SALTY – Improving End of Life Care in Long Term Care

Janice Keefe
Scientific Lead and Co Lead Stream 4

Matthais Hobin
PDF and Co-lead Stream 1

Funding Partners

Canadian Institute of Health Research (CIHR), Michael Smith Foundation for Health Research (MSFHR), Nova Scotia Health Research Foundation (NSHRF), Alzheimer Society of Canada (ASC)

Gratefully Acknowledged
OUTLINE

1. Getting to Know each other
2. Why is End of Life in LTC important?
3. What we know already?
4. Introducing SALTY – Seniors Adding Life to Years
5. Lessons learned already
6. Advice and Feedback
WHERE ARE YOU LOCATED?
Demographics

Life expectancy in years by year of birth and selected developed countries

Causes of death in the last decade


2015 Alzheimer's Disease Facts and Figures

Today
1,519 LTC facilities
149,488 residents
90% 65+ years old

By 2038
Demand for LTC care expected to almost double

Canadian Institutes of Health Information (2014) 
Alzheimer Society of Canada (2010)
Long Term Care as Late Life Care

LTC is late life care

- 80% of LTC residents will die in the facility
- On average, residents die 18 months after admission

Up to 90% of residents with advanced Dementia will receive care in a LTC facility

LTC is dementia care

EoL care is challenging for NHs

- Dementia is not well recognized as a terminal disease
  (van der Steen et al. 2014)
- Difficult to determine when final stage begins
  (Mitchell et al. et al. 2009)
- Multiple clinical complications associated with Dementia
  (Mitchell et al. et al. 2009)

Residents receive interventions which are inconsistent with an optimal end of life care approach

Unnecessary suffering

End of Life with Dementia

Burdensome symptoms at the EoL of 323 residents with advanced dementia

**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).
Previous Research

- Communication difficulties
- Dementia
- Physical dependency
- Complex care needs

Poor communication and collaboration among involved partners

- Dissatisfaction with care provided
- Guilt, fear and anxiety
- Lack of information
- Feeling overwhelmed

- Lack of training
- Poor quality of worklife
- Staff/time shortages
- High turnover

- Crowded rooms
- Little privacy
- Noisy environment
- Poor learning culture

- Entry to LTC viewed as failure
- Demographic changes
- Policies focusing on safety/clinical outcomes rather than comfort and quality of life
9 academic researchers from 11 universities
10 diverse disciplines
  - nursing, health services, medicine, social work, management, geography, sociology, gerontology, political economy
3 Research Chairs
  - 1 Canada Research Chair Tier I; and 2 CIHR Research Chairs – Gender, Work & Health
9 trainees and more to come
22 knowledge users
  - clinicians, decision makers,
  - representatives of family, persons with dementia, staff, volunteers
Work focused in four provinces – ON, BC, AB, NS
  - Facility level, regional level, provincial level
Research design includes both cross sectional and longitudinal and multiple methods
4 funding partners
  - CIHR, MSFHR, NSHRF and Alzheimer Society of Canada
To add quality of life to late life for people living in residential long term care.
Gender

Dementia

Under-represented Voices
FOUR INTER-RELATED STREAMS OF WORK TO ACHIEVE OUR COLLECTIVE AIM

Stream 1 – Monitor Care Practices
Stream 2 – Map Care Relationships
Stream 3 – Evaluate Innovative Practice
Stream 4 – Examine Policy Context

To add quality of life to late life for people living in residential long term care.

Inter dependent activities and outputs
Symptoms of End of Life at Home

Dyspnea & pain symptoms, last 12 months of life among residents with dementia
(RAI-MDS 2.0 data from 3,647 residents in 36 TREC 1.0 facilities in AB, SK, MB, 2008-2012)

Estabrooks et al., Dying in a nursing home: Treatable symptom burden and its link to modifiable features of work context. JAMDA 2009: 16(6), 515-520.
Stream 1 – Monitor Care Practices (Leads: Estabrooks, Hobin)

- Use RAI-MDS 2.0 data to develop set of quality indicators that will be used to monitor care in the year prior to death
  - Rank symptoms and practices based on multiple sources
  - Analyze sub-sample of deceased residents
  - Validate with CIHI data
  - Panel discussions with stakeholders

Stream 2 – Map Care Relations (Leads: Daly, Bourgeault, Aubrecht)

- Longitudinal research to map the social and relational dimensions of quality of life and quality of care
  - Scoping review and key informants to identify best practice for relational care
  - Case studies in four provinces
  - Transfer of approaches across jurisdictions
Stream 3 – Evaluate Innovative Practice (Leads: Stajduhar, Cloutier, MacDonald)

- evaluate the implementation of the QI Project, Vancouver Island, BC
  - Assess the impact of the implementation project
  - Assess indicators of quality of care at the end of life pre and post implementation
  - Identify process for successful implementation in Island Health and influencing contextual factors (facilitators, barriers and lessons learned for scaling up to other facilities)

Stream 4 - Examine Policy Context (Leads: Cook, Keefe, Taylor)

- content analysis of policies to assess how they can support or limit application of end of life practice
  - Identify relevant policies – literature, KI interviews
  - Analyze policies re facilitators and barriers
  - Develop alternative approaches
Governance Model

SALTY Advisory Group
Resident, Family & Staff Representatives, Scientific Lead
Led by H. Fifield (Patient/Family Lead)

SALTY Management Committee,
J. Keefe (Scientific Lead); C. Estabrooks, (Co-Principal); H. Cook, (Knowledge User Lead); L. MacDonald, (Clinical Lead);
H. Fifield, (Patient/Family Lead), Stream Leads (see below)

Stream 1
Led by Estabrooks (Co-Principal & CRC I) and Hoben (PDF).

Stream 2
Led by Daly and Bourgeault (CRC IIs) and Aubrecht (PDF)

Trainee Network Across Streams

Stream 3
Led by MacDonald (CL) Stajduhar and Cloutier (Senior Researchers)

Stream 4
Led by Cook (KU Lead), Keefe (SL), and Taylor (KU & PDF)

Knowledge Translation Advisory Group
Includes Knowledge Users & Clinicians
Led by Taylor (KU)
PROVIDE RICH, INTEGRATED TRAINING ENVIRONMENT FOR EMERGING SCHOLARS – interdisciplinary, applied health interactions.

Support the development of emerging scholars interested in advancing both the science of late life care for LTC residents and application in this sector.
Hearing from the Resident/Family perspective

“…utilize expertise and experiences of persons with dementia in moving forward…”

“Don’t want sympathy or pity – want to be a part of what you are doing.”

Sense of being overwhelmed at first – but gradual recognition of the contributions care aide workers can make

“Forefront is resident and families but need to create a culture of change within facilities”

“We as health care providers have an idea of what we think quality [of life] is…but we have to consult with them [seniors] and get their perspective.”

Happy to see that volunteers are included in this initiative

“Be conscious of end users voice and family voices. Communication is key.”

“Important outcome? Moving results into action…”
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Project governance and management</td>
<td>STR 1-validated indicators</td>
<td>STR 2-case studies complete</td>
<td>STR 4-policy workshops</td>
</tr>
<tr>
<td>Team meeting (Halifax)</td>
<td>STR 3- QI project evaluation complete</td>
<td>Team meeting (Ottawa)</td>
<td>At least 10 publications</td>
</tr>
<tr>
<td></td>
<td></td>
<td>STR 3-Provincial Sector Engagement Workshops</td>
<td>Video and other KT products</td>
</tr>
</tbody>
</table>

SALTY ADVISORY GROUP
KT ADVISORY GROUP
AIM: To add quality of life to late life for people living in residential long term care.

SALTY: What difference can we make...
Janice M. Keefe, PhD  
Professor  
Director, Nova Scotia Centre on Aging  
Lena Isabel Jodrey Chair in Gerontology  
Mount Saint Vincent University  
Email: janice.keefe@msvu.ca

Matthias Hoben, PhD  
AIHS Postdoctoral Fellow  
Translating Research in Elder Care (TREC)  
Faculty of Nursing, University of Alberta  
mhoben@ualberta.ca

Email: SALTY@msvu.ca  
Website: www.SALTYltc.ca  
Twitter: @SALTY_LTC  
Facebook: www.facebook.com/NovaScotiaCentreOnAging