End-of-Life and Palliative Home Care

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Introduction

- In recent years, there have been many major healthcare and socio-demographic developments – ones that are impacting and will continue to impact home care.
- This talk focuses on two key questions:

  1. Should “dying in place” become a major policy and practice focus? and

  2. Is it possible for terminally-ill or dying Canadians to receive enough palliative or end-of-life care at home for a good death?

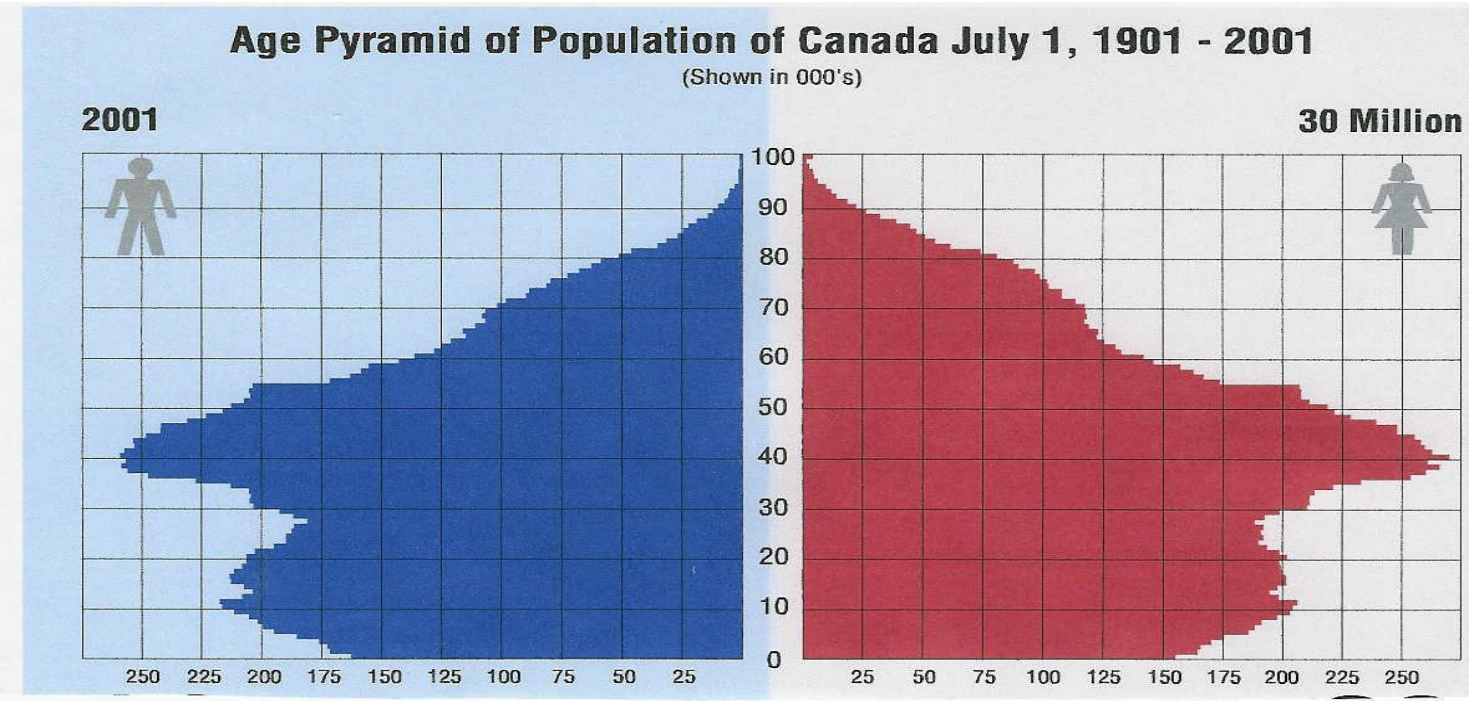
Five Topics

- The number of deaths taking place each year in Canada and expected trends,
- Lifespan or age at death and other developments that are impacting the end of life (EOL),
- The changing location of death,
- End-of-life care needs, and
- End-of-life home care provision.

1. Annual Decedent Numbers

- In 1950, there were 123,590 deaths and in 2008, there were 238,617 – a gradual increase over 60 years to a number that is nearly 100% greater.
- The large babyboom cohort (1/3 or 10 million Canadians) started to reach age 65 in 2011. There are also 4.6 million Canadians older than the babyboomers.
- The number of deaths each year will increase more rapidly now, to double again in as little as 10-20 years.

Looking Ahead



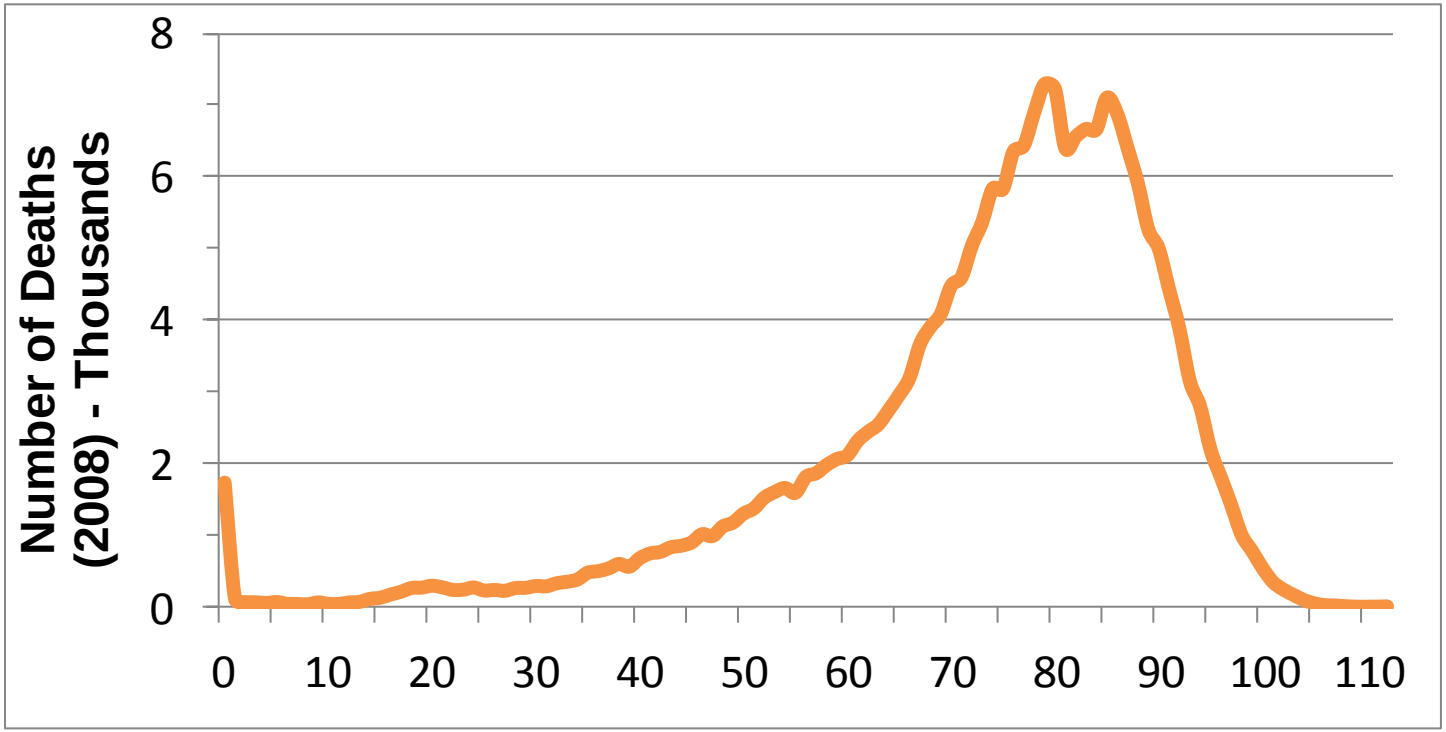
http://www12.statcan.gc.ca/census- recensement/2006/as-sa/97-551/vignettes/cda06pymd.swf

2. Lifespan and Other Trends

- Increased lifespan, with both aging and advanced aging evident (331% increase since 1950 at deaths among 85+ year olds)
- Women are continuing to live longer.
- Reduced birthrate, with babyboomers having more siblings than children.
- Under ½ now are married at the end of life.
- Increased outpatient and daysurgery care.

* These and other trends impact EOL care needs and EOL care provision.

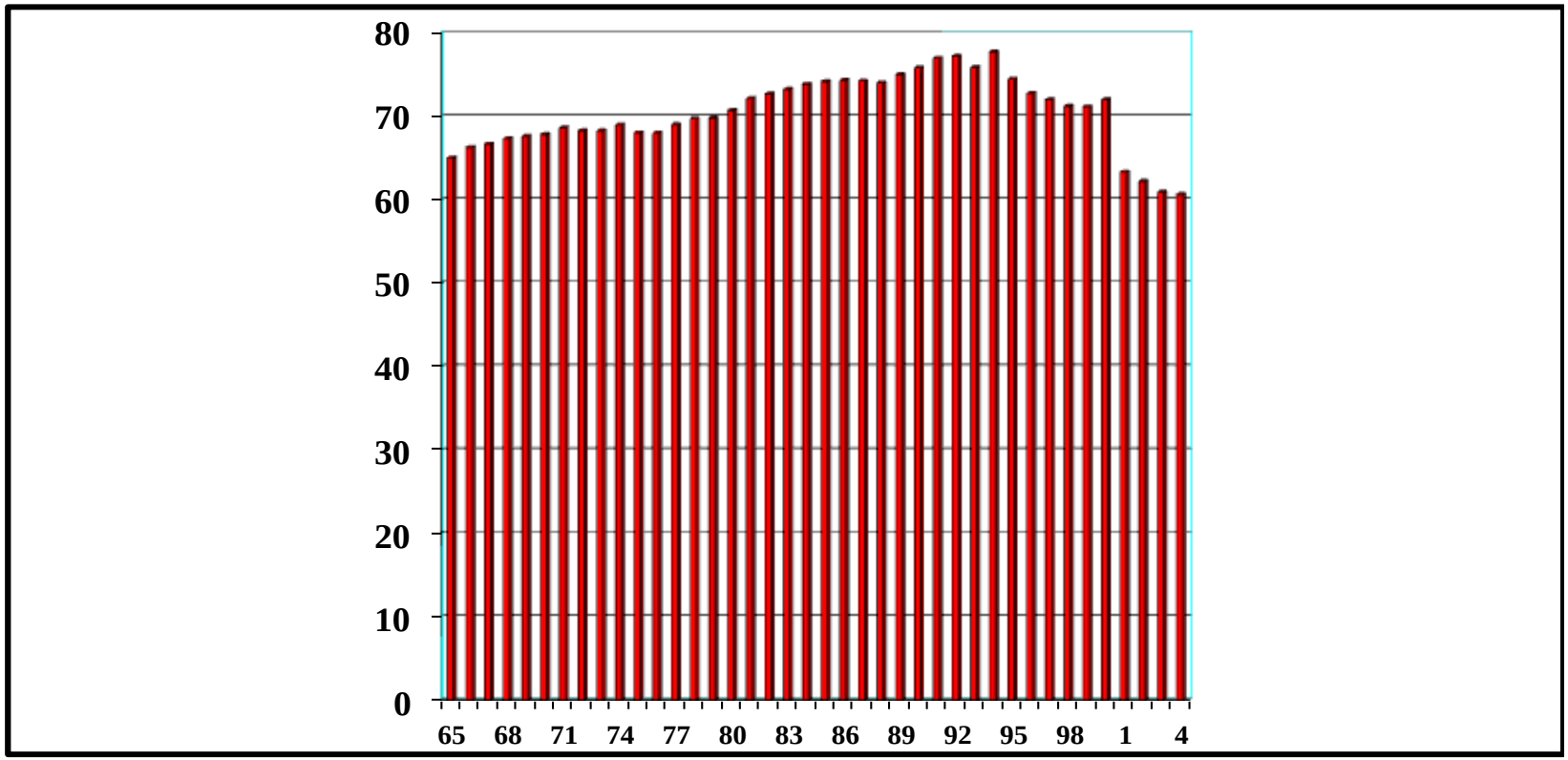
Age at Death In Canada



2% were aged 0-22, 22% were aged 0-64, and 22% were aged 87+

3. Location of Death.

Hospital Deaths Declined After 1994



4. EOL Care Needs

- EOL care needs are under researched, but:

1. Diverse – ranging from 0 needs for the 10% of decedents with sudden and unexpected deaths to nearly 100% need over 3-4 years because of long dwindling or lingering dying processes for some younger persons and the 3-4% of older persons who require nursing home level care.
2. The vast majority (80%) are relatively well and ambulatory until the last 1-3 days of life, and are aware of their life-limiting illness(es).

4. Quality EOL Care / Good Deaths

- Singer et al.'s 1999 qualitative study of LTC residents, HIV and dialysis patients identified 5 domains of quality end-of-life care:

1. receiving adequate pain and symptom (nausea, fatigue, dyspnea…) management,
2. avoiding inappropriate prolongation of dying,
3. achieving a sense of control,
4. relieving burden, and
5. strengthening relationships with loved ones.

(Singer P. et al., 1999. Quality end-of-life care. Patients' perspectives. JAMA, 281(2), 163-168)

5. EOL Home Care Provision

- More studies are needed but some show:

1. A small proportion of home care recipients are designated as palliative (i.e. 4-6% of home care recipients in Alberta).
2. Home care for palliative clients is typically provided for 90 days and at a rate of 2 hours per day (vs 2 hours/wk for long-term clients).
3. 70% of care hours and care visits are provided by unlicensed care aides, who are working alone but under RN supervision and RN case management or care planning.

Conclusions

- There will be a rapid increase now in the number of persons (mainly babyboomers) who need periodic home care because of serious life-limiting illnesses, and also a rapid increase in the number of persons who will need home care services because they are acutely dying.
- Hospices will be increasingly needed, and greater supports of all kinds for family caregivers and also for nursing care aides.
- The alternative is an increase in the use of hospitals and ERs for EOL care.

Information to provoke thinking on questions:
1. Should “dying in place” become a major policy and practice focus? and
2. Is it possible for terminally-ill or dying Canadians to receive enough palliative or end-of-life care at home for a good death?

Thank you!

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