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Dementia Concerns and Considerations: A CADTH Panel of People With Lived Experience



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Conflicts of Interest

None of the participants had any conflicts of interest to declare that were relevant to this report.



Table of Contents

Key Messages	6
Background	6
Objectives	
Approach	7
Panel Selection	
Discussion Questions	7
Expressed Needs	
Maintaining Personhood	
Recognizing Young-Onset Dementia	8
Balancing Safety and Empowerment	9
Navigating the Health Care System	9
Communicating With Persons With Dementia	10
Considerations for the Health System	11
Privacy and Ethics	11
User As Co-Designer	11
Equitable, Diverse, and Inclusive Approach to Care	12
References	13



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ш	151	UI	Ιd	UI	162

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Iania	I. FAUGLE DOUG	Namhare		
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Key Messages

- As the number of Canadians living with dementia rises, so does the demand for dementiarelated care across the country.
- CADTH convened a 5-member panel of individuals with lived experience of dementia to hear about and learn from their firsthand experiences with dementia-related care, treatment, supports, and services.
- The panel highlighted the need for care, treatment, supports, and services that prioritize
 personhood, are inclusive of individuals with young-onset dementia, strike a balance
 between safety and empowerment, help with navigating the health care system, and
 involve dignified and respectful communication.
- Supporting people transitioning into dementia and their loved ones and ensuring that they
 receive care that meets their unique needs, abilities, personal preferences, and values will
 require meaningful involvement of individuals during planning, development, and delivery
 of treatment, supports, and services.
- These insights from the panel will be available for upcoming CADTH reviews of medical procedures, devices, diagnostics, and drugs related to dementia. They will also be used to identify health technologies and potential topics for future CADTH work about dementia.

Background

The number people living in Canada who are aged 65 and older is growing steadily. As a result, the number of people living with Alzheimer disease (AD) and other forms of dementia is also increasing. Canadian health care system costs and out-of-pocket costs for caring for people with dementia were an estimated \$10.4 billion in 2016 and are projected to double by 2031. With seniors expected to make up 23% of Canadians by 2030, the demand on caregivers and Canada's health care and long-term care resources is also increasing.

Presently, there are no disease-modifying therapies to treat or cure dementia available in Canada, and current recommendations for the treatment of AD are limited to pharmacological and psychosocial interventions that may alleviate associated symptoms. Non-pharmacological treatments for AD are also being developed; in a recent Horizon Scan,³ CADTH reviewed neuromodulation, which is being considered for the treatment of AD.

Given the rising number of people in Canada living with dementia, it is essential that the care available to them addresses their concerns. By starting the conversation with "What are your concerns? What are your needs?", treatments, supports, and services can better align with the goals of the people they intend to serve.

Objectives

The objectives were to:

- facilitate a roundtable discussion to hear about and learn from patients' and caregivers' firsthand experiences with dementia-related care, treatment, supports, and services to help understand the diverse individual needs that currently exist for dementia care in Canada
- make insights from the panel available for use in upcoming CADTH reviews of medical procedures, devices, diagnostics, and drugs related to dementia



 identify health technologies and potential topics for future CADTH work in the area of dementia.

Approach

Panel Selection

CADTH directly contacted 15 Canadian patient groups as well as 3 individuals living with dementia who had reached out to CADTH in the past 2 years to introduce CADTH and invite individuals to apply to be part of the panel. Interested individuals completed a webform describing their connection to dementia and how their experiences could add to the diversity of ideas being shared.

A 5-member panel was selected that consisted of 2 individuals living with dementia and 3 individuals with experience providing care to loved ones with dementia (Table 1). All panel members were required to comply with existing CADTH policies regarding disclosure and management of conflicts of interest.

Discussion Questions

A facilitated roundtable discussion took place on December 14, 2021. Two discussion questions were developed based on overlapping priorities from the James Lind Alliance

Table 1: Expert Panel Members

Role	Name	Background
Individuals with lived experience of dementia	Christine Thelker	Christine is a former nurse who has been heavily involved in the dementia community since being diagnosed with vascular dementia 7 years ago. She is a Dementia Advocacy Canada board member and works with the Canadian Consortium on Neurodegeneration in Aging (CCNA), Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life (Age-Well) Canada, Translating Research into Elder Care (TREC), and Engagement of People with Lived Experience of Dementia (EPLED).
	Bob Murray	Bob was diagnosed with dementia in 2013. He is on the Alzheimer Society Advisory Group of People with Lived Experience of Dementia. He also chronicles his experiences via a biweekly blog called <i>My Voyage with Dementia</i> .
Caregivers with lived experience of dementia	Emily McLellan	Emily has lived experience as a caregiver to a family member with young-onset Alzheimer disease. She is also part of CCNA's EPLED.
	Karen Barnett	Karen is a caregiver to a family member who is living with dementia. She is also part of CCNA's EPLED.
	Wayne Hykaway	Wayne has lived experience as a caregiver to a spouse with dementia. He has worked with Dementia Advocacy Canada, Dementia Network Calgary, and EPLED.



Priority Setting Partnership from the Canadian Dementia Priority Setting Partnership⁴ in 2017 and the Seniors' Health (Alberta, Canada) Priority Setting Partnership⁵ Top 10 in 2019.

The following questions were shared with panellists before the meeting:

- What are some considerations and concerns about care, treatment, supports, and services? These concerns could be related to costs or services that are not covered, costs to family (financial and other costs), safety, access to services or specialists, quality of life, the impact of stigma, ethical dilemmas, or other aspects.
- What dementia-related care, treatment, supports, and services are needed for people living with dementia and their family care partners?

Expressed Needs

Reflecting on their personal experiences, panel members highlighted areas of concern about care, treatment, supports, and services that warranted more attention. The following is a summary of key ideas that were shared plus verbatim guotes to help illustrate them.

Maintaining Personhood

"I am a person. I am not a patient. I am a person first and foremost" was a fundamental message shared by panellists that resonated throughout their discussion. Both the individuals living with dementia and the care providers who were present recalled occasions when a diagnosis of AD or another dementia overshadowed personhood.

Personhood describes how a person living with dementia perceives themselves and how this perception is honoured and supported by those around them.^{6,7} Sustaining a strong sense of self when faced with cognitive decline and communication difficulties as well as needing to rely on others to accomplish daily activities is difficult. And when personhood — which is at the core of person-centred care — is not a priority, people with dementia fear losing their dignity and the respect of their loved ones and care providers.

The panellists highlighted how technologies that appeal to users' needs and preferences and encourage their decision-making can be a tool to protect the self-identity of people living with dementia. For example, 1 individual spoke about hospital rooms being equipped with touch screen computers that can play music that the person with dementia enjoys.

This concept is essential in guiding efforts to develop and improve care, treatment, supports, and services. As 1 of our panellists so aptly stated, "We don't want our personhood and our vibrancy taken away from us."

You will notice that personhood is a key theme reflected throughout this report and that personhood and the key considerations that follow are all interconnected.

Recognizing Young-Onset Dementia

"A lot of people think of dementia as 'an old person's disease.' It's not." Young-onset dementia is when the presentation and diagnosis of dementia happens before the age of 65 years.8



Individuals who are younger and may have milder cognitive impairment are often overlooked. As the number of Canadians diagnosed with dementia (and young-onset dementia) grows, so does the number of children and family members caring for them. This has important clinical implications for health care professionals working with these families, especially those involved in service design and delivery looking to effectively assist them.⁹

Our panellists have felt the consequences of this gap in knowledge and awareness that exists among patients, care providers, and the public. They see how education about young-onset dementia could lead to timely access to information and services and ultimately support patient and caregiver preparedness.

However, this gap in knowledge has also led to a lack of appropriate and inclusive supports and programs for people with young-onset dementia. Many existing programs do not cater to the needs of otherwise healthy and active people. Some of our panellists have had firsthand experience with this. They are people looking to be challenged, to remain physically active, and to be socially engaged in their community. For some individuals with young-onset dementia, the burden of advocating for them and of keeping them engaged is placed on their informal caregivers.

The panel agreed that having accessible and affordable dementia-inclusive supports, services, and programs (e.g., exercise^{10,11} and art programs) would provide opportunities for Canadians living with young-onset dementia to continue to thrive.

Balancing Safety and Empowerment

One panel member reminisced about her dad cycling around the neighbourhood: "We let him live at risk. It's his right to do so. He's a free person." This sentiment was shared by panel experts, who recognized that living freely and independently with dementia meant living with some level of risk. For this caregiver, electronic monitoring allowed them to monitor their dad's location, while respecting their independence. And panellists agreed that there is a place for technology to help strike a balance between safety and empowerment.

Appropriate use of technology (such as GPS electronic monitoring) is 1 example. It allows people with dementia to explore independently and to nurture their sense of self, autonomy, and quality of life. Moreover, it is a tool that offers peace of mind to caregivers who are concerned about safety.

The panellists also pointed to other ways that technologies can help offset functional deficits to enable people to age in place longer and prevent premature or unnecessary admissions to hospital or long-term care. These also include medication patches for effective delivery of medication. The literature also points to designing health technology with the user in mind and matching the user's individual aspirations and abilities to the technology, whether it be for in-home monitoring of lifestyle, health, and safety; supporting memory; performing daily activities, or facilitating communication between people with dementia and their caregivers. 12-14

Navigating the Health Care System

The panellists expressed frustration over the lack of dedicated support available to patients and their families navigating the health care system. They recognized that these challenges are amplified for (but not limited to) newcomers for whom English is not their first language



and are interacting with the Canadian health care system for the first time, for people living in rural and remote communities, and for individuals experiencing homelessness.

They spoke candidly about feeling overwhelmed and afraid when visiting the hospital — a situation made especially difficult during the COVID-19 pandemic. For this reason, the panellists see an opportunity for dedicated support staff to help persons with dementia and their caregivers access and navigate the health care system: "Sometimes it's just having an additional person who is well educated."

For example, they described positive experiences interacting with a nurse facilitating entry into hospital or a social worker providing emotional support. They also spoke about the need for support staff to help carry out medical tests for measuring and benchmarking health status. One panel member recalled lying down next to their loved one during a CT scan to keep them still and walking behind them on the treadmill during an exercise stress test to prevent a fall. "They were lucky they had me, but there are so many folks who don't have somebody to help."

People living with dementia have individual needs that often require care from many providers in multiple settings. Thus, helping people with dementia navigate uncoordinated care would ensure they receive appropriate and timely service.¹⁵

Communicating With Persons With Dementia

"I have dementia; I'm not stupid." As 1 panellist candidly described it, "You have dementia, so they don't bother. I've had to stop someone to please just tell me what's happening and what you're doing. I was lucky, I was able to express what I needed. There's times when I can't."

Panellists have highlighted the need for people involved in making decisions about their care and offering dementia-related care, treatment, supports, and services to take the time to communicate what is happening. Moreover, education in interpersonal and communication skills should be part of the training the care providers receive. People living with dementia, especially those with advanced dementia who have more severe communication impairments, may be nonverbal but do communicate through body language. All individuals, regardless of disease severity, deserve to have dignified, person-centred, and respectful interactions. Often the burden is placed on individuals receiving care to ask questions and risk feeling like they are burdening care providers.

Panel experts offered easy and effective ways to enhance communication that allow them to retain their dignity, such as writing down information about upcoming medical tests on a whiteboard in their hospital room. "Don't direct your conversation to the caregiver. It's really important that you direct it to the person who has dementia. Ask them questions and use the caregiver as a translator to help you understand."

The information being communicated to people with dementia and their families is also important. The panellists agreed that it is necessary to have conversations around end of life, hospice, and palliative care: "They are realities and people should have information about them and talk to people that are qualified."



Considerations for the Health System

Developing and delivering inclusive and effective person-centred care, treatments, supports, and services requires careful planning. The following is a summary of considerations that stemmed from the discussion with panel members that warrant further attention.

Privacy and Ethics

The panel members recognized that aging in place is demanding on informal caregivers, whether it be spouses, children, or other relatives, who are providing unpaid care. Several described how technology offers a reliable tool that gives their loved ones autonomy and allows them to age in place safely. For example, the panellists spoke about the peace of mind that location tracking devices provide.

There are many assistive technologies available to support people living with dementia and their caregivers, and each is designed to serve a different purpose. They can monitor health and safety (e.g., location tracking device, health-related cellphone app, fall detector), support memory and daily living activities (e.g., reminder system, smart medicine dispenser), facilitate communication (e.g., video conferencing), encourage leisure activities (e.g., musical interventions, group activities), and more. 16

As reliance on assistive technologies and technology-based interventions increases, so do the ethical considerations around data collection and privacy. Panel members were vocal about the importance of educating and empowering individuals living with dementia and highlighted the importance of inclusive person-centred care. These align with risk mitigation strategies proposed in the literature, which suggest that companies restrict data use and guarantee data security (e.g., opt-in data sharing), require data transparency (e.g., how the data are collected and used), ensure that consent from users is fully informed, and proactively educate consumers about the technologies using language that emphasizes person-centred care practices (e.g., disclosures, onboarding materials, service wrap-around).¹⁷ In doing so, consumers can feel supported in their decision-making about the technologies that best align with their personal preferences and values.^{17,18} Like our panel, Berridge et al.¹⁷ acknowledged that to fully understand the potential risks, benefits, risk mitigation efforts, and impact of technologies on people living with dementia, people living with dementia must be part of the conversation.

User As Co-Designer

The panellists had considerable experience in endeavours that champion the role and contributions of people with lived experience: "It helps provide purpose." When reflecting on their collective experiences, they recognized the importance of being part of a "respectful and collaborative environment" and having an influence on the work in which they are involved.

Although panellists shared their appreciation for assistive technologies, adoption rates of technologies in dementia care are low, which may be because they do not meet the needs of consumers. Giving people living with dementia influence and ownership over the development of technologies and other dementia-related supports could help address this issue. Too often, people living with dementia, their families, and their caregivers are tasked with commenting on the effectiveness, usefulness, and acceptability of technologies instead of being actively involved early on, during planning and designing. In keeping with



a person-centred approach, people living with dementia should have a choice in their level of involvement during the development of health technologies.

It is also important to recognize that peoples' preferences may vary based on their stage and type of dementia. Although it may be challenging for individuals experiencing more severe cognitive impairment to communicate their needs, informal caregivers can play a supportive role to facilitate translation, as previously quoted by a panellist. However, the contributions of individuals living with dementia are not interchangeable with the experiences of caregivers — both offer different firsthand perspectives, ideas, and opinions that that are equally beneficial and deserve to be included.¹⁹

Equal partnership and co-production of technologies and supports provide an opportunity for people with lived experience to share continued insight into the range of needs, unique abilities, and preferences of end users from beginning to end. Moreover, they can shed light on considerations around equity and diversity to ensure the result is inclusive. But doing so successfully requires that designers and developers be receptive to those insights. A well-developed co-design approach involves building trust between participants and cultivating an environment welcoming of thoughtful discussions and deliberative thinking to achieve a common goal. Without conditions that favour collaboration, knowledge sharing, and reciprocity, there is a risk of further marginalizing or adding burden to those who are asked to participate.

Equitable, Diverse, and Inclusive Approach to Care

The panellists recognized the need for person-centred and inclusive care. This is essential if we want to achieve the broader goal of improving population health and achieving health equity in Canada.

Equity is achieved when every person — regardless of age, income level, gender, ethnic background, or any other social or economic reasons — has access to opportunities to be healthy.²¹ To be effective, care, treatment, supports, and services must address the specific needs of the population they intend to serve.

For example, understanding how health and personhood are culturally defined is relevant to the way that dementia and people living with dementia are recognized, understood, and cared for.²² Providing appropriate care also requires understanding the environmental, economic, and infrastructure barriers affecting aging populations' ability to be cared for in place. Therefore, designing treatment, supports, and services for populations living in rural and remote communities must consider the lack of health care resources and limited internet and cellular connectivity.^{23,24}

Developing dementia-related care, treatment, supports, and services that are safe, accessible, and inclusive for members of marginalized and underserved populations requires commitment from designers and developers. To understand how to best to support people transitioning into dementia and to ensure that they receive person-centred and inclusive care, meaningful and continued involvement of service users is essential.

Reflecting on a recent interaction with their care team, a panellist said it best when describing a positive experience: "They [the care team] were honouring who I am and what I want."



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