada | - ICE Co-investigator, '05-'08 learn research team development/management |
| Alix Carter | - NI, Project 3, pediatric advanced care directives |
| Heather Castleden | - NI, Project 4, aboriginal peoples at end of life |
| Anne Frances D'intino | - NI, Project 8, informal caregiving |
| Rebecca Earle | - NI, Project 3, pediatric advanced care directives |
| Jan Jensen | - NI, Project 6, novel paramedic-long term care |
| Sue Korol | - NI, Project 8, informal caregiving |
| Monique Lanoix | - '08 develop ICE literature data base; now tenure track Asst Prof |
| Emily Marshall | - NI, Project 5, LTC geriatric assessment |
| Delores Mullings | - NI, Project 4, social work role in support of informal caregivers |
| Andrew Travers | - NI, Project 6, novel paramedic-long term care |
| Gail Wideman | - NI, Project 4, social work role in support of informal caregivers |
| Yoko Yoshida | - '08-'10, develop equity measurement |

success: Expanded interdisciplinary team

Post Doctoral Fellows

- Judith Fisher** - Post Doctoral Fellow, '09-'10, in '08 PhD student in Pharmacy at U of Toronto
Victor Maddalena - Post Doctoral Fellow '06-'07, in '08 tenure track Assistant Professor at MUN

PhD Students

- Dorothy Barnard** - PhD candidate, '06-'07 knowledge translation literature review for ICE
Rebecca Earle - PhD candidate
Cathy Simpson - PhD candidate
Robin Urquhart - NET Coordinator, PhD candidate, '07-'09 ICE knowledge exchange

Clinical/Admin.

- Christine Beck** - Family Medicine Resident, '08-'09 ICE Project 6 qualitative, nursing home
Nicole McQuinn - ICE Research Coordinator, BA graduate, '09-'11 management/KE trainee
Dorianne Rheume - Radiation Oncologist, '08 sabbatical, equity in palliative radiotherapy
Elsie Rolls - CHSRF EXTRA Fellow, '08-'10 ICE Project 6 nursing home intervention
Joanne Young - Respiratory Therapist, '07-'10 ICE develop/manage ICE Project 7 home COPD

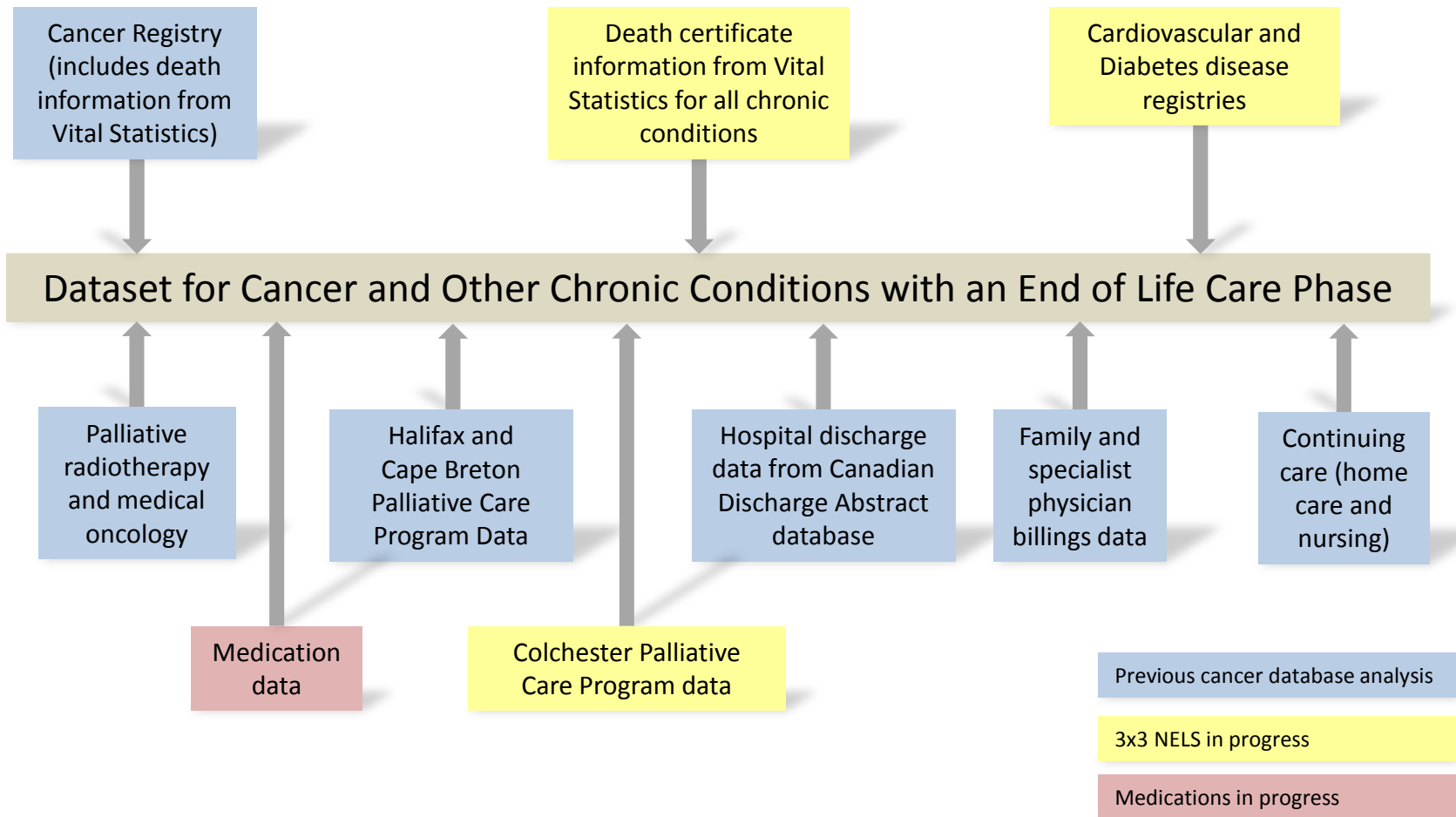
success: Expanded interdisciplinary team

Masters & Recent Grads

Jennifer Barnes	- MN '10, ICE Project 3 on end of life care in pediatric ICU
Shawn Chhabra	- MHA '11, ICE Project 4
Jessica Dooley	- CHE MSc '07, ICE Project 3
Jun Gao	- Statistical Analyst, '06-'11, develop NELS ICE surveillance, reporting, measures
Jenn Gillis	- MHA '09
Farhana Kant	- MHSA '08, ICE Project 4 Immigrants; now Policy Analyst, NS DOH
Junaid Kapra	- MHI '06, palliative program data review
Ruth Lavergne	- CHE MSc '07, ICE Project 2; '08-09 develop Surveillance measures
Andre Madison	- CHE MSc '09, Equity measures for ICE Project 2, ICE Project 9 literature review
Suha Masalmeh	- MHSA '08, ICE Project 8 Review of Family Caregiver Policy
Shauna McVorrان	- MHSA '07, develop Surveillance report
Patricia Murray	- MHSA '08, ICE Project 3 Documentation of End of Life Pediatric care
Sarbjee Singh	- MHA '09
Dorothy Wang	- MHA '11
Hao Wu	- MSc candidate '13, ICE Project 4 Chinese Immigrant Population
Alison Zwaagstra	- MHI '07, develop Vulnerable Population Surveillance system

success: NIS / surveillance

Network Information



success: Beyond cancer surveillance systems

Project streams

1. Surveillance of Inequity in Quality End of Life Care.
2. Vulnerable Populations at End of Life: An Ethical Analysis
3. End of Life Care for Children and Youth
4. Palliative Care for African Nova Scotians and Other Populations: Deaf, SE Asian Immigrants, Aboriginal
5. Mortality Follow-Back Study from Death Certificates
6. Elderly in Nursing Homes
7. Community Care for COPD
8. Policies to Support Family Caregivers
9. Medication Use at End of Life

success: New grants

Additional grants received, related to NELS ICE research, by NELS ICE investigators since 2006

Total number of grants: 25

Total dollar value of grants: \$10,905,100

success: New grants

Some examples:

PI	Award (years)	Amount
Yukiko Asada	CIHR New Investigator Award (2008)	\$300,000
Fred Burge and Bev Lawson	<i>Mortality Follow Back study</i> CIHR Operating Grant (2008-12)	\$432,188
Eva Grunfeld	<i>Towards measuring and improving access to quality cancer services in Nova Scotia</i> CIHR NET ACCESS Grant (2007-12)	\$1,598,660
Graeme Rocker	<i>Palliation of dyspnea in advanced COPD: Patient and caregiver experiences opioid therapy</i> CIHR Regional Partnership Grant (2009-10)	\$130,000
Serge Dumont with P.McIntyre, G.Johnston, F.Burge, M.Scales and others	<i>Palliative care in Canada II: The economic perspective - Capital District and Colchester East Hants Health Authorities</i> CIHR (2008-10)	\$876,330

success: Knowledge translation

NELS News

- Issues highlight events and features completed and ongoing studies by ICE project streams.
- More issues to be released in 2011

The collage features several NELS News newsletters and articles:

- Comorbidity when Cancer is Underlying Cause of Death in Nova Scotia:** A newsletter discussing the impact of comorbidities on mortality.
- Estimating Potential Palliative Care Population:** An article detailing the methodology for estimating the number of patients who may benefit from palliative care.
- Medication:** A section discussing medication management at the end of life.
- Improving end of life care in long facilities: Perspectives of healthcare providers:** An article featuring insights from healthcare providers on improving care in long-term care facilities.
- Death Certificate Data Analysis:** A newsletter discussing the importance and use of death certificate data.
- The ICE Team:** A newsletter highlighting the work of the Interdisciplinary Capacity Enhancement (ICE) team.
- End of Life Care in Long Term Care Facilities:** An article discussing the challenges and opportunities for end-of-life care in long-term care facilities.
- Thanks to Alison Zwaagstra:** A newsletter expressing gratitude to Alison Zwaagstra for her contributions.
- Welcome to Lynn Leithridge:** A newsletter welcoming Lynn Leithridge to the NELS team.
- Publications and presentation medication from Judith Fisher post-doctoral fellowship:** A newsletter highlighting Judith Fisher's research and presentations.
- End of Life Care for elderly residents of long term care facilities (LTC):** An article discussing the specific needs of elderly residents in long-term care facilities.
- Chronic disease and end-of-life care:** An article discussing the impact of chronic diseases on end-of-life care.
- Chronic disease and end-of-life care:** Another article discussing the impact of chronic diseases on end-of-life care.
- Chronic disease and end-of-life care:** A third article discussing the impact of chronic diseases on end-of-life care.

At the bottom left, a bar chart shows the number of deaths by age group and sex. The chart has two bars for each age group, representing males and females. The y-axis is labeled 'Number of Deaths' and ranges from 0 to 100. The x-axis is labeled 'Age Group' and includes categories like '0-14', '15-24', '25-34', '35-44', '45-54', '55-64', '65-74', '75-84', and '85+'. The bars show a general upward trend in the number of deaths with age, with a significant increase in the 75-84 and 85+ age groups.

At the bottom right, a group photo shows five people standing together. They are identified in the caption as study investigators: L.R. Bradley-Lawson, Principal Investigator Fred Burge, Gordon Howeslow, Yukiko Ando, and Greg Johnson. Missing are Graeheld and Paul McEwen.

At the bottom right, a text box contains the following information:

To be added to our NELS e-mail list and to receive future issues of NELS News, please e-mail nelshd@dal.ca. NELS News and Events are posted on our website at nelshd.ca.

success: Knowledge translation

Events

- Work-in-Progress Sessions
- Management Meetings
- 2009 Local Poster Event
- 2010 NELS Reception at the 18th International Congress on Palliative Care
- 2011 Highlighting NELS ICE Successes



Visiting Scholars

2007 - Harvey Chochinov, Craig Earle, Dan Hausman

2008 - Scott Murray, Serge Dumont, Konrad Fassbender

2009 - David Kuhl, R. Sean Morrison

2010 - Vickie Baracos, Allan Kellehear, Kevin Brazil

2011 - Mary Lou Kelley, Maxine Hancock



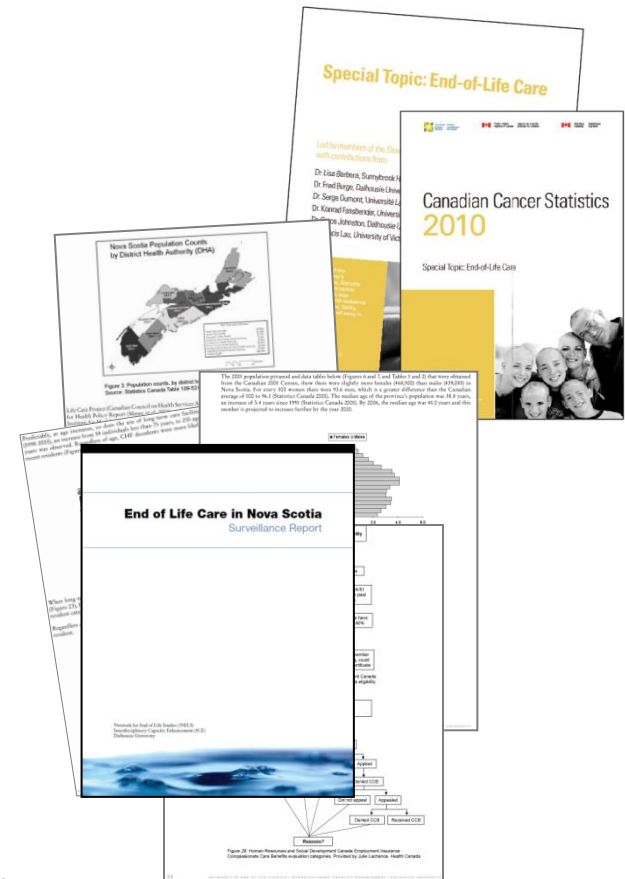
success: Knowledge translation

Reports

- Surveillance and Stakeholder Reports
- Project reports (nels.dal.ca/ice.html)
- Department of Health adapting NELS ICE report for district palliative care programs
- Special topic, end of life with cancer, in Canadian Cancer Statistics 2010

Collaborators

- **Julie Lachance**, Health Canada (2005-11)
- **Gail Page**, Canadian and Nova Scotia Hospice Palliative Care Associations (CHPCA, NSHPCA) (2005-09)
- **Ann McKim**, CHPCA and NSHPCA (2009-11)



success: Knowledge translation

- 65+ publications
- 170+ presentations

UNMET NEEDS & UNFULFILLED WISHES AT THE END OF LIFE
 A POPULATION-BASED MORTALITY FOLLOW BACK STUDY - THE PROCESS

Background
 Our knowledge about health service utilization at the end of life (EOL) among cancer patients is improving, but we have much more to learn.
 Variations in service use by population characteristics have been identified:
 • Elderly use less specialized palliative care
 • Males are more likely to die in hospital
 However, we do not know if these inequalities in utilization represent inequalities in need.
 Inequalities may be due to variations in patient need or preferences for care.
 Inequalities due to patient need are inequitable, while inequalities due to preferences for care are not.
 Currently, we have no information on patient need or their care preferences related to the EOL, in population based data. Little knowledge of service use among people dying of diseases other than cancer.

Information gaps that we seek to fill
 Information gaps to be addressed include:
 • Exploration (or better definition) of "need"
 • Data on decision-making and choices
 • Inclusion of deaths due to other chronic disease

Approach
 Obtaining information prospectively from dying persons is very difficult.
 • Challenge of identifying who is terminally ill
 • Shortening the very if
 • Missing data due to poor function, cognition etc.
 Alternatively, the experience of EOL care may be examined from the family's perspective
 • A "family follow back survey" approach

Mortality follow back surveys
 A population-based design strategy to describe the events around death.
 • Used in the UK, USA, Italy
 Retrospective
 Allows representative sampling of decedents
 Limitation: validity of proxy responses


Linking EOL Care to Andersen's Behavioural Model of Health Service Utilization

Project Goal
 To examine the experience of EOL care among adults in Nova Scotia & to identify unmet needs, unfulfilled wishes regarding care preferences & satisfaction with EOL care using a population-based approach.

Specific Objectives
 From the perspective of the decedent's family or informal caregiver (informant), we will:
 1. Estimate the prevalence of unmet need.
 2. Estimate whether decedent care preferences (deaths) were fulfilled.
 3. Estimate the satisfaction with EOL care received.
 4. Examine the associations between age of care with decedent unmet need and preferences (wishes) & satisfaction level.

Method
 Design
 Population based follow back survey
 • Administered by telephone

Subjects
 Death certificate informants of Nova Scotia during a 2 year study period (n=1200)
 Exclusions:
 • <18 years of death
 • Death due to external or surgical, pregnancy cause
 • Incomplete informant of

Sampling and Process
 Population
 All eligible deaths, (<15,000 over 2 years)
 Sample
 Total random sample of 3000 to obtain 1200 participants
 Sampled in waves of 500, every 4 months, among deaths occurring 4 to 8 months prior to sampling date
Initial Contact
 By mail through Nova Scotia Vital Statistics
Research Contact & Survey Interview
 Interested informants to supply their contact information to researchers

Survey Instrument
 "After-death bereaved family member interview"
 (Time: 10 to 15 min)
 • Adapted for Canadian use
 • Good validity, reliability
 • 2 scale score domains: 7 scale score of life

Measures Used
Unmet need
 Primary outcomes
 Physical comfort & emotional support
 (pain control, breathing problems, dressing with safety or aid/aid)
 Focus on individual personal care, treatment with respect & dignity
Unfulfilled preferences (wishes)
 Advanced care planning, procedures & provision of care consistent with decedent wishes
 Location of death
Satisfaction
 Satisfaction scale score (patient focused, family centered care)
 Other variables of interest
 Predictors of interest: Covariates
 Age
 Sex
 Location of care
 • Hospital
 • Long term care
 • Home
 • With PCP
 • With home care
 • With external support
 Environmental factors
 • Health system factors
 • Residence, year of death
 Population characteristics
 • Preexisting characteristics
 • Enabling resources
 • Need (unmet & perceived)
 Health behaviours

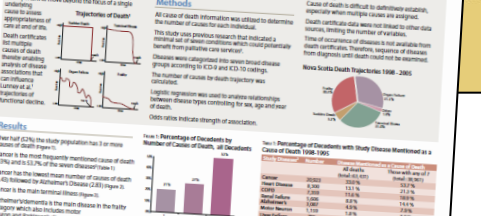
Planning for Palliative Care: An analysis of associations between causes of death

Grace Johnson, PhD; Lynn L. Brinkman, PhD; Judith Fyles, PhD; Alison Zeigler, MSc; Kathleen Simons, PhD; Susan Hogg, PhD; Alison Zeigler, MSc; Judith Fyles, PhD

Objective
 To better understand needs at the end of life by examining predictors between causes of death and unmet needs.

Methods
 All cause death information was utilized to determine the impact of cause of death on unmet need. The final set of unmet needs included: physical comfort, emotional support, and location of death. Cause of death was categorized into broad death categories: natural, surgical, and external. Logistic regression was used to examine associations between cause of death and unmet need. Odds ratios and 95% confidence intervals were calculated.

Results
 Over half (52%) of the study population had unmet need at the end of life. The most common unmet need was pain control (57% of the unmet needs). Cause of death was a significant predictor of unmet need. Unmet need was higher for those who died of natural causes compared to those who died of surgical or external causes. Unmet need was also higher for those who died of natural causes compared to those who died of surgical or external causes. Unmet need was also higher for those who died of natural causes compared to those who died of surgical or external causes.



Conclusions
 Palliative care is a health care specialty that is essential to study health conditions that affect the end of life. The utilization of palliative care services at the end of life is high, but the utilization of palliative care services at the end of life is low. The utilization of palliative care services at the end of life is low. The utilization of palliative care services at the end of life is low.

Narrative review
Preventive medication use among people with limited life expectancy

Vol. 41 No. 4 April 2012

Special Article
Exploring Care for Community
 M. Ruth Lavigne, M. Serge Dumont, PhD
 Department of Geriatrics (G.M.), and Division of Geriatrics and Palliative Care, St. Elizabeth's Hospital, Montreal, Quebec

Abstract
Context. Palliative study subjects. **Objectives.** This study aimed to assess generalizable prescribing care at the end of life. **Methods.** Study of treatment decisions of three populations: PCP to assess select study site bias to participate in end Results. Comparison study subjects were longer in the PCP (P < 0.0001) and were compared with all 4 were on average 2.0 (P < 0.0001) and were compared with all 4 were on average 2.0 (P = 0.03) persons who declined. **Conclusion.** If the study subjects, in fact 2011; 41: 779-787. © All rights reserved.

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Research article
Vulnerability in palliative care: an application and extension of the risk chain model

Yukiyo Asada
 Department of Community Health and Epidemiology, Dalhousie University, Halifax, Nova Scotia, Canada

The terms "inequity" and "vulnerability" have increasingly become popular in publications concerning health research and policy, including those on palliative care. Often, these words are used with ethical connotations but without precise definitions. In addition, despite the seeming affinity between these two terms, it remains vague how they might relate to each other. This paper proposes a way to understand the meaning of, and relationship between, inequity and vulnerability in palliative care. I start by introducing the risk chain model proposed by Abalos and his colleagues that describes how vulnerability occurs. Then I expand the risk chain model from ethical perspectives specifically in the context of palliative care and explore the meaning of inequity and vulnerability in palliative care. The paper concludes with identification of who are the vulnerable in palliative care and when palliative care is inequitable.

Introduction
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Upcoming ICE events

- African Nova Scotians at end of life KT workshop
 - Friday, October 14, 2011, AM – Rm 544 Bethune
- Visiting Scholar Maxine Hancock
 - 2012

Projects beyond ICE

- *Supportive care for women with advanced breast cancer*



- GoldHELP



New initiative

- CIHR Community based grant



Questions?

