Quality of Care & Quality of Life in Residential LTC

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What is Long Term Care (LTC?)

- Settings providing facility-based care where residents live permanently with 24/7 housekeeping, personal, and healthcare services
  - Combination of social and health services
- Funding: public or private, profit or not-for-profit
- Not covered under Canada Health Act
- ~1800 LTC facilities in Canada
  - 748 West, 640 ON, 216 QC, 195 Atlantic, 15 North
- About 300,000 people live at any one time in LTC (all ages, all causes) of which ~200,000 are over 65
Figure 1. LTC users as share of the population, 2008 or latest available year

OECD average 2.3%

% of population

Source: Help Wanted?

Figure 2. Public and private LTC expenditure in the OECD, 2008 and 2050

Source: Help Wanted?

Who lives in LTC?

- A typical resident is female (2/3), over 80, lower income, single and has dementia (2/3) plus two or more other chronic diseases
- A medically and socially complex, frail, and highly vulnerable population
- A small proportion (4-10%) are the “unbefriended elderly” with no family or friend support, where the “state” is the legal guardian.
- The profile of residents is changing rapidly
The Changing Profile of Residents

 Admitted increasingly late in their trajectories, higher dependency needs, more medical complexity, social engagement is more difficult

 Dementia follows a frailty pattern of decline with,
  ✓ severe disability in the last year of life
  ✓ Substantial, often dramatic decline in function in the last months of life
  ✓ co-occurring illnesses may accelerate the decline but the dementia trajectory is generally one of steady prolonged dwindling

 The resident profile is changing but staffing and other key resources have remained at steady state
Framing the Challenge

- We have a global opportunity to consider the adequacy and quality of social and health care provisions to support those for whom self-care is a diminishing or unobtainable option.\(^1\)

- As a consequence of history, including under-investment and piecemeal regulatory responses to sub-standard practices, working in nursing homes is afforded low status giving rise to quality challenges and workforce instability.\(^1\)

- At their most fundamental, the choices we make are value choices – who is valued and thus to whom are resources allocated?

\(^1\)Tolson et al (2011), Global agenda. JAMDA.
Long-Term Care Task Force on Residential Care and Safety: An Action Plan to Address Abuse and Neglect in Long-Term Care Homes: Long-Term Care Task Force Ontario; 2012.
CIHI. When a Nursing Home Is Home: How Do Canadian Nursing Homes Measure Up on Quality; 2013.

Long history of reports over the last 35 years, many of them describing similar issues... and still quality problems persist.
Suggesting a large, international, system level problem
The real goal in LTC is a **good last stage of life** and a good death despite advancing age, loss of family and friends, and the natural course of life limiting dementia and other chronic diseases.

It is an enormous – but achievable – challenge, that requires intention, will and resources.
Relatively little work exploring relationship of quality of care to quality of life but we do know it is not a straight-forward 1:1 relationship

- Most consider quality of care a necessary but insufficient condition for quality of life.
- Quality of life encompasses:
  - Feeling safe
  - Maintaining identity
  - Belonging
  - Sensory pleasures (touch, taste, sound, smell, freedom from pain)
  - Continuity (to experience connections)
  - Purpose
  - Achievement
  - Significance (that you matter as a person)
  - Maintaining movement/free from restraint
  - Shared decision-making
  - Spirituality as one wishes and is able to experience it
  - A good end of life
  - A good death
Symptom control has been a major approach to monitoring quality of care

Last 30 days of life (Italy):
- 72% antibiotics
- 37% anxiolytics
- 7.8% anti-depressants
- 21% tube fed
- 67% IV/hypodermaclysis
- Physical restraints 58%
- CPR/some emerg. intervention 43%


Last month of life (USA):
- Pain 47%
- Dyspnea 48%
- Cleanliness 90%
- Symptoms affecting intake 72%

Hanson et al (2008) JAGS

Last week of life (Netherlands):
- Pain 52%
- Agitation 35%
- Short of breath 35%
- Pain & Agitation 15%

Hendriks et al (2014) JSPM

Dying peacefully (no physical or psychological distress):
- 54% died peacefully (Belgium)
- 56% died peacefully (Netherlands)

DeRoo et al (2015) JSPM
Figure 3. Proportion of Nursing Home Residents Who Had Distressing Symptoms at Various Intervals before Death.

Mitchell et al., The Clinical Course of Advanced Dementia. NEJM. 2009: 361(16).
Dyspnea & pain symptoms, last 12 months of life among residents with dementia
(RAI-MDS 2.0 data from 3647 residents in 36 LTC facilities in AB, SK, MB, 2008-2012)*

Implications

- A values based discussion about what we are willing to do to support older adults with dementia in the last stage of life
- Meaningful engagement of persons with dementia and their caregivers in the conversation
- Workforce stability discussions
- Resource reallocation discussions
- A Canada wide data system that enables us to systematically measure quality in every nursing home in every province
Among people turning 65,
four in 10 will need long-term care for two or more years