

# Bridging care for advanced chronic disease into end-of-life care:

*transition*  
*integration*  
*coordination and*  
*personalization*

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Today 739 Canadians will die.

Two-thirds of them will die of known chronic conditions.

More than half of them will die where they don't want to.

Along with their families, many face their dying lacking the information and support they wanted.

By 2056, 1400 Canadians will die daily. How will it be?

# Outline

- Challenges on the front line of care
- What we know can ease those challenges
- Comment on the way forward
- Be bold (says Walter)
- While focusing on what I think are the 'touch points'
  - Transitions
  - Integration
  - Coordination
  - Personalization

# Mr. JD in transition



# The 'consumer' perspective

## Experience of care during the end of life: The Nova Scotia mortality follow-back study

- 1316 decedent interviews

# Survey

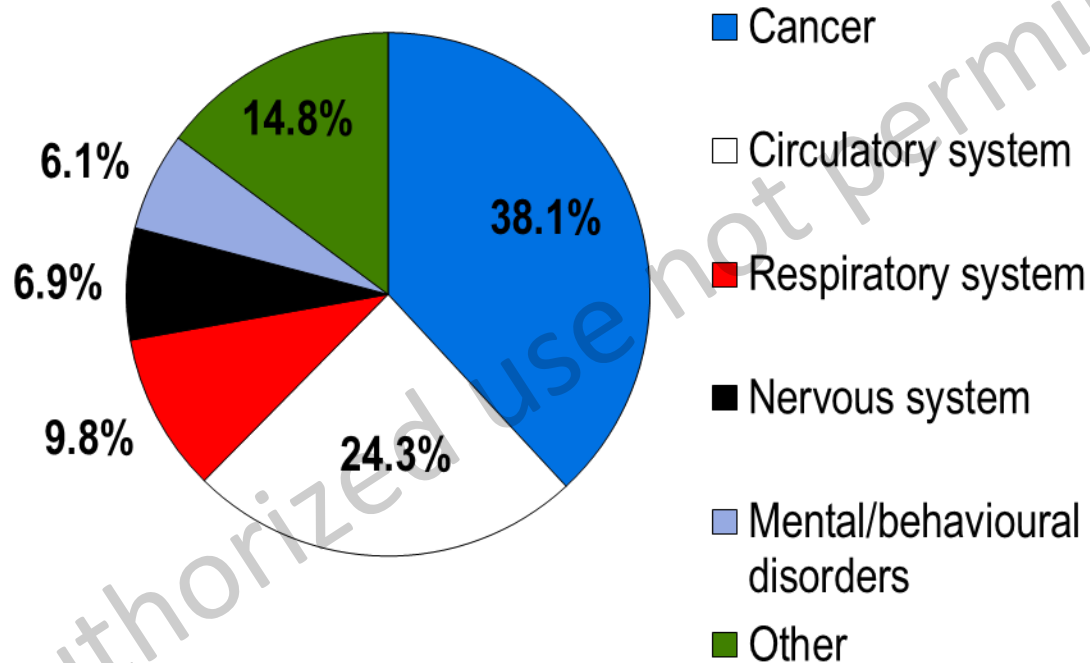
- Mortality follow-back survey
  - ‘After-death bereaved family member interview’ (Teno J et al. 2004) plus additional questions
  - Six patient-focused, family centered domains of care plus overall satisfaction
    - i. Physical comfort & emotions
    - ii. Shared decision making /Communication
    - iii. Treatment with respect
    - iv. Attention to family needs (information, what to expect)
    - v. Family emotional and spiritual support
    - vi. Co-ordination of care
  - Added additional questions of interest
  - Targeted last 30 and ‘few’ days of life.

# Primary outcomes

- **Experience of care: Are needs being met?**
  - Perceptions of unmet need/concerns with care
    - Each domain
    - By location where majority of care was provided
  - Overall satisfaction
- **Care preferences** (wishes)
  - Location of death (desired vs realized)
  - Advanced care planning
    - Desire for medical treatment, medical procedures & provision of care being consistent with decedent wishes
- **Service utilization.**

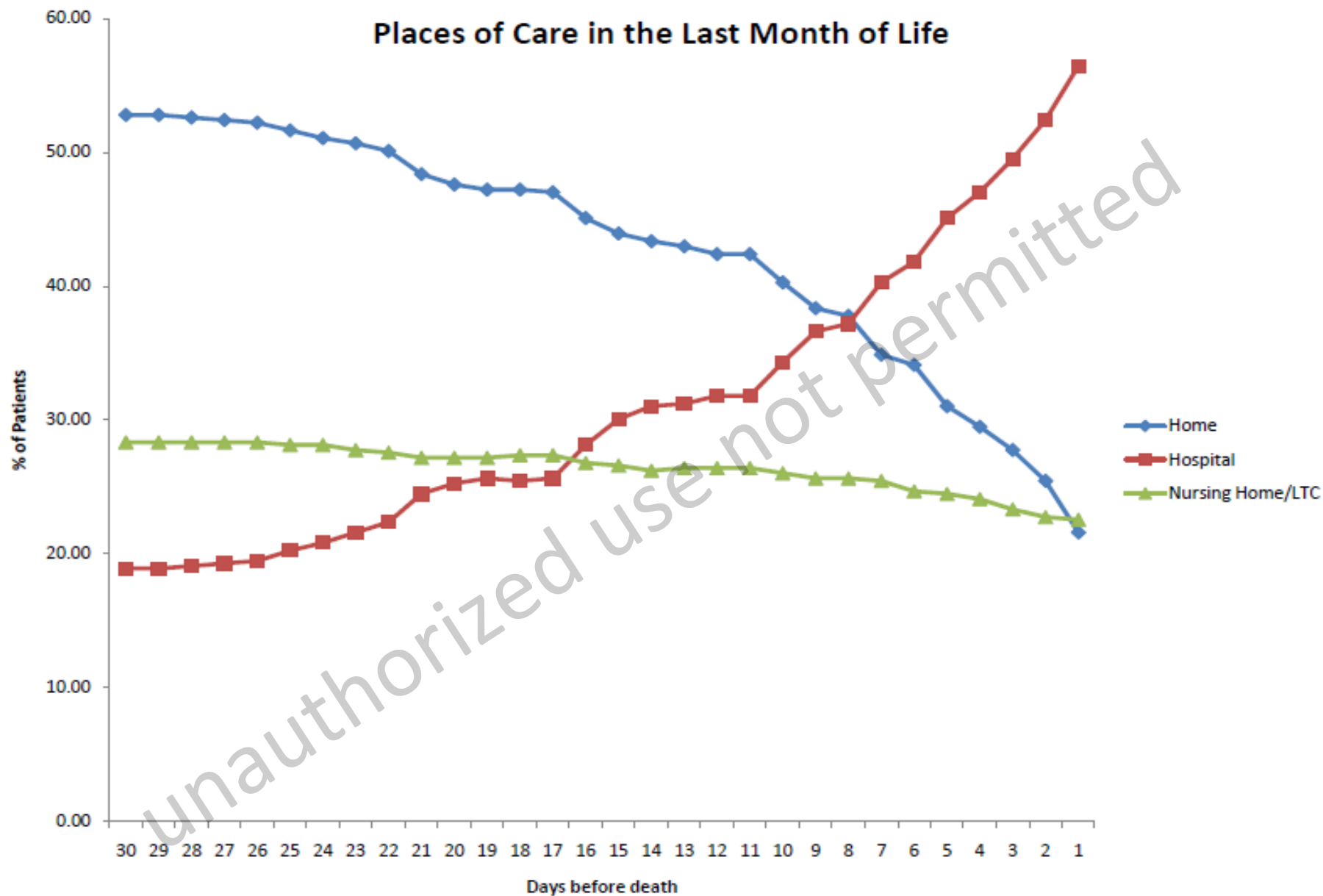
# Decedents

Cause of death

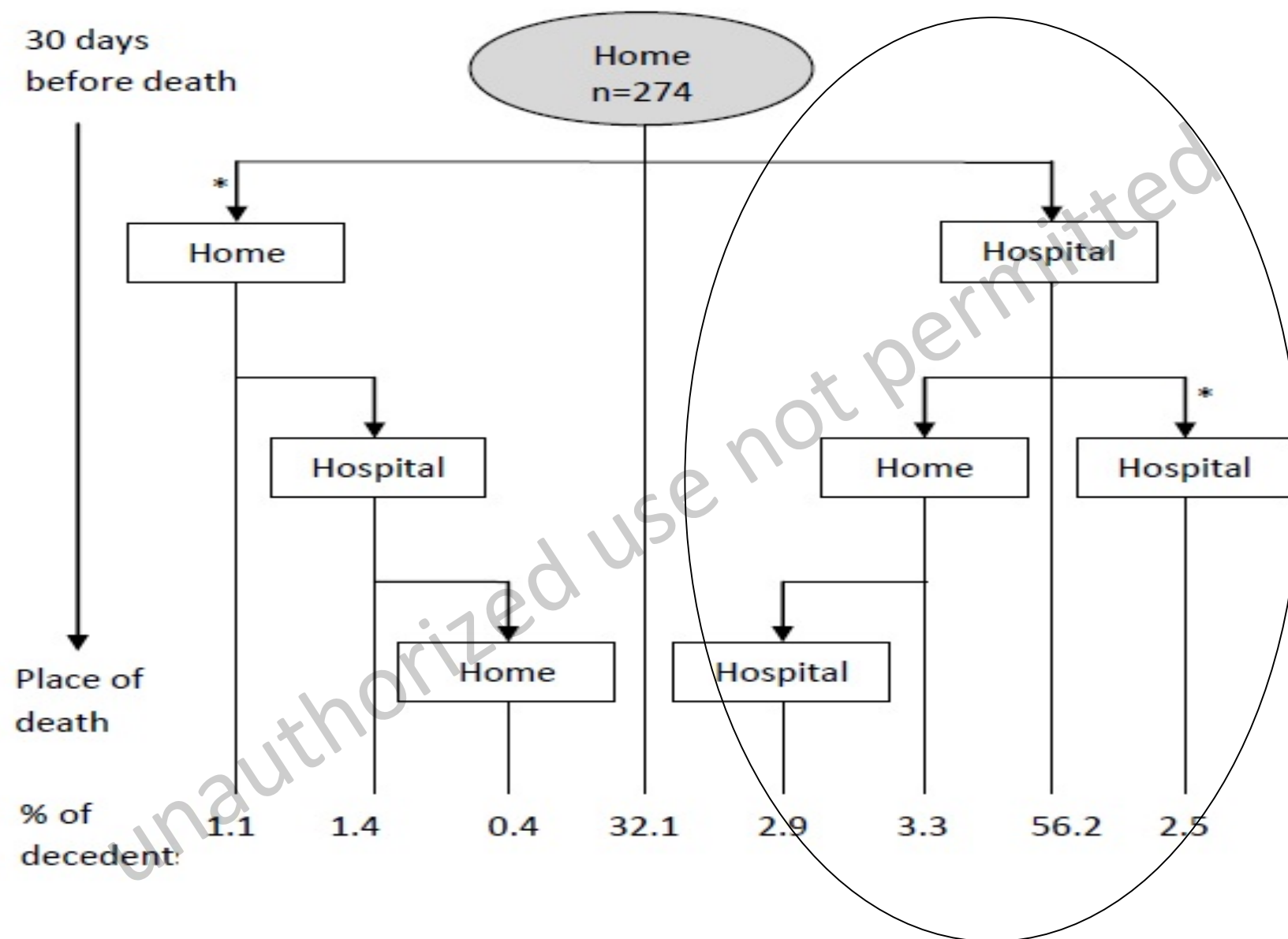




## Places of Care in the Last Month of Life



30 days  
before death



# Transition

- Make the transition to acknowledging dying as a likely outcome too late to plan well
- Make the transition to re-aligning goals of care so late that medications aren't reviewed and reduced, that diagnostic testing and referral aren't limited
- Making multiple transitions between 'places of care' and between 'providers', creating system weak moments

# Transition questions:

- Can earlier transition to acknowledging life limiting disease coupled with ACP actually improve patient/family/provider outcomes while reducing cost and utilization?
- Can we make the transition to 'preferred place of dying' and align resources to stay?
- Can we make the transitions between care settings/provider smooth?
- How do we reduce the number of transitions?
- What is 'smooth' in a transition?

# Integration

- Hospital and home
- Specialists and primary care
- Health professional and personal/home care
- Health care and social care
- It's about integrated 'thinking' as much as systems.
- In the 'old days' we had 'practice-attached' homecare RNs

# Coordination

- From the patient and family perspective
- From the provider perspective
- From the system perspective

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# The changing structure of Primary Healthcare

- The waves of change:
  - Collaborative teams
  - Rostered patients
  - Alternative funding
  - Improved access
  - Electronic Medical Records
  - Practice facilitation
  - Negotiated deliverables with new models
  - .....and then there's our societal change!



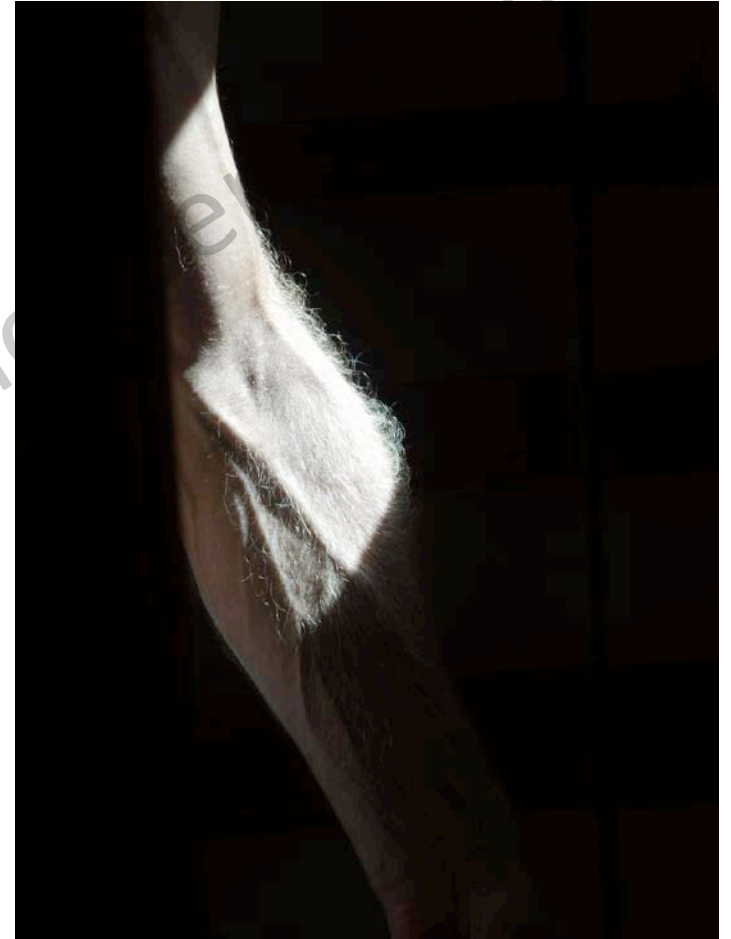
# The innovation responses at End of Life

- System design
  - Supporting continuity in collaborative primary care teams
  - Expanded role paramedics
  - Care by Design teams in long term care
- Clinical information systems
  - Identification of those 'at risk' of dying using EMRs
  - Shared team communication (within and beyond!)



# The innovation responses at End of Life

- Clinical decision support
  - Frailty portal
- Prepared proactive practice teams
  - Gold Standards Framework
  - Integrated teams across primary and specialty care
- Prepared communities
  - Community health teams

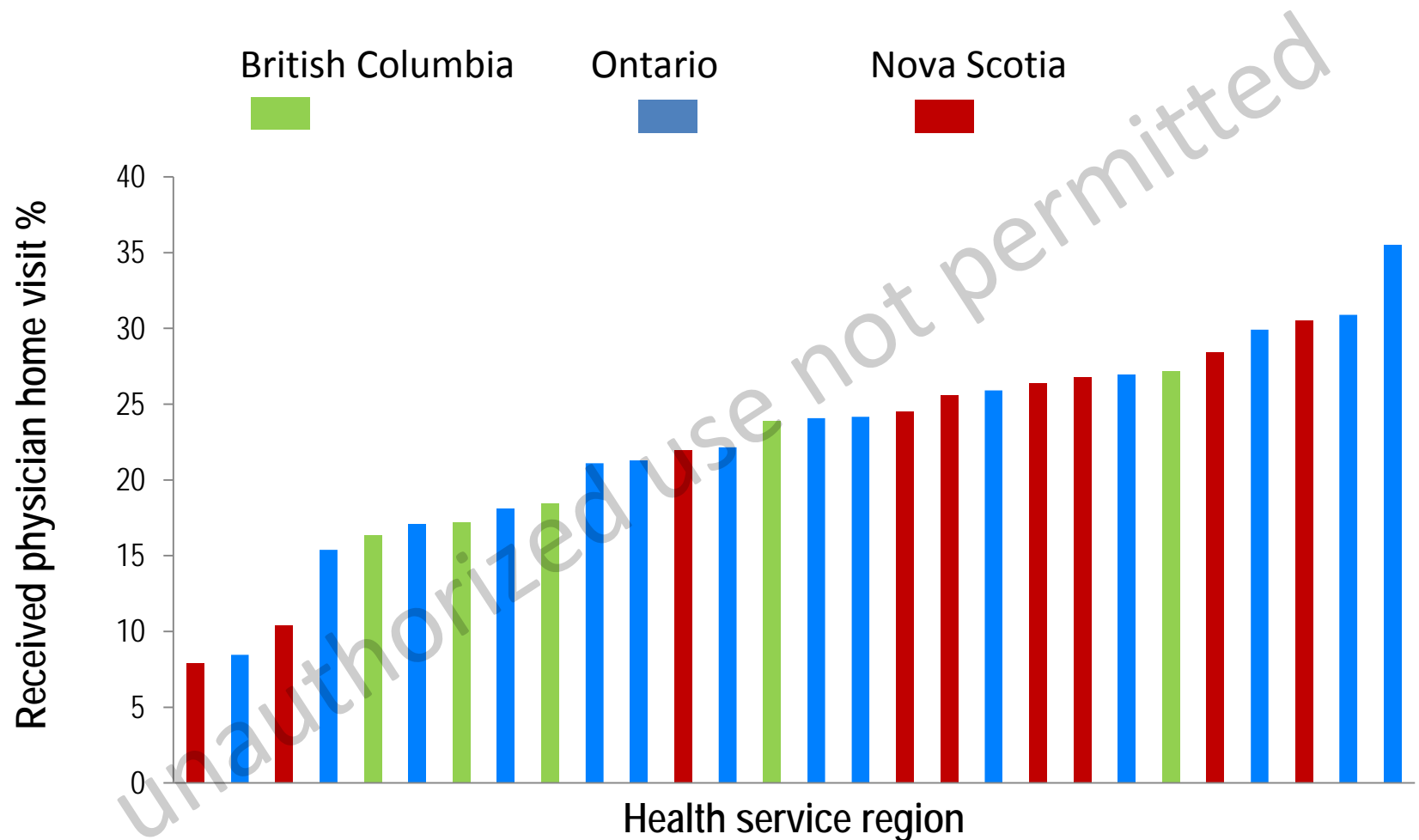


## And the research in PHC at end of life shows...

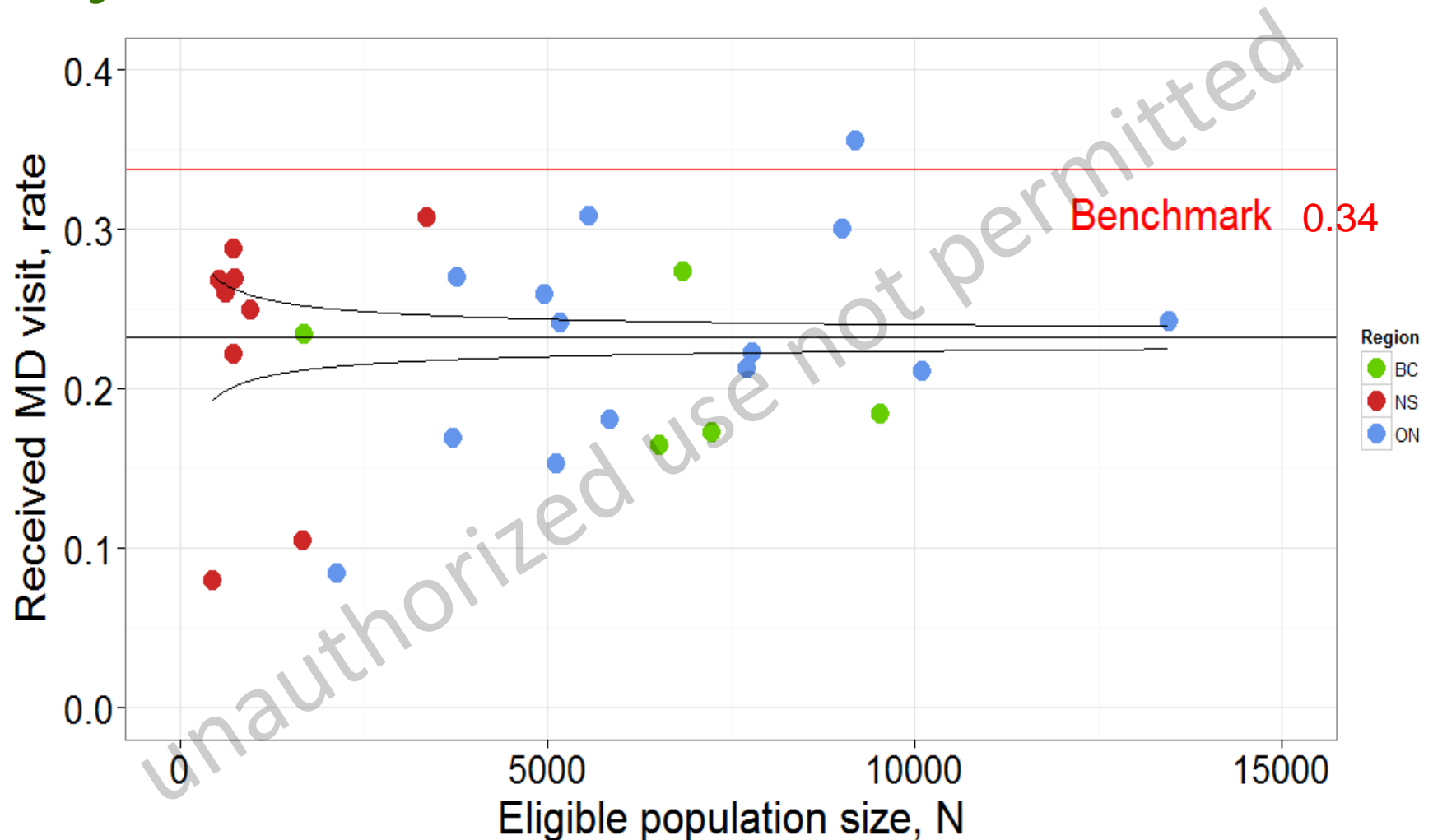
- Continuity matters
- Comprehensive team based care matters
- Health system redesign matters
- Family doctor and nurse home visits matter
- Integrated care models matter
- Some communities/settings do it better, but how, matters



# Proportion of decedents receiving at least one home visit during the last 14 days



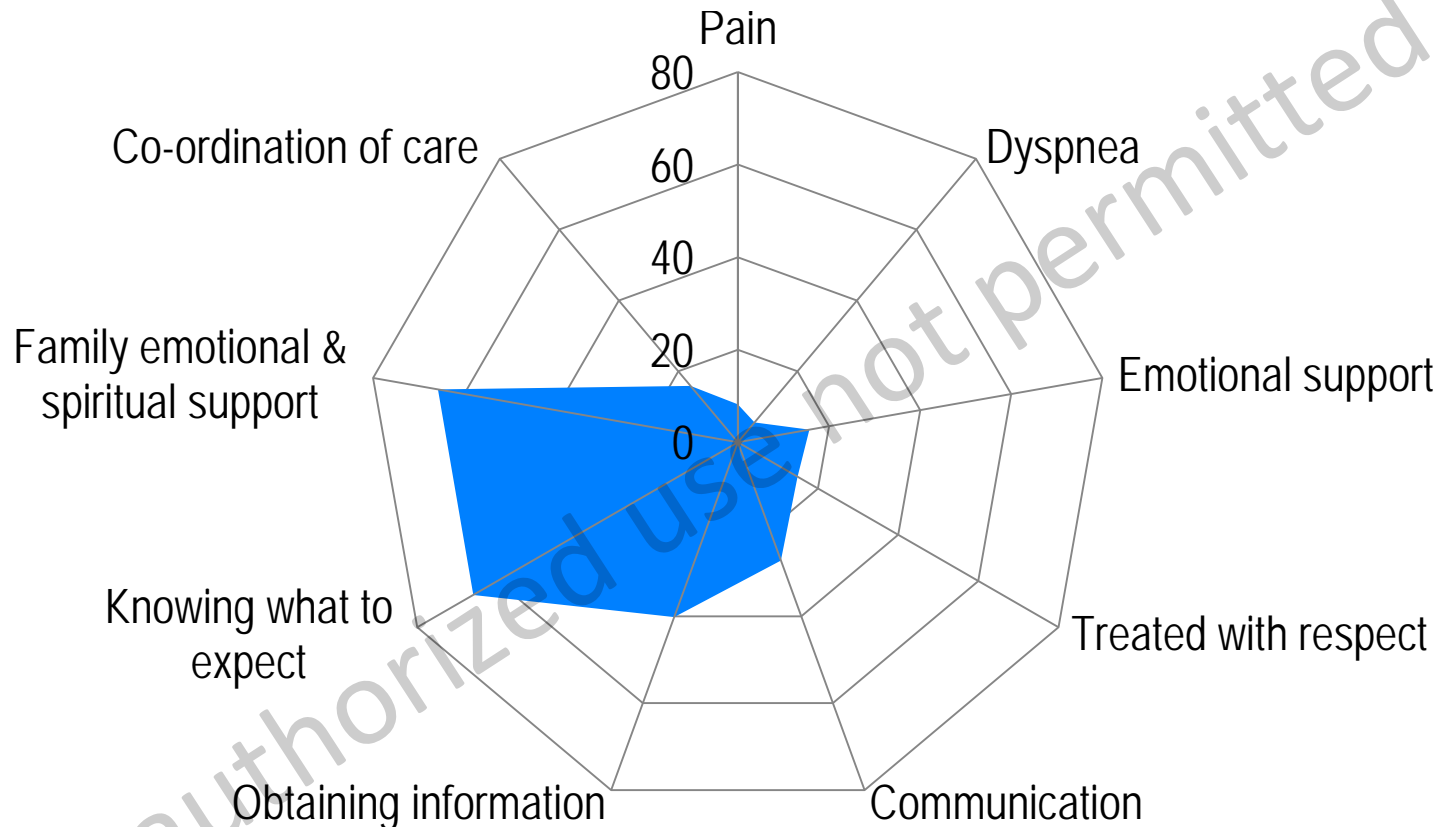
# Receipt of physician home visit during last 14 days (more is better!)



# Experience of care: Are needs being met?

Domain	Perception of unmet need/concerns Frequency (%)
<b>Physical comfort and emotions</b> <i>Decedent did NOT receive enough support for:</i> Pain Dyspnea § Emotional support†	 108 (8.2) 74 (5.6) 205 (15.7)
<b>Promotion of shared decision making</b> Concerns with communication §	332 (27.2)
Concerns with decedent being treated with respect §	194 (14.9)
<b>Attend to needs of the family</b> Unmet need in obtaining information† Concerns with knowing what to expect†	525 (40.2) 862 (66.0)
Concerns about family emotional & spiritual support	860 (65.8)
Coordination of care concerns†	202 (15.9)
Overall – Not completely satisfied	729 (57.0)

## Proportion of informants expressing unmet need/concerns within each domain (n=1316)



Note: Overall mean satisfaction score = 8.7 / 10 (SD1.8); 57% were not 100% satisfied



# Personalization



# Primary Healthcare Innovation for End of Life Care





# My parting research question...

Can “intensive primary and integrated care” in the community for those with advanced chronic disease improve outcomes for patients, families, providers and the system (cost)?



## In the last 30 minutes:

- 15 Canadians died
- 10 of advanced chronic conditions
- I wonder how it went for them?



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# Adjusted\* odds of experiencing unmet need / concerns by location

Domain	Location where majority of care provided (last 30 days) (versus home)		
	LTC	Hospital (acute)	Hospital-PCU
Received desired help for:			
Pain	1.2 (0.7-2.2)	0.8 (0.5-1.5)	0.8 (0.4-1.9)
Dyspnea	<b>0.2 (0.1-0.5)</b>	<b>0.3 (0.1-0.6)</b>	100% needs met
Emotional support	0.7 (0.4-1.1)	1.1 (0.7-1.7)	0.6 (0.3-1.1)
Shared decision making	1.2 (0.8-1.8)	<b>2.0 (1.4-2.8)</b>	1.3 (0.8-2.1)
Treated with respect	<b>2.3 (1.4-3.8)</b>	<b>3.2 (2.1-5.0)</b>	<b>2.1 (1.1-3.9)</b>
Coordination of care	1.0 (0.6-1.6)	1.4 (0.9-2.0)	<b>0.5 (0.2-1.0)</b>
Family needs:			
Obtaining information	<b>0.7 (0.5-1.0)</b>	1.0 (0.8-1.4)	<b>0.6 (0.4-1.0)</b>
Knowing what to expect	<b>0.7 (0.5-0.9)</b>	1.1 (0.8-1.5)	1.1 (0.7-1.7)
Emotional & spiritual support	<b>0.7 (0.5-1.0)</b>	0.9 (0.6-1.2)	1.0 (0.6-1.6)
Not 100% satisfied with care	1.2 (0.8-1.6)	<b>1.6 (1.2-2.3)</b>	1.1 (0.7-1.7)