

Need for a comprehensive model of palliative support and end of life care in Nova Scotia

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Provincial Cancer Network Meeting

Concurrent Session:

Exploring a Model of Palliative Support for Persons with Advanced Cancer

April 20, 2012

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



Outline

- Demographics and risk of death
- Health services in an historical context
- Conceptualizations of palliative and end of life care
- Context of NELS research knowledge exchange
- Insights into situation for persons living with cancer in Nova Scotia
- Purposes of today's concurrent session



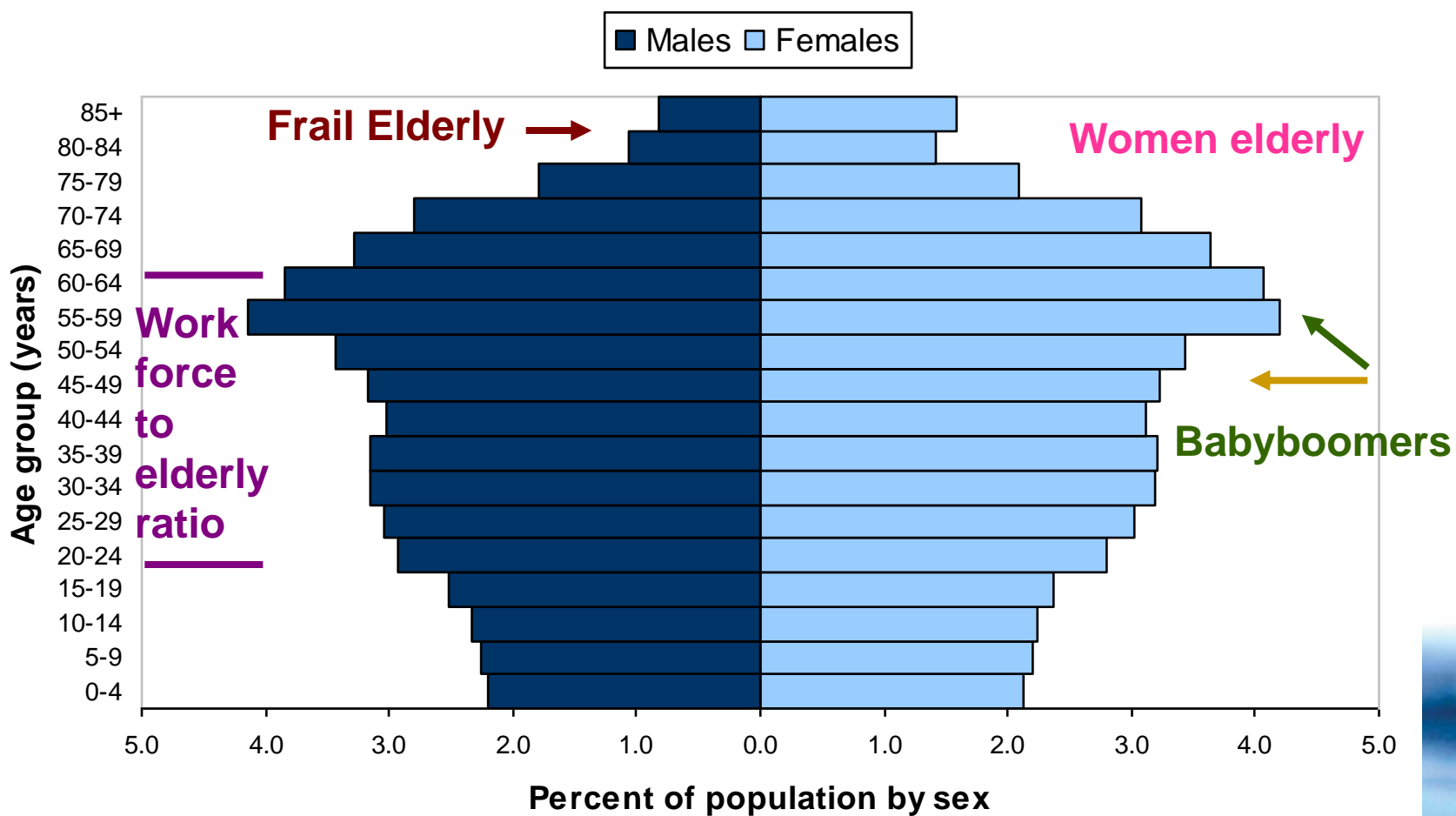
Impact of aging population, increasing and inevitable risk of death with age, and resource implications



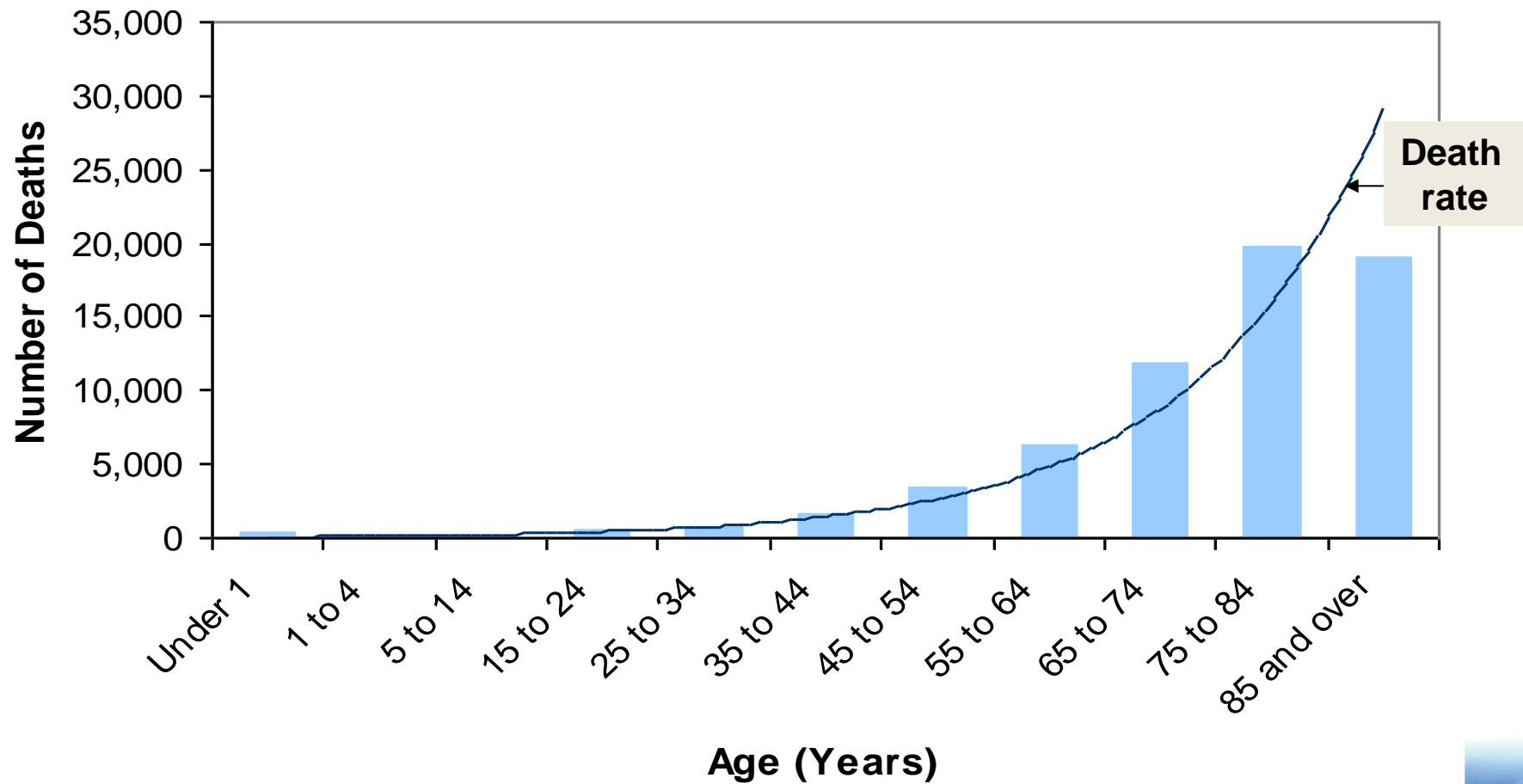
Aging of the Population

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

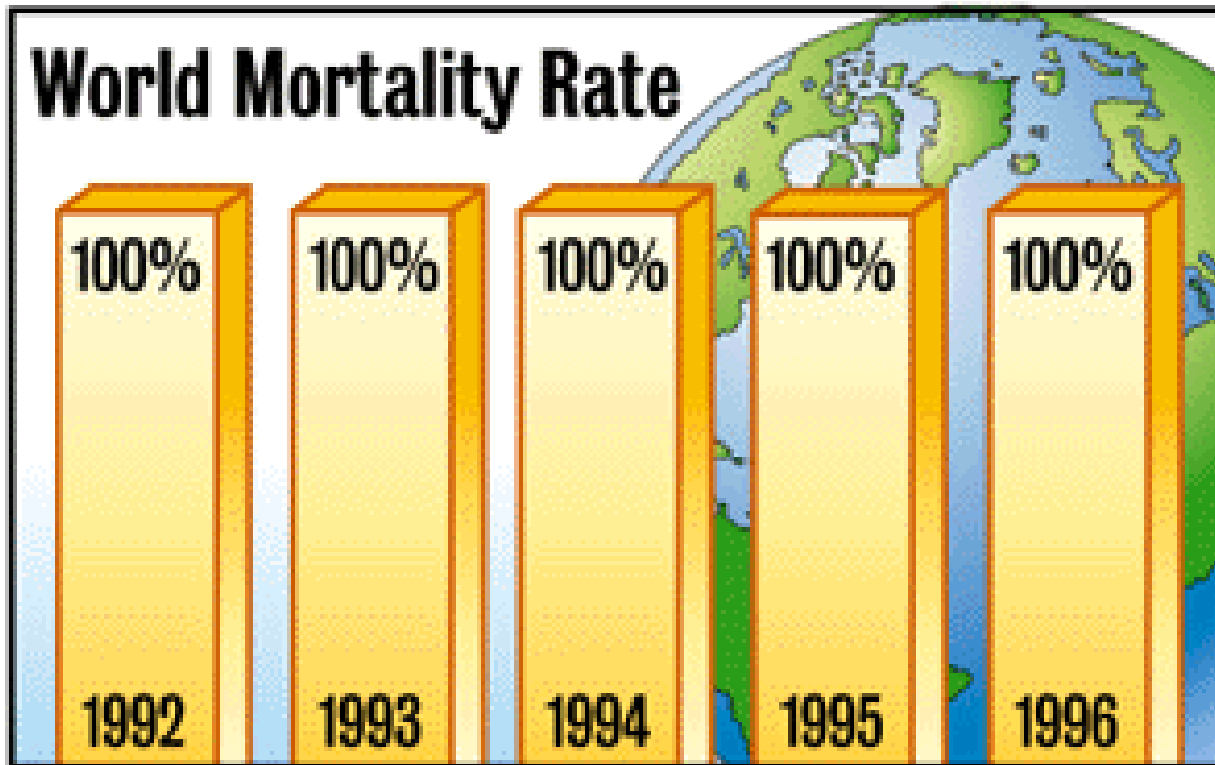
Population pyramid, by five year age categories, Nova Scotia, 2020



Nova Scotia Deaths by Age, 1998 - 2005



What is the likelihood that we will die?

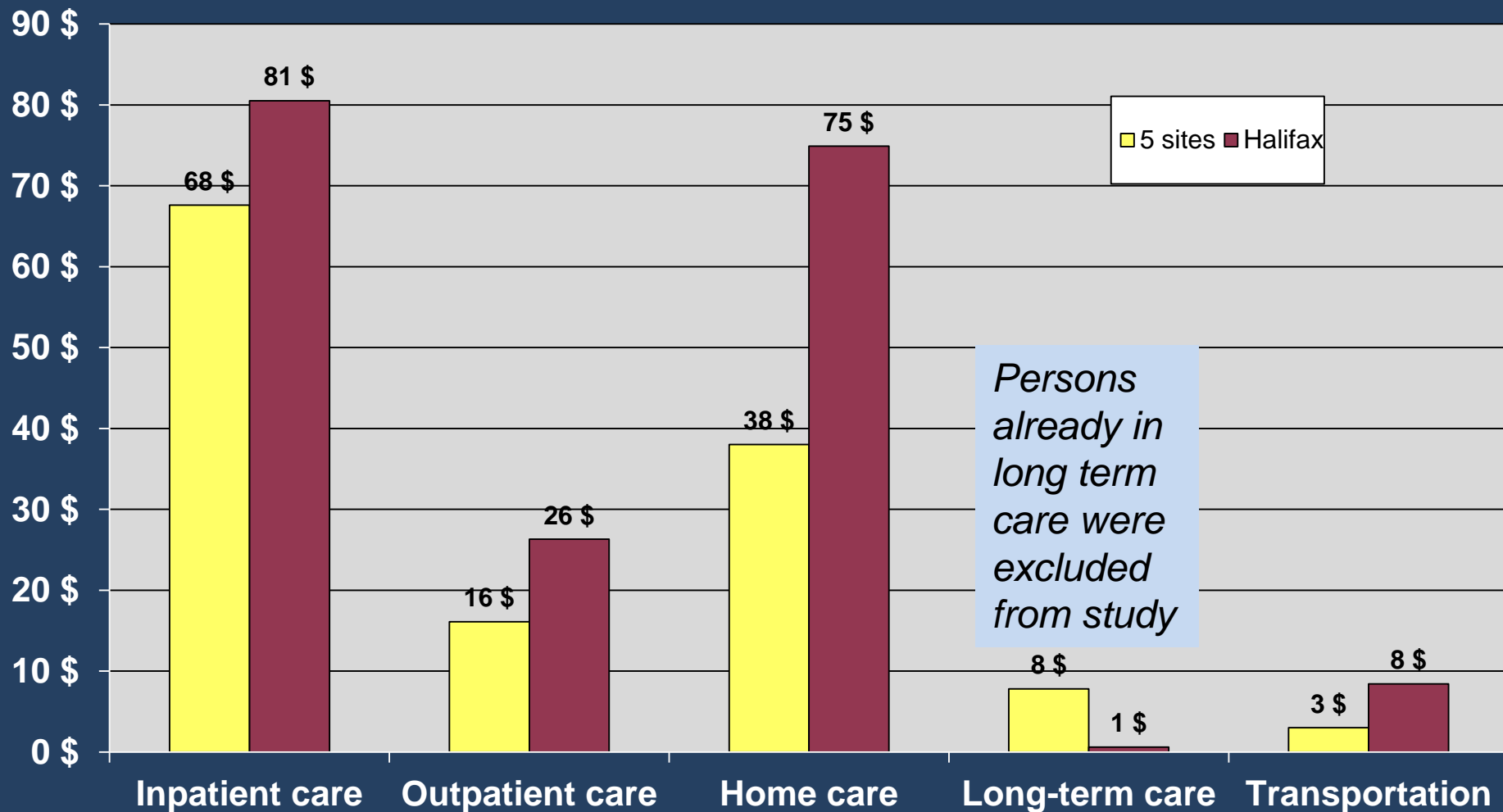


Avoidance of discussion of death and dying – someone else’s issue.

Consider the language we use: “if” we die versus “when” we die.

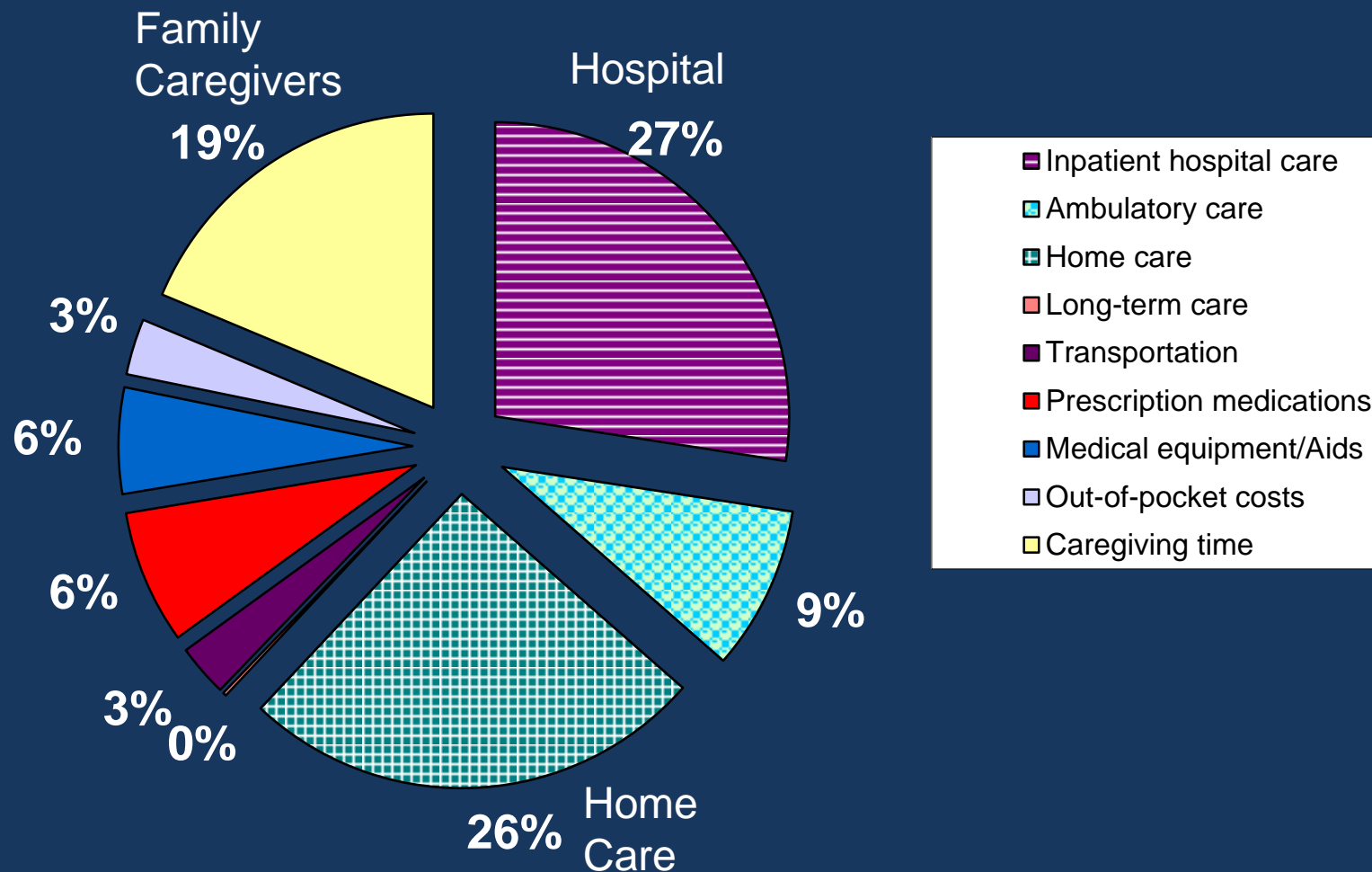
Need public health and societal shift in thinking which encompasses new information technology, transformation in primary and community health, in context of comprehensive collaborative chronic disease management

Mean daily costs per palliative care patient



Preliminary findings from 2009 presentation by Serge Dumont. Findings now published as:
Dumont S, Jacobs P, Fassbender K et al. (2009) Costs associated with resource utilization during the palliative phase of care: A Canadian perspective. Palliative Medicine 23(8):708–717

Cost distribution for palliative care patients



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Health services context



Brief Historical Context - Canada

Health is a **provincial** not a federal responsibility: BNA Act
Post WW II – in 1950's built hospitals
1960's – Canada-wide **hospital insurance**
1970's – Canada-wide **physician insurance added**
Led to Canada Health Act; Recent Health Accord discussions


Concurrently, palliative medicine began. Dr Balfour Mont in Montreal after studying hospice care with Dame Cicely Sanders in UK. In Canada became physician and hospital based where costs of services were publicly funded. For decades, palliative care had cancer focus and urban-based champions.

Out-of-hospital , community-based health care is underdeveloped in Canada

Ranking countries by quality of end of life care. (2010, July 14). *The Economist*. Retrieved from http://www.economist.com/node/16585127?story_id=16585127&fsrc=rss Lien Foundation.

Palliative care problems are known

Since mid 1990's, Sharon Carstairs and other Canadian reports show:

- societal and professional avoidance of death and dying
 - inadequate access to care
 - underdeveloped palliative care
 - lack and challenges in communication
 - poor **continuity and coordination of care across providers and in transitions in care location**
 - lack of central **leadership and vision**; improved by local champions
 - care and planning of **care is often in disease 'silos' but people at end of life usually have more than one condition**
 - quality of care and need for care and accreditation standards
 - limited research and surveillance data
- 

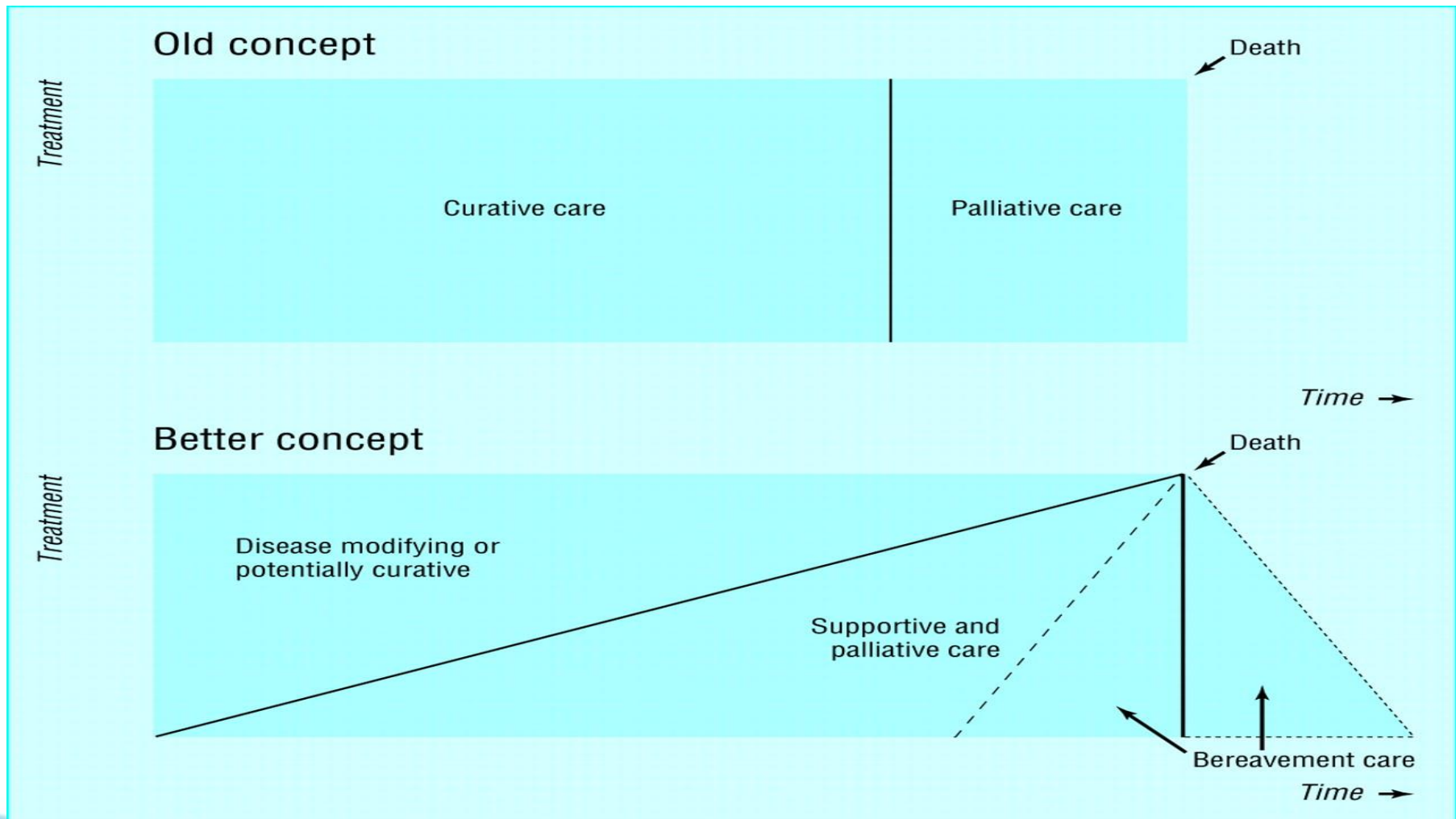
Definitions and conceptualizations of palliative and end of life care

Palliative “Care” versus “Approach”

End of life care is all health care in the last weeks, months (or years) of life



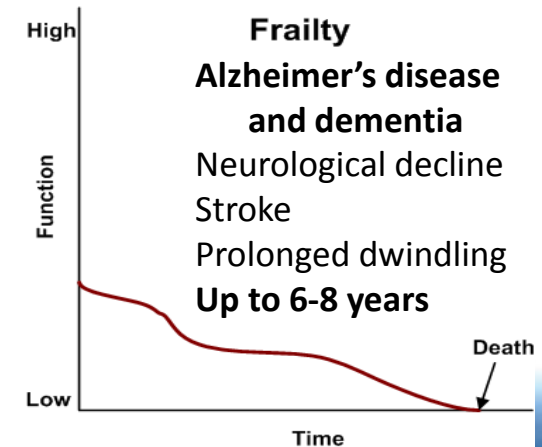
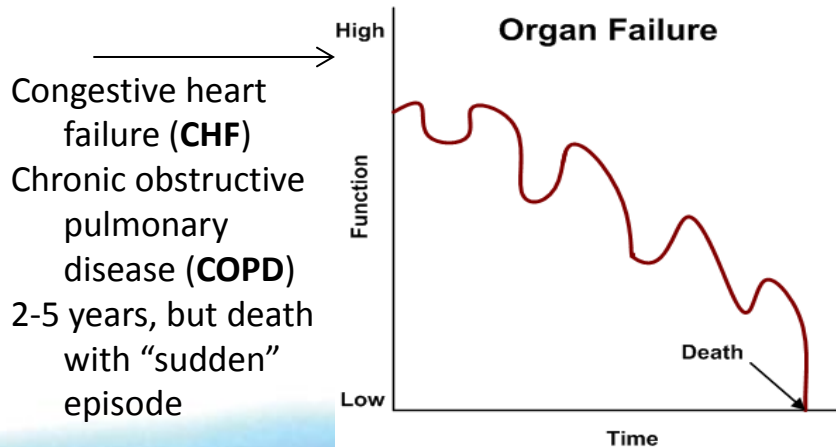
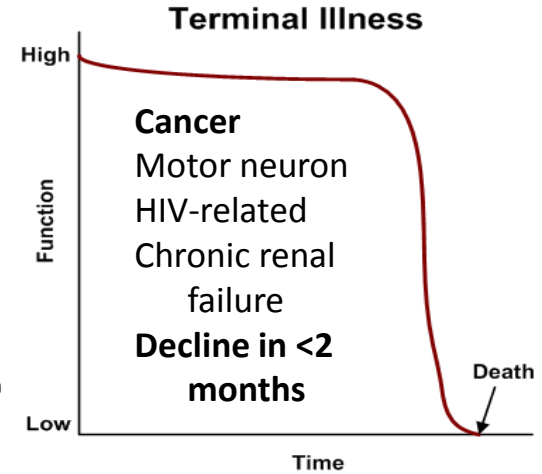
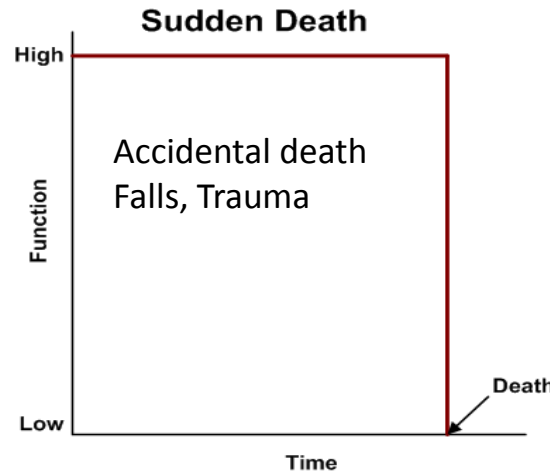
Palliative Care



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

End of Life Trajectories

Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at end of life. *JAMA*. 2003; 289:2387-2392.

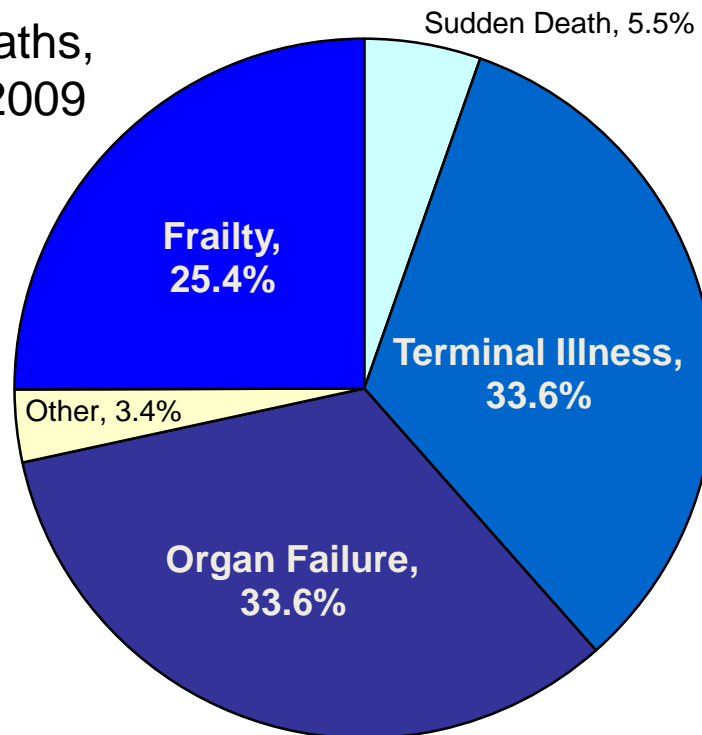


Trajectories Distribution

95% of people die of a life threatening disease with end of life stage

They access many services: nursing home, home care, specialty chronic disease care, diagnostic testing, primary care, inpatient hospital, emergency department, palliative care, ...

Nova Scotia deaths,
all ages, 1995-2009



Population priorities in context of U.S. Institute of Medicine's quality goals

Divides population into eight groups: 1) in good health, 2) maternal/child, 3) with an acute illness, 4) stable chronic conditions 5) serious but stable disability, 6) **failing health near death**, 7) **advanced organ system failure**, 8) **long-term frailty with failing health**.

Definitions of optimal health and priorities for services. Framework to plan resources, care arrangements, and service delivery.

Joanne Lynn, BM Straube, KM Bell, SF Jencks, RT Kambic (2007) Using population segmentation to provide better health care for all: The "**Bridges to Health**" model. *The Millbank Quarterly*, 85(2), 185-208

Gold Standards Framework in UK

International best practice standard

Covers all places of care

Continuing to evolve

<http://www.goldstandardsframework.org.uk/>

Key issues: When is the beginning of end of life time period? And, how to transition into end of life care

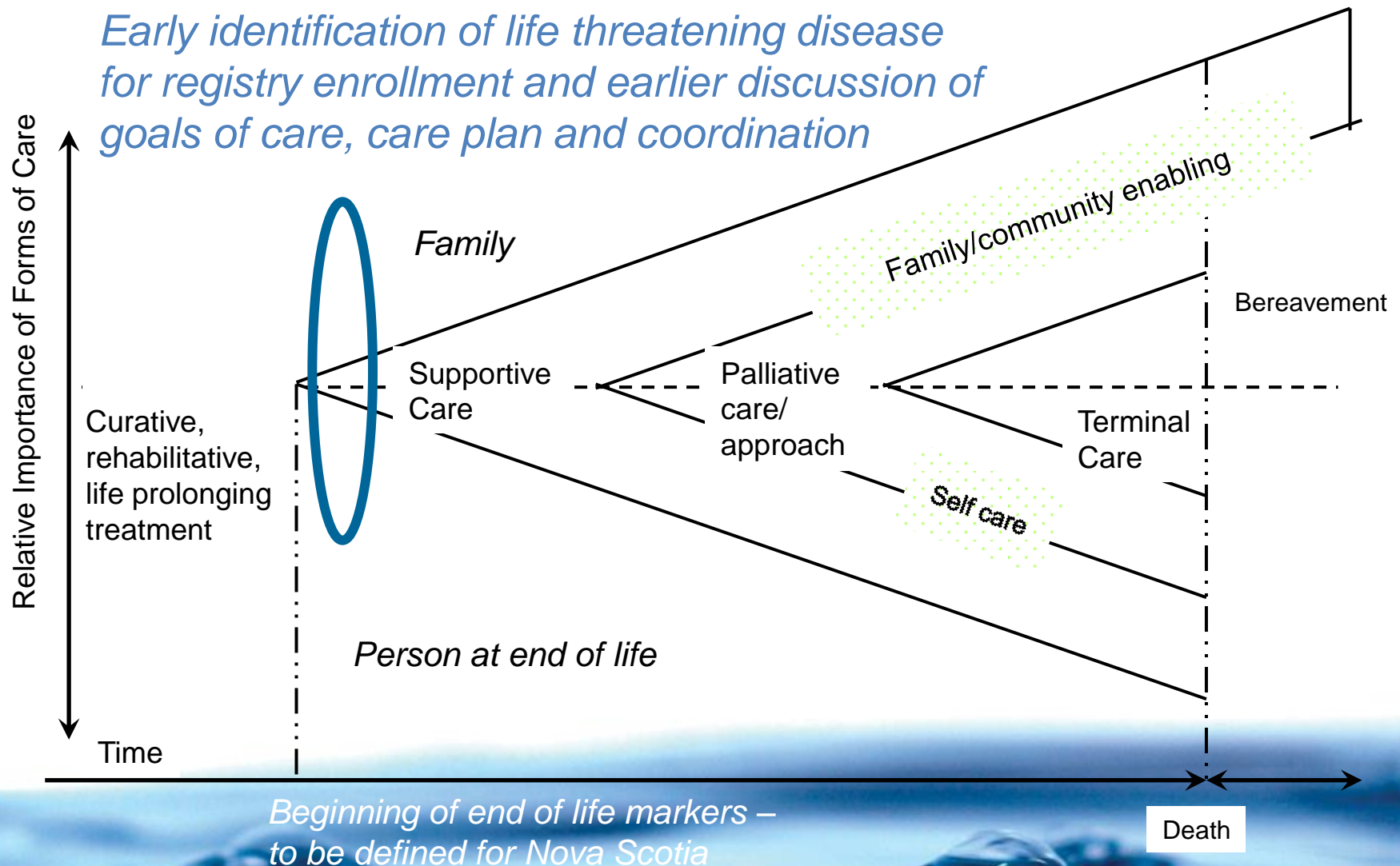
Primary care is a focus for training and audit

Registry of persons at end of life is a key component

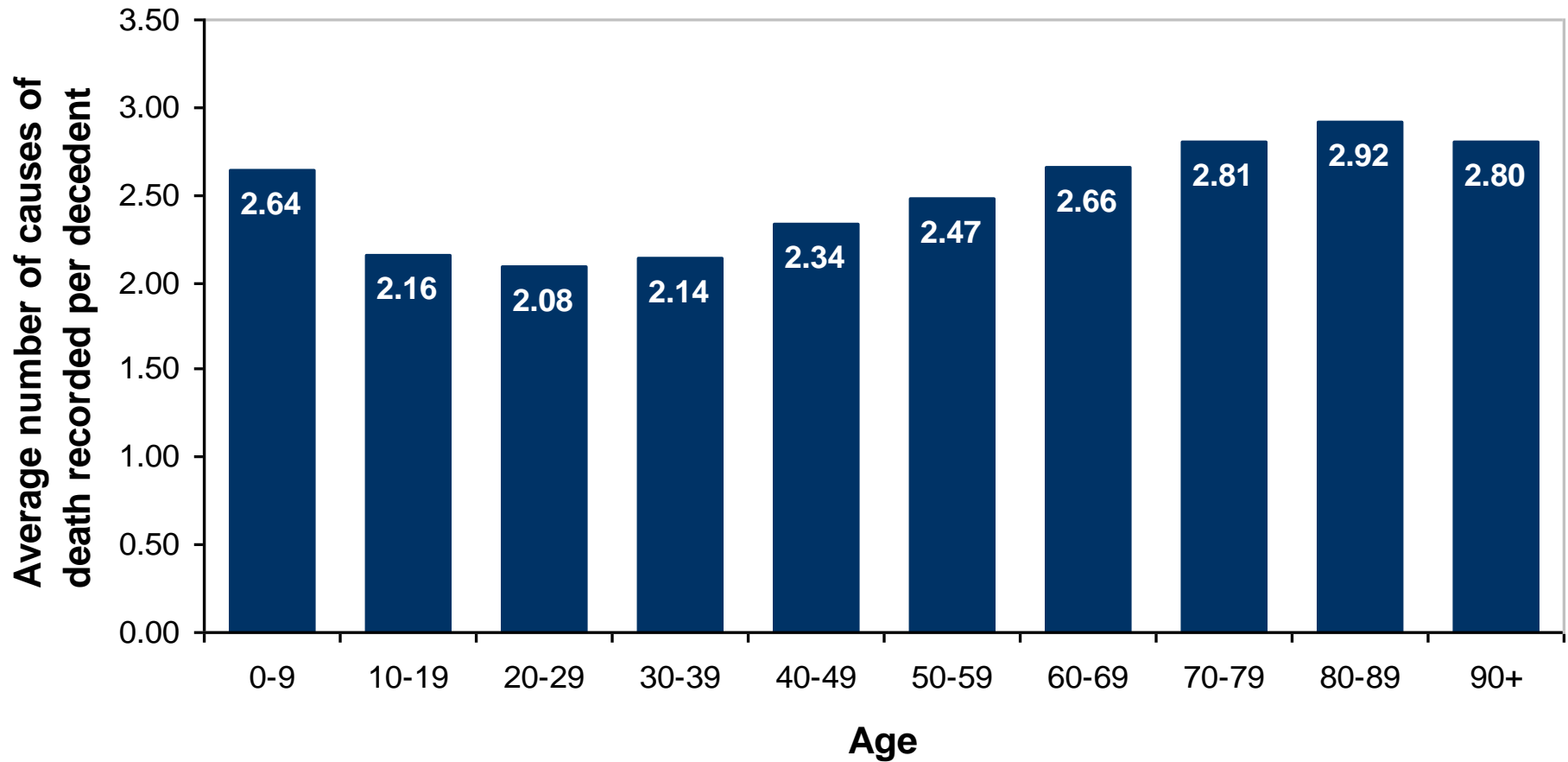
<http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/PDF%20Documents/QIP%20Flyer%20Oct10%20v%202023.pdf>



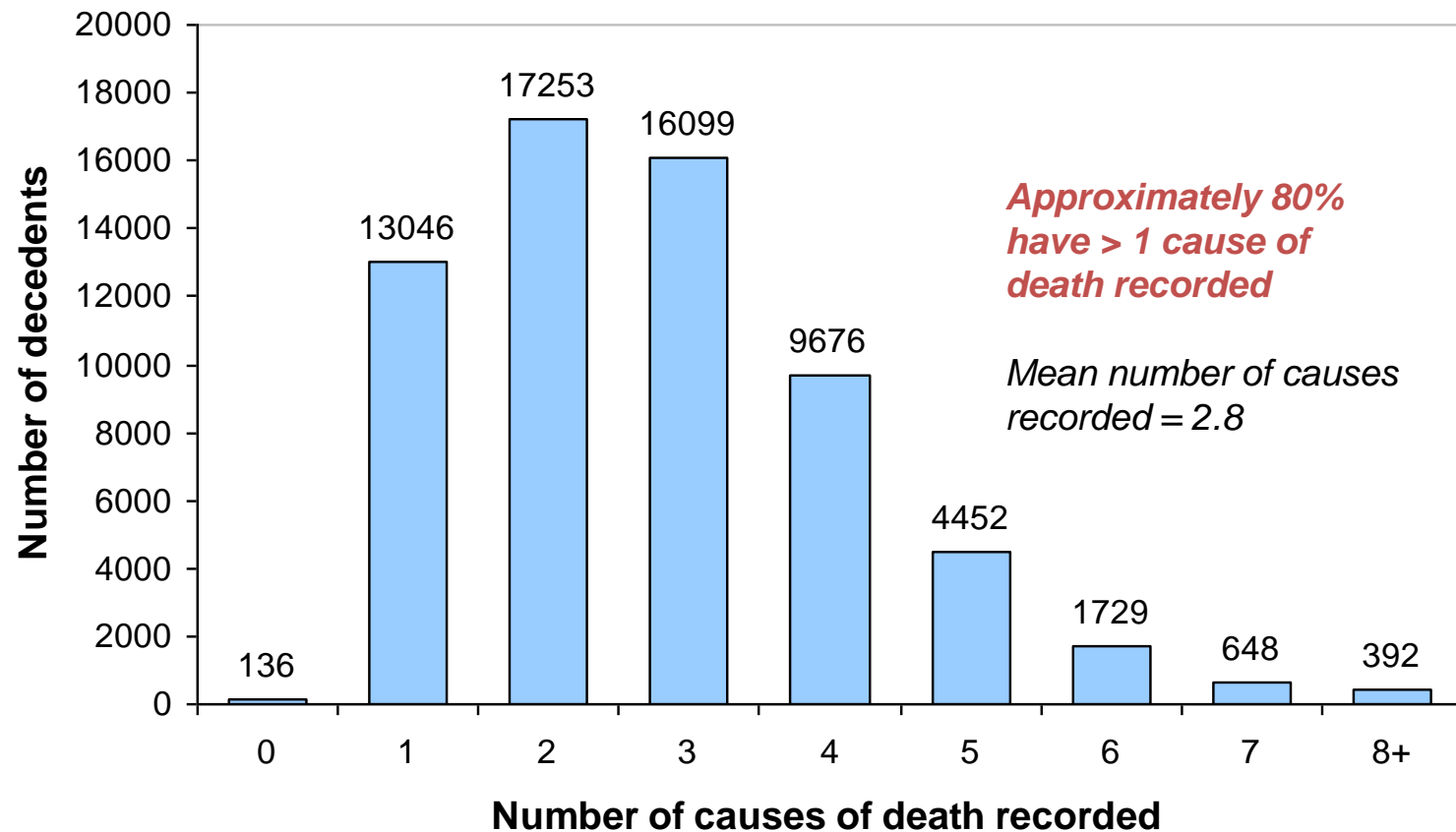
Creation of an end of life care registry



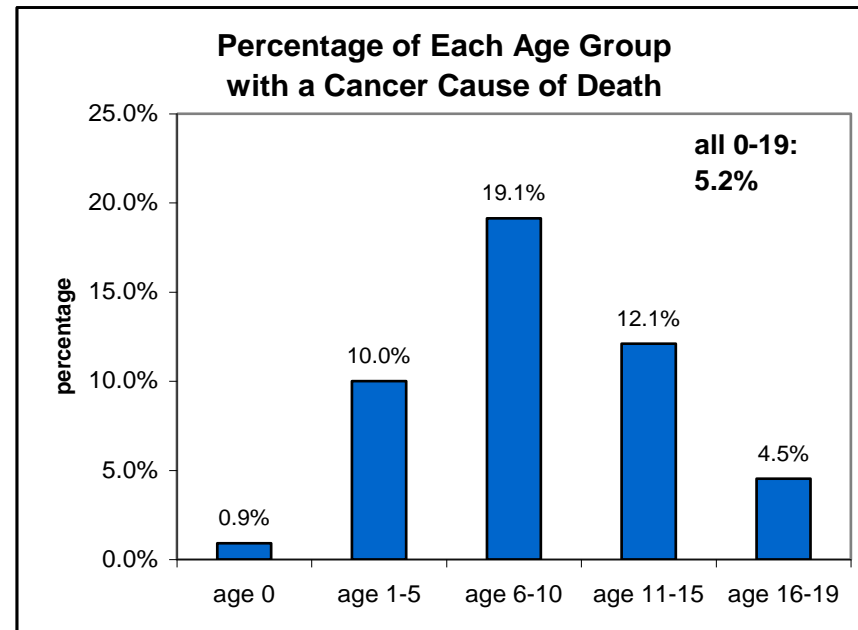
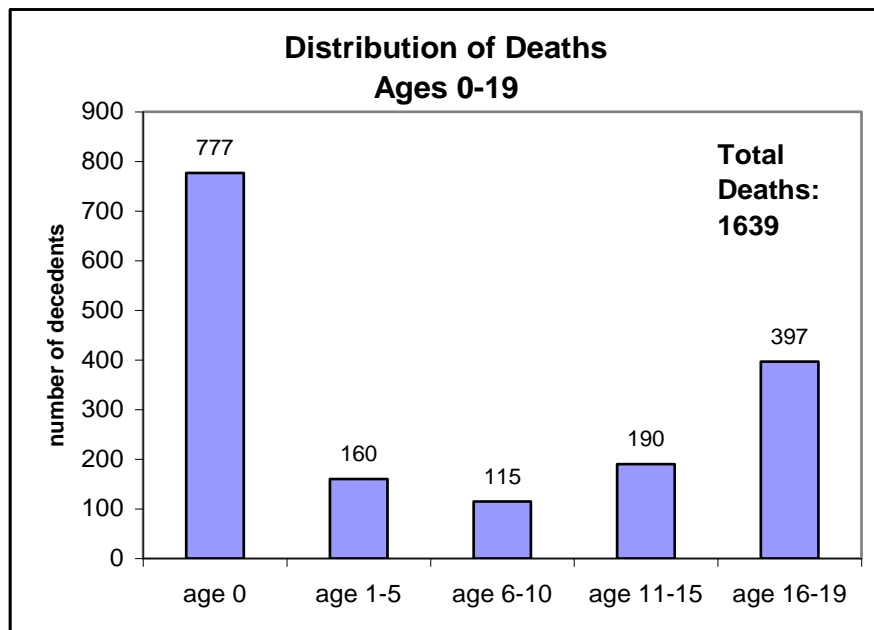
Average number of causes of death, per decedent by age, Nova Scotia, 1998-2005



Distribution of number of causes of death, Nova Scotia, 1998-2005



Children and youth who died in Nova Scotia, 1995-2009



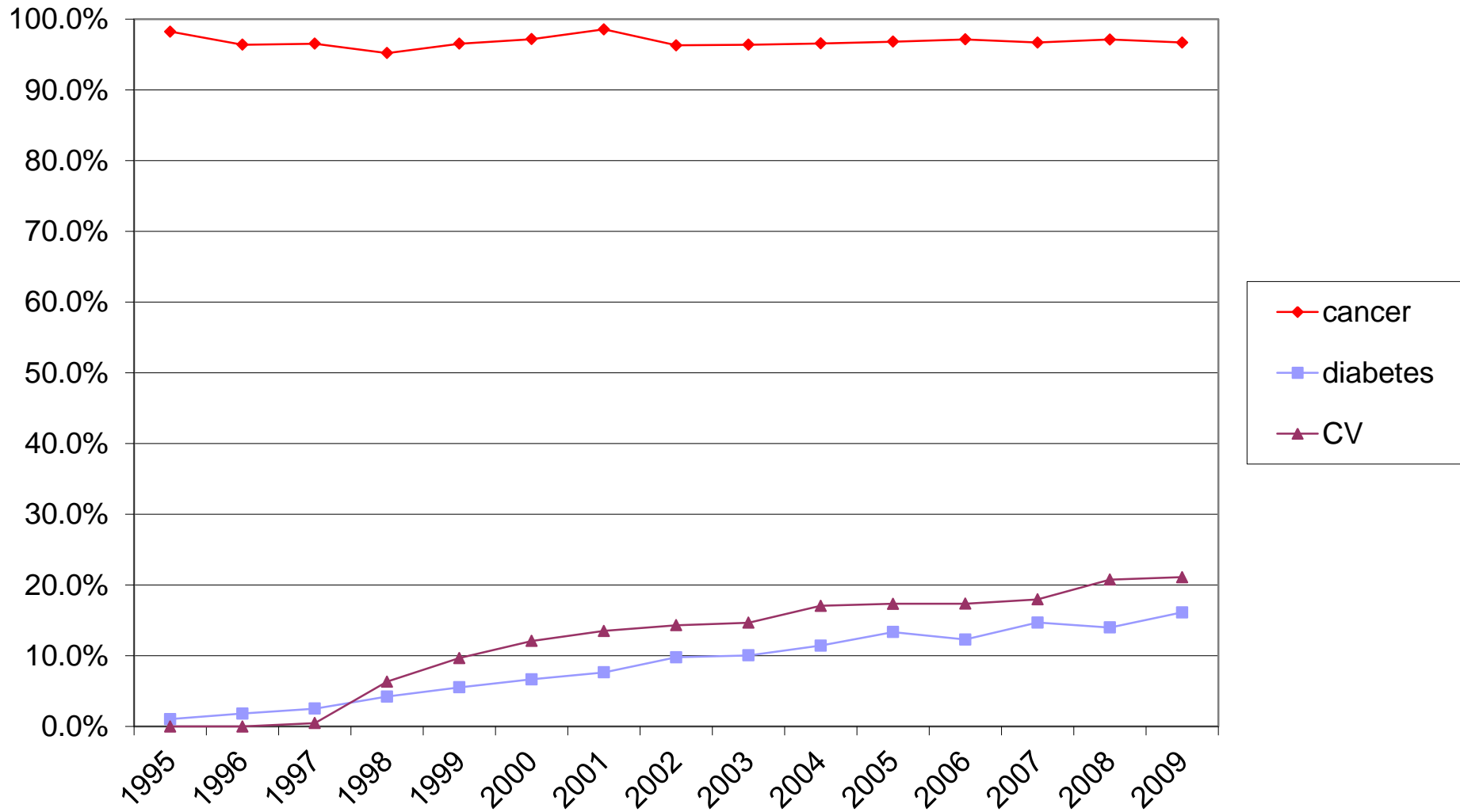
Nova Scotia Hospice Palliative Care Association meeting, Halifax, May 10-12, 2012 Dr Alix Carter and Rebecca Earle “Breaking Down Silos: Building Better Advance Directives”

Non-cancer causes of death for Cancer decedents, Nova Scotia, 1998-2005

Selected non-cancer causes of death	Percentage of persons dying of cancer who have this additional disease as a cause of their death
Cardiovascular including CHF and IHD	11.6%
COPD	7.9%
Diabetes	6.0%
Renal	4.6%
Dementia	3.4%

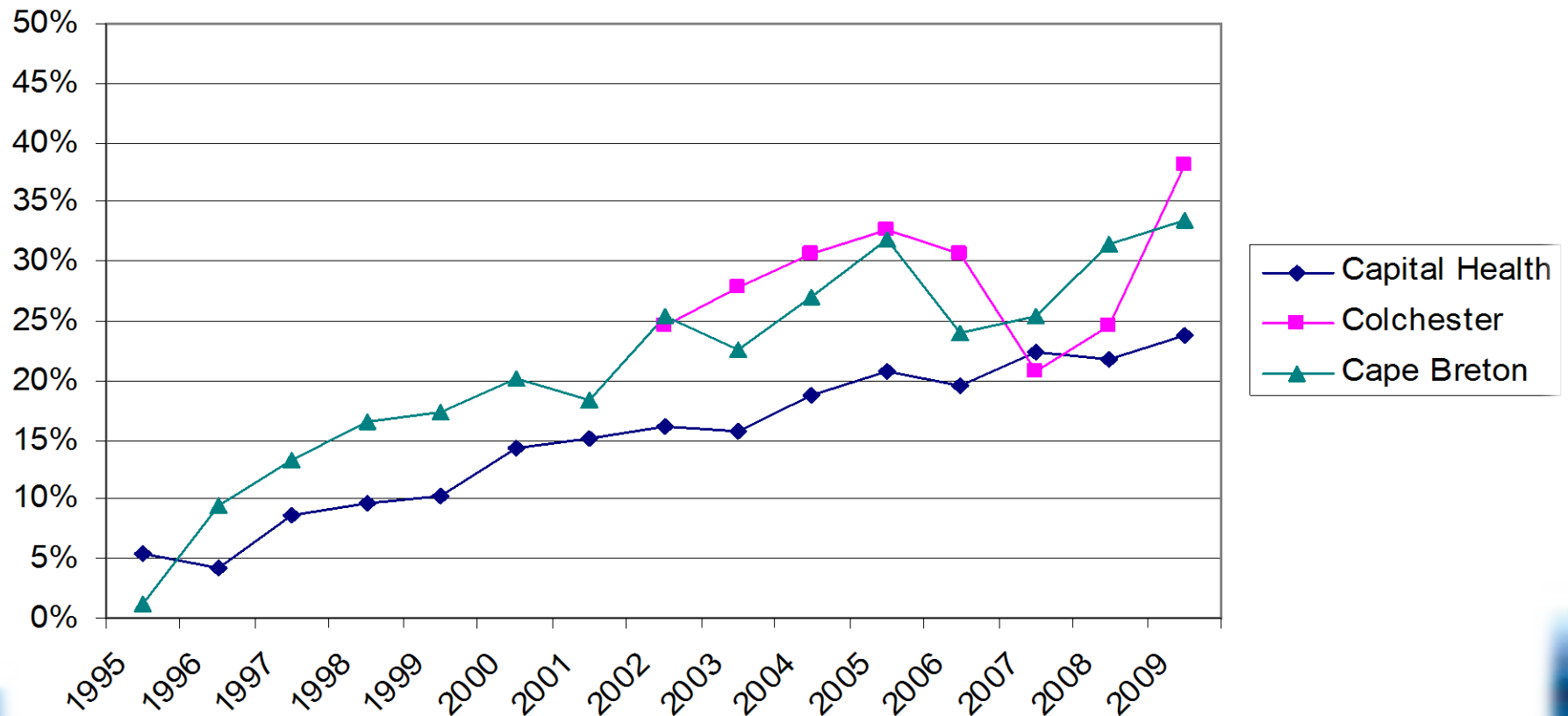


Percentage of Nova Scotia Cancer decedents in provincial chronic disease registries



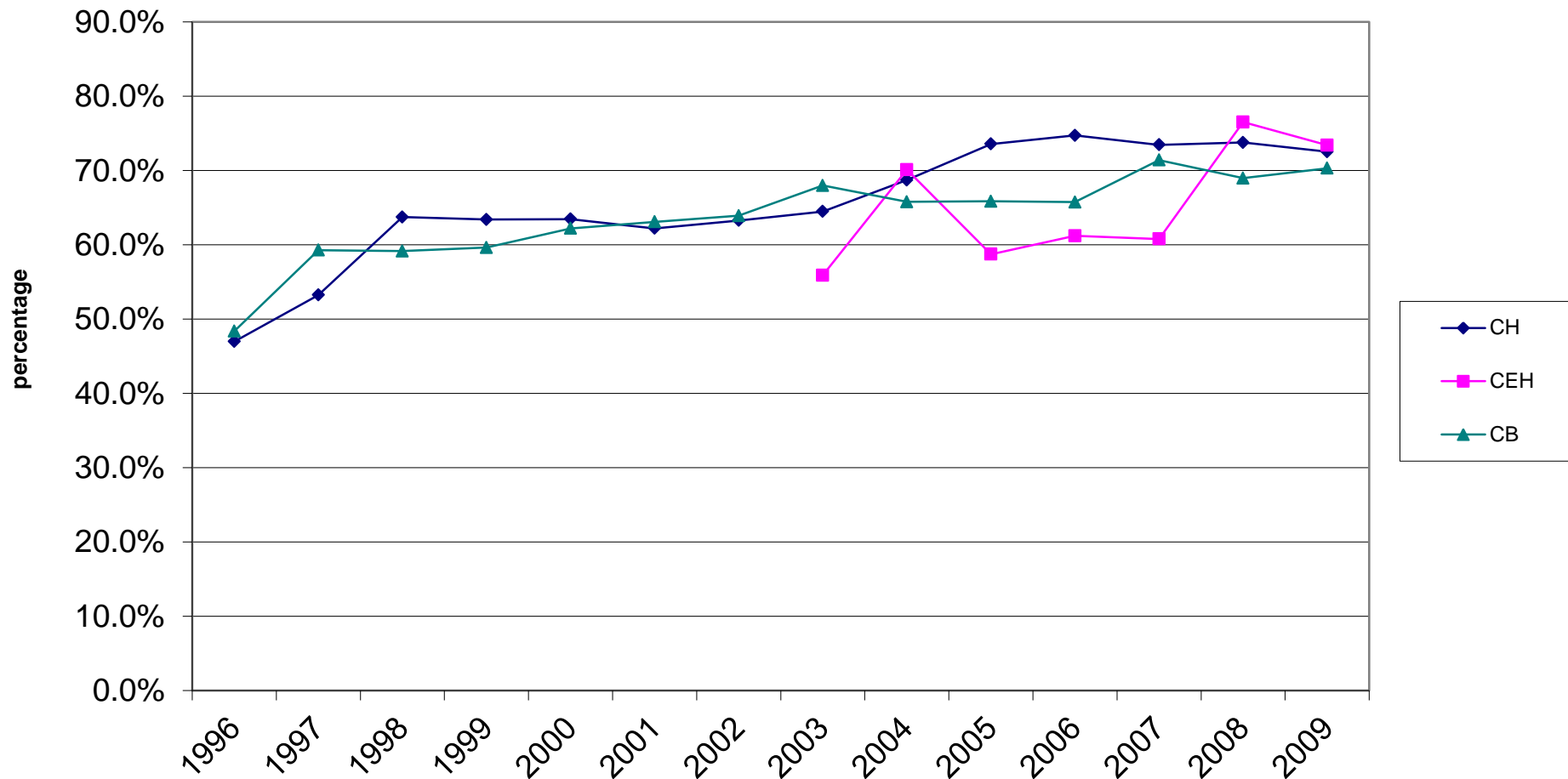
Palliative Care is seeing an increase in number of persons who do not have cancer

Percentage of PCP Enrollees Without a Cancer Cause of Death by Year



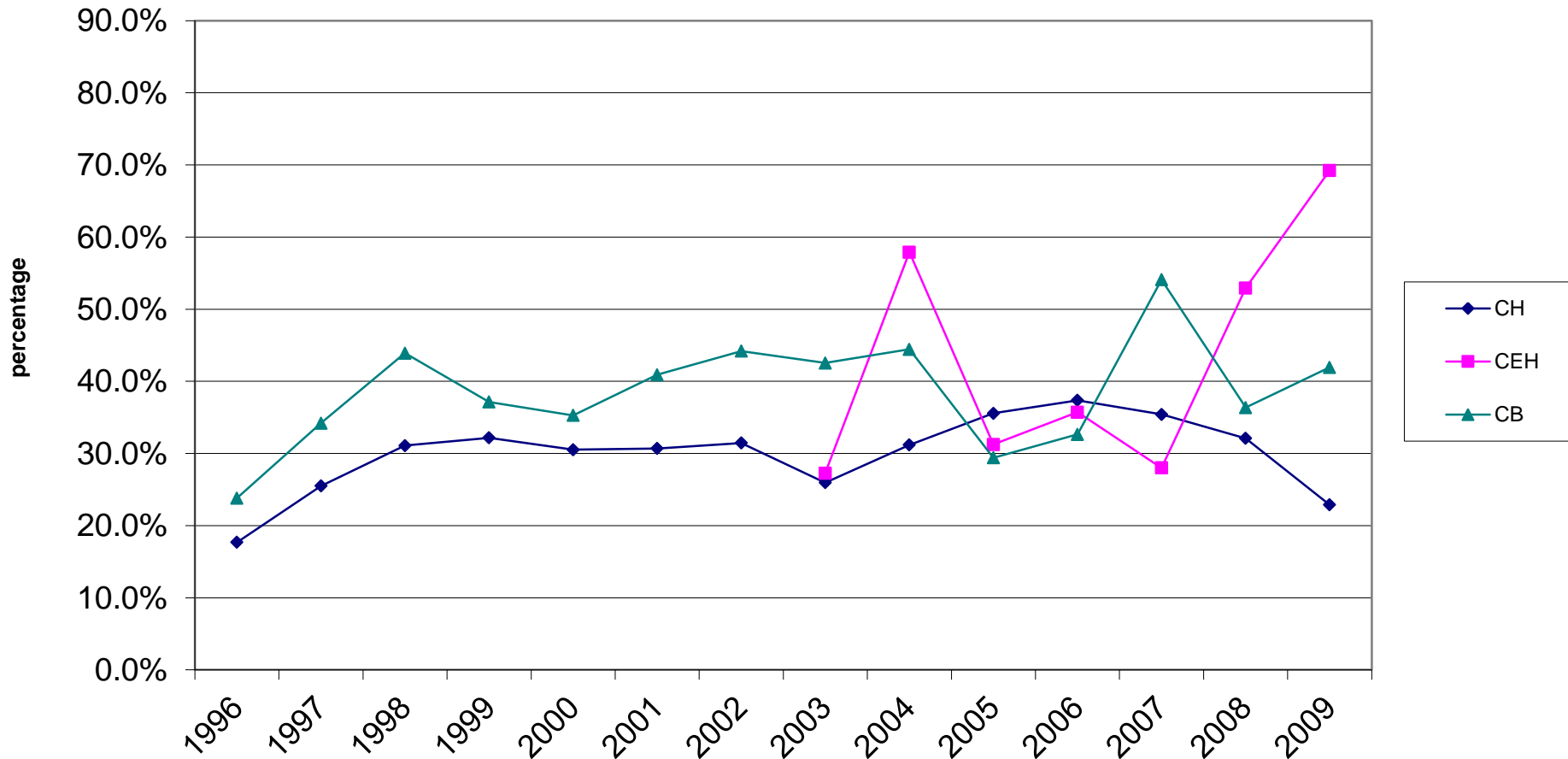
Percentage of Cancer decedents seen by Palliative Care Program in Nova Scotia

Percentage of Deaths with Cancer as a Cause Enrolled in Palliative Care Program by Year



Nursing Home residents dying of cancer seen by a Palliative Care Program

Percentage of Nursing Home Residents with Cancer as a cause of death enrolled in Palliative Care Program by Year



Time from Palliative Care enrollment to death for Cancer decedents, NS, 1996-2009

Enrollment days before death	Palliative Care Program		
	Capital Health	Colchester East Hants	Cape Breton
≤7 days	13.2%	15.0%	20.4%
≤14 days	21.7%	23.3%	28.8%



Percentage who died within 6 months of cancer diagnosis among adults diagnosed with colorectal cancer (CRC) from 2001-2005 who died* between 2001 and March 2008

*excluding those dying within 30 days of surgery

φ in 2 years before diagnosis

33.3% (578) of 1733 CRC decedents

I, II, III **Stage at diagnosis** **IV, Unknown**

20.5%

49.0%

≥9.5 **Number of specialist visits^φ** **<9.5**

37.7%

65.1%

<0.5 **Number of days spent in hospital^φ** **≥0.5**

54.4%

75.8%

Among those diagnosed with stage IV or unknown stage CRC with <9.5 specialist visits and ≥0.5 day in hospital in 2 years before CRC diagnosis, 75.8% died within 6 months of diagnosis

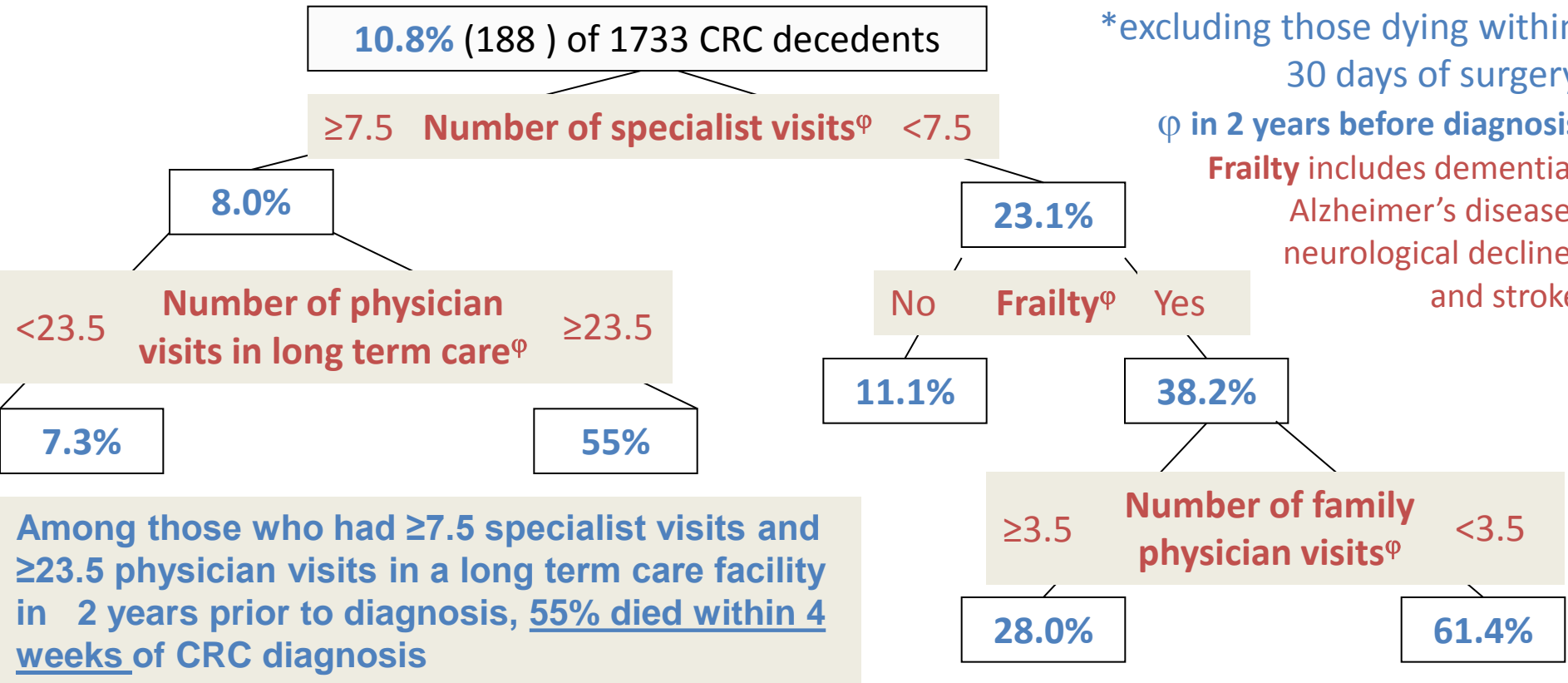
Other possible predictors included in the analysis were **age, sex, DHA, urban/rural, socioeconomic indicators** plus the following measures of health service utilization in the 2 years before CRC diagnosis: **co-morbidities, nursing home resident, number of family physician visits, physician continuity, emergency room visits, number of hospital admissions**

Percentage who died within 4 weeks of cancer diagnosis among adults diagnosed with colorectal cancer (CRC) from 2001-2005 who died* between 2001 and March 2008

*excluding those dying within 30 days of surgery

φ in 2 years before diagnosis

Frailty includes dementia, Alzheimer's disease, neurological decline, and stroke



Among those who had **≥7.5 specialist visits** and **≥23.5 physician visits in a long term care facility in 2 years prior to diagnosis**, **55% died within 4 weeks of CRC diagnosis**

Among those who had **<7.5 specialist visits**, were frail, and **<3.5 family physician visits in 2 years prior to diagnosis**, **61.4% died within 4 weeks of CRC diagnosis**

ABC-SC

Advanced Breast Cancer - Supportive Care

Principal Applicants:

Grace Johnston, PhD

Robin Urquhart, PhD Candidate

Co-applicants:

Frederick Burge, MD, FCFP

Judith Fisher, PhD

David Haardt, PhD

Janice Howes, PhD

Melanie Keats, PhD

Jennifer Payne, PhD

Geoffrey Porter, MD, FRCSC, FACS

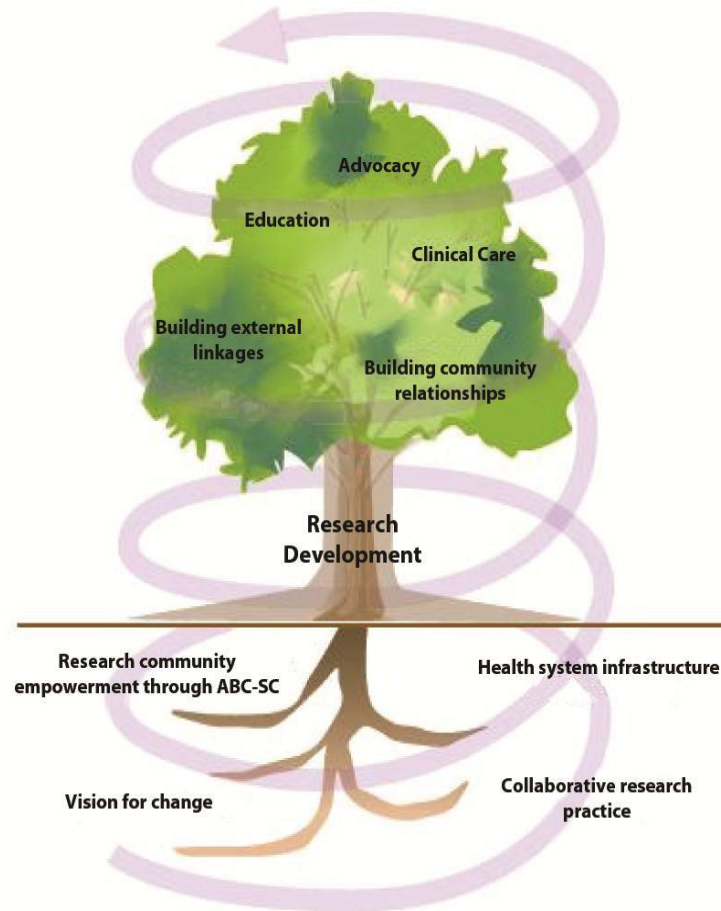
Danny Rayson, MD, FRCPC, FACP

Tallal Younis, MBBCh, FRCP

Collaborator:

Marianne Arab, MSW/RSW

Process of Supportive Care Development



Sequential Phases
of the Model:

4. Growing the program

3. Creating the team

2. Catalyst - ABC-SC
research grant

1. Antecedent
community conditions

Palliative Support Program (PSP) for British Columbia



PSP End of Life Care Algorithm

GPAC Part I – Approach to Care

Identify and Create Registry

- "Surprise Question"
- Choice or Need for Comfort Care
- Clinical Indicators
- Sentinel Events

Assess

- Seniors Assessment Tool
- Palliative Performance Scale (PPS)
- Edmonton System Assessment Scale
- Goals of Care
- Domains of Care

Manage Symptoms

- GPAC Part II – Pain and Symptom
- Fraser Health Symptom Guidelines

Attention to symptom distress can be early in the illness trajectory & should not be linked with prognosis.

Would not be surprised if patient died in the next year

Prognosis approximately 6 months and PPS 50%

Concern about ability to support client at home given increasing care needs

Anticipating death in the next few days or weeks

Death and Bereavement

Transition 1
Disease advancement

ROLES

- Recognition and registry
- Advance Care Planning
- Identify client's values and beliefs
- Clarify illness trajectory, possible complications, prognosis, expected outcomes to inform goal
- Consider need for referral/coordination with H&CC

How to Break Bad News

H&CC Referral forms

My Voice – Including initial conversation

End of Life Care Plan templates

Transition 2
Decompensation, experiencing life-limiting illness

Plan and Collaborate

ROLES

- Discuss care coordination
- Consider hospice palliative care referrals

BC Palliative Care Benefits Form

Medical Supplies and Equipment

Palliative Care Drug Formulary

H&CC/Palliative Care forms

No CPR Form

Family Meeting

EI Compassionate Care Form

Transition 3
Dependency & symptom increase

ROLES

- End of Life Care Planning, including assess for preferred location for care

EoL Care Checklist

Home Death Protocol

Notification of Expected Death at Home

What to consider when caring for someone dying at home

Caregiver Resources

Transition 4
Decline & last days

ROLES

- Discuss meds required in home with HCN
- Assess pt/family are comfortable with their EoL care plan and support required changes

"When Death is Close at Hand"

Online Resources

Transition 5
Death & Bereavement

ROLES

- Have follow-up bereavement visit/call and send condolence card to family

Death Certificate

Bereavement

GPAC Part III - Grief & Bereavement

Purposes of this concurrent session

1. Follow from February 29, 2012 NELS workshop/ report recommendation to explore adapting British Columbia's Palliative Support Program (PSP) for Nova Scotia (NS)
2. Obtain input from cancer network stakeholders on
 - i) relevance of adapting BC PSP for Nova Scotia,
 - ii) aspects already in place in Nova Scotia,
 - iii) aspects of care/measures that are missing,
 - iv) barriers to implementation,
 - v) supports needed to reduce barriers & ease implementation



Questions? Comments?

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and Epidemiologist, Cancer Care Nova Scotia



CIHR IRSC
Canadian Institutes of Health Research
Institut de recherche en santé du Canada

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