The "Rising Tide" of dementia in Canada: What does it mean for pharmacists and the people they care for?

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Introduction

Dementia is an umbrella term for a large class of brain disorders. The prevalence of dementia was estimated at 44.4 million people worldwide in 2013, and in the absence of any significant new scientific discovery, prevalence rates are estimated to increase to 75.6 million in 2030 and 135.5 million in 2050.[1] Alzheimer's disease is the most common irreversible form of dementia. It is a fatal, progressive and degenerative disease that destroys brain cells.[2] The syndrome consists of a number of symptoms that include changes in memory, judgment, reasoning, mood, behaviour, communication abilities and the ability to function on a day-to-day basis.

Rising Tide: The Impact of Dementia on Canadian Society[3] is a report released by the Alzheimer Society in 2010 following 2 years of intensive study. It is the first study to estimate the health and economic burden of dementia in Canada over the next 30 years. It also reviews and makes recommendations on policy options to address this issue. The 5 main pillars are as follows:

- Provide support for family caregivers (family includes anyone in the supportive network of the individual).
- Emphasize risk reduction and early intervention.
- Build an integrated system of care.
- Strengthen and supplement Canada's dementia workforce.
- Increase investment in dementia research.

Approximately 747,000 Canadians are living with cognitive impairment including dementia.[4] Additional statistics from *Rising Tide* are similarly compelling. Despite advancing age being the biggest risk factor for Alzheimer's disease, more than 70,000 of those living with dementia are under the age of 65. Women make up 72% of those living with Alzheimer's disease. Within a generation, incidences of new cases will increase from 1 every 5 minutes to 1 every 2 minutes. The total cost of care for persons with dementia was about $15 billion in 2008 in Canada; this is expected to rise to $153 billion in 2038.[3]

Moreover, long-term care beds are projected to have a shortfall of 157,000 in Canada by the year 2038. The number of older persons with dementia living at home is expected to steadily rise from 55% to 62%.[3] All of these trends will require community or home-based care to become more responsive to the needs of those living with dementia.

Pharmacists play a vital role in the health and overall well-being of all Canadians. Pharmacists are highly visible and regularly accessed by members of the community, forming long-standing relationships with their patients. They are trained to understand pharmacotherapy that can benefit or impair cognitive function, and they can monitor for progression and related issues such as medication adherence. However, like many health care professionals, pharmacists may feel ill-equipped to support the unique needs of people living with dementia and their families or caregivers. *Simply put, many pharmacists*

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BOX 1 Common misconceptions about Alzheimer's disease

- A diagnosis of Alzheimer's disease means my life is over.
- Because someone in my family has Alzheimer's disease, I'm going to get it.
- Alzheimer's disease is an old person's disease.
- There is a cure for Alzheimer's disease.
- Memory loss means Alzheimer's disease.
- Aluminum causes Alzheimer's disease.
- You can prevent Alzheimer's disease.
- Taking supplements can prevent Alzheimer's disease.
- All people with Alzheimer's disease become violent and aggressive.
- People with Alzheimer's disease cannot understand what is going on around them.

Adapted from Myths and Realities About Alzheimer's Disease, *Alzheimer Society of Canada 2015 (www.alzheimer.ca/en/About-dementia/Brain-health).*

are uncomfortable dealing with patients with dementia. This article is the first in a series that aims to identify roles, strategies and resources pharmacists can apply in daily practice in service of people with dementia.

Provide support for individuals, family and caregivers

Despite our growing understanding of dementia, many myths are still prevalent and persist. Box 1 outlines common misconceptions about Alzheimer's disease. Pharmacists can play an important role in educating people with dementias and their caregivers, addressing their questions and directing them to additional resources as necessary. This is especially helpful at the onset of new symptoms or diagnosis but also is important as the disease progresses and questions about expectations and management arise.

Communication changes are common among people with dementia. These can negatively affect work and social interactions as well as personal relationships. A list of common communication challenges is provided in Box 2; not every person with dementia will experience all of these challenges and not all at the same time. Some tips for improving communication are listed in Box 3.

Dementia is somewhat unique in that its impact on families is as important to consider as the impact on the person with the disease. Caregivers of people with dementia often have more serious health impacts than caregivers of people with other conditions. For example, caregiving stress can translate into an increased risk for cerebral vascular disease and mortality.[5] While people living with dementia can often remain actively involved in their own lives for many years after diagnosis, the progression of dementia will make this increasingly difficult. Caring for someone who is less and less able to direct his or her own care and whose behaviour may be increasingly difficult to understand can create significant stress for caregivers of a person with dementia. Caregiver burnout can manifest as physical and mental symptoms.

Emphasize risk reduction and early intervention

In dementia, early intervention is important.[3,6] It allows the persons affected to adjust to the diagnosis, take action to slow disease progression and maintain function and plan for long-term transition. While Alzheimer's disease cannot be prevented, strokes and vascular disease are implicated in over 50% of dementias. It is known that the risk for strokes and other cardiovascular disease can be reduced by maintaining physical activity, having good nutrition, controlling blood pressure and being socially active. To learn more about the risk factors, please visit www.alzheimer.ca/en/About-dementia/Alzheimer-s-disease/Risk-factors.

Patients commonly ask, "Is this aging, or do I have dementia?" While aging is still the biggest risk factor for Alzheimer's disease, dementia or Alzheimer's disease is not a normal, inevitable part of aging. For example, forgetting where one has put one's car keys now and then is quite normal. Forgetting what they are for is not. Box 4 and Table 1 outline some characteristics that can help pharmacists distinguish early concerns.

Pharmacists who suspect deteriorating cognitive function in a patient or who are directly approached about the issue can offer to administer a mental state examination for screening. A number of cognitive function screening tests can be carried out in the primary care setting,[7,8] and pharmacists are capable of delivering them.[9,10] To learn more about screening and diagnosis, please visit www.alzheimer.ca/en/About-dementia/For-health-care-professionals/Screening-and-diagnosis.

Validated tests such as the 7-Minute Screen (7MS), AD8 informant interview or Mini-Cog take only a few minutes to perform and can be done in a private counselling area.[8,11,12] Persons showing indications of cognitive decline should

be referred for prompt medical assessment and follow-up.[13] They and their families or caregivers will also benefit from referral to the Alzheimer Society for education and access to community resources (www.alzheimer.ca/en/provincial-office-directory or for French, www.alzheimer.ca/fr/provincial-office-directory).

Build pharmacists into the integrated system of care

Opportunities in pharmacological management

Four agents are currently marketed in Canada for the treatment of Alzheimer's disease and other related dementias. Three of the 4 agents are acetylcholinesterase inhibitors (AChEIs)[14,15] and one is an *N*-methyl-D-aspartate (NMDA) receptor antagonist.[15]

Acetylcholine is the primary neurotransmitter involved in learning and memory.[16] Research indicates that depleting levels of choline acetyltransferase, responsible for catalyzing the formation of acetylcholine, as well as decreasing levels of cholinergic cells, may be responsible for producing the cognitive impairment in affected individuals.[14] AChEIs prevent the breakdown of acetylcholine into choline and acetate in the synaptic cleft, making more acetylcholine available to stimulate postsynaptic receptors.[14,16,17]

The participants of the 4th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD4) recommend the use of all 3 AChEIs—donepezil, galantamine and rivastigmine—for the treatment of mild to severe Alzheimer's disease, Alzheimer's disease with cerebrovascular disease and dementia associated with Parkinson's disease.[13] However, due to inconsistent and insufficient evidence, no recommendation for or against the use of these agents is made for the treatment of vascular dementia. These 3 drugs generally display similar effectiveness in the treatment of dementia. Drug-related factors, such as the adverse effect profiles, usability and pharmacokinetic parameters of the different agents, drive the choice of agent used for treatment.[13,16] Once medication has been initiated, patients should be monitored for emerging side effects and the severity and tolerability of these side effects. If a side effect is intolerable or severe, the offending AChEI may be discontinued or dose decreased with the option of increasing the dose at a later date. Patients may be switched to another AChEI once the benefits and risks are adequately considered.[15] Cardiovascular conditions such as atrioventricular block and sick sinus syndrome are considered relative contraindications to treatment with AChEIs.[18] Common side effects of AChEIs include nausea, vomiting, diarrhea and decrease in or loss of appetite. AChEIs also increase the risk of syncope. The presentation of these side effects can be decreased by introducing the AChEI at a low dose, titrating

BOX 2 Changes and challenges with communication

- Have difficulty finding a word.
- Create new words for ones that are forgotten.
- Repeat a word or phrase (perseveration).
- Have difficulty organizing words into logical sentences.
- Curse or using other offensive language.
- Revert to the language that was first learned.
- Talk less than usual.

Early stage:

- Have difficulty understanding humour, jokes and fast talk.
- Have difficulty following multiple-step instructions.
- Require increased concentration to follow conversations.
- Have trouble staying on topic.
- Need more time to respond to questions.
- Experience increased frustration.
- Have trouble finding the right word.
- Lose their train of thought more often.

Mid-stage:

- Have trouble understanding everyday conversation.
- Often ask the speaker to repeat simple sentences.
- Find it difficult to follow long conversations.
- Have difficulty understanding reading materials.
- Repeat the same word or information over and over (perseveration).
- Unable to interpret facial expressions (like a wink or the nod of the head).
- Have trouble explaining or understanding abstract concepts (e.g., "I feel blue").
- Experience decreased speech and ability to raise or lower voice.
- Have difficulty finishing sentences.
- Lose interest in talking.
- Speak in vague and rambling sentences.

Late stage:

- Unable to understand the meaning of most words.
- Lose the capacity for recognizable speech, although words or phrases may occasionally be uttered. Language often does not make sense to others.
- Become totally mute in some cases.

Adapted from Ways to Communicate, *Alzheimer Society of Canada 2012 (www.alzheimer.ca/en/Living-with-dementia/Ways-to-communicate)*

BOX 3 How to enhance communication with people with dementia

- Believe communication is possible.
- Focus on abilities and skills, not deficiencies.
- Reassure and encourage.
- Don't underestimate the value of nonverbal communication—a smile and direct eye contact can help a person feel included and respected.
- Try not to address a family caregiver when talking with or about the person living with dementia. Be as inclusive as possible in your conversation.
- If the person with dementia is actively involved in the conversation, connect with that person—don't correct him or her.
- Strive to understand what the person with dementia is trying to convey and honestly admit if you are not sure you are following.
- Remember that building a lasting, positive relationship is key.

Adapted from Ways to Communicate, *Alzheimer Society of Canada 2012 (www.alzheimer.ca/en/Living-with-dementia/Ways-to-communicate)*

BOX 4 Ten Warning Signs

1. **Memory loss affecting day-to-day abilities**—forgetting things often or struggling to retain new information.
2. **Difficulty performing familiar tasks**—forgetting how to do something you've been doing your whole life, such as preparing a meal or getting dressed.
3. **Problems with language**—forgetting words or substituting words that don't fit the context.
4. **Disorientation in time and space**—not knowing what day of the week it is or getting lost in a familiar place.
5. **Impaired judgment**—not recognizing a medical problem that needs attention or wearing light clothing on a cold day.
6. **Problems with abstract thinking**—not understanding what numbers signify on a calculator, for example, or how they're used.
7. **Misplacing things**—putting things in strange places, like an iron in the freezer or a wristwatch in the sugar bowl.
8. **Changes in mood and behaviour**—exhibiting severe mood swings from being easy-going to quick-tempered.
9. **Changes in personality**—behaving out of character, such as feeling paranoid or threatened.
10. **Loss of initiative**—losing interest in friends, family and favourite activities.

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the dose to the most optimal therapeutic dose or administering medications with food.[13,16,18] The rivastigmine patch produces a lower incidence of gastrointestinal side effects compared with the oral formulation. Other side effects of AChEIs include sleep disturbances, vivid dreams and nightmares.[14] Pharmacodynamic potentiation of side effects, such bradycardia or syncope, can occur, and drug interactions with agents such as β-blockers should be reviewed periodically.[18] Additionally, the use of both over-the-counter and prescribed anticholinergics must be assessed to optimize the effectiveness of AChEIs.

Discontinuation of AChEIs is only recommended in those cases where an informed decision has been made by the patient or his or her proxy decision maker, where the side effects are intolerable, where the patient is nonadherent to medications and caregiver assistance with medication administration is not possible, or where rate of cognitive and functional decline is such that continued treatment is futile or potential for benefit is not clinically meaningful.[13] The dose of AChEI should be tapered to the lowest dose prior to discontinuing.[13]

Memantine is a noncompetitive NMDA antagonist that works by blocking NMDA receptors, thereby controlling synaptic plasticity and memory.[17] It is used in the treatment of moderate to severe Alzheimer's dementia with or without donepezil[18]; however, the CCCDTD4 makes no recommendations for or against the use of this agent with donepezil due to lack of sufficient evidence.[13] Memantine is well tolerated by patients both alone or in combination therapy with AChEIs; side effects include constipation, dizziness, headache, hypertension and somnolence.[18] Memantine is renally excreted,[17] so renal function should be ascertained prior to initiating treatment, and a lower dose is recommended in those with decreased renal function. Weekly titration can be used to reach the therapeutic dose over 3 weeks.[17] It may not be covered by provincial health insurance plans, thereby incurring an extra limitation on its use.

To help affected persons learn more about the approved medications, please visit www.alzheimer.ca/en/About-dementia/Treatment-options/Drugs-approved-for-Alzheimers-disease.

Helping people understand nonpharmacological strategies

Nonpharmacological strategies to delay progression in cognitive impairment include cognitive training, environmental interventions and physical activities.[16] There is a high degree

TABLE 1 Normal aging vs dementia

Normal aging	Dementia
Not being able to remember details of a conversation or event that took place a year ago	Not being able to recall details of recent events or conversations
Not being able to remember the name of an acquaintance	Not recognizing the name of a friend or family member
Forgetting things and events occasionally	Forgetting things or events more frequently
Occasionally having difficulty finding words	Frequent pauses and substitutions when finding words
You are worried about your memory but your relatives are not.	Your relatives are worried about your memory, but you are not aware of any problems.

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of variability in the design of the studies, the population studied, and the type and duration of cognitive interventions and physical activity regimens in these studies. Therefore, it is difficult to recommend a specific cognitive intervention or physical activity to improve or delay progression of cognitive impairment.[19,20] However, physical activity is encouraged for general cardiovascular health. Management of other vascular risk factors such as hypertension and diabetes is also recommended. Strategies such as music therapy, aromatherapy, pet therapy and massage may prove beneficial for some. To learn more about a "healthy brain lifestyle," please visit www.alzheimer.ca/en/About-dementia/Brain-health.

Strategies and resources to strengthen person-centred care

Person-centred language

Do you ever find yourself speaking to the accompanying person instead of the person with dementia?[21] People with dementia often feel excluded or treated differently because of stereotypes. In fact, a 2012 survey conducted by Alzheimer's Disease International[22] revealed the following:

- 75% of people with dementia felt there were negative associations for people diagnosed in their country.
- 40% of people with dementia reported they had been avoided or treated differently after diagnosis.
- 1 in 4 respondents cited stigma as a reason to conceal their diagnosis.

Person-centred care is a philosophy that recognizes that individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect and full participation in his or her environment.

The ultimate goal of person-centred care is to create partnerships among health care providers, people with dementia and their families to enhance the quality of life and the quality of care of people with the disease. Within a person-centred approach, all services and supports are designed and delivered in a way that is integrated, collaborative and mutually respectful of all persons involved.

For example, how guilty are pharmacists of making dementia "jokes"? People tend to make jokes about the things that scare them the most, but when clinicians, including pharmacists, make offhand comments about dementia (such as declaring that we are experiencing a "senior moment"), it can trivialize the real challenges of living with this condition.

By using person-centred language, clinicians address and refer to people with dementia as the whole people they are, sending the message that they are valuable individuals deserving of respect. Language that reinforces the worth of a person with dementia helps to combat the stigma that often surrounds this condition.

Person-centred language guidelines can be found at www.alzheimer.ca/en/About-dementia/For-health-care-professionals/culture-change-towards-person-centred-care/person-centred-language-guidelines.

BOX 5 Reflecting on practice

KNOWLEDGE: How current are you in your knowledge of dementia? Perhaps it is time for a refresher. The information on the Alzheimer Society's website may be a good place to start! (www.alzheimer.ca)

VALUES and BELIEFS: Do you engage actively with those in your practice who are living with dementia? Do you believe that their lives can still be meaningful and fulfilling, given the right support?

PRACTICE: Do you actively build relationships with community partners like the Alzheimer Society who can help you to support your clients living with dementia?

First Link

First Link, an Alzheimer Society referral program for physicians, health care providers and community service providers, links individuals and their families to learning, services and support as early as possible in the disease process. By being proactively connected to their local Alzheimer Society and other support services, people living with dementia and their families will be in a stronger position to respond to the many challenges that the disease can bring. In fact, on average, those who were connected to the Alzheimer Society via First Link as opposed to other channels were referred 11 months sooner.[23] For people with dementia and their caregivers, First Link has a positive impact on their understanding and awareness of the disease, knowledge of available community resources and confidence in their ability to manage the disease.

MedicAlert Safely Home

People with dementia can become lost even in familiar places. The MedicAlert Safely Home program is an effective way to help identify the person who is lost and bring the family back together. To learn more, visit www.medicalert.ca/safelyhome.

Conclusion

The statistics about dementia in Canada and around the globe are frightening. But like most scary things, they can galvanize us into action. What are you, as a pharmacist, going to do to change the experience of Canadians who are living with dementia? What does the rising incidence and prevalence of dementia mean for your practice?

Future articles in this series will further explore the disease, its manifestations and its management, including pharmacy-based interventions and pharmacist roles in community-based memory programs.

Alzheimer Society of Canada

This series is developed in collaboration with the Alzheimer Society of Canada. The Alzheimer Society is Canada's leading nationwide health charity for people living with Alzheimer's disease and other dementias. Active in communities across Canada, the society offers help for today through programs and services for people living with dementia and hope for tomorrow by funding research to find the cause and the cure. Health care professionals can access useful resources at www.alzheimer.ca. Information on the Alzheimer Society Research Program and grant opportunities can be found at www.alzheimer.ca/en/Research. ■

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