

Cross-cultural End of Life Studies in Nova Scotia

**Farhana Kanth, Shauna McVorrán,
Victor Maddalena, Greta Rasmussen,
Grace Johnston**

Annual Research Day of “Palliative Care in a Cross Cultural
Context: A NET for equitable and quality cancer care for
ethnically diverse populations” New Emerging Teams:
Palliative and End-of-Life Care Strategic Initiative, funded by
Canadian Institutes of Health Research (CIHR)

June 15, 2007

Outline

- ✓ Overview of NELS-ICE
- ✓ ICE Surveillance Report
- ✓ ICE Communications:
www.nels.dal.ca and BLS
- ✓ African Canadians in Nova Scotia
- ✓ Asian Indian Immigrants to Nova Scotia

Network for End of Life Studies ICE Team

Research Investigators	Collaborators - Local, National, and International
Grace Johnston, PI Fred Burge, co-PI Eva Grunfeld Graeme Rocker Paul McIntyre Yukiko Asada Bev Lawson Victor Maddalena	Health Association of African Canadians IWK Children's Health Science Centre Capital Health Health Science Centre Faculty of Health Professions, Dalhousie U Faculty of Medicine, Dalhousie U Gael Page, CHPCA Julie Lachance, Health Canada Earle Craig, Dana-Farber, Boston Dan Hausman, Univ of Wisconsin-Maddison and WHO

Co-ordinator – Greta Rasmussen, nels@dal.ca

CIHR funded ICE

To build research capacity to reduce health disparities and promote equity for vulnerable populations at end of life with chronic disease

\$820,000 over 5 years (1996-2011) for

- ✓ Surveillance Report development
- ✓ Research Trainees - Masters, PhD, Post Doc
- ✓ Eight research pilot projects



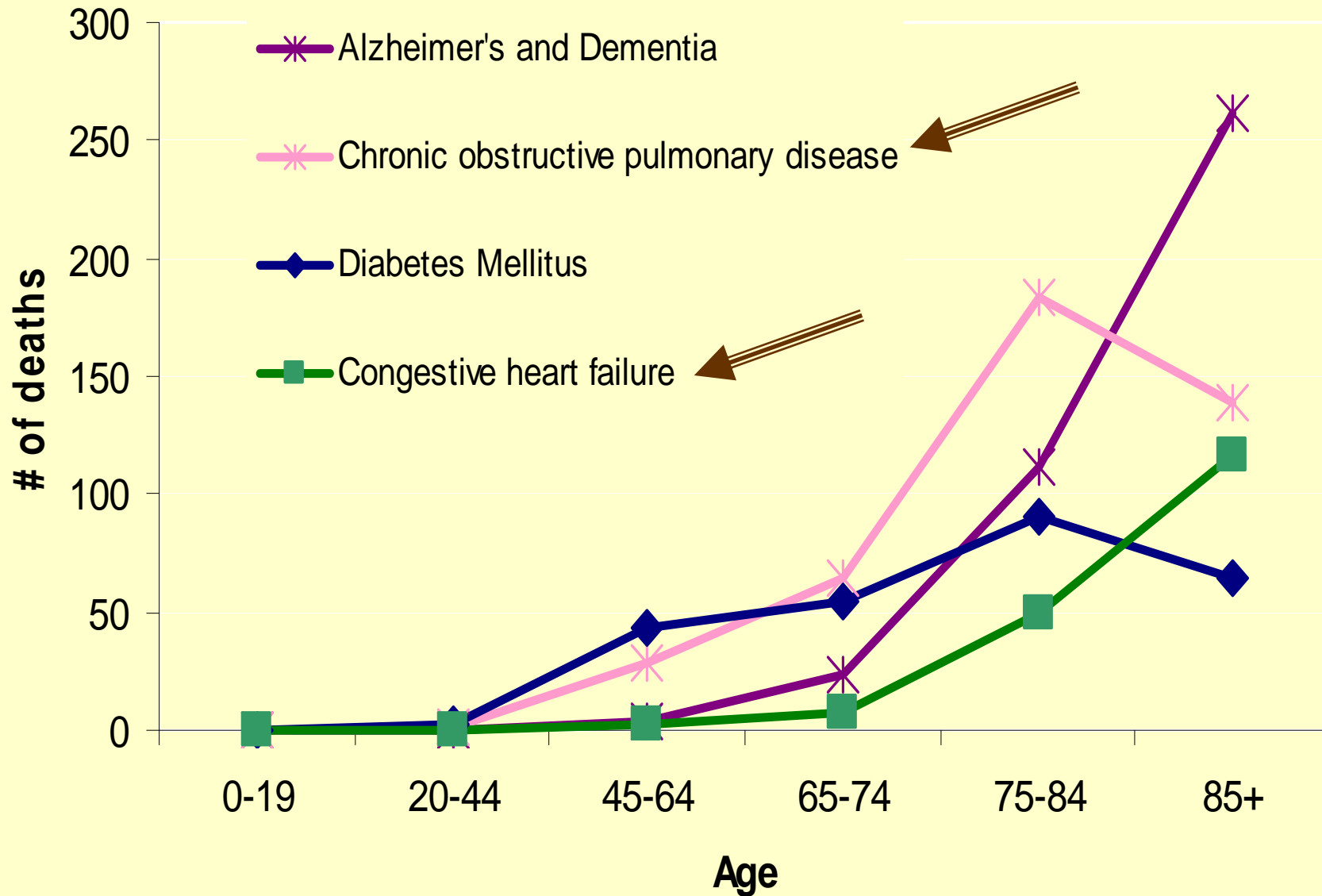
Pilot Projects

1	Development of a Surveillance System and Report of inequity in quality care at end of life	GJ, FB	Team SMcV
2	Defining vulnerable populations at end of life: Ethical Analysis	YA	DH
3	Quality pediatric terminal care and vulnerabilities	LP, GF	IWK
4	African Canadians, Asian Indians, and End-of-Life Care	VM	HAAC FK

Pilot Projects (continued)

5	Attaining a better understanding of gender and age at end of life	BL, FB	EL
6	Quality end of life cancer care for vulnerable elderly	PM EG	GP LL
7	Community based quality care at end of life with COPD (Chronic Obstructive Pulmonary Disease)	GR PM	NB
8	Canadian Compassionate Care Benefit: Is it working?	GJ PM	GP MF

Other chronic disease deaths, Nova Scotia, 2004



Surveillance Report and System

What is Surveillance?

- ✓ “the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health” (US Centre for Disease Control, 2001)
- ✓ Data disseminated by a public health surveillance system can be used for immediate public health action, program planning and evaluation, and formulating research hypotheses

Surveillance Report and System

Purpose

- ✓ To define vulnerable populations and to describe disparities in health services use at end of life among those populations
- ✓ To provide template for production of surveillance reports to aid in understanding health care disparities and inequities at end of life among vulnerable populations

Surveillance Report and System

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Surveillance Report and System

Western Canada End-of-Life (EOL) Care Project

- ✓ Project currently being undertaken by CIHI that has similar objectives to our surveillance work
- ✓ Goal of the CIHI Western Canada EOL Care project is to inform and improve planning for end-of-life care

[http://secure.cihi.ca/cihiweb/dispPage.jsp
?cw_page=eol_e](http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=eol_e)

NELS-ICE Knowledge Translation: Our Website

Network for End of Life Studies (NELS), Dalhousie University - Microsoft Internet Explorer

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Address http://nels.schoolofhealthservicesadministration.dal.ca/

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NELS: Network for End of Life Studies

Goal

To improve end-of-life care for persons with terminal illness by enhancing interdisciplinary research capacity through rigour and growth in our **Network of End of Life Studies (NELS)**.

Rationale

Canadians value their health system and expect ready access to effective care, but, there is uneven and inadequate access to quality end-of-life care. End-of-life is often a time of considerable health service utilization, substantial service needs, and major health care costs. We need to appraise whether care received is consistent with the standards of quality palliative care, optimization of quality of life for persons affected, and provision of adequate community based support. Nova Scotians say that access to palliative and supportive care close to home is critically important, but less than 20% are satisfied with the current provision of services.

Chronic disease deaths will continue to increase as our population ages. As a result, we will face further challenges of providing adequate quality end-of-life care. Advances in palliative care have typically focused on cancer. It is increasingly being recognized that end of life care for other terminal disease such as congestive heart failure and chronic obstructive pulmonary disease requires attention.

Who We Are

NELS is a group of researchers from the Faculties of Medicine and Health Professions at Dalhousie University, and the Capital Health District Authority in Halifax, Nova Scotia, Canada. We have a range of research and clinical expertise including epidemiology, ethics, palliative medicine, family medicine, oncology, chronic obstructive pulmonary disease (COPD), and intensive care. We have national and international collaborators.

Our Approach

Our research has been grounded in retrospective analyses using population based linked administrative data. We are now expanding our work to include surveillance, qualitative studies of vulnerable populations, and development in clinically based intervention studies.

We are guided in our research by the beliefs and values of:

- integrity and respect,
- innovation and excellence/rigor,
- transparency and cooperation,
- promotion of academic freedom,
- thoughtful and sustainable/stable growth,
- usefulness to all people at end of life, their families and care providers, and,
- fostering the development of new NELS research leaders.

NEWS & UPDATES:
Call for Graduate Student and Post Doctoral Trainees
[details...](#)

Congratulations! New Emerging Team Grant: Access to Quality Cancer Care.
Dr. Eva Grunfeld with...
[details...](#)

Videoconference: June 15, 12:30-3:00pm BC NET Research Day & Net Investigator Meeting
[details...](#)

Sept 20, Dr. Craig Earle Oct 22-25, Dr. Harvey Chochinov ... more details to follow

THIS WEBSITE IS UNDER CONSTRUCTION-- MORE INFORMATION COMING SOON

Email: NELS@dal.ca

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NELS-ICE Team/Internal Communications: Blackboard (BLS)

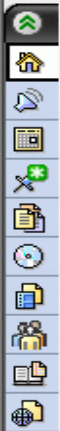


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**In-progress Surveillance
Report & Discussions**

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- 2 [Surveillance Overview-FBurge \(Jan 17, 2007\)](#)
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DISCUSSION: Surveillance Report

Discussion on 2nd draft report, which will be posted by June 15, begins on Fri June 15 and continues to Fri June 29.

- 2. [Definitions](#) (1 Messages)
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- [Other](#) (1 Messages / **1 New**)

Farhana



Victor



**Example:
Knowledge
Exchange
to develop
Surveillance
Report**

**Victor Maddalena, BN, MHSA, PhD in
Health region governance and African Nova Scotians,
CIHR-NET Postdoctoral Fellow 2005/06**

- ✓ Cancer Care Experiences and the Use of Complementary and Alternative Medicine (CAM) and Home Remedies in Nova Scotia's Black Community: A Pilot Study, completed in 2006
- ✓ Co-Investigators: Wanda Thomas Bernard, Josephine Etowa, Sharon Davis-Murdoch, Donna Smith, Phyllis Marsh Jarvis.
- ✓ Cancer and CAM Pilot study Article prepared for publication (submitted to Canadian Journal of Public Health June 07)
- ✓ Nova Scotia Health Research Foundation, 2007 Health Research Grants Competition, Cancer Care Experiences and the Use of Complementary and Alternative Medicine and Home Remedies in Nova Scotia's Black Community

Publications and Presentations

- [Book chapter]** Maddalena, V., Bernard, WT, Etowa, JB, Davis-Murdoch, S., Smith, D., Marsh-Jarvis, P. (2007). Cancer Care Experiences and the Role of Caregivers in Nova Scotia's Black Communities. [Book Chapter for "Black Women on the Margins: From Research to Action"] submitted
- [Poster]** (April 26-29, 2006). Maddalena, V, Bernard, WT, Etowa, JB, Davis-Murdoch, S., Smith, D., Marsh-Jarvis, P. Cancer Care Experiences and the Use of Complementary and Alternative Medicine (CAM) and Home Remedies in Nova Scotia's Black Community: A Pilot Study. 16th International Congress on Care of the Terminally Ill, Montréal, Canada.
- [Abstract]** Maddalena, V, Bernard, WT, Etowa, JB, Davis-Murdoch, S., Smith, D., Marsh-Jarvis, P. (Autumn 2006). Cancer Care Experiences and the Use of Complementary and Alternative Medicine (CAM) and Home Remedies in Nova Scotia's Black Community. Journal of Palliative Care, 22(3), 246.
- [Presentation]** (November 10, 2006). Cancer Care Experiences and the Use of Complementary and Alternative Medicine (CAM) and Home Remedies in Nova Scotia's Black Community. 2006 Dalhousie Cancer Research Symposium. Halifax, N.S. [Co-Presented with Dr. Wanda Thomas Bernard].

CIHR-ICE Post-Doctoral Fellow 2006/07

Assessing the Knowledge of African Canadians Living in Nova Scotia Regarding Options Available for Palliative and End of Life Care Using **Participatory Action Research**: A Pilot Project

Co-Investigators: Wanda Thomas Bernard, Josephine Etowa, Sharon Davis-Murdoch, Donna Smith, Phyllis Marsh Jarvis

- ✓ To learn more about knowledge, beliefs and understandings of options and services to support individuals and families at end of life in the Black community
- ✓ To provide information about services available to support and facilitate culturally competent end of life care
- ✓ To develop knowledge translation strategies to communicate research findings to the community and to policy makers in the health and social service sectors

New NELS Research Project

Weerasingh S (PI), Maddalena V (Co-PI), Kanth F (2007). Culturally Competent End of Life Care for Asian (South, Southeast and Middle Eastern) Immigrants in Halifax. Funded by Atlantic Metropolis Centre, May 2007 Submitted to REB