People, Partners & Possibilities

Transforming dementia care in the community

June 13th & 14th, 2014

Increasing primary care's capacity to respond to the needs of community-dwelling people with dementia and their caregivers.

Why?

As the number of older Ontarians increases so does their risk of developing some form of cognitive impairment, along with other chronic conditions often related to aging. Treating dementia and other conditions is challenging. It begins with diagnosis and an appreciation of how conditions interact to affect a person's overall health and well-being. Primary care plays a critical role in diagnosing dementia and managing complex care needs.

What?

The Alzheimer Society of Ontario (ASO) and the Ontario College of Family Physicians (OCFP) hosted a symposium to respond to the increasing need to build capacity within primary care to support the needs of people living with dementia. The specific objectives were to:

- Identify people with dementia & care partner needs
- Understand provider challenges
- Identify and learn about existing initiatives
- Develop solutions and strategies that can be acted on

Who?

50 people living with dementia, family members, clinicians from several disciplines and sectors, researchers and people from policy and stakeholder groups gathered for a day and a half in June 2014 to work together to understand needs and challenges, identify opportunities and develop solutions.

Alzheimer Society
ONTARIO

ONTARIO COLLEGE OF FAMILY PHYSICIANS

An emerging need

- By 2020, nearly 250,000 people will be living with dementia – an increase of 28% from 2012
- Some Local Health Integration Networks will see increases in dementia prevalence up to 50%
- People diagnosed with dementia living in the community have 50% more visits to primary care compared to people without dementia
- Persons with dementia are 2 times as likely to be admitted to hospital compared to other seniors and 2 times as likely to visit emergency departments for potentially preventable conditions
- Caregiver stress is 5 times higher for people caring for seniors with moderate to severe cognitive impairment (CIHI 2010)

Research-based evidence

A review of qualitative studies found that when entering into primary care, people with dementia are interested in:

1. Seeking a diagnosis;
2. Accessing supports and services;
3. Addressing information needs;
4. Disease management; and
5. Communication and attitudes of health care providers that provide insights into the potential gaps of existing health services.

In another review*, Aminzadeh et al. "identified a multitude of highly inter-related obstacles to optimal primary dementia care, including challenges related to:

1. Complex biomedical, psychosocial, and ethical nature of the condition;
2. Gaps in knowledge, skills, attitudes, and resources for people living with dementia, caregivers and their primary care providers; and
3. Broader systemic and structural barriers negatively affecting the context of dementia care."

*A review of barriers and enablers to diagnosis and management of persons with dementia in primary care, 2012

How?

A Planning Committee of people from different disciplines, including researchers, educators, and representatives of key stakeholder associations worked together to plan the agenda content and process, develop and analyze a pre-symposium survey and relevant research, and suggest potential participants.

Before the symposium a survey was sent to people living with dementia and their care partners to understand:

- What must the health care system start, stop or continue doing to better meet the needs of people with dementia and their caregivers?
- What programs, tools or other supports have you found useful along your journey?

A second survey was sent to service providers and other health professionals to understand:

- What challenges are limiting primary care's ability to respond effectively to the needs of community-dwelling people with dementia and their caregivers?
- What programs, tools or other supports have you provided or are aware of that have helped meet the needs of these patients and their caregivers?

For a summary of results visit **brainxchange.ca/primarycare**

Getting to work

The symposium opened with a screening of a video entitled '*Deconstructing Dementia*' created for the Alzheimer Society of Niagara that included two symposium participants who are living with dementia.

With the focal question front and centre:

What must we do to increase primary care's capacity to respond effectively to the needs of community-dwelling people living with dementia and their care partners along their journey?

Participants then identified many possible topics for discussion, grouped these ideas by theme and finally selected six they felt were most important.

Early Identification and Diagnosis	Collaboration
Whole Person Needs	Define the Role of Primary Care Providers (Management and Assessment)
Accessibility	Primary Care / Family Health Team Training

Through breakout sessions, participants worked together to better understand the challenges, identify possible solutions and develop goals and ideas that could be acted on each for theme.

From the many discussions and reflections, a powerful story began to emerge.

Dementia is a complicated disease in a complicated system. It is a condition that continues to grow, and because there is no known cause, is often mistreated. Fear and stigma further get in the way of individuals, their families and sometimes their health care providers recognizing the symptoms and providing appropriate care. Improving awareness of the disease and resources, making roles clear, minimizing duplicate efforts, accountability and leadership are needed in all areas of primary care, especially in rural settings.

Participants could see potential for a healthcare system for all Ontarians that:

- Is pro-active rather than crisis oriented
- Involves people with dementia and their entire Circle of Care
- Provides compassionate care
- Shifts the culture of health service from I to We

Participants thought this could be achieved because there are:

- Willing partners ready to step up
- Existing models, networks, best practices to build on
- Ways to maximize all skill sets

Getting to work (continued)

What would be the payoff? Participants thought that success would mean building an aligned and sustainable service delivery that improves support and quality of life along the journey by offering a system that:

- Is organized to provide community supports and care before a crisis
- Provides better access and improved quality with better supports for primary care providers; and
- Promises better interaction of all involved to ensure more compassionate care along the journey.

Challenge
A complicated disease in a complicated system.

Opportunity
To (re)connect the dots around the person / care partners for a better outcome.

Focus Area
Early identification and diagnosis of cognitive impairments.

Focus Area
A person-centered, high quality model of care for people with dementia and their care partners.

Focus Area
Increased coordination, communication & collaboration across the system.

Payoff
Aligned and sustainable service delivery that improves support & quality of life along the journey.

Our Purpose
Increase primary care's capacity to meet the needs of people with dementia along their journey.

Our goals:

What must we do to increase primary care's capacity to respond effectively to the needs of community-dwelling people living with dementia and their care partners along their journey?

The answer:

1. **Increase coordination, communication and collaboration across the system.**
   Make it easier for people to know where and who to turn to by making dementia resource people available through primary care hubs that are connected across the province.
2. **Expand capacity for early identification and diagnosis of cognitive impairments.**
   This needs to start with more public awareness to decrease stigma and increase information. Assessments need to be holistic and look at the cognitive, functional, behavioural strengths of the person and also be aware of the needs of care partners.
3. **Nurture person-centered, high quality models of care.**
   The successful Chronic Disease Management (CDM) approach uses interdisciplinary primary care teams providing opportunities for different disciplines to learn from each other. Support from system leaders is critical to make this model available to all Ontarians. Introducing incentives may have an impact across the system.

Practice-based and lived experience

Themes identified through the pre-symposium surveys confirmed research-based evidence about the needs of people living with dementia for primary care and provider challenges.

These included:

- Disease identification, assessment and diagnosis
- Meeting holistic needs of person and family
- Provider time, funding and resources
- System navigation and coordination
- Training and education for care providers

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Lived experience from survey

"The health system must recognize the needs of the dyad – both the person with dementia and the care partner."

"Dementia is being identified earlier, but many who are under the age of 65 cannot find support programs or get access to services that are considered 'seniors' services."

Symposium feedback from persons with lived experience

"It was such an experience to be there. There is urgency for us to do something with our lives."

"I felt honoured to be there. This is something I will never forget. I hope that this will go somewhere."

"It is important to engage and provide guidance to families because once you get that label [diagnosed with dementia], you go inward."

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Staying connected

We are thankful to our co-host, the Ontario College of Family Physicians, our sponsors, survey respondents and our planning committee. We are especially grateful to the symposium participants. We are committed to staying connected and championing this work going forward.

What's next?

Participants in the symposium sensed an openness of thought and a time of opportunity, as well as an urgency and apprehension should change be delayed.

Policy and evidence

The following activities indicate we are living in a moment of great possibility.

- The new government is committed to addressing dementia related health needs.
- Ontario recently renewed its commitment to work with other provinces through the Council of the Federation to enhance primary care's capacity to serve persons with dementia.
- The upcoming Alzheimer Society report by the Institute for Clinical and Evaluative Sciences and ASO will show the important role that primary care provides to people with dementia living in the community.
- The public is becoming more concerned with stories of "failed care" for persons with dementia.
- The Alzheimer Society is working with many organizations such as the Heart and Stroke Foundation, Ontario Stroke Network and Neurological Health Charities Canada to support better care for seniors with complex needs.

HealthLinks and other resources

Some HealthLinks have identified persons with dementia as a priority population. Sharing knowledge and building capacity amongst those who are "early leaders" in dementia in HealthLinks and promoting promising practices will help others to learn how they can improve practice.

There are other innovations and research in Ontario that we can learn from. These include the new psychogeriatric role to support primary care, primary care memory clinics, the seniors Community Care Access Centre program and the Alzheimer Society's First Link® program.

Learning and development

ASO is partnering with the Ontario Brain Institute and several Local Health Integration Networks to support training of primary care practitioners and our local Society staff in a primary care memory clinic model. We are looking at how to support individual health care providers in taking part in learning opportunities. We will be approaching other health charities to look at working together to support training especially about managing complexity.

Facilitation services including design, facilitation and summary were provided by System 45.

For more information visit: brainxchange.ca/primarycare

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