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Quality of Care & Quality of Life in Residential LTC

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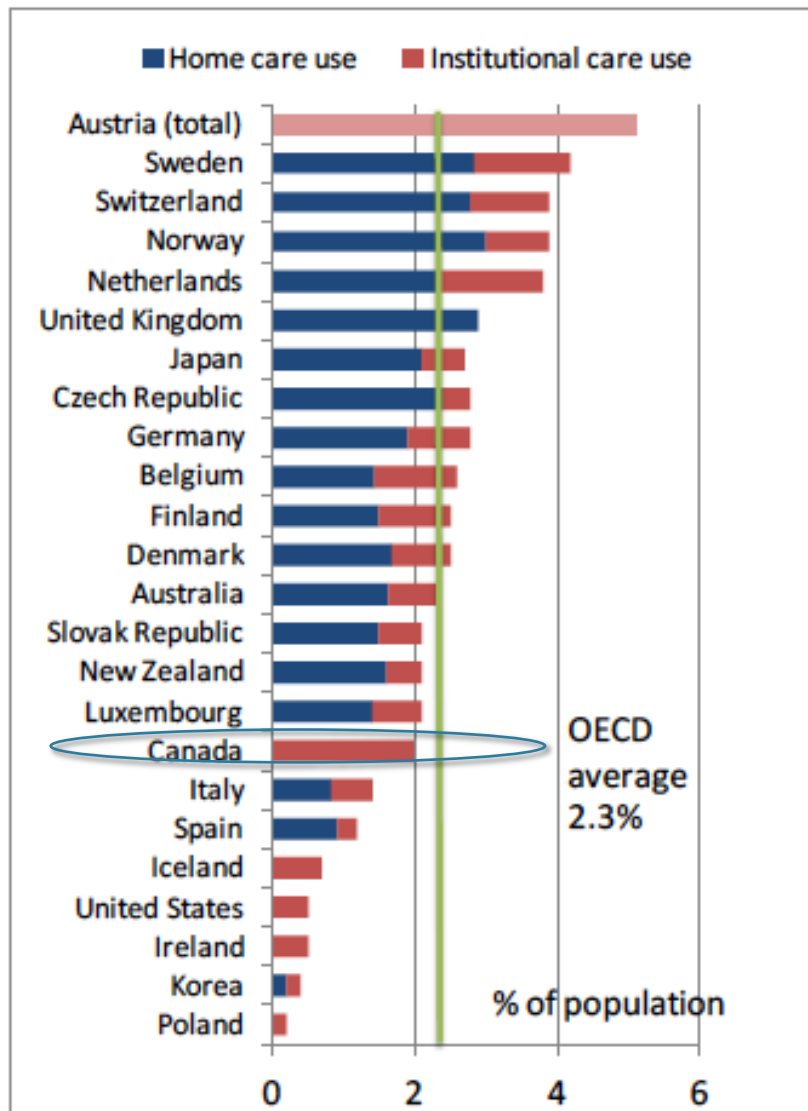




What is Long Term Care (LTC?)

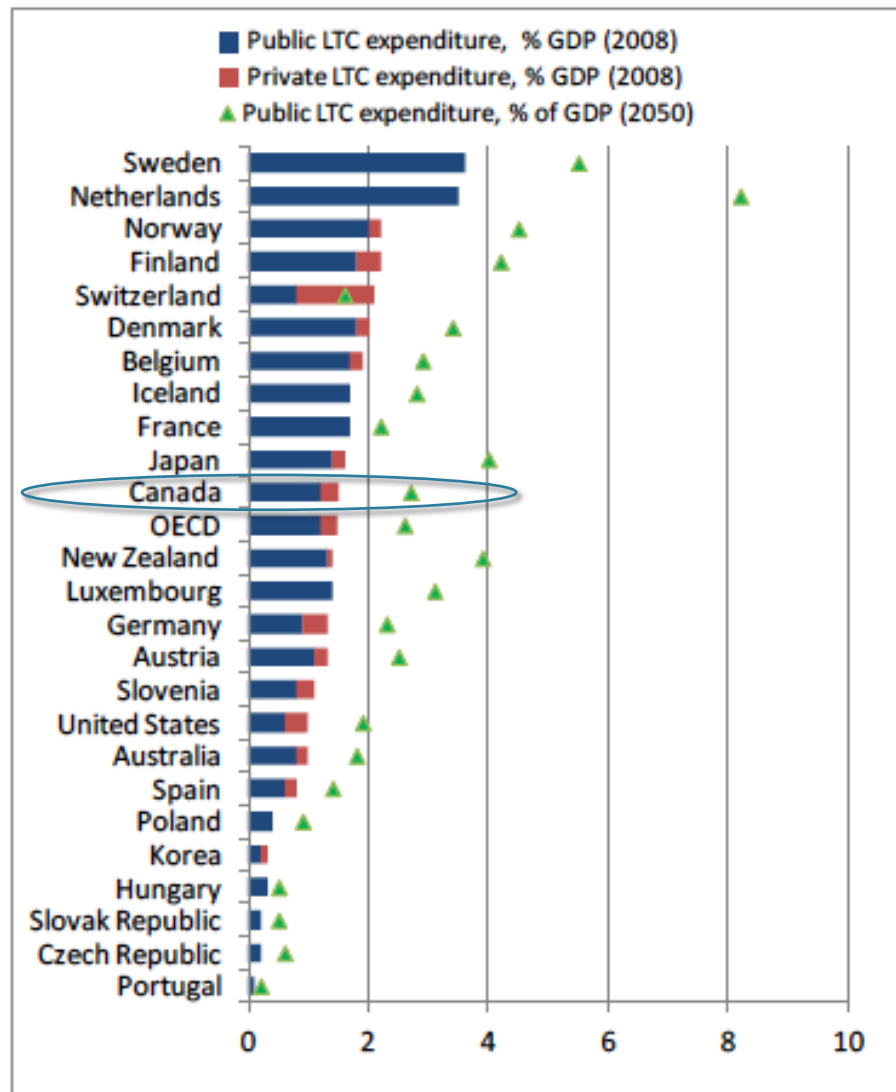
- ▶ Settings providing facility-based care where residents live permanently with 24/7 housekeeping, personal, and healthcare services
 - ✧ Combination of **social** and **health** services
- ▶ Funding: public or private, profit or not-for-profit
- ▶ Not covered under Canada Health Act
- ▶ ~1800 LTC facilities 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



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 option¹
- ◆ 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 instability¹
- ◆ At their most fundamental **the choices we make are value choices** – who is valued and thus to whom are resources allocated?

¹Tolson et al (2011), Global agenda. JAMDA.

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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/hypodermoclysis
- Physical restraints 58%
- CPR/some emerg. intervention 43%

DiGiulio et al (2008) J Pall Med

Dying peacefully (no physical or psychological distress):

- 54% died peacefully (Belgium)
- 56% died peacefully (Netherlands)

DeRoo et al (2015) JSPM

Last month of life (USA):

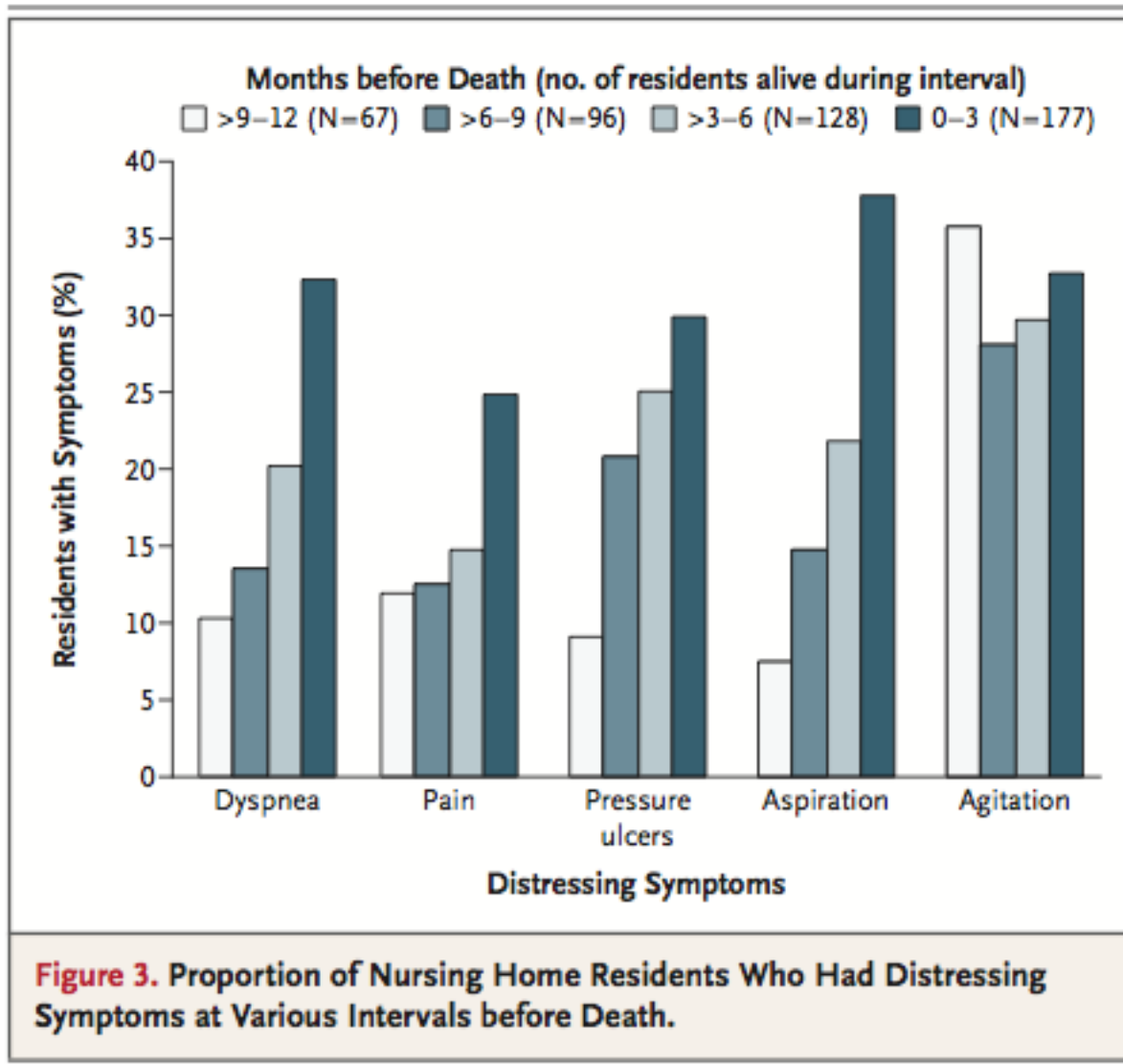
- Pain 47%
- Dyspnea 48%
- Cleanliness 90%
- Symptoms affecting intake 72%

Hanson et al (2008) JAGS

Last week of life (Netherlands):

- Pain 52%
- Agitation 35%
- Short of breath 35%
- Pain & Agitation 15%

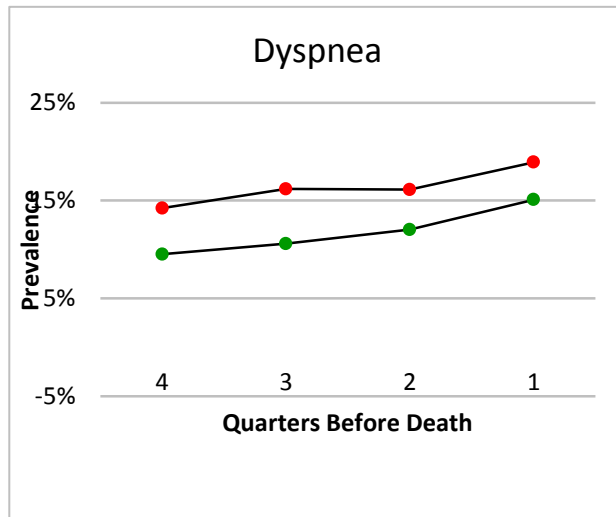
Hendriks et al (2014) JSPM



Mitchell et al., The Clinical Course of Advanced Dementia. NEJM. 2009: 361(16).

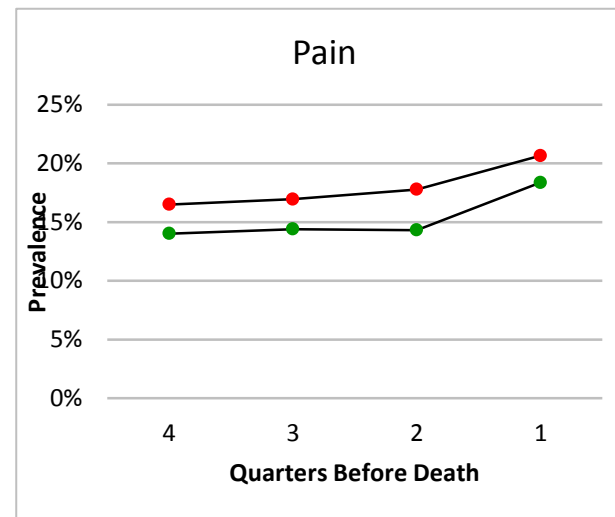
Dyspnea & pain symptoms, last 12 months of life among residents with dementia

(RAI-MDS 2.0 data from 3647 residents in 36 LTC facilities in AB, SK, MB, 2008-2012)*



● Low Context
● High Context

($P_{Dem} < .0001$; $P_{Ctxt} < .0001$; $P_{time} < .0001$)



● Low Context
● High Context

($P_{Dem} < .0001$; $P_{Ctxt} < .0001$; $P_{time} < .0001$)

*Estabrooks, C.A., Hoben, M., Poss, J.W., Chamberlain, S.A., Thompson, G.N., Silvius, J.L., Norton, P.G. (2015). Dying in a nursing home: Treatable symptom burden and its link to modifiable features of work context. *Journal of the American Medical Directors Association*, 16(6), 515-520.



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**

Robert Wood Johnston Foundation. (2014). Long term care: What are the issues?