Planning Health Services for Persons with Dementia in Ontario: Current Challenges and Opportunities

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Disclosures

- Commercial Interests: none
- Grants/Research Support: CIHR, Ontario Brain Institute, Queen’s University
- Consulting: Cancer Care Ontario, Dementia Capacity Planning
- No disclosures related directly to my presentation
- No in-kind or other financial support for this presentation
Confessions

- Planning person centred services for people with dementia is complicated
- Resource constrained environment, how to do “better” with our resources
- Services are interconnected, need multiple services working in coordinated fashion for optimal outcomes
- Need solutions yesterday, but no quick fixes
- Data for decision making is not always complete
Objectives

1.) To understand the importance of health service planning for persons with dementia;
2.) Examine promising evidence-based models of care for persons with dementia;
3.) Review the Dementia Capacity Planning model for Ontario
Capacity Planning in Action!

- Take out your phones!
- #37607
- Text: dallasseitz
- Response indicating you have been registered
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Challenges in Dementia Services

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Mrs. S. has been living with mild symptoms of dementia for 3 years and has a MMSE = 23/30. She is happy and content with her life. Mrs. S does not have any significant limitations in her basic activities of daily living. She is medically stable and has no significant behavioural changes. She can use the phone, has some difficulties with preparing meals, needs reminders about her medications, and is not able to drive. She lives in a basement suite at her adult daughter's home, her daughter works.
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When completed text: leave
What is your background?

Respond at PollEv.com/dallasseitz

Text DALLASSEITZ to 37607 once to join, then A, B, C, D, or E

- Physician: A
- Nursing: B
- Allied Health Professional: C
- Person with Dementia/Care Partner: D
- Other: E
Which of the following services are most helpful for supporting community dwelling persons with dementia?

- Adult day programs
- Caregiver training or support programs (e.g., Alzheimer Society)
- Dementia Specialty Programs (e.g., geriatric psychiatry)
- Out of home respite (e.g., overnight respite)
- In-home supports (e.g., PSW support, in-home respite)

When poll is active, respond at PollEv.com/dallasheitz
Text DALLASSEITZ to 37607 once to join
What are the biggest gaps you see right now related to in-home supports for persons with dementia in Ontario?

When poll is active, respond at PollEv.com/dallasseitz

Text DALLASSEITZ to 37607 once to join

Amount of in-home supports (i.e. number of PSW hours)

Consistency and convenience of in-home supports

Not qualifying for services (e.g. in-home supports for mild dementia)

Training or background of individuals providing in-home supports

Difficulties in system navigation or connecting to in-home supports

0%
Mrs. S. has been living with mild symptoms of dementia for 3 years and has a MMSE = 23/30. She is happy and content with her life. Mrs. S does not have any significant limitations in her basic activities of daily living. She is medically stable and has no significant behavioural changes. She can use the phone, has some difficulties with preparing meals, needs reminders about her medications, and is not able to drive. She lives in a basement suite at her adult daughters home, her daughter works.
How many PSW hours each do you feel would be needed for Mr. S. to be able to continue to live at home safely and with a good quality of life for her and her daughter?

When poll is active, respond at PollEv.com/dallasseitz

Text DALLASSEITZ to 37607 once to join

- None
- 3 hours once per week
- 3 hours three times per week
- 1 hour twice a day
- 3 hours twice a day

0%
What if Mrs. S. lived alone?

When poll is active, respond at PollEv.com/dallasseitz
Text DALLASSEITZ to 37607 once to join

- None
- 3 hours once per week
- 3 hours three times per week
- 1 hour twice a day
- 3 hours twice a day
Which of the following characteristics of persons with dementia has the greatest impact on remaining at home?

- Stage or severity of dementia
- Incontinence
- Mobility problems
- Medical co-morbidity or complexity
- Behavioural symptoms

When poll is active, respond at PollEv.com/dallasheitz
Text DALLASHEITZ to 37607 once to join

0%
What is the anticipated growth in the number of people with dementia in Champlain LHIN between 2015 and 2020?

When poll is active, respond at PollEv.com/dallasseitz

Text DALLASSEITZ to 37607 once to join
What is the anticipated growth in the number of community-dwelling persons living with dementia who will be on a LTC waitlist between 2015 and 2020 in the Champlain LHIN?

Respond at PollEv.com/dallasseitz

Text DALLASSEITZ to 37607 once to join, then A, B, C, D, or E
Dementia in Canada

- Populations in Canada are aging
- ~500,000 individuals diagnosed with dementia in Canada
  - 7% of all adults over age 65
- ↑ prevalence to 1.4 million by 2031, 1.8 million by 2041
- Majority of people with dementia live in community

2. Alzheimer Society of Canada, 2010
Dementia and Health Services

- Majority of costs associated with dementia related to LTC (50%) and acute care (30%)\(^1\)
- Acute care use by older adults with dementia\(^2\):
  - ER visits: 40% dementia vs 24%
  - Admissions: 22% dementia vs 10%
- Dementia and alternative level of care\(^3\):
  - \(\frac{1}{4}\) of all ALC hospitalizations, \(\frac{1}{3}\) ALC days
  - Median ALC LOS 23 days vs. 10 days

1. Ng, Brain Disorders in Ontario, 2015
2. Bronskill, ICES, 2011
3. Walker, Healthcare Quart, 2009
Economic Impact of Dementia

- Cumulative costs of dementia over next generation in Canada: $872 billion
- Canada, annual total costs: $15 billion → $153 billion by 2031
  - $8 billion direct costs, $5 billion indirect (caregiver) costs
- Informal care in Canada: 230 million hours, 50% in is community settings
- U.S. 17.9 billion hours of unpaid caregiver time (average 20 hours per week) = $217 billion

1. Rising Tide, Alz Soc Canada, 2010
Health System Costs Associated with Dementia

- Globally: $645 billion annually
- Most developed countries spend 3 to 5% of total health care budget on dementia care
- U.S. direct health care costs (excluding caregiver costs) $226 billion per year
- Total direct healthcare costs in Canada: $8 billion
- Mean and median direct annual costs of services for person with dementia: $29,000, $21,000
  - ~ double that age matched population

1. Hurd, NEJM, 2013
2. Ng, Brain disorders in Ontario, 2015

OECD, Addressing Dementia
‘I shouldn’t have had to push and fight’: health care experiences of persons with dementia and their caregivers in primary care

Jeanette C. Prorok\textsuperscript{a,b}, Maria Hussain\textsuperscript{a,b}, Salinda Horgan\textsuperscript{a,b} and Dallas P. Seitz\textsuperscript{a,b}

Communication

Care Partner as Manager

System Navigation

Ease of Access
Health Care Experiences of Persons with Dementia

- Meta-ethnography of qualitative studies evaluating health care experience of persons with dementia and care providers
- Themes:
  - Seeking a diagnosis
  - Accessing supports and services
  - Addressing information needs
  - Disease management
  - Communication and attitudes

Prorok et al., CMAJ, 2013
Framework for Dementia Policy

OECD, 2015
Canadian Alzheimer’s Disease and Dementia Partnership

1. Research:
   - Support key research initiatives (CCNA, SPOR)
   - Develop national standards for care based on evidence

2. Prevention
   - Develop and adopt targets for dementia screening (75% screening at risk)
   - Support “Dementia Friends” – businesses and employers
   - Public awareness campaign to promote prevention, reduce stigma

3. Living well with Dementia
   - Improve caregiver leave benefits
   - CME programs for dementia care
   - Curriculums for health care professional training programs
   - First Link programs
   - Go to hubs for evidence based practice and virtual collaborations
Ontario Dementia Strategy

1. Supports for People Living with Dementia
2. Accessing Dementia Services
3. Coordinated Care
4. Supports for Care Partners
5. Well Trained Dementia Workforce
6. Awareness Stigma and Brain Health

https://www.ontario.ca/page/developing-ontarios-dementia-strategy-discussion-paper
Senate Committee Report

DEMENTIA IN CANADA:
A National Strategy for Dementia-friendly Communities

Standing Senate Committee on Social Affairs, Science and Technology

The Honourable René Cormier, Chair
The Honourable Art Eggleton, P.C., Deputy Chair

November 2016
Dementia Capacity Planning Project

Partnership between Cancer Care Ontario, MOHLTC, Institute for Clinical Evaluative Sciences, Ontario Brain Institute (September 2015 – March 2017)

Vision: Support persons living with dementia at home and in the community safely, as long as possible
Dementia Capacity Planning Project

Purpose:
• To establish a planning framework, processes and tools to address the needs of persons living with dementia and care partners
• Capacity planning implications for the Dementia Strategy

Outcomes:
1. Scenario analysis informed by quantitative and qualitative research and ongoing engagement with health system partners with system and lived experience (What are some of the best ways to help?)
2. Knowledge transfer and exchange plan to inform future population-based planning activities within the MOHLTC (How can this be used in Ontario?)
Framework for Dementia Capacity Planning
Dementia Capacity Planning Model

- Understanding the current state of persons with dementia and caregivers using administrative data and qualitative data
- Develop model to simulate future state
- Identify current actual needs of persons with dementia, care partners from multiple perspectives
- Develop “what if” scenarios – changes to supports and services based on evidence
- Evaluate the impact of possible scenarios on outcomes
  - E.g. Time able to remain in community, caregiver stress, costs, use of community services
Establishing the Current State
What does our current population look like?

**Population**
- Who are the persons living with dementia?
- Where are they?
- How long since they were physician diagnosed?

**Profiles**
- What are the cognitive, functional and clinical characteristics of persons living with dementia?
- Are there subgroups that require attention?

**System Use**
- What is the current resource utilization patterns?
- What are health system transition trends?
Identifying Persons with Dementia

Approach:
This number is based on meeting the following criteria from clinical/administrative datasets:

i. 1 hospitalization record from DAD or
ii. 3 physician claim records at least 30 days apart in a 2-year period from OHIP or
iii. 1 prescription drug reimbursement record from ODB for cholinesterase inhibitor

<table>
<thead>
<tr>
<th>Performance:</th>
<th>Value (with 95% Confidence Intervals)</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Measure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sensitivity</td>
<td>79.3 (72.9 – 85.8)</td>
<td>Algorithm will correctly flag dementia for 79.3 of the 100 individuals who have dementia</td>
</tr>
<tr>
<td>Specificity</td>
<td>99.1 (98.8 – 99.4)</td>
<td>Algorithm will correctly avoid flagging dementia for 99.1 of the 100 individuals who don’t have dementia</td>
</tr>
<tr>
<td>Positive Predictive Value</td>
<td>80.4 (74.0 – 86.8)</td>
<td>For every 100 people flagged with dementia, 80 truly have dementia</td>
</tr>
<tr>
<td>Negative Predictive Value</td>
<td>99.0 (98.7 – 99.4)</td>
<td>For every 100 people not flagged with dementia, 99 truly don’t have dementia</td>
</tr>
</tbody>
</table>
Modelling Changes to Dementia Care

Model Warm Up Period – Historical Data Used

Validate Results with historical data

Transition Period – Projections Unavailable

5 year planning horizon begins

Simulation Period – Projections Used

Simulation Begins

1 April 2009

1 April 2014

1 April 2015

Simulation Ends

31 March 2020
How many people are living with dementia in Ontario?
What supports and services do people with dementia currently use?
How many people in the community need support?
Change in Number of Community Dwelling PLwD (2009/10 and 2014/15)

Provincially, the community dwelling population has grown from 76,416 to 106,940 from 09/10 to 14/15 (+40%).

North West LHIN has the smallest community dwelling population (2,094) and Central LHIN has the largest community dwelling population (14,219).

The highest growth was seen in Central West LHIN (+77%) and lowest growth was seen in HNHB (+23%).

Note: All results are preliminary, and should not be used for decision-making.
Who is receiving any support?

Homecare Utilization by Community Dwelling PLwD

In 14/15, 68% (71,990 PLwD) of the community dwelling dementia population received homecare. This varies across regions. The highest homecare utilization occurs in the North East LHIN (83%) and the lowest homecare utilization occurs in Central West LHIN (59%).

Note: All results are preliminary, and should not be used for decision-making.
How much support is currently provided?
Use of Personal Services by PLwD in the Community

Average PS/HM Contacts per PLwD (2014/15)

Of the 71,900 community dwelling PLwD receiving homecare provincially, on average they received 117 PS/HM contacts per PLwD in 2014/15 (or ~2 contacts per week).

The highest number of contacts per PLwD were delivered in the Toronto Central LHIN (165) and the fewest number were delivered in the North East LHIN (87).

Note: All results are preliminary, and should not be used for decision-making.
How much time do persons living with dementia spend in the community?
SIMULATION MODELLING TO UNDERSTAND THE FUTURE
CHAMPLAIN LHIN CASE STUDY
Future State
What does dementia in Ontario look like in five years according to status quo scenario?

Status quo scenario projects how the dementia cohort and associated system use may change to 2020/21 given:

**Physician Diagnosed Population:** Incidence trends at the sub-LHIN level observed from 2009/10 to 2014/15 continue into the future, allowing for 10% and 20% uncertainty in case ascertainment.

**Transitions:** Healthcare status transitions follow historical rates and LTCH capacity remains fixed at the 2014/15 level.

**Utilization:** Health service consumption rates at 2014/15 levels.
Status Quo Scenario | Champlain
How many people will be living with dementia?

Baseline projections indicate that from 2015 to 2020, total community dwelling population may increase from 10,803 to 15,116 (+40%).

Note: All results are preliminary, and should not be used for decision-making.
Status Quo Scenario | Champlain Long-Term Care Requests and Waitlists

PLwD LTCH requests in Champlain will increase only by 16% over the projection horizon, however, fixed LTCH bed capacity and transitions out of LTCH will cause those waiting for first LTC placement to increase by 73%.

*The analysis on this slide assumes baseline population projections.

Note: All results are preliminary, and should not be used for decision-making.
Status Quo Scenario | Champlain
What is the expected increase in CCAC supports required?

If Champlain’s 2015 CCAC utilization rates continue to 2020, Champlain LHIN can expect a 66% increase in the use of CCAC services by 2020 for persons living with dementia.

*The analysis on this slide assumes baseline population projections.

Note: All results are preliminary, and should not be used for decision-making.
Identifying Strategies to Help Support Living in the Community

- Evidence from health partner engagement, clinical advisory committee
- Scoping literature review to identify priority areas
- Setting: Individuals with dementia living in the community
- Context: current availability and potential for scaling up, alignment with relevant MOHLTC (e.g. Patients First, Dementia Strategy)
What might help better support people at home?

- Scoping review of interventions to support persons with dementia

Outcomes:

- Impact on supporting people at home longer
- Benefits for persons living with dementia (functioning, behaviours)
- Impact on care partners (stress, burden)
- Economic evaluation
- Other health system outcomes (e.g. hospitalization)
Capacity Planning Modelling
Scenarios Initial Priority Areas

- Programs currently funded by MOHLTC
  - Care Partner Education and Support
  - In-Home Respite
  - Adult Day Programs
  - Institutional Respite
  - Comprehensive Community Supports (combinations of the above)

- Optimization of current resources, reducing variation in home care utilization in province
## Evidence for Dementia Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Support People at Home Longer</th>
<th>Improved Caregiver/Patient QoL</th>
<th>Costs</th>
<th>Hospitalizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Partner Education and Supports</td>
<td>Strong evidence in favor (1A)</td>
<td>Strong evidence in favor (1A)</td>
<td>Strong evidence in favor (1A)</td>
<td>NA</td>
</tr>
<tr>
<td>Day Programs</td>
<td>Weak evidence in favor (2B)</td>
<td>Strong evidence in favor (1B/1C)</td>
<td>Weak evidence in favor (2B/2C)</td>
<td>NA</td>
</tr>
<tr>
<td>In-home Respite</td>
<td>Weak evidence in favor (2C)</td>
<td>Strong Evidence in favor (1B/1C)</td>
<td>Weak evidence in favor (2B/2C)</td>
<td>NA</td>
</tr>
<tr>
<td>Institutional Respite</td>
<td>Weak evidence against (2A)</td>
<td>Weak evidence against (2B)</td>
<td>Weak evidence in favor (2B/2C)</td>
<td>NA</td>
</tr>
<tr>
<td>Comprehensive In Home Support</td>
<td>Strong evidence in favor (1A)</td>
<td>Weak evidence in favor (2B)</td>
<td>Weak evidence in favor (2B)</td>
<td>Weak evidence in favor (2B)</td>
</tr>
</tbody>
</table>
Other scenarios for literature and evidence review:
- Specialty services (e.g. geriatric psychiatry, geriatric medicine, neurology)
- Primary Care, Care Provider Education
- Care Management or Care Coordination
- Rehabilitation
- Pharmacological and Nonpharmacological Treatments (e.g. cognitive training)

Impact of changes to dementia detection and diagnosis (e.g. earlier diagnosis)

In-hospital services and acute care utilization
Using Model to Evaluate “What if”

- Persons with Dementia Receiving Current Care
- Persons Receiving Additional Services
- Persons Awaiting LTC
- Persons with Dementia Transitioned to LTC

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>Persons with Dementia Receiving Current Care</th>
<th>Persons Receiving Additional Services</th>
<th>Persons Awaiting LTC</th>
<th>Persons with Dementia Transitioned to LTC</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011/12</td>
<td>76,876</td>
<td>5,585</td>
<td>7,512</td>
<td>31,933</td>
</tr>
</tbody>
</table>

- How well does this service support people with dementia?
- How many people can we provide this service to?
- Are there any changes to LTC availability (i.e. more or less beds)?
Impact of hypothetical intervention “Care Partner Education” on remaining at home (e.g. ↑ time at home by 30%)

Percentage of Persons Eligible for “Care Partner Education” (e.g. 70% of all persons with dementia)

- Mr. Wong with current Services
- Dx
- Provide 3 Additional units of Service A
- Expressed LTC Need
- 1st Admittance to Long Stay
- Mr. Wong with enhanced Service A
- Dx
- Expressed LTC Need
Care Partner Education and Support Program
Modelling Effective Community Based Interventions

This scenario projects how the dementia cohort and associated system use may change to 2020/21 given:

**Care Partner Education Key Specifications:**

- Target population: Urban dwelling PLwD
- Retention rate: 92.2%
- Delay: 557 days with uncertainty between 239 and 647 days
- Percent of Target Population who will participate in program: 54% of urban dwelling PLwD (based upon historical percentage of RAI-assessed PLwD in urban areas with a live-in Care partner)
- Physician Diagnosed Population: Incidence and deaths are unchanged
- Utilization: Health service consumption rates at 2014/15 levels
If Champlain were to implement a Care Partner Education program, by FY 2020 they could need up to 6,835 monthly counselor hours in order to serve up to 7,033 urban PLwD with a live-in care partner.

*The analysis on this slide assumes only urban individuals would be able to access the Education Services. Additional services would be required to serve rural and remote PLwD.

* The analysis on this slide assumes baseline population projections.

Note: All results are preliminary, and should not be used for decision-making.
Care Partner Education | Champlain
Impact on Long-Term Care

If an effective Care Partner Education program were implemented, by FY 2019 the number of LTC requests could be reduced up to 8.5%, and the number of persons waiting in the Community for LTC could be reduced up to 17%.

This implies 692 more PLwD in Champlain could be living well in the community.

Note: All results are preliminary, and should not be used for decision-making.
Dementia Capacity Planning
Future Steps

- Ongoing engagement with health systems partners and MOHLTC
- Evaluation of additional scenarios different potential service scenarios
- Detailed case studies with persons living with dementia and care partners, determine actual needs
- Evaluation of the impact of receipt of different services in current state on transitions (e.g. specialty services, home care)
- Evaluate other outcomes such as hospitalization, ER use, ALC
Conclusions

- There are increasing numbers of individuals with dementia in Ontario
- Helping people stay healthy in their homes requires careful planning and evidence
- Capacity planning methods can be useful in helping health system planners identify optimal strategies to support persons with dementia
Acknowledgments

- Cancer Care Ontario
  - Kerry Allerton
  - Alivahit Esenvoy
  - Natalie Warrick
  - Tannaz Mahootchi
  - Danielle Shawcross
  - Azadeh Mostaghel
  - Esti Heale
  - Marnie MacKinnon

- Ontario Brain Institute
  - Janine Paul
  - Kirk Nylen

- Institute for Clinical Evaluative Sciences
  - Madga Nunes de Melo

- Ministry of Health and Long-Term Care
  - Michael Robertson
  - Jade Woodruffe
  - Katie O’Connell