

Palliative and end of life care:

Exploration of opportunities for your research career

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with Network for End of Life Study (NELS)
Interdisciplinary Capacity Enhancement (ICE)
Colleagues

September 24, 2009

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

C RTP “Integrated” Learning Session

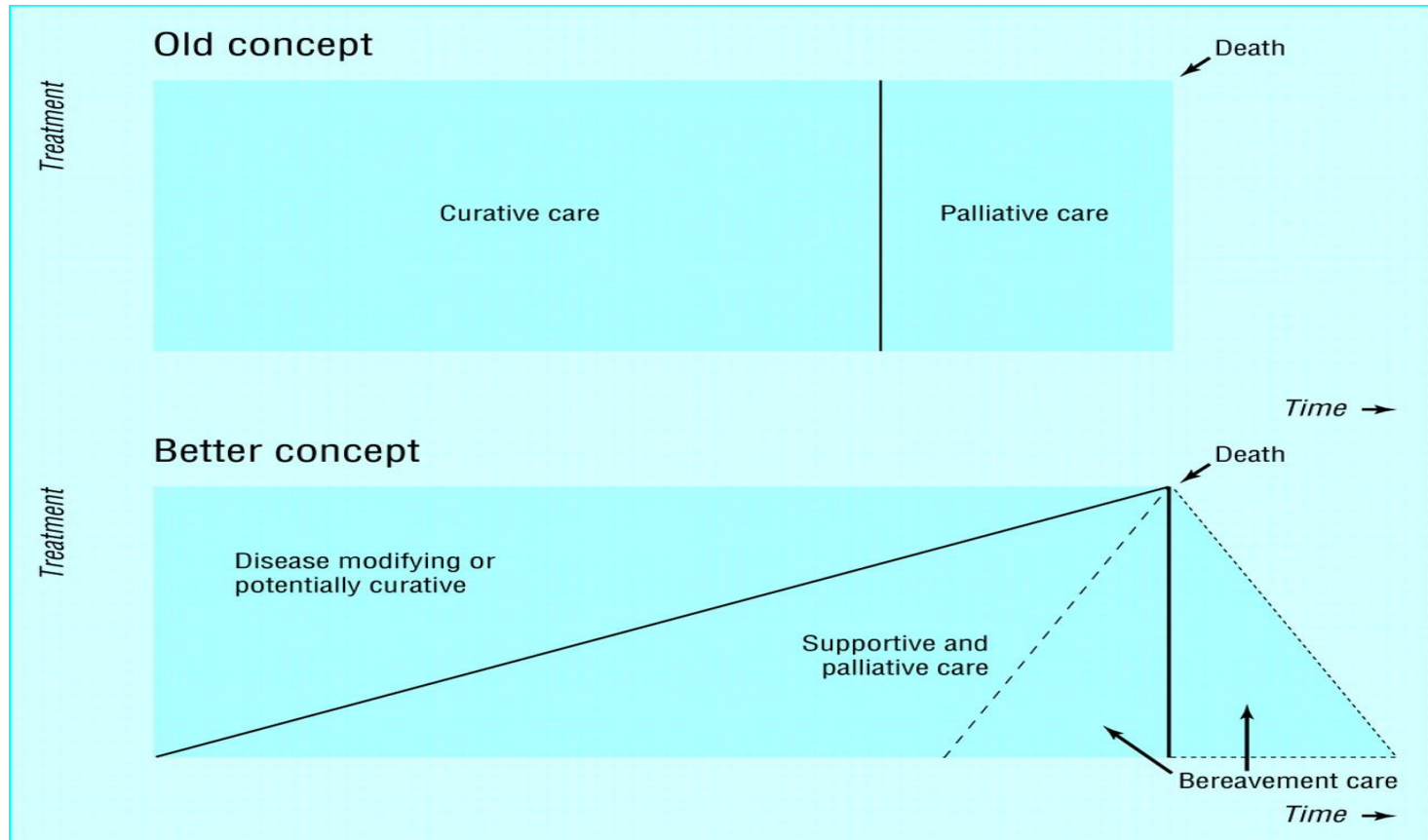
Outline

- What is palliative care?
- Why are palliative and end of life care important?
- What is NELS ICE?
- What is interdisciplinary research and integrated learning?
- What are some examples?

Discussion:

1. What might your discipline and/or research contribute to improve palliative and end of life care?
2. How might interdisciplinary research and integrated learning occur in relation to palliative and end of life care?

Palliative Care



Murray, S. A et al. BMJ 2005;330:1007-1011

Definitions

End of Life

- Last 6 months
- Predicted by health professionals
- Determination is still a challenge

End of Life Care

- Live as well as possible until death within weeks/months/years of life threatening illness
- Includes all care: curative, palliative and terminal

Caregivers

- Persons assist in (mobility, transportation, communication, housework and self care)
- Becoming more complex

Supportive Care

- Help patients + caregivers cope better
- Not specific to disease/time

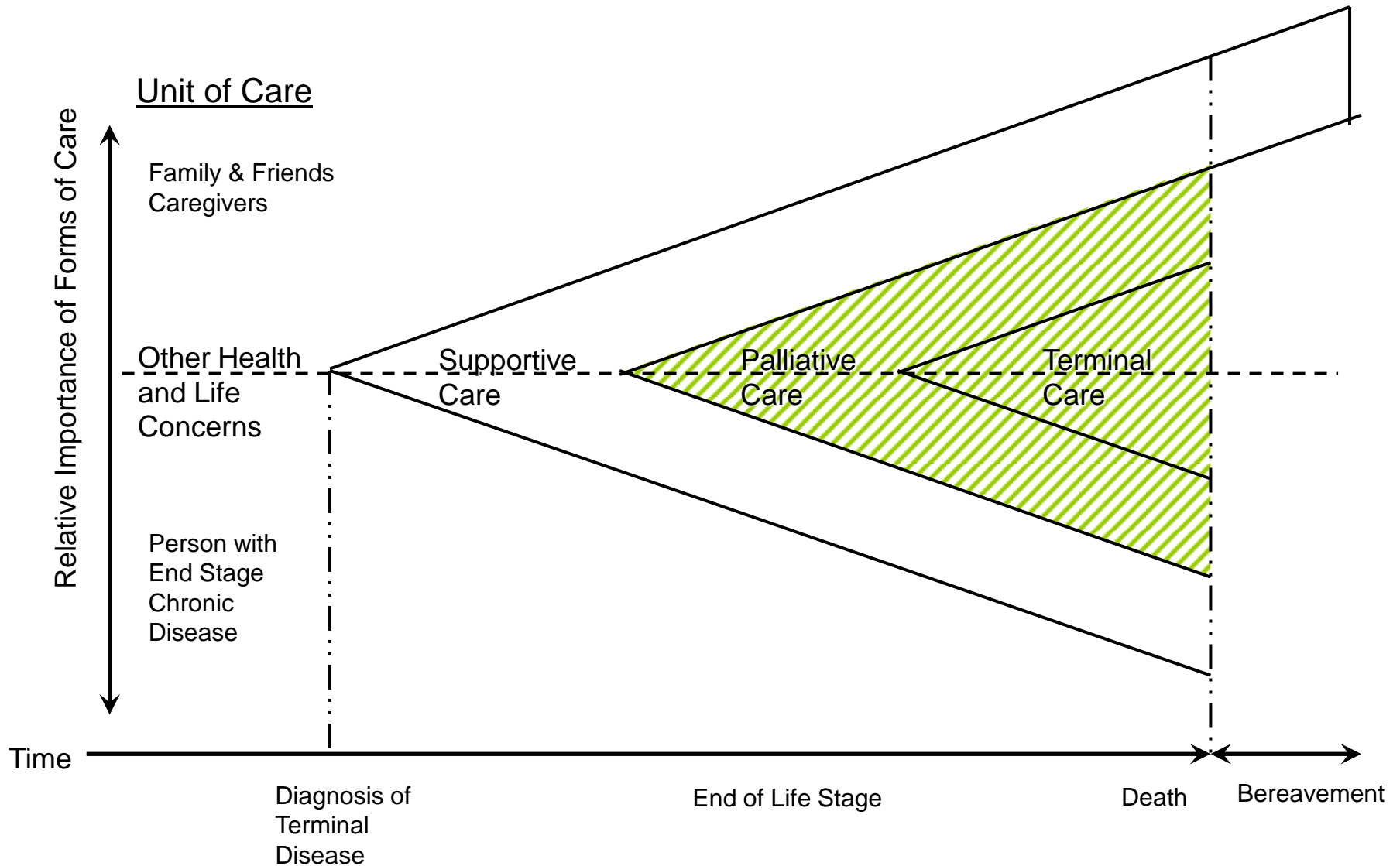
Palliative Care

- Improve quality of life at latest stages
- Focus on physical, psychological, social and spiritual factors
- Delivered by specialized personnel
- Can overlap curative treatment

Terminal Care

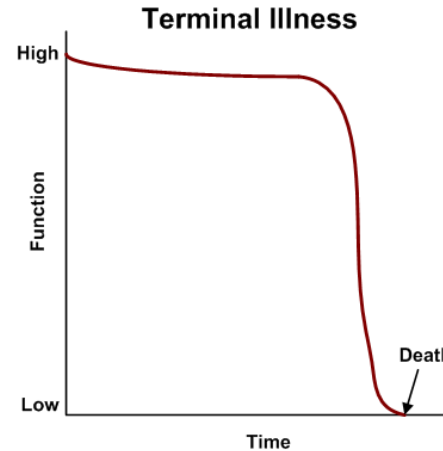
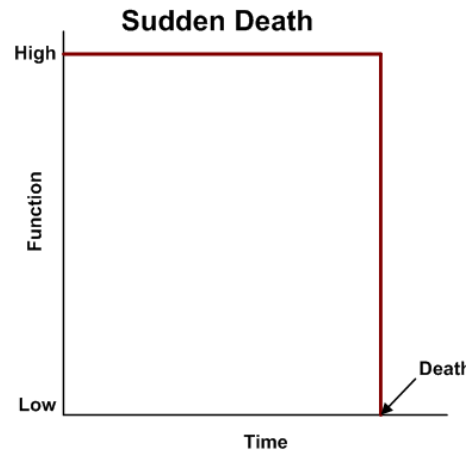
- Services provided at last days or hours of life

Proposed Conceptualization of End of Life Caregiving



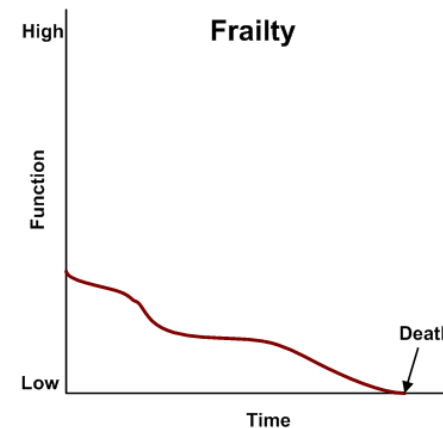
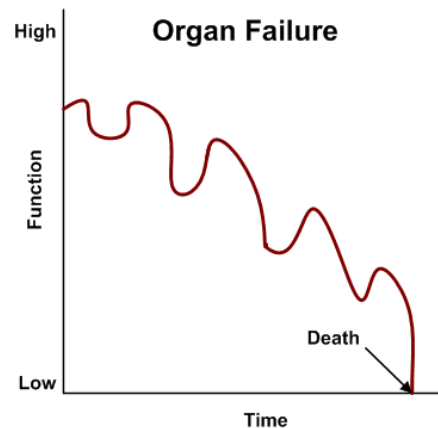
End of Life Trajectories (Function over Time)

Accidental death
Falls
Trauma



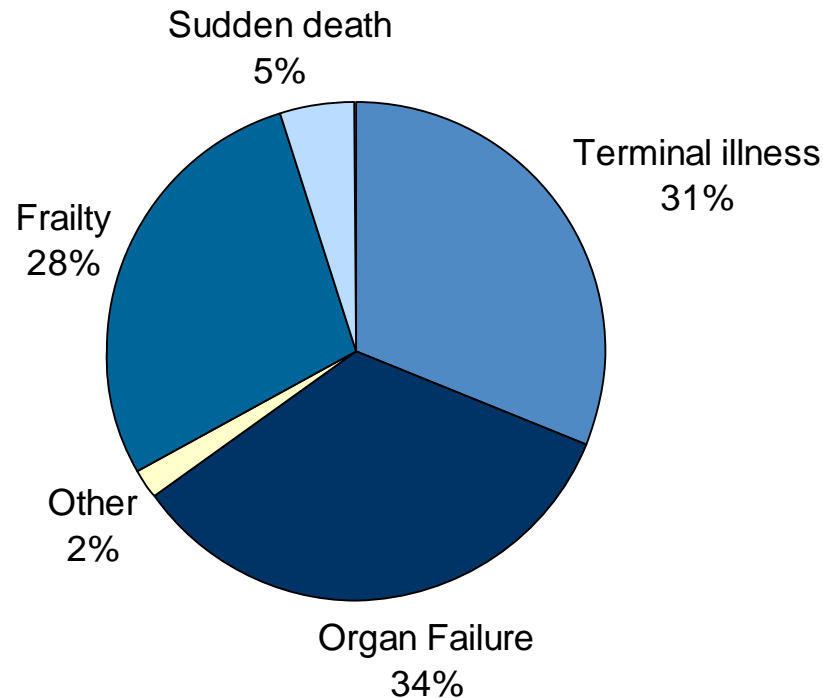
Cancer
Motor neuron disease
HIV-related diseases
Chronic renal failure

Congestive heart failure
Chronic obstructive pulmonary disease



Alzheimer's disease and dementia
Neurological decline
Late effects of stroke

Deaths by Trajectory of Dying, 2000-2005, NS



Decedents were assigned to trajectories using methods defined by:
K. Fassbender et al., *Costs and Utilization of Health Care Services at End-of-Life*
(Edmonton, Alta.: Institute for Public Economics Health Research Group, March 2006).

Estimating who could have benefited from palliative care services: Minimal estimate

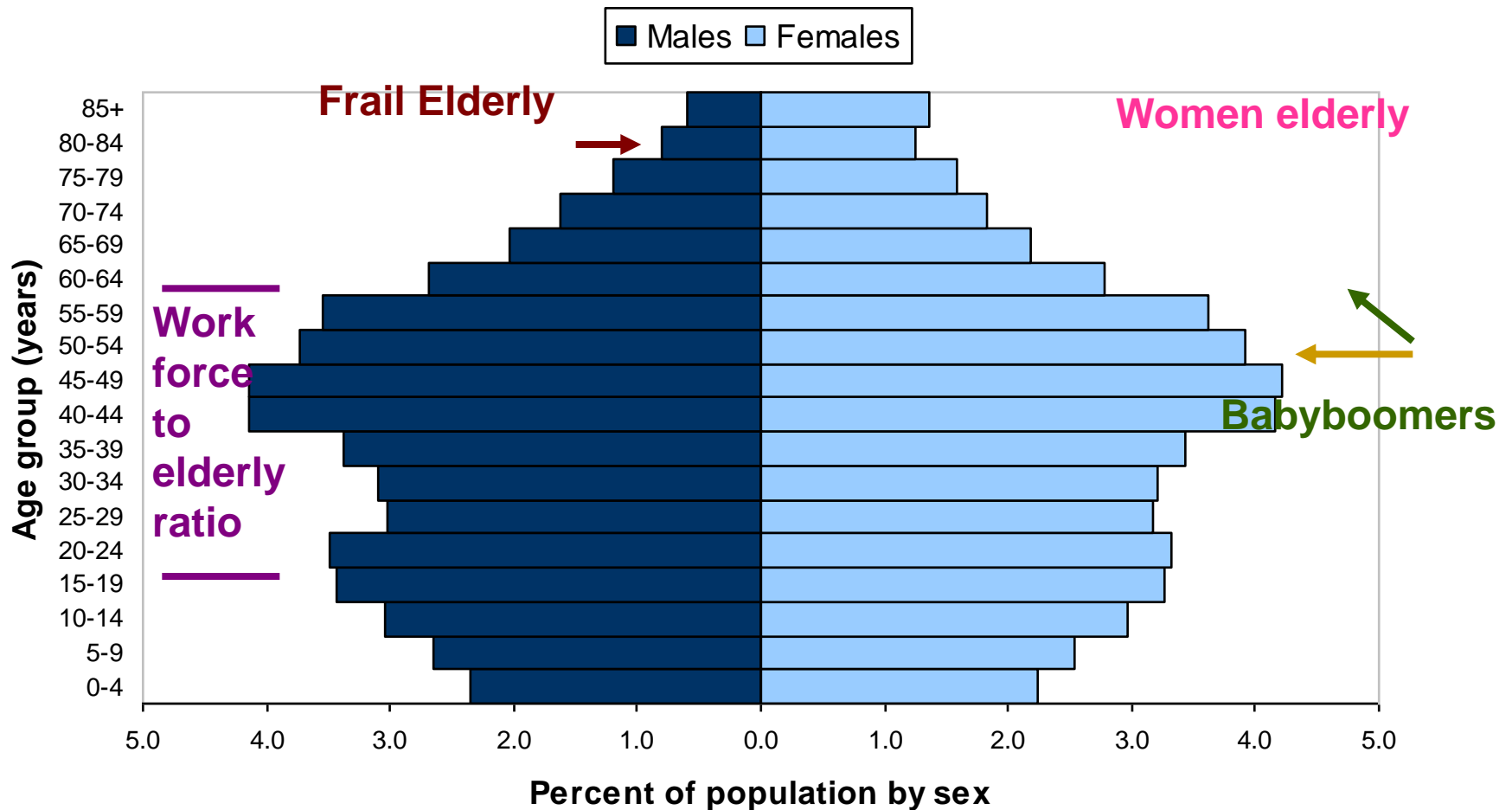
Nova Scotia deaths, 2000-2005 (n = 47,895)¹

Underlying cause of death (ICD-10 codes)	N	% of all deaths
Neoplasms (C00-D48)	14,454	30.2
COPD (J40-J44)	2,336	4.9
Alzheimer's disease (G30)	1,436	3.0
Heart failure (I11.0, I13.0, I13.2, I50)	1,358	2.8
Renal failure (I12.0, I13.1, N17-N19)	934	2.0
Parkinson's disease (G20-G21)	361	0.8
Motor neuron disease (G12.2)	136	0.3
Liver failure (K70.4, K71.1, K72.1, K72.9)	111	0.2
HIV/AIDS (B20-B24)	35	0.1
Huntington's disease (G10)	30	0.1
TOTAL	21,191	44.2

¹ Excluded 13 records that were missing an underlying cause of death.

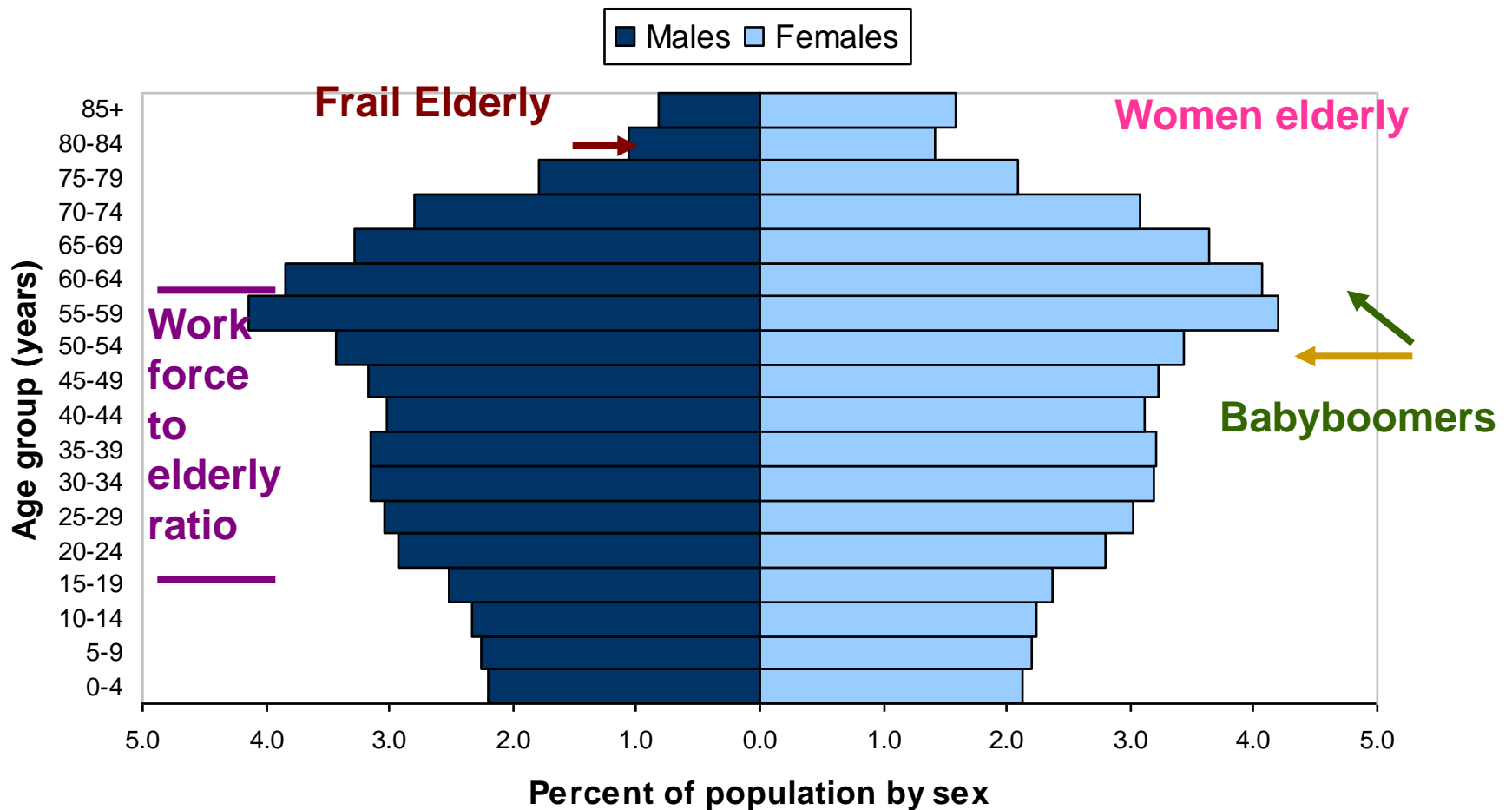
Aging of the Population

Population pyramid, by five year age categories, Nova Scotia, 2001

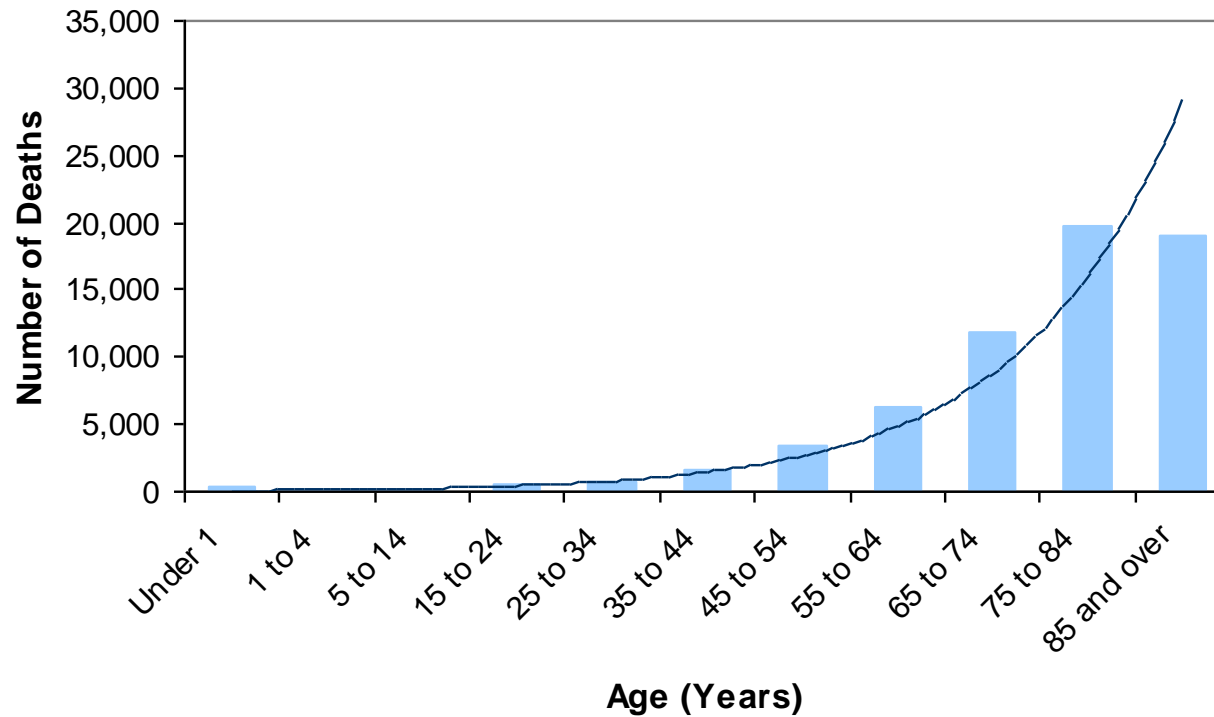


Aging of the Population

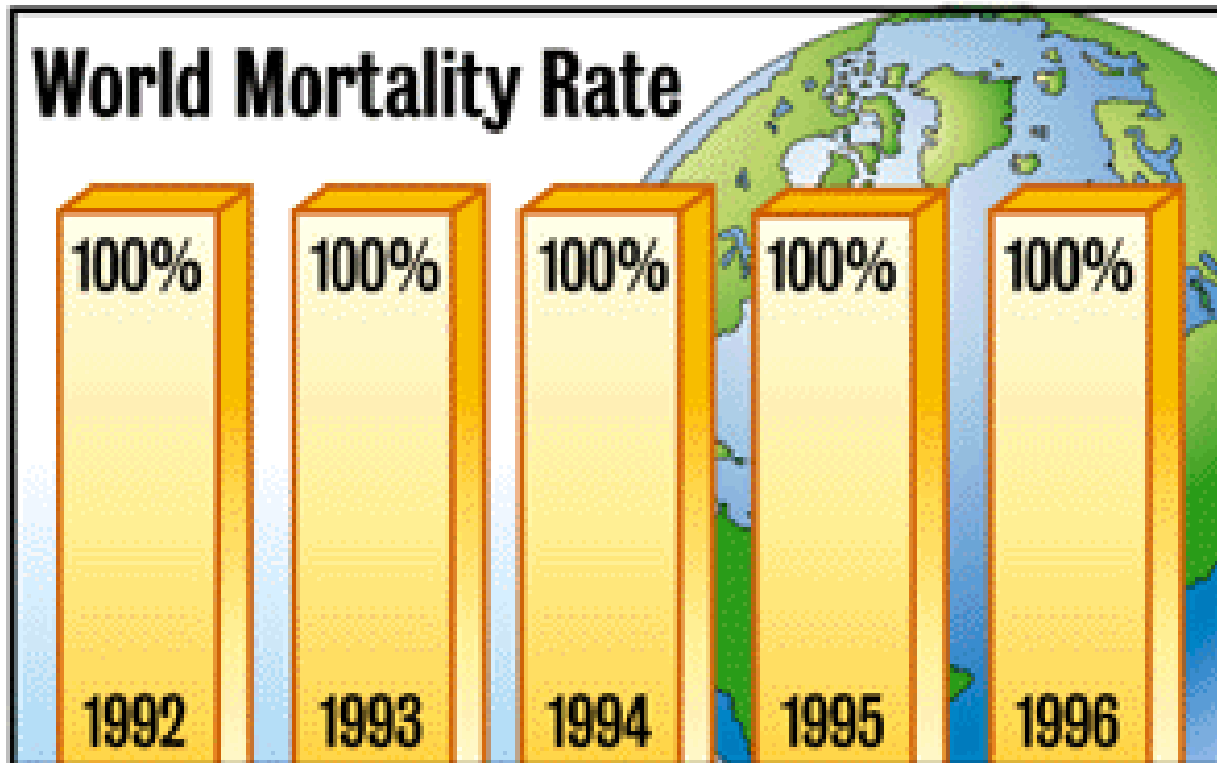
Population pyramid, by five year age categories, Nova Scotia, 2021



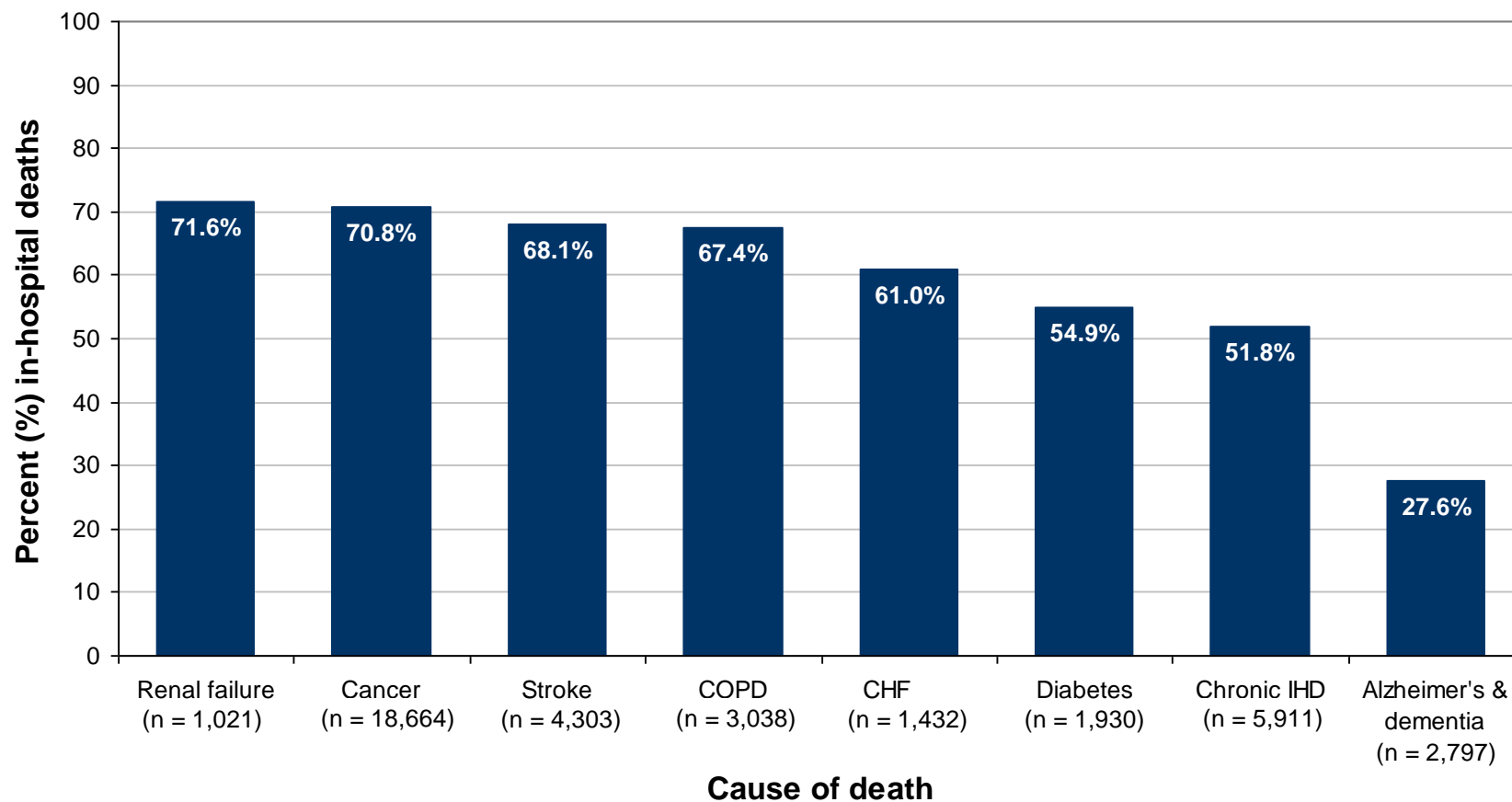
Nova Scotia deaths by age, 1998 - 2005



What is the likelihood that we will die?



Percentage of in-hospital deaths for selected underlying causes, all ages, Nova Scotia, 1998-2005



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

NELS

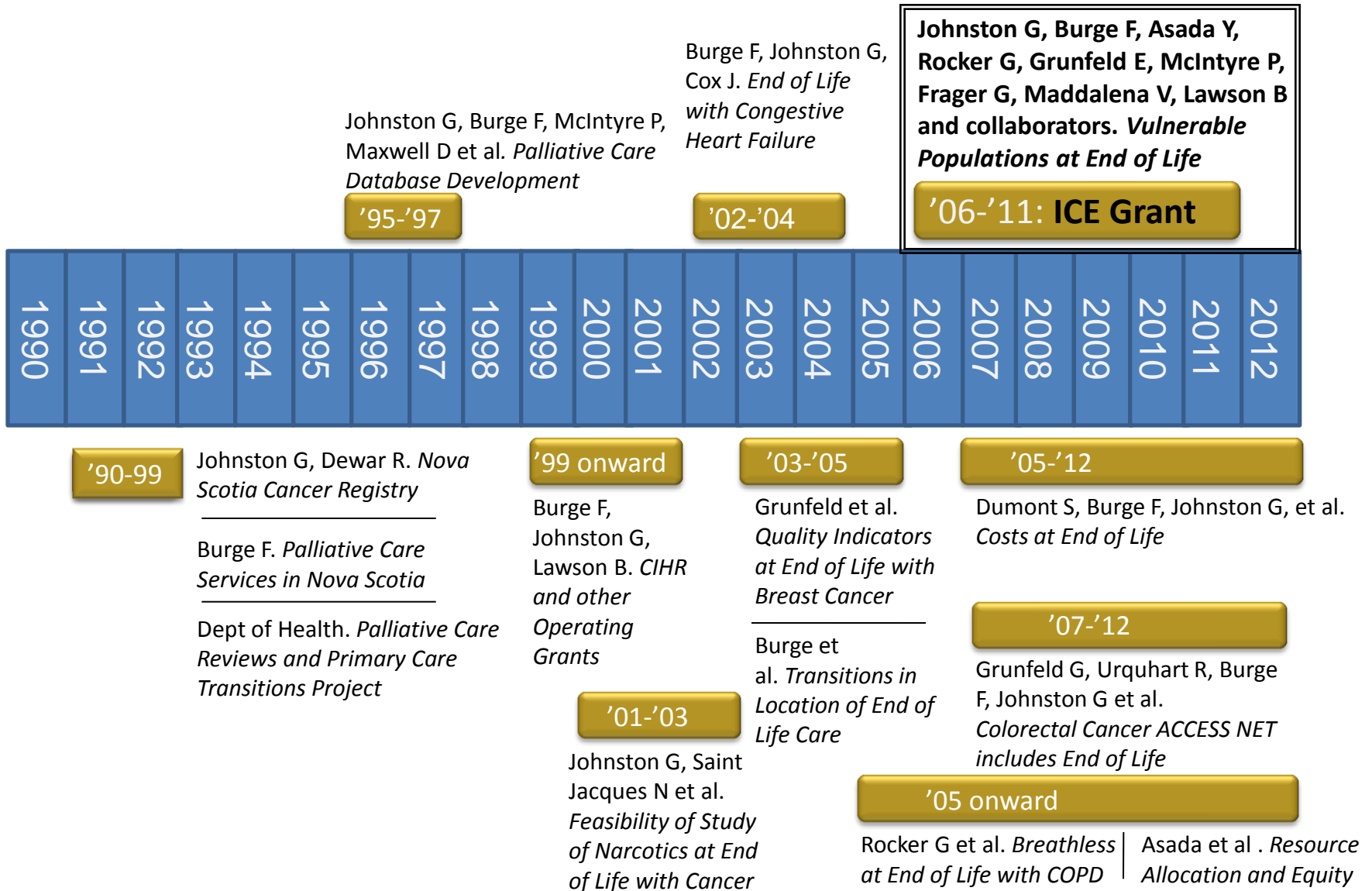
Projects over more than 10 years by Halifax based researchers to investigate end of life care

ICE

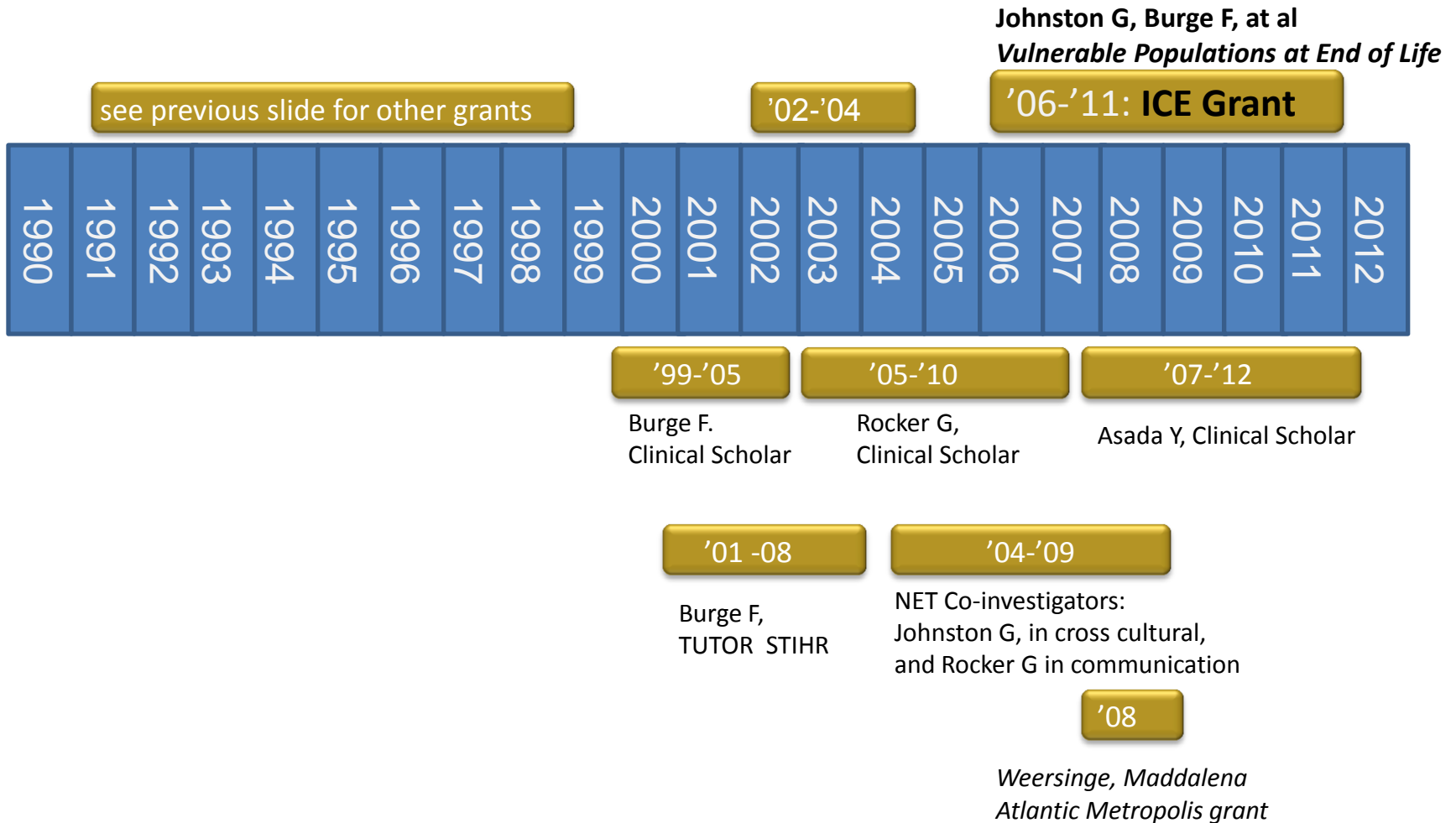
Grant was awarded by CIHR to NELS in 2006 for five years to build research capacity to improve access to care for vulnerable populations. ICE grants are similar to but differ from New Emerging Team (NET) and Strategic Training in Health Research (STIHR) grants in that they are all Team and infrastructure development grants, rather than research project Operating grants

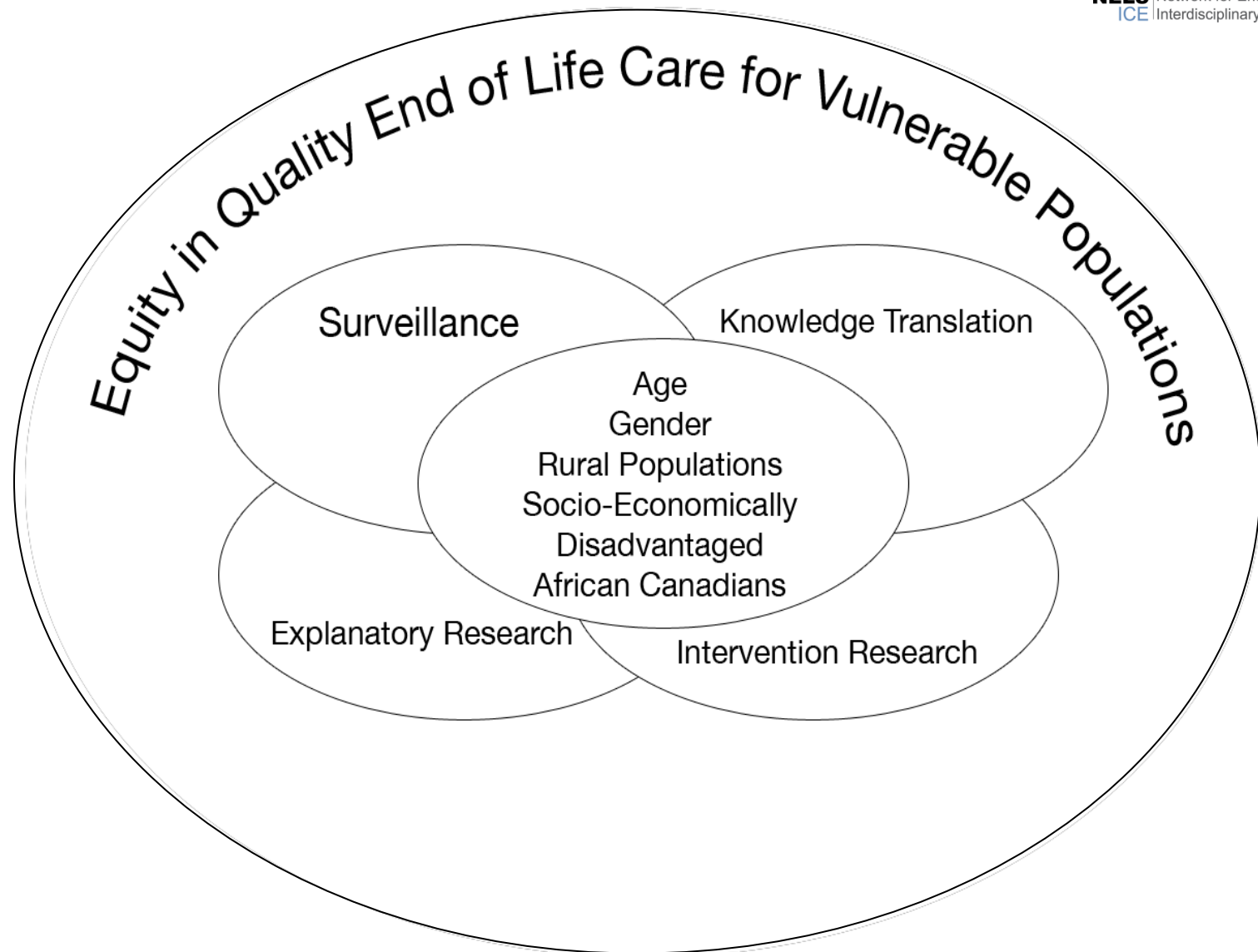


NELS Development with ICE, Operating and Seed Grants



NELS Development through ICE, Clinical Scholar, NET, STIHR, and Other Research Grants





NELS ICE Research Framework

Goals of NELS ICE

1. Create an **interdisciplinary team** of researchers, trainees, health professionals, and community partners
2. Develop **surveillance system** and reports to identify **vulnerable populations** at end of life
3. Design and conduct **pilot studies** for full **research** proposals to examine and address vulnerability and inequity in provision of quality end of life care
4. Engage in “**knowledge translation**”

Population-Based Surveillance Reporting

End of Life Care in Nova Scotia
Surveillance Report

www.nels.dal.ca

In progress:

*Cancer Care Nova
Scotia Report*

*Canadian Cancer
Statistics 2010*

Network for End of Life Studies (NELS)
Interdisciplinary Capacity Enhancement (ICE)
Dalhousie University

**Listening to Stakeholders
Report of Consultation on**
“End of Life Care in Nova Scotia
Surveillance Report”

Network for End of Life Studies (NELS)
Interdisciplinary Capacity Enhancement (ICE)
Dalhousie University

NELS ICE Question

Interdisciplinary study prerequisite is an overarching “complex question” (Repko, p. 6):

For NELS ICE, this overarching complex question is :

How can equity be achieved in the provision of quality care for persons living with life threatening chronic disease?

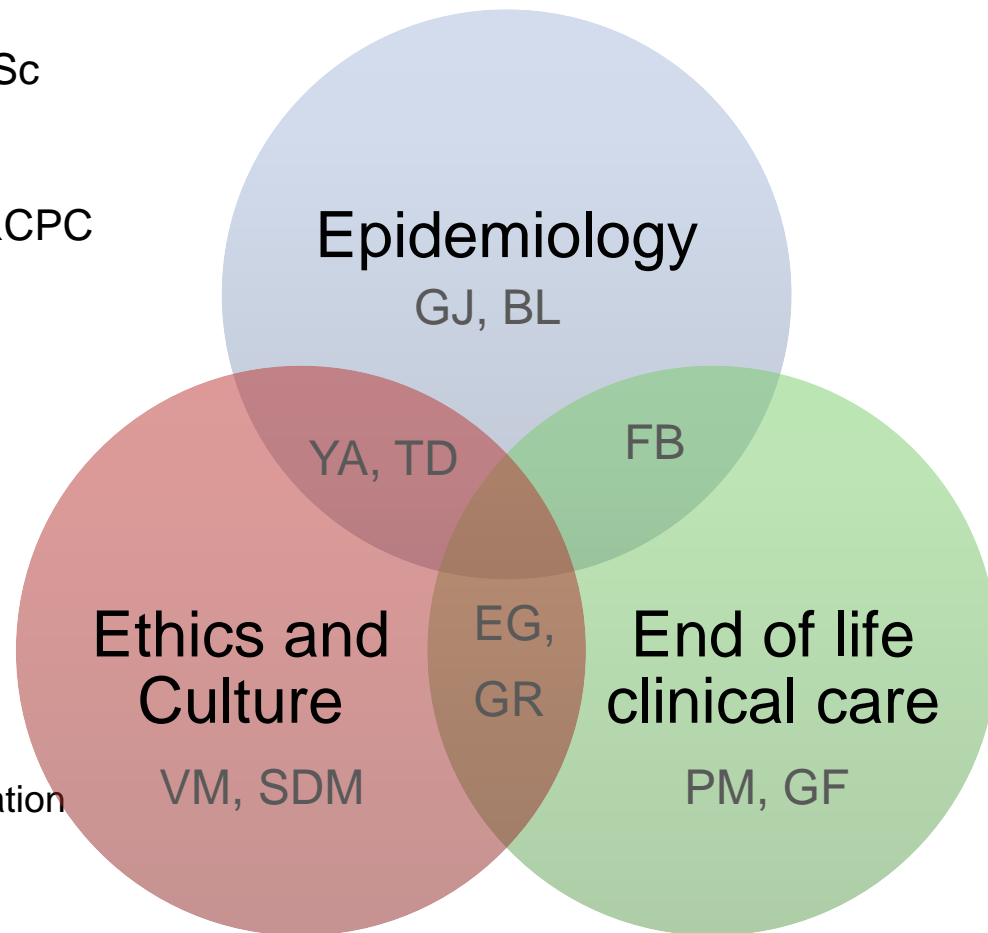
NELS ICE “Interdisciplinary” Team

PI: Grace Johnston, MHSA PhD
Co-PI: Frederick Burge, MD FCFP MSc
Yukiko Asada, MSc PhD
Eva Grunfeld, MD DPhil CCFP FCFP
Graeme Rocker, MHSc DM FRCP FRCPC
Beverley Lawson, MSc
Paul McIntyre, MD FCFP
Victor Maddalena, BN MHSA PhD
Gerri Frager, MD FRCPC

PLUS

**Trainees,
Staff, and
Collaborators**

Julie Lachance, Health Canada
Gael Page / Ann McKim, Nova Scotia (NS)
Canadian Hospice Palliative Care Association
Sharon Davis Murdoch, NS Dept of Health
Others ...



Disciplinary Studies



Humanities



Social Sciences



Basic Sciences



Applied
Professions

A **discipline** is a “particular branch or body of knowledge whose defining elements, i.e., phenomena, assumptions, epistemology, concepts, theories, and methods, distinguish it from other knowledge formations. ... Its knowledge domain consists of an enormous body of *facts* ... that has been recorded in human history ... *concepts or ideas* ... generates *theories* ... uses *methods* that involves critical analysis of primary sources ... to present a picture of past events or persons within a particular time and place”.

(quotes from Repko, 2008, p. 4-5)

CIHR Pillars



Population
Health

+



Health Services/
Systems

+



Clinical



**Bio-
medical**



**A current gap
in NELS ICE**

Interdisciplinary “studies”

- Focus is on integrating knowledge to answer a complex question rather than being constrained by disciplinary thought
- Detaches a subject from existing disciplinary boundaries, and fills in knowledge gaps
- Thinking creatively and bridging forms of communication are important
- Does not have an existing unique body of knowledge or methods; borrows from disciplines
(Repko, pages 6-9)
- Studies is plural as a result of interactions between disciplines
(Klein 1996 as reported in Repko p 8)



Integrated study

- Purposeful process to gather together expertise from two or more foundational disciplines, rather than a method
- Methodological flexibility to better understand our world
- **Reflexive scholarship generating new insights/understanding of problem**
- Confronts differences to seek a common ground and unify knowledge
- Aims for a whole; more than sum of parts; not merely rearranging
- Tentativeness rather than absolute answers typically emerges

(Repko, p 8, 12, 20)



“Smoothie”

Multidisciplinary study

Two or more disciplines provide insights on a problem of mutual interest with no attempt to integrate data, concepts, theory, and methods.

(Repko, 2008, p. 13-15)

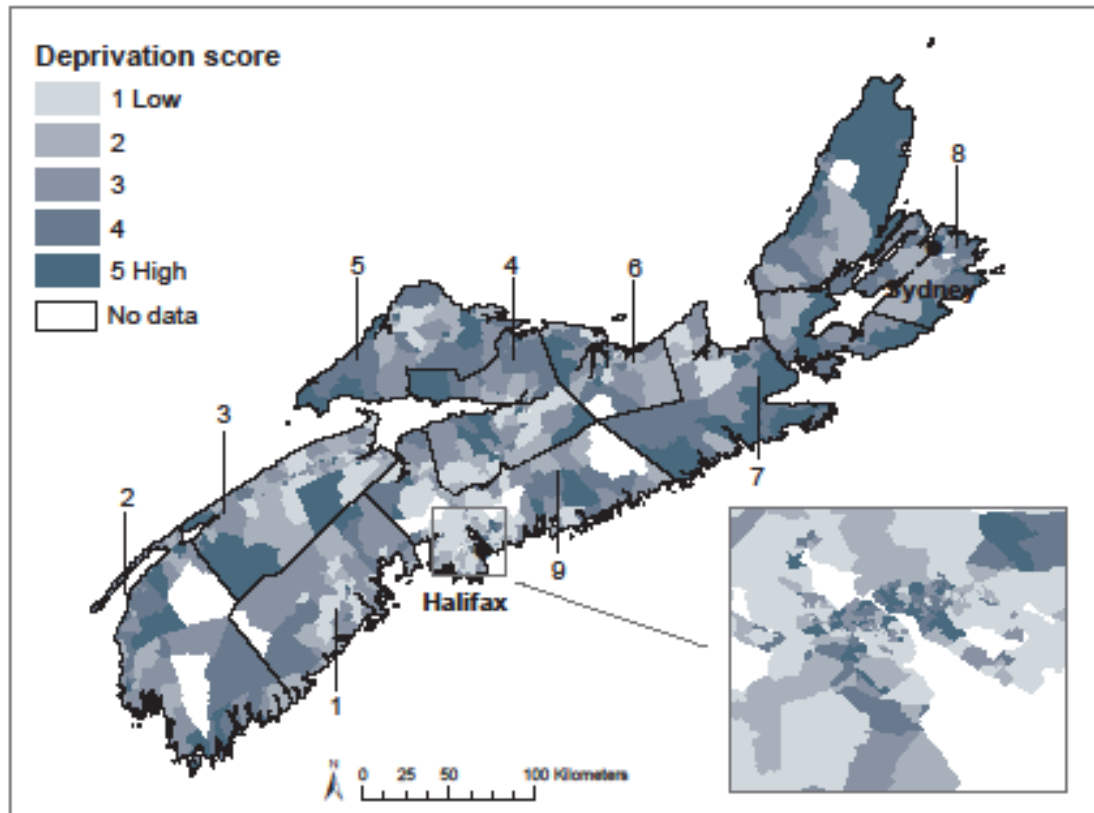


Non Disciplinary Knowledge

- Perspective, practice, and tradition of health professionals
- Views and preferences of person at end of life and their families, friends, and other respected persons
- Cultural, religious, and societal context and norms
- Fears and anxieties including coping practices and what is unspoken or silenced
- Laws, regulations, health and other systems, funding sources and volunteer/lay support perspectives, constraints and enablers

(developed from thoughts from Repko, pages 10 ...)

An NELS ICE Example: Combining Geography and Epidemiology using Census-based Deprivation Scores



DCRP Integrated Learning Session Three: **When Cancer might not be Cured** - *Friday, March 12, 2004*

Research relevant to “When cancer might not be cured”

- Dr Jana Sawynok, Department of Pharmacology
- Dr Anita Unruh, School of Health and Human Performance
- Jan Sutherland, Health Law Institute
- Dr Pat McGrath, Department of Psychologist

NELS ICE 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; qualitative, participatory
5. Mortality Follow-Back Study from Death Certificates
6. Elderly in Nursing Homes
7. Community Care for Chronic Obstructive Pulmonary Disease
8. Family Caregiving
9. Medication Use at End of Life
10. Economic Analysis
11. *What can you and your discipline/research contribute?*

Also Visiting Scholars, work-in-progress, pilot projects, trainees, data base development, surveillance reports,....

Comments, Questions?

Contact Information

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CIHR IRSC

Canadian Institutes of Health Research
Instituts de recherche en santé du Canada



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UNIVERSITY**

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Capital Health



IWK Health Centre



*Cancer Care
Nova Scotia*

Nursing Home Residents versus Others ≥65 years Dying of Cancer, 2000-2003

Quality Indicators	Nursing Home		Non Nursing Home	
	n	Statistic	n	Statistic
HOSPITAL DAYS IN LAST MONTH OF LIFE				
> 1 admission, # (%)	893	46 (5%)	6237	898 (14%)
> 14 days, # (%)	893	118 (3%)	6237	2220 (36%)
Mean days	893	5	6237	12
≥ 1 ICU admission	893	25 (3%) 177	6237	318 (5%)
Died in hospital # (%)	893	(20%)	6237	3697 (59%)
PALLIATIVE CARE PROGRAM				
Enrolled in CH/CB, # (%)	354	131 (37%)	2965	2040 (69%)

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CHEMOTHERAPY				
In last 6 months, # (%)	893	7 (0.8%)	6237	350 (6%)
Mean days from last chemo to death	7	112	350	74
EMERGENCY ROOM VISITS				
> 1 visit in last month, # (%)	893	25 (3%)	6237	399 (6%)
Mean visits in last month	893	0.2 visits	6237	0.4 visits
FAMILY PHYSICIAN VISITS				
Mean visits (for those with > 2 visits)	293	6.2	4867	8.0
Home/office visits in last two weeks, # (%)	870	139(16%)	6015	487(8%)

Population Surveillance Dataset

