

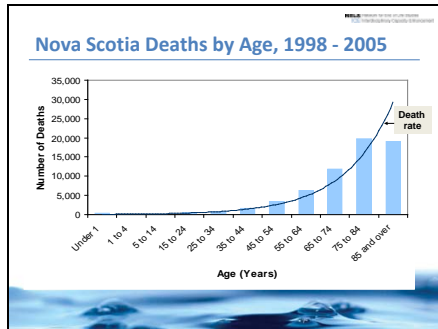
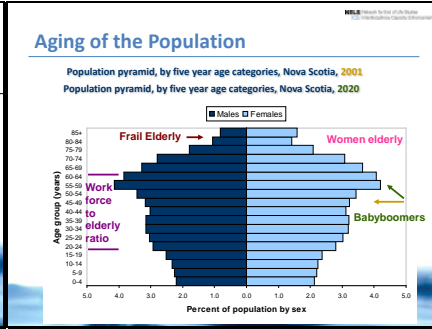
Appendix E – Planning for Symptom and Outcome Measurement in the Provision of Palliative and End of Life Care in Nova Scotia (abridged)

Planning for Symptom and Outcome measurement in the provision of Palliative and End of Life Care in Nova Scotia

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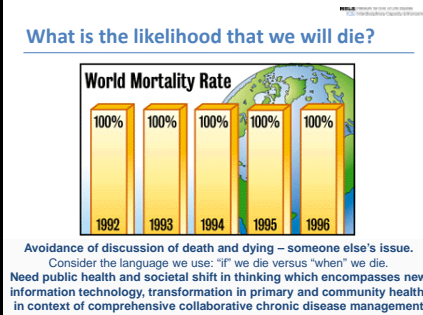
NELS Network for End of Life Studies
 I.C.E. Interdisciplinary Capacity Enhancement

February 29, 2012

What is the likelihood that we will die?

World Mortality Rate



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


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

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/16686127?story_id=16585127&fr=china 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



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

NELS ICE research

Analyses of linked administrative databases to determine service use in last months of life for persons who die of cancer and other diseases
 Mortality follow-back interviews of next of kin
 Other, e.g. vulnerable populations

Emerging valuable potential

Capitalize on diversity of "natural experiments" to inform best practices

Provider-driven studies and data analyses for rapid grass roots discovery and knowledge transfer, e.g. Elsie Rolls; Jan Jensen and Andrew Travers; others
 References: see papers by Amy Abernathy

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, Gurinik 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, 1998-2005, all ages

Gold Standards Framework in UK

International best practice standard
 Covers all places of care
 Continuing to evolve

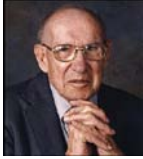
Primary care is a focus for training and audit
Registry of persons at end of life is a key component

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

Early identification of life threatening disease for registry enrollment and earlier discussion of goals of care, care plan and coordination

Beginning of end of life markers – to be defined for Nova Scotia

<p>Workshop Premise</p> <p>“You can’t manage what you can’t measure.”</p> <p>Peter F Drucker</p> 	<p>Outcomes</p> <p>Improve</p> <ul style="list-style-type: none"> pain and symptom control for all persons at end of life community and professional understanding and support coordinated 24/7 care for all persons at end of life satisfaction with care and control of family and provider distress assurance of quality, timely and cost-effective care <p>Decrease</p> <ul style="list-style-type: none"> delay in commencement of a palliative approach multiple assessments, referrals and transfers ineffective use of hospital beds, emergency department and diagnostic testing <p>What else?</p>
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<p>Address limitations of current measures</p> <ol style="list-style-type: none"> Need symptoms, not just diagnoses, recorded in a standardized form for all persons in their last months of life Need useful outcomes recorded in a standardized form so that current and new approaches to the delivery of care at end of life can be more efficiently and fully evaluated Need coordination/bridging across care settings and diseases in electronic data entry and administrative database sharing while maintaining strengths and value of each care setting and disease program; coordination does not mean centralization Develop plans for a future using person based real-time web-portal health information that maximizes self management and community-based coordinated care 	<p>Purposes of this workshop</p> <ol style="list-style-type: none"> Demonstrate need for and measures of symptoms and outcomes for persons at end of life Identify strengths, weaknesses, and implementation challenges in Nova Scotia Brainstorm on collaboration and leadership to enable coordinated, evidence-based community practice in Nova Scotia to improve care for persons at end of life
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