

Canadian Academy of Health Sciences
Académie canadienne des sciences de la santé



IMPROVING THE QUALITY OF LIFE AND CARE OF PERSONS LIVING WITH DEMENTIA AND THEIR CAREGIVERS

CANADIAN ACADEMY OF HEALTH SCIENCES' ASSESSMENT
OF DEMENTIA CARE IN CANADA

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THE CANADIAN ACADEMY OF HEALTH SCIENCES

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ABOUT THE CANADIAN ACADEMY OF HEALTH SCIENCES

The Canadian Academy of Health Sciences (CAHS) brings together Canada's top-ranked health and biomedical scientists and scholars from all disciplines across our nation's universities, healthcare and research institutes to make a positive impact on the urgent health concerns of Canadians. Founded in 2004, CAHS now has over 600 Fellows. These Fellows evaluate Canada's most complex health challenges and recommend strategic, actionable solutions. Since 2006 the CAHS has successfully engaged a wide variety of public and private organizations that have co-invested in rigorous, independent assessments that address key health issues with outcomes that have shaped their strategic policy and initiatives. These sponsors represent patients and families, professionals, health system leaders, policy-makers, NGOs, philanthropic organizations and private industry providers. Our common goal is to provide advice as the authoritative, informed voice that helps put change into action for a healthier Canada.

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THE CANADIAN ACADEMY OF HEALTH SCIENCES' EXPERT PANEL ON DEMENTIA

Canada's aging population and the increasing prevalence of Alzheimer's disease and other dementias pose a significant challenge for Canadian families and their caregivers, and more broadly, for the health care system. Recognizing the importance of developing and implementing an effective strategy to address this challenge, the Minister of Health of Canada, through the Public Health Agency of Canada, asked the Canadian Academy of Health Sciences (CAHS) to provide an evidence-informed and authoritative assessment on the state of knowledge to help advance federal priorities under the *National Strategy for Alzheimer's Disease and Other Dementias Act*. To address the charge, the CAHS assembled a multidisciplinary, multi-sectoral panel. The following CAHS Expert Panel members were selected to bring a range of expertise, experience, and demonstrated leadership in this domain and with regard for appropriate balance.

Chair: **Howard Bergman**, MD, FCFP, FRCPC, FCAHS, Chair of the Department of Family Medicine, Professor of Family Medicine, Medicine and Oncology, McGill University

David Hogan, MD, FRCPC, Academic Lead of the Brenda Strafford Centre on Aging, O'Brien Institute for Public Health, Cumming School of Medicine, University of Calgary

Janice Keefe, PhD, Professor and Chair, Department of Family Studies and Gerontology and Director, Nova Scotia Centre on Aging, Mount Saint Vincent University

Carrie McAiney, PhD, Schlegel Research Chair in Dementia, Schlegel-UW Research Institute for Aging, Associate Professor, School of Public Health and Health Systems, University of Waterloo

Debra Morgan, PhD, RN, FCAHS, Professor, College of Medicine Chair in Rural Health Delivery, Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan

Isabelle Vedel, MD, PhD, Assistant Professor, Department of Family Medicine, McGill University

Project Director: **Sonya Kupka**, MAdEd, RD, SJK Consulting

This report was undertaken with the approval of the CAHS Board. Responsibility for the final content of this report rests entirely with the CAHS Expert Panel. Any opinions, findings, or conclusions expressed in this publication are those of the authors and do not necessarily represent the views of their organizations of affiliation or employment.

MESSAGE FROM THE CAHS EXPERT PANEL

The Canadian Academy of Health Science Expert Panel charged by the Public Health Agency of Canada with assessing the evidence and best practices for the development of a Canadian dementia strategy has completed and is respectfully submitting this assessment report.

The Expert Panel members would like to dedicate this report to all persons living with dementia, their caregivers and other family and friends. We know that while there may be many positive experiences throughout the progression of dementia, there are also very difficult times. We strove to understand and reflect the full reality of persons living with dementia and their caregivers and other family and friends, recognizing that each individual's experiences are unique.

We appreciate that there are many very dedicated health and social care providers who work with or on behalf of persons living with dementia their caregivers and other family and friends. Their work has contributed to the many pockets of excellence in the provision of care and supports from across Canada that inspire us all.

We are very excited that Canada will soon have a national dementia strategy. We thank the Public Health Agency of Canada for entrusting the Canadian Academy of Health Sciences to bring forward the best of the dementia evidence and practices and are honoured that we were selected to do this important work.



Chair:
Howard Bergman, MD, FCFP, FRCPC, FCAHS



Debra Morgan, PhD, RN, FCAHS



David Hogan, MD, FRCPC



Isabelle Vedel, MD, PhD,



Janice Keefe, PhD



Project Director: Sonya Kupka, MAdEd, RD



Carrie McAiney, PhD

MESSAGE FROM THE CAHS PRESIDENT

On behalf of the Canadian Academy of Health Sciences (CAHS), I am pleased to present this report on **Improving the Quality of Life and Care of Persons Living with Dementia and their Caregivers**.

CAHS is extremely grateful to the Chair of the Expert Panel, Howard Bergman, and to panel members David Hogan, Janice Keefe, Carrie McAiney, Debra Morgan, and Isabelle Vedel. We thank you for tirelessly giving your time and expertise to this important project. We also thank Sonya Kupka for bringing the panel's vision to reality in this report, and Amanda Johnston for supporting the panel.

Thank you to Sharon Straus, who served as Report Review Monitor, to the report reviewers, and to the members of the CAHS Standing Committee on Assessments, especially its Chair, Jean Gray.

We also acknowledge the contributors of commissioned reports found in the report's appendix: Debra Morgan, Maxime Guillette, David Lanneville, Yves Couturier, Selma Tannouche Bennani, Yacine Thiam, Louise Belzile, Kristen Jacklin, Melissa Badger, Sharon Koehn, Carly Whitmore, Mélanie Le Berre, Nancy Jokinen, Arlene Astell.

This assessment was sponsored by the Public Health Agency of Canada (PHAC) to inform the development of a national dementia strategy. CAHS is grateful to PHAC for turning to our expertise for this work, and for PHAC's ongoing commitment to evidence-informed policy making.

Sincerely,

A handwritten signature in black ink that reads "Linda Rabeneck". The signature is written in a cursive, flowing style.

Linda Rabeneck, FCAHS
President, Canadian Academy of Health Sciences

REPORT REVIEW

This report was reviewed in draft form by the individuals listed below — a group of reviewers selected by the Canadian Academy of Health Sciences (CAHS) for their diverse perspectives and areas of expertise. The reviewers assessed the objectivity and quality of the report. Their submissions — which will remain confidential — were considered in full by the Panel, and many of their suggestions were incorporated into the report. They were not asked to endorse the conclusions, nor did they see the final draft of the report before its release. CAHS wishes to thank the following individuals for their review of this report:

Sube Banerjee, MBE, Professor of Dementia and Deputy Dean, Brighton and Sussex Medical School, University of Sussex, U.K.

Carole Estabrooks, FCAHS, CM, Professor and Canada Research Chair in Knowledge Translation, School of Nursing, University of Alberta

Geoff Fernie, FCAHS, CM, Creaghan Family Chair in Prevention and Healthcare Technologies, and Senior Scientist, Toronto Rehabilitation Institute – University Health Network, and Professor, Department of Surgery, University of Toronto

John P. Hirdes, FCAHS, Professor, School of Public Health Systems, University of Waterloo.

Dorothy Pringle, FCAHS, OC, Professor Emeritus, LS Bloomberg Faculty of Nursing, University of Toronto.

Paula Rochon, FCAHS, Vice President Research, Women's College Research Institute, Women's College Hospital, and Professor, Department of Medicine, University of Toronto.

On behalf of CAHS, the report review procedure was monitored by **Sharon E. Straus**, FCAHS, Professor, Division of Geriatric Medicine, University of Toronto and Interim Physician-in-Chief and Director of the Knowledge Translation Program, St. Michael's Hospital. The role of the report review monitor is to ensure that the Panel gives full and fair consideration to the submissions of the report reviewers. The Board of CAHS authorizes public release of a report only after the report review monitor confirms that CAHS's report review requirements have been satisfied. CAHS thanks Dr. Straus for her diligent contribution as report review monitor.

EXECUTIVE SUMMARY

Dementia touches the lives of many Canadians. It has a profound impact on the person living with dementia, their caregivers and other family and friends, as well as on our health and social care systems. It is estimated that approximately one in five baby boomers will develop dementia in their lifetime. Each year, one in three seniors die with dementia. The health and social care system and out-of-pocket caregiver cost of dementia are already very high and anticipated to increase significantly.

Persons living with dementia experience deterioration in memory, thinking and behaviour, reducing their ability to perform everyday activities and live independently. Although dementia mainly affects older people, it is not a normal or inevitable part of aging. Alzheimer's disease is the most common cause of dementia.

A national dementia strategy is needed to provide a compelling central vision that provides direction for mobilizing resources needed to meet the needs of the increasing number of persons living with dementia and their caregivers. A national strategy should also help Canada prepare for the advent of pre-symptomatic biomarkers with associated disease-modifying medications. This exciting development will positively impact the lives of many people, and at the same time may lead to additional pressures on the Canadian health and social care system and raise challenges in ensuring equitable access.

The *National Strategy for Alzheimer's Disease and Other Dementias Act* was passed by Parliament in 2017. It provides for the development of a national dementia strategy for Canada. The federal Minister of Health, through the Public Health Agency of Canada, asked the Canadian Academy of Health Sciences (CAHS) to provide an evidence-informed and authoritative assessment to inform national dementia strategy priorities.

In response, the CAHS convened an Expert Panel to examine the strength and the state of the evidence and emerging best practices and gaps relevant to the Canadian context. This report is the result of an extensive, highly iterative process akin to a rapid review and is best described as a blend of evidence, emerging ideas and consensus.

The CAHS Expert Panel recognizes the central role that must be played by persons living with dementia and their caregivers. The quality of life of persons living with dementia and their caregivers can be improved across all stages of the condition through a complex combination of person-centred, high quality health and social care.

OVERARCHING THEMES:

A. Building on the rich Canadian experience

- Provincial dementia plans have been in place since the late 1990s
- Four Canadian Dementia Consensus Conferences were held since 1989
- Research and emerging best practices exist

B. Recognizing the centrality of engaging persons living with dementia and their caregivers in a meaningful and respectful manner

- Acknowledging the rights of persons living with dementia and accommodating their needs is fundamental
- The needs of caregivers are not identical to those of care recipients and need to be specifically addressed
- Recognizing the diversity of persons live with dementia is essential

C. Addressing dementia as a societal, health and social issue, emphasizing the complex combination of health and social needs of persons living with dementia and their caregivers

- Education on maintaining brain health and preventing dementia empowers individuals and societies to take action
- With timely diagnosis and mobilization of the right amount and type of health and social supports, persons diagnosed with dementia can actively participate in making decisions about their lives and lead personally meaningful lives
- Assessment, management and treatment are anchored in team-based primary care and integrated with other components of the health and social care system
- A person-centered, and not a disease-centred, approach to care is based on knowledge of the person with dementia and their caregiver, a commitment to partner with them, and an understanding that needs will evolve

D. Ensuring an adequately trained and supported dementia workforce is available to deal with current and anticipated demand

- Both training needs and organizational supports for quality team-based care by an appropriate mix of health care providers need to be addressed

E. Assuring an equitable balance in research investment across biomedical, clinical, health services, and social, cultural, environmental, and population health research and between creating and translating knowledge

- Canada has specific research needs and there are opportunities to capitalize on our unique advantages

F. Creating, seeking and utilizing evidence and best practices to implement the strategy in a coherent and practical way

- Key elements include continuous evaluation to inform implementation and flexibility to allow local adaption

COMPILATION OF KEY FINDINGS

1. Overall Approach

- a) Dementia is a societal, health and social issue.
- b) In Canada, we have the opportunity to improve the quality of care and lives of persons living with dementia and their caregivers. This requires us to recognize that dementia disproportionately impacts women.
- c) With the increasing number of persons living with dementia, there is a need to ensure the sustainability of the health and social care system, including preparing for the demands on the health system that will come with increased availability of biomarkers in the detection of pre-symptomatic Alzheimer's disease (and other dementias) and disease-modifying medications.
- d) Canada can be proud of the contributions made by the multiple provincial dementia strategies already developed and implemented. These plans compare very favourably with international ones. They highlight a number of distinctive features such as an approach anchored in team-based primary care and integrated with other components of the health and social care system.
- e) A national dementia strategy that recognizes the extensive experience and contributions of provincial dementia plans will enhance Canada's engagement with international organizations.
- f) Given the geographic, demographic and cultural diversity across Canada, a national plan that facilitates learning and collaboration is most likely to be well received within Canada.
- g) Current evidence and emerging best practices must be translated in a coherent and practical way for use within the health and social care system.

2. Engaging persons living with dementia

- a) There is increasing interest in promoting, recognizing and protecting the rights of persons living with dementia. This has taken various forms, including statements of principles in dementia strategies, the designation of dementia as a disability, and the recognition of rights for persons with dementia and their caregivers.
- b) It is becoming more common to engage persons with dementia in their own care, as well as in shaping health services and conducting research. This approach is almost unanimously supported in dementia strategies within Canada and internationally as an emerging best practice.
- c) When engaging those with dementia, consideration should be given to the diversity within this population, recognizing that some groups have unique and additional challenges.

3. Prevention, awareness and living well with dementia

- a) There is sufficient evidence to encourage the adoption of health promotion endeavours (improving educational attainment, healthy eating, exercise, smoking cessation, prevention of head injury) and prevention interventions (early detection and treatment of hypertension, hyperlipidemia and diabetes) that address protective and risk factors for dementia.
- b) Public awareness and understanding of dementia is improving, but there are still specific knowledge gaps. Many people continue to believe that dementia is a normal part of aging and that there is nothing they can do to prevent cognitive decline and dementia as they age.

- c) Public understanding is also needed to address the stigma and fear, to show how it is possible to live well with dementia and to empower persons with dementia and their caregivers.
- d) Dementia-friendly communities are emerging as a promising approach to increasing awareness and understanding of dementia while making communities more livable for persons with dementia. These require local adaptation and the meaningful involvement of persons living with dementia and local adaptation.

4. Improving health and social care for persons living with dementia

- a) Despite improvements, many persons living with dementia and their caregivers are still experiencing limited access to dementia assessment and services, fragmented care, and inappropriate end-of-life care.
- b) Most persons with dementia have other chronic conditions and require a complex combination of social and health care. A person-and-family-centred approach, rather than a disease-centred approach, is essential to providing good care. Relationship-centred care extends this partnership to include health and social care providers and the influences they have on each other.
- c) An integrated care approach positions primary health care to provide more timely diagnosis, earlier access to treatments, improved coordination of care and earlier support for caregivers, which may increase quality of life, reduce caregiver burden, and delay long-term care placement.
- d) Within Canada, there are examples of well-supported primary health care, and various approaches to providing comprehensive and coordinated dementia diagnosis, treatment and care are being implemented. Evidence-informed care requires regular updating of clinical practice guidelines and pathways.
- e) As a person's care needs increase and become more complex, they need a widening web of community-based supports. Technology may play a promising role in supporting individuals to remain at home as long as possible.

- f) The current quantity and quality of long-term care homes may not be adequate to meet the future needs of persons living with dementia, even with increased community-based supports. Incorporating a dementia-friendly approach, including design and meaningful activities, will improve the quality of life of all residents.
- g) Having clear goals of care, advanced-planning, a fully informed family and a common understanding of these goals are essential to having a dignified and respectful death and avoiding possible unwanted, futile or burdensome interventions.

5. Education and support for caregivers

- a) Caregivers want to provide care and derive positive benefits from their role. Caregivers experience challenges related to their increasing responsibilities for the person living with dementia, which impacts their own health, employment and finances.
- b) It is critical that caregivers be supported in their caring roles. Certain interventions (i.e., education, training, counselling, supportive workplace) may help preserve their quality of life and resiliency and may help sustain or increase their availability as caregivers.
- c) The needs of caregivers vary over time. Ongoing needs assessment is essential to understanding how to support caregivers.
- d) The economic and health consequences of providing care are exacerbated by gender-based expectations. Any policy or program to support caregivers must include a gender-based analysis to assess the intended and unintended consequences for women.
- e) Alzheimer Societies and caregiver associations in Canada play an essential role in empowering, educating and supporting caregivers.
- f) Timely access to needed health and social care for the person living with dementia has a significant impact on caregiving and on the caregiver.
- g) No one policy or practice for providing financial support is a panacea for caregivers. Caregivers are a diverse group and require a flexible range of services and supports applicable to a diverse population.

- h) In-home or in-facility respite is the most common support offered to caregivers through home care programs. However, such services for caregivers can only be accessed if the person living with dementia is a client. Greater efforts must be made to improve access to these programs.
- i) Workplace policies with supportive cultures need to be developed and expanded along with commitment from supervisors and managers to enable caregivers of persons living with dementia to continue to be employed.

6. Building and supporting the health and social care workforce

- a) All provincial strategies and most international ones recognize the need to support and strengthen the workforce. Workforce planning is critical to ensure there are adequate numbers of the needed type of care providers to meet the quality-of-life and care needs of persons living with dementia and their caregivers.
- b) Special attention is needed to address workforce planning and training for the large numbers of direct care providers who provide most of the hands-on care to this highly vulnerable and medically and socially complex population.
- c) Training alone is insufficient to achieve the desired changes in care. Work environments that value and support health and social care providers in providing good dementia care address factors such as time constraints, workload, compensation, leadership and managerial supports. Task-sharing models involving specialists, primary care and other health and social care providers are a key element in workforce planning, training and organization.
- d) It is important to embed dementia care into the curriculum and practice training of all health and social care providers. Case-based/practice-based and solution-focused dementia training is most beneficial to support the application of learning in practice. Used in isolation, traditional didactic and passive strategies (lecture-style meetings, in-services, printed materials and guidelines, and passive materials) are ineffective strategies for increasing knowledge of, and confidence in, dementia management.
- e) Supports for the implementation of evidence-based practice and guidelines are essential for ensuring good quality care.

7. Research and Innovation

- a) An equitable balance in research investment is required across the four research themes (i.e., biomedical, clinical, health services, social, cultural, environmental, and population health) and between creating and translating knowledge.
- b) While international collaborations must be strengthened, the Canadian dementia research agenda needs to address our specific needs and capitalize on our unique advantages.
- c) More research funding is required, along with coordination between the different levels of government, industry, and charitable funders in order to maximize benefit and avoid waste.
- d) The engagement of persons living with dementia is critical, but our understanding on how best to do this is at an early stage and should be considered an emerging practice. Examples can be built upon to improve the acceptance and recognition of contributions from persons living with dementia.
- e) Different research priorities have been identified and are best established with broad stakeholder input, which must include persons living with dementia and their families, friends, caregivers, and health and social care providers as well as the research community and funders.
- f) When putting the dementia research and innovation plan into action there is a need to move from abstract, broad goals to specific performance measures, indicators and targets that are quantifiable, accountable and feasible within a predetermined time horizon. There is also a need to support studies on how to effectively scale up evidence-based interventions to large populations.

8. Implementation

- a) Strong government leadership with broad stakeholder collaboration and clearly defined roles is critical to leading, inspiring and evaluating change.
- b) A dementia implementation action plan requires:
 - i. A compelling central vision and direction balanced with flexibility to adapt to local needs and contexts,
 - ii. A long-term commitment and appropriate resources to achieve identified priorities, as well as research and evaluation,
 - iii. A concrete action plan with targets and timelines,
 - iv. Consideration of the various approaches to implementation that have been used, including both widespread and phased implementation, and
 - v. Planning at the outset for continuous evaluation of the dementia strategy to inform implementation and modifications as needed.
- c) The introduction of national dementia standards of care along with an accreditation process will complement quality improvement efforts that are aligned with dementia strategy priorities.



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CHAPTER 1

Overall Approach

Dementia touches the lives of many Canadians. It has been estimated that one in five baby-boomers will develop dementia (Licher, Darweesh, Wolters *et al.*, 2018). One in three seniors die with dementia (Alzheimer's Association, 2013). Dementia has a profound impact on the person living with dementia, their caregivers¹ and other family and friends, as well as on the health and social care and systems.

With timely diagnosis and the right amount, type and timing of health and societal supports, persons diagnosed with dementia can actively participate in making decisions about their current (and future) care and lead personally meaningful lives in which they are treated with dignity and respect. As with many other chronic health conditions, caregivers are both partners in the delivery of care and recipients in need of support themselves.

A national dementia strategy is needed to provide a compelling central vision and direction to meet the health and social needs of the increasing number of people living with dementia and their caregivers. With the assent of the *National Strategy for Alzheimer's Disease and Other Dementias Act* (2017), the federal government committed to "develop and implement a comprehensive national strategy to address all aspects of Alzheimer's disease and other forms of dementia."

The Federal Minister of Health, through the Public Health Agency of Canada (PHAC), asked the Canadian Academy of Health Sciences (CAHS) to provide an evidence-informed and authoritative assessment of the state of knowledge on dementia to inform the development of this national dementia strategy. In response to this charge, the CAHS convened an Expert Panel to build on the work done to date, seeking out validated current and emerging best practices as well as gaps relevant to the Canadian context. At PHAC's request, the CAHS Expert Panel organized an expedited process.

In preparing this assessment report, the CAHS Expert Panel recognized the need to address implementation issues, emphasizing how evidence-informed and emerging best practices can and must be translated, in a coherent and practical way, into the existing Canadian health and social care system. With this approach, the CAHS Expert Panel believes a national strategy can make a difference for persons living with dementia and their caregivers.

1.1 CONTEXT

1.1.1 What is dementia?

Dementia is a broad term describing a symptom complex with multiple possible causes, not a specific disease. The *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) now uses the term "major neurocognitive disorder" instead of "dementia." This report and most Canadian provincial strategies and Alzheimer Societies in Canada continue to use the term "dementia." The Quebec Federation of Alzheimer Societies and other groups have identified concerns with the term and limit their use of the word dementia (Fédération Québécoise des Sociétés Alzheimer, 2018).

Dementia describes a combination of acquired cognitive and functional impairments that reduce a person's ability to perform everyday activities and live independently. Changes in mood and behavior commonly occur. Dementia is not a normal or inevitable part of aging, even though the probability of developing the condition increases after middle age.

Dementia is caused by disorders affecting the brain. Diseases such as Alzheimer's disease (which accounts, in whole or in part, for approximately 60 per cent of all cases of dementia), vascular disease, Lewy Body disease, frontotemporal dementia, and mixed pathologies (where

1 Caregivers include family members, friends, neighbours and other unpaid individuals who provide regular care or supervision to an individual who needs assistance because of illness or disability. Other possible terms are informal caregiver, family or friend caregiver, and unpaid caregiver (Nova Scotia Health Research Foundation, 2014).

a person has more than one brain disease leading to dementia) are the most common causes of dementia (Alzheimer Society of Canada, 2017b). Most types of dementia are progressive and irreversible.

1.1.2 Sex, gender,² diversity and dementia

Dementia impacts more women than men. Of the over 400,000 individuals living with dementia in Canada, over two-thirds are women (PHAC, 2017b). The difference between men and women in both prevalence and incidence increases with age. In long-term care homes, women account for 72% of those with dementia (PHAC, 2017a).

Caregivers of persons living with dementia are equally likely to be spouses or adult children and spousal caregivers are equally likely to be male or female; however, among adult children caregivers, 72% are women (PHAC, 2017a). Studies suggest that about 90% of the dementia workforce is made up of women (Estabrooks, Squires, Carleton, Cummings, & Norton, 2015). Furthermore, women play a key role in driving much of the change through Alzheimer associations throughout the world (Alzheimer's Disease International, 2015a). Throughout all aspects of a dementia strategy, it is important to recognize that dementia disproportionately affects women, both those living with dementia and those caring for them.

Dementia has many faces, and affects persons of every culture, ethnicity, religion, citizenship, sexual orientation and ability. However, certain populations face unique challenges. For example, available evidence suggests that compared to the general population, the prevalence of dementia is 34% higher in First Nations populations and is increasing at faster rates; as well, dementia's onset is 10 years earlier and males have higher rates of diagnosis (Jacklin, 2018).

1.2 WHY A NATIONAL DEMENTIA STRATEGY?

A national dementia strategy is needed in order to provide a compelling central vision and direction to meet the health and social needs of the increasing number of persons living with dementia and their caregivers. At the same time, a strategy will help in planning for the sustainability of the health and social care system and prepare for future developments that will bring new pressures on the system.

1.2.1 Planning for now and for the future

Dementia is age-related and therefore, as more people live longer, more people will live with dementia (Ahmadi-Abhari *et al.*, 2017). A proportion of this anticipated increase might be preventable at a population level through positive lifestyle changes (Banerjee, 2013). In fact, research suggests that the number of new cases (incidence) may be declining in economically advantaged nations including Canada (Pelletier, Robitaille, McRae, & Toews, 2017; Satizabal *et al.*, 2016). However, risk factor modification can go both ways and any increase in unhealthy behaviours (e.g. smoking, obesity) might increase the incidence of dementia (Banerjee, 2013). Without targeted and population-wide interventions, the decrease in incidence may not fall evenly across Canada and those in lower socio-economic groups may be least likely to benefit from these advances.

In 2011, caregiver time to support persons living with dementia was estimated to be 19.2 million hours (Chambers, Bancej, & McDowell, 2016). In addition to dementia's personal toll, it also poses a challenge for our health and social care system. Estimated total health care system and out-of-pocket caregiving costs for persons with dementia are already high and are projected to reach \$16.6 billion by 2031 (Chambers *et al.*, 2016; PHAC, 2017b).

2 The panel recognizes that sex and gender have different meanings and has strived to use the correct term throughout the documents using the following CIHR definitions: Sex refers to the biological attributes of humans and animals. Gender is the socially constructed roles, behaviours, expressions and identities of girls, women, boys, men and gender-diverse people.

A national dementia strategy is also needed in order to prepare for future advances, particularly the likely advent of pre-symptomatic biomarkers with associated disease-modifying medications. This is a very exciting development that will positively impact the lives of many people, and at the same time may lead to additional pressures on the health and social care system and raise challenges in ensuring equitable access.

1.2.2 Facilitating collaboration

Dementia strategies outline the steps that government can take, in collaboration with community organizations, health and social care providers, persons living with dementia and their families, friends and other caregivers, to make the changes needed to address this health and social challenge. Dementia strategies provide direction for high-level priorities and inform public policy. They are perceived as one of the main determinants of the quality of care and services provided for persons living with dementia (Banerjee, Willis, Graham, & Gurland, 2009).

The InterAcademy Partnership for Health (2018) issued a call for action to address the challenges of dementia³ and recognized the establishment of a national dementia strategy that promotes, coordinates and harmonizes activities as a key element to addressing gaps and ensuring efficient use of resources.

Rockwood, Bergman, and Hogan (2010) voiced their support for the development of a national strategy that facilitates learning and inspires collaboration amongst provinces, with the recognition that “more must be done, but it cannot be more of the same.”

1.2.3 The rich experience of Canadian provincial dementia strategies

Within Canada, a number of provinces have rich experience in developing and implementing provincial dementia strategies, dating back almost 20 years (see Table 1). This assessment does not identify any published territorial strategies; however, the unique challenges of dementia care in rural and remote communities need to be specifically addressed (Morgan, 2018). Most provinces have developed dementia strategies that are in various stages of implementation. Some have already updated original strategies; for example the recently released *Alberta Dementia Strategy and Action Plan* builds on a 2002 report (Alberta Health, Continuing Care, 2017). The new strategy recognizes dementia’s impact on society as a whole, in contrast to the earlier report that focused on continuing care health services.

These provincial dementia strategies are based on known best practices, research evidence, and an analysis of local population health and resource data. Many of these strategies were informed by the work being done in communities and the voices of persons who live with dementia. In most cases, an attempt was made to align these strategies with other key provincial policy directions. These plans compare very favourably with international ones. They note a number of distinctive features of the system developed in Canada for persons living with dementia, such as health and social care being anchored in primary care and an emphasis on social supports (Guillette *et al.*, 2018).

3 The InterAcademy Partnership for Health is a network of 78 of the world’s national medical academies and academies of science with strong medical sections. This statement is modified from a position paper that was initially commissioned by the Canadian Academy of Health Sciences, and written, approved and submitted by the Research Executive Committee of the Canadian Consortium on Neurodegeneration in Aging.

Table 1: Provincial dementia strategies

Year	Strategy
1999	<i>Ontario's Strategy for Alzheimer Disease and Related Dementias: Preparing for Our Future</i>
2002	<i>A Strategy for Alzheimer Disease and Related Dementias in Manitoba</i>
2002	<i>Provincial Strategy for Alzheimer Disease and Other Dementias (Newfoundland)</i>
2002	<i>Alzheimer Disease and Other Dementias: Strategic Directions in Healthy Aging and Continuing Care in Alberta</i>
2004	<i>A Strategy for Alzheimer Disease and Related Dementias in Saskatchewan</i>
2007	<i>BC Dementia Service Framework</i>
2009	<i>Meeting the Challenge of Alzheimer's Disease and Related Disorders: A Vision Focused on the Individual, Humanism, and Excellence (Quebec)</i>
2012	<i>The Provincial Dementia Action Plan for British Columbia: Priorities and Actions for Health System and Service Redesign</i>
2014	<i>Manitoba's Framework for Alzheimer's Disease and Other Dementias</i>
2015	<i>Towards Understanding: A Dementia Strategy for Nova Scotia</i>
2016	<i>Provincial Guide to Dementia Care in British Columbia: Achievements and Next Steps</i>
2017	<i>Alberta Dementia Strategy and Action Plan</i>
2017	<i>Ontario's Dementia Strategy</i>
Forthcoming	A dementia strategy New Brunswick is underway as committed to in their <i>We are all in this together: An aging strategy for New Brunswick</i>

1.2.4 Contributing to international leadership

In addition to strong provincial leadership in dementia strategy development, key steps have also been taken at the federal level. In 2014, the federal government released the *National Dementia Research and Prevention Plan* to support improved understanding and care of dementia dementia (Government of Canada, 2014). The Standing Senate Committee on Social Affairs, Science and Technology examined the issue of dementia and, in 2016, released their report, *Dementia in Canada, A National Strategy for Dementia-friendly Communities* (Ogilvie & Eggleton, 2016).

Internationally, the World Health Organization and Alzheimer's Disease International released a joint report in 2012 titled *Dementia: A Public Health Priority* in an effort to stimulate governments, policy-makers and other stakeholders to address dementia as an increasing threat to global health (World Health Organization & Alzheimer's

Disease International, 2012). In 2013, G8 health ministers met to discuss how to shape an effective international response to dementia and issued the *G8 Dementia Summit Declaration* with commitments to innovation, research and engagement (Department of Health & Social Care [UK], 2013). In 2017, the World Health Organization adopted a global plan on dementia (World Health Organization, 2017a) and launched the Global Dementia Observatory (World Health Organization, 2017b) to monitor and review data on dementia, including the progress being made towards the targets set in the global plan. Canada is the 30th country to develop a national dementia strategy (Alzheimer's Disease International, 2017, June 22).

Since the *National Strategy for Alzheimer's Disease and Other Dementias Act* (2017) has come into effect, the federal government has an opportunity to build on this legacy. To that end, our report builds on pre-existing provincial strategies by considering additional evidence-informed and emerging best practices in Canada and internationally.

1.3 THE CHARGE, METHODOLOGY AND STRUCTURE

1.3.1 The charge

The CAHS Expert Panel was charged with establishing an evidence and practice base that will inform the development of a comprehensive national dementia strategy for Canada by examining the key questions listed in Table 2.

1.3.2 Methodology

This assessment is the result of an extensive, highly iterative process over eight months. It can best be described as a blend of evidence, emerging ideas and the CAHS Expert Panel's consensus.

The body of evidence related to the charge is simultaneously overabundant and insufficient. In preparing this report, the CAHS Expert Panel members attempted to use a methodology that was akin to a rapid review and that was a scientifically reasonable and proportionate response to the challenge posed.

Each CAHS Expert Panel member took responsibility for providing an initial orientation and, throughout the assessment, for reviewing evidence, identifying best practices for the assigned areas that aligned with their expertise. In many cases, members actively participated in writing these parts of the report. Rather than risk limiting the review through the use of formal criteria in evaluating the literature, we took an iterative approach. The CAHS Expert Panel used their knowledge of provincial, national and global research and of best practices, as well as their networks. They relied mainly on reviews of the available evidence, but when necessary looked at the primary sources as well.

Table 2: Assessment questions for the CAHS Expert Panel

Charge	Response
1. What is the strength and/or state of the evidence and emerging practices related to the elements in the <i>National Strategy for Alzheimer's Disease and Other Dementias Act</i> ?	
Investments in all areas of research related to dementia, including biomedical and clinical research, as well as research related to health systems, health services and population health	Chapter 7
Coordinating with international organizations to address dementia on a global level	All chapters
Developing and disseminating emerging clinical diagnostic and treatment guidelines	Chapters 4 and 6
Assessing and disseminating best practices, including greater integration of care, chronic disease prevention and management, and coordinating community support and care aimed at minimizing familial impacts	Chapters 4 and 5
Developing and disseminating information to health care professionals and the general public on the importance of prevention and management of, and early intervention in, dementia	Chapters 3 and 6
Developing national guidelines for standards of dementia care	Chapter 8
2. Based on current evidence and thinking in the field, what other aspects of dementia knowledge, prevention and care not identified in question one might be included in a national dementia strategy?	Engaging persons with dementia (Chapter 2) Building and supporting the dementia workforce (Chapter 6) Implementation Chapter 8

Table 3: Reports commissioned to inform the work of the CAHS Expert Panel

Commissioned reports	Authors of commissioned reports
Rural Dementia Care	Debra Morgan, PhD, RN, FCAHS
Literature Review: Alzheimer's Disease Policies in OECD Countries: Executive Summary and Key Learnings	Maxime Guillette, PhD student; David Lanneville, PhD student; Yves Couturier, PhD, Réseau1; Selma Tannouche Bennani, PhD; Yacine Thiam, MSc student; Louise Belzile, PhD; Isabelle Vedel, MD, PhD; Howard Bergman, MD, FCFP, FRCPC, FCAHS
Current Evidence on Alzheimer's Disease and Its Related Dementias and Indigenous Populations in Canada	Kristen Jacklin, PhD
Current Knowledge on Alzheimer's Disease or Related Disorders Among Ethnic Minorities and Recent Immigrants	Melissa Badger, MA, and Sharon Koehn, PhD
Young Onset Dementia	Carly Whitmore, RN, MScN
Current Knowledge on Alzheimer's Disease or Related Disorders and Sexual Minorities	Mélanie Le Berre, MScPT
Dementia and Adults with Intellectual or Developmental Disabilities	Nancy Jokinen, MSW, PhD
Technology for Dementia	AGE-WELL (prepared by Arelene Astell, PhD, and Dorina Simeonov, MSc)

Commissioned reports informed the writing of this report by providing further depth regarding some key issues and populations when additional expertise was needed. These reports are listed in Table 3 and are available as an addendum to this report (<https://www.cahs-acss.ca/improving-the-quality-of-life-and-care-of-persons-living-with-dementia-and-their-caregivers/>).

In addition to commissioning a report on Canadian provincial and international strategies (Guillette *et al.*, 2018), the CAHS Expert Panel drew upon findings from Canadian teams (Chow *et al.*, 2018; Edick, Holland, Ashbourne, Elliott, & Stolee, 2016; Wilson, Mattison, & Waddell, 2018). The provincial strategies provided direction for what could realistically be translated, in a coherent and practical way, into the existing health and social care system. The panel also drew upon the 2015 CAHS Forum, which had already begun to explore potential solutions to the “unprecedented impact” of dementia on the social, economic and health landscapes of Canada (Feldman & Estabrooks, 2017).

Through three in-person and many group and individual conversations, the CAHS Expert Panel reviewed, interpreted and built on current evidence and emerging best practices. This assessment report underwent a rigorous peer review process to ensure that the charge is fully addressed and that report findings are adequately supported by the evidence, analyses and arguments.

All CAHS Expert Panel members reviewed and discussed the full report throughout the process. All have agreed to the final submission, a comprehensive assessment where all statements are grounded in the available evidence.

1.3.3 Structure of the report

Dementia strategies within Canada and internationally generally converge around similar key priorities and actions, including increased awareness, improved care and support for persons with dementia and their caregivers, education and training of the workforce, research, and implementation (Chow *et al.*, 2018; Edick *et al.*, 2016;

Guillette *et al.*, 2018; Rosow *et al.*, 2011; World Health Organization & Alzheimer's Disease International, 2012). We've used these priorities and actions to inform the organization of this report.

We begin by exploring the literature related to the engagement of persons with dementia and their caregivers, as this is a core element touching all parts of any strategy. Next we delve into three areas of intervention for persons living with dementia and their caregivers:

- Raising public awareness that, by necessity, extends beyond the dissemination of information about dementia itself and includes health promotion and preventive actions and strategies for living well with dementia
- Health and social care and how these are shaped by clinical diagnostic and treatment guidelines and standards of care
- Caregiver education and supports that effectively minimize familial impacts

Underpinning these direct actions and supports are three key enablers: workforce planning, research and innovation, and implementation. An overarching theme is that given the geographic, demographic and cultural diversity across Canada and the need to address inequities, we recommend an adaptive and flexible approach to implementing best practices rather than a "one size fits all" approach.

In each chapter, this report:

- Highlights the **challenges** from the perspectives of persons living with dementia, their caregivers and the health and social care system
- Summarizes **public policy responses** as expressed in dementia strategies and relevant legislation
- Identifies **current evidence and emerging best practices** that are relevant to the Canadian context, emphasizing how they can and must be translated into the existing health and social care system in a coherent and practical way
- Summarizes important **key findings** in a logical, but not priority, order.

1.4 SCOPE AND LIMITATIONS OF THE REPORT

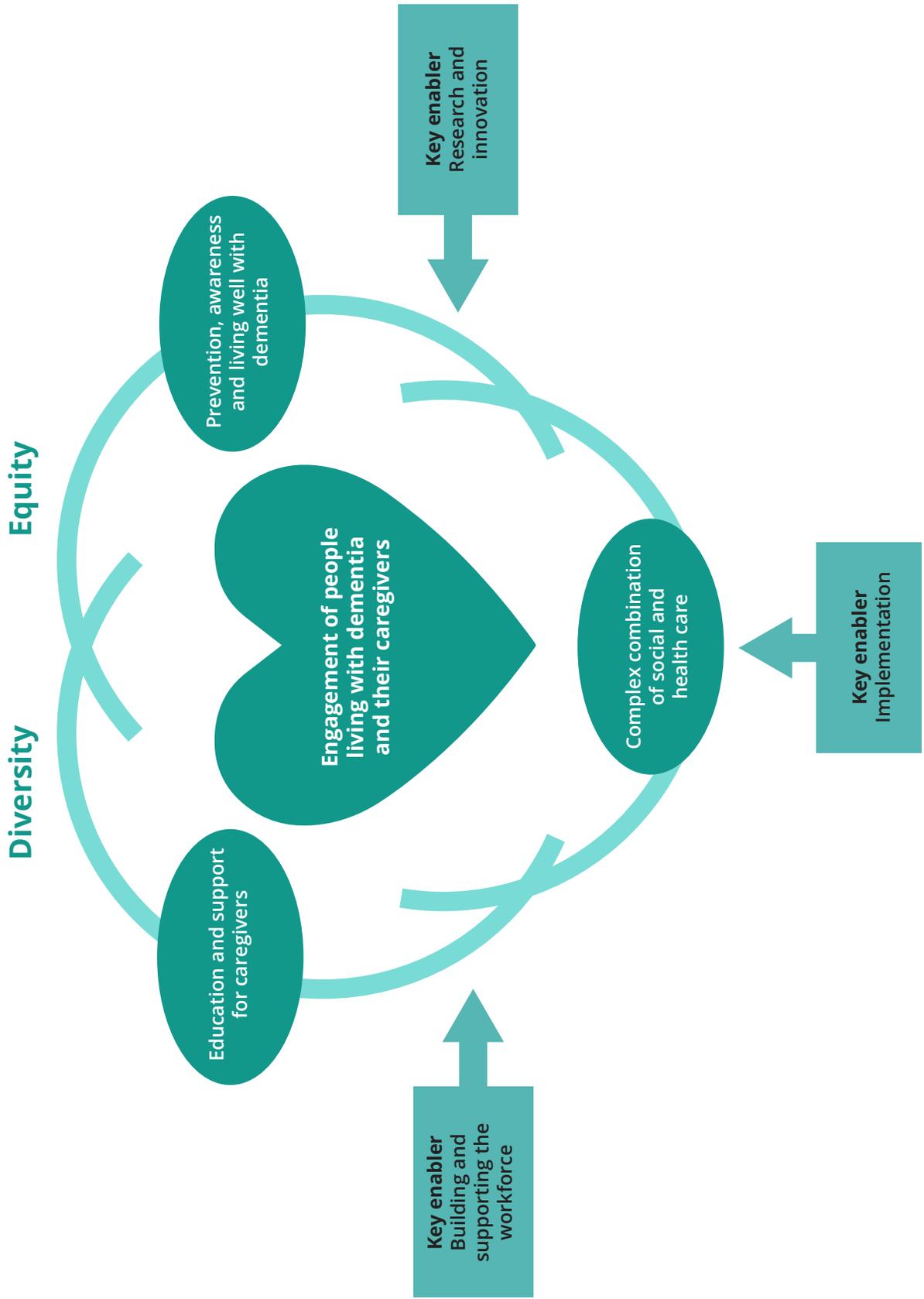
The Public Health Agency of Canada defined the scope for this assessment, which was to cover the published literature and validated best and emerging practices related to the questions outlined in Table 2. The direct engagement of persons living with dementia, caregivers, and the health professionals and organizations that advocate for them was beyond the mandate of this assessment. This broad and necessary engagement is, however, part of the overall process being taken by the Public Health Agency of Canada in developing the national dementia strategy for Canada.

The detail and length of each element of the report does not reflect these elements' relative importance, but rather, reflects the existing evidence base and best practices reviewed by the panel. Examples of best practices are provided as illustrations of what is feasible. Through sharing and collaboration, it is possible to adapt and implement these and other excellent practices already underway, while respecting local context.

The CAHS Expert Panel recognizes the diversity of persons living with dementia and their caregivers. With a mandate to inform the development of a national strategy, the focus of this report is on the general population while considering sex and gender differences, diversity and the need to ensure inclusivity and equity as cross-cutting themes. This report does not capture the unique consideration of specific populations, nor the targeted interventions that may be necessary; however, some of the commissioned reports in the addendum of this report offer valuable insights (see Table 3).

For persons living with dementia and their caregivers, dementia affects many parts of their lives. This report does not presume to address every need of all those affected, nor does it capture every action required to effectively develop a dementia strategy. As requested, this assessment focuses on the health and social needs of persons living with dementia and their caregivers. It identifies how they can be supported to live well, be active and engaged, and stay as independent as possible for as long as possible. While recognizing a broad societal approach is required, the questions the CAHS Expert Panel were asked to examine were primarily related to health and social care.

Figure 1: Relationship of chapters within this report



The majority of persons living with dementia also live with other chronic conditions (Griffith *et al.*, 2016). In 2010, the Canadian Academy of Health Sciences report *Transforming Care for Canadians with Chronic Health Conditions* (Nasmith *et al.*, 2010) examined how the health care system could better meet the needs of persons with multiple chronic conditions, including dementia. This report only briefly touches on the need for overall health system transformation; please refer to the 2010 report for more detail.

1.5 KEY FINDINGS

- a) Dementia is a societal, health and social issue.
- b) In Canada, we have the opportunity to improve the quality of care and lives of persons living with dementia and their caregivers. This requires us to recognize that dementia disproportionately impacts women.
- c) With the increasing number of persons living with dementia, there is a need to ensure the sustainability of the health and social care system, including preparing for the demands on the health system that will come with the increased availability of biomarkers in the detection of pre-symptomatic Alzheimer's disease (and other dementias) and disease-modifying medications.
- d) Canada can be proud of the contributions made by the multiple provincial dementia strategies already developed and implemented. These plans compare very favourably with international ones. They highlight a number of distinctive features, such as an approach anchored in team-based primary care that is integrated with other components of the health and social care system.
- e) A national dementia strategy that recognizes the extensive experience and contributions of provincial dementia plans will enhance Canada's engagement with international organizations.
- f) Given the geographic, demographic and cultural diversity across Canada, a national plan that facilitates learning and collaboration is most likely to be well received within Canada.
- g) Current evidence and emerging best practices must be translated in a coherent and practical way for use within the health and social care system.

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CHAPTER 2

Engaging persons living with dementia

Based on current evidence and thinking in the field, the CAHS Expert Panel was asked to include “other aspects of dementia knowledge, prevention and care... that might be included in a national dementia strategy” (Section 1.3.1). In response, we identified the broad and ongoing engagement of persons living with dementia as a central theme, which we address in this chapter.

In our examination of the engagement of persons living with dementia, issues related to equity, diversity and inclusion, emerged, as well as the movement to protect the rights of persons with dementia. This chapter introduces examples of the unique challenges faced by some groups of persons living with dementia to provide context and rationale for the importance of both broad and targeted efforts to engage persons living with dementia. Subsequent chapters also consider issues and practices related to equity, diversity and inclusion, as these are cross-cutting themes.

2.1 CHALLENGES

The engagement of persons living with dementia has many facets, including involving individuals in decisions about their care, future plans and daily activities as well as in program and service planning, policy development, advocacy and research (Swaffer, 2018). How individuals are involved will vary based on their interests, abilities and preferences, as well as the specifics of the activities. The following are some of the challenges related to the engagement of persons living with dementia.

2.1.1 Participation in decision-making

Once a diagnosis of dementia is made, some mistakenly assume that the diagnosed person no longer has the capacity to participate in decisions and contribute to society (Bartlett & O’Connor, 2010). Persons living with dementia have reported that after receiving their diagnosis they were advised to give up their current activities, get their affairs in order, and wait to die (Swaffer, 2014). Kate Swaffer, an advocate and person living with dementia, describes the cost of this action as:

“... increasing the stigma and discrimination persons with dementia experience; it disempowers, devalues and demeans the person and lowers self-esteem; it increases isolation, loss of identity, lost employment and, therefore, reduced income. It also potentially increases health and travel costs. It is unhealthy, unhelpful and the wrong advice.” (Swaffer, 2014, p. 4)

Persons living with dementia want to be provided with opportunities to engage in decisions about their lives and activities (Gill, White, & Cameron, 2011; Span *et al.*, 2018). It should not be assumed that persons living with dementia are not interested or able to participate. Yet, persons living with dementia often report not being provided with such opportunities (Hamann *et al.*, 2011; Miranda-Castillo, Woods, & Orrell, 2013).

An additional challenge occurs when, because of the nature of the illness, the capacity of persons with dementia to make decisions, communicate and advocate for their own interests diminishes over time. As a result, others (typically family members) may act as substitutes or proxies for those living with dementia, potentially taking away some opportunities for persons with dementia to be involved in decision-making about their care and other activities.

2.1.2 Differing perspectives of persons with dementia and their caregivers

It is important to recognize that persons with dementia, their caregivers and their health care providers may have different perspectives on whether the needs of the person with dementia are being met (Miranda-Castillo *et al.*, 2013). For example, persons with dementia and their caregivers may disagree regarding how much the person with dementia wishes to be involved in everyday decisions (Miller, Whitlatch, & Lyons, 2016) and regarding their preferences for care (Reamy, Kim, Zarit, & Whitlatch, 2011). When compared to persons living with dementia, caregivers underestimate the importance persons with dementia place on values that may influence decisions (i.e., autonomy, safety, burden, family and control) (Reamy

et al., 2011), and caregivers' perceptions regarding the importance of these values, as well as care preferences, decrease over time (Miller *et al.*, 2016; Reamy, Kim, Zarit & Whitlatch, 2012). While perceptions regarding how interested individuals with dementia are in being involved in decision-making are lower among caregivers than among those with dementia (Miller *et al.*, 2016), it remains important to consider the perspective of caregivers in decision-making (Groen-van de Ven *et al.*, 2017).

2.1.3 Meaningful and respectful engagement of a diversity of persons with dementia

Individuals living with dementia may be engaged in decision-making or activities (such as research, advocacy or service development), but currently this often occurs in a tokenistic manner. Research about how best to engage persons living with dementia in meaningful and respectful ways is beginning to emerge (Alzheimer Society of Canada, 2017a; Dupuis *et al.*, 2011; Mann & Hung, 2018; Rivett, 2017; Scottish Dementia Working Group Research Subcommittee Sub-Group; 2014; Swarbrick, Doors, Educate, Davis, & Keady, 2016; Tanner, 2012) but more research is needed. In addition, it is important to recognize the diversity that exists among persons living with dementia, and that there may be pre-existing inequities. It is unclear the extent to which this diversity is considered when engaging individuals with dementia. Thus it is important to be thoughtful about who is engaged, and to ensure there is diversity.

The addendum to this report includes a series of commissioned papers that describe some of the diverse groups of persons living with dementia. While each of these groups may represent a relatively small proportion of those living with dementia, ensuring their engagement is essential to effectively address the unique challenges they may face. For example:

- Older adults from different ethnic minority groups may have alternative understandings of health and illness. Their traditional religious and spiritual beliefs about the cause and nature of dementia may prevent them from seeking help. Also, access to dementia information and supports from a trusted source and in a language they understand may be lacking (Badger & Koehn, 2018).

- Individuals with young-onset dementia⁴ have increased likelihood of having a delayed diagnosis and being initially misdiagnosed, suffering adverse financial impacts because of the threat of dementia to continued employment, losing social connections and resources, facing a limited availability of age-appropriate services, and seeing additional significant impacts on caregivers and children who are often teenagers or even younger (Whitmore, 2018).
- Older Indigenous adults with dementia may find that mainstream (i.e., Western biomedical) health services and approaches to care are culturally unsafe spaces. As a result, they may delay seeking diagnosis or services and supports. Long-term care homes may be considered a last resort and can be associated with traumatic memories of residential school and other institutional experiences (e.g., jails, tuberculosis sanatoriums) (Jacklin, 2018).
- Some lesbian, gay, bisexual, transgender, queer and two-spirit people living with dementia feel excluded from services, avoid formal care and may experience additional anxiety related to fear of disclosure of their sexual orientation or gender (Le Berre, 2018).
- Persons with intellectual disabilities have a high level of multimorbidity and some are at increased risk of developing dementia at younger ages than is commonly seen in the general population. Their caregivers have often already provided decades of support and may be especially challenged to continue caregiving with the onset of dementia (Jokinen, 2018).

Other important groups to consider because of their greater risk of cognitive decline or unique challenges related to dementia include:

- People living with HIV (Kimani, 2018; Manji, Jäger & Winston, 2013),
- People with a history of excessive alcohol use (Ridley, Draper & Withall, 2013; Sachdeva, Chandra, Choudhary, Dayal, & Anand, 2016),
- Imprisoned older adults with dementia (Maschi, Kwak, Ko, & Morrissey, 2012), and
- People with traumatic brain injuries (Nordström & Nordström, 2018; Shively, Scher, Perl, & Diaz-Arrastia, 2012).

4 Young-onset dementia, also known as early-onset dementia or working-age dementia, is a condition that affects adults before the age of 65 years (CIHI, 2018e).

Sept. 7, 2018

“How long have you got?” This is what my boss asked me when I informed him, in July 2014, that I had early-onset Alzheimer’s.

I hadn’t expected it would sound a death knell for my employment. I had new challenges, but I was still a capable employee who brought, I believed, a lot to the table.

I was still the same person I was the day before I received my diagnosis. I just needed to tackle my job — and my life — in a different way.

... we patients still have to contribute to society. It feels good to have my opinions valued and my story heard. It has lifted my spirits, and I believe my packed schedule keeps the disease at bay.

Wendy Mitchell

Author of a memoir: *I Had Alzheimer’s. But I Wasn’t Ready to Retire.*

<https://www.nytimes.com/2018/09/07/opinion/early-onset-alzheimers-work.html>

2.2 PUBLIC POLICY RESPONSES

Some persons living with dementia (and their caregivers) may have a history of experiencing marginalization or being at risk for infringement of their human rights through, for example, abuse, financial exploitation or the use of physical restraints (World Health Organization [WHO], 2015). Because of this, there is a movement to ensure that the human rights of persons living with dementia are acknowledged and respected (World Health Organization, 2015; Dixon, Laing, & Valentine, 2018). In the World Health Organization’s *Global Action Plan on the Public Health Response to Dementia 2017-2025* (2017a,p. 9), member states are asked to

promote mechanisms to monitor the protection of the human rights, wishes and preferences of people with dementia and the implementation of relevant legislation, in line with the objectives of the Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments. These mechanisms include safeguards for concepts such as legal capacity, self-determination, supported decision-making, and power of attorney, and for protection against exploitation and abuse in institutions as well as in the community.

The United Nations Convention on the Rights of Persons with Disabilities (including dementia) states that persons living with dementia have the right to the full range of

healthcare, including diagnosis, treatment, rehabilitation, health promotion, disease prevention, risk reduction, social support and palliative care (Batsch, Mittler, & Kingston, 2017; Dixon *et al.*, 2018). There should be no barrier to access these services on the basis of a dementia diagnosis or because of the stage of dementia. Canada was the first member country to formally recognize dementia as a disability at the United Nations Convention on Rights of Persons with Disabilities (United Nations, Committee on the Rights of Persons with Disabilities, 2017), and the Canadian delegation included a person living with dementia.

Internationally, some governments have adopted a human rights approach to dementia. For example, the cross-party group on Alzheimer’s (2009) in the Scottish Parliament developed a Charter of Rights for People with Dementia and their Carers.

A review of international dementia plans identified the inclusion of the person with dementia in decision-making as fundamental to best practices in care and education methods (British Columbia Ministry of Health, 2016). In England, government policy requires the engagement of individuals and members of the public in care and research (Public Participation Team, 2017).

Most Canadian provincial strategies highlight the engagement of the person living with dementia in care decisions or speak about the need to ensure that

care is individualized to the needs and preferences of individuals with dementia. Three of these strategies (Alberta, Newfoundland and Manitoba) include specific action items to engage persons living with dementia in care decisions. Persons living with dementia are engaged in the development of the national strategy, including through participation in a national dementia conference (PHAC, 2018a) and as members of the Advisory Committee (PHAC, 2018b).

Canada's primary funding agency for health-related research, the Canadian Institutes of Health Research (CIHR), has acknowledged the importance of engaging individuals with lived experience in research. The Strategy for Patient-Oriented Research (SPOR) is a partnership involving partners at the federal, provincial and territorial levels. The aim is to engage patients as research partners throughout the research process, from the identification of research questions and priorities to knowledge mobilization (Canadian Institute for Health Research, 2017b).

2.3 CURRENT EVIDENCE AND EMERGING BEST PRACTICES

Many individuals and groups have supported the recognition of the valued contributions of persons living with dementia and have advocated for their rights (e.g., Bartlett, 2014, 2016; Batsch & Mittelman, 2012; Clare, 2002; Dupuis *et al.*, 2011; Mann & Hung, 2018; Wiersma, McAiney, Loiselle, Hickman, & Harvey, 2016). This appears to be an emerging set of best practices. In fact, the first two of the seven principles in the *Global Action Plan on the Public Health Response to Dementia 2017-2025* (World Health Organization, 2017a) emphasize this:

- The need for persons with dementia, their caregivers, and the organizations that represent them to be empowered and involved in advocacy, service provision and research;
- The basic human rights of persons with dementia.

Persons with dementia have been leaders, for example establishing groups and organizations of individuals living with dementia to educate, advocate and promote the engagement of persons living with dementia (Dementia

Alliance International, 2017; Ontario Dementia Advisory Group, 2017). Recently, the Alzheimer Society's Advisory Group of persons with dementia released a *Canadian Charter of Rights for People with Dementia* to "help people with dementia as well as their families challenge situations where they experience stigma, are treated unfairly, discriminated against, or are denied access to appropriate care" (Alzheimer Society Canada, 2018). These efforts are in line with the principle endorsed by many individuals living with dementia, "nothing about us, without us" (Bartlett, 2014; Swaffer, 2014).

Evidence shows that persons living with dementia benefit from being involved in decisions and activities related to their own care as well as in shaping services and conducting research. These benefits include feeling useful, having a purpose (Cahill *et al.*, 2004; Span *et al.*, 2018) and contributing to a better quality of life for persons with dementia in the future (Span *et al.*, 2018).

2.3.1 Recognizing the diversity of persons living with dementia

Each person's experience living with dementia is unique, and not only because of the variability in how dementia may progress. For example, women and men approach dementia and caring in different ways and access support in different ways (Alzheimer's Disease International, 2015a). Also, it is well established that culture influences an individual's understandings and behaviours around illness, including their beliefs regarding approaches to decision-making and what are considered appropriate models of care (Jacklin, 2018). Furthermore, amongst persons living with dementia there are variances in education, literacy, access to care, and genetic, social, financial, and health status; this may also provide theoretical support for culturally relevant interventions (Rovner, Casten, Hegel, & Leiby, 2018). Community organizations and groups such as local Alzheimer's Society Resource Centres and peer support programs can play a significant role in outreach, as can targeted approaches to establish relationships, such as organizing "road shows" at community centres and religious establishments (Badger & Koehn, 2018). Nationally representative data on subgroups is still limited, but is improving and may be encouraging greater inclusion (Le Berre, 2018).

2.3.2 Engaging persons living with dementia in decisions about their care

In the UK, the updated National Institute for Health and Care Excellence (NICE) guidelines for the assessment, management and support of persons living with dementia and their caregivers recommend that health professionals actively promote and enable persons living with dementia to give their views and opinions about their care (Pink, O'Brian, Robinson, Longson, & Guideline Committee, 2018). The NICE guidelines recognize that persons living with dementia may not always volunteer their own thoughts on their care—especially as the dementia progresses—so it may be necessary to modify ways of soliciting input, such as making use of structured tools (Pink *et al.*, 2018). Persons living with dementia are able to express needs and preferences, even in the later stages of the disease when decision-making ability is compromised (Boyle 2014; Groen-van de Ven *et al.*, 2017; Miller *et al.*, 2016; Robinson *et al.*, 2012a; Whitlatch & Menne, 2009). Emotions and social interactions that influence the values and preferences upon which decisions are made are present even in advanced dementia (Groen-van de Ven *et al.*, 2017).

While not specific to dementia, engaging individuals in care and ways to improve it is becoming increasingly common (Gove *et al.*, 2017). Engaging individuals in their care decisions can result in improved health outcomes (Hibbard & Greene, 2013; Kane *et al.*, 2015), including well-being (Fetherstonhaugh, Tarzia, & Nay, 2013; Menne, Tucke, Whitlatch, & Feinberg, 2008) and enhanced care experiences (Rathert, Wyrwich, & Boren, 2013), and may reduce healthcare costs (Charmel & Frampton, 2008). Shared decision-making involves a discussion between care providers and care recipients regarding care options, the evidence related to each option, and the person's values in order to determine their preferences. While shared decision-making is promoted as the favoured approach to decision-making (Elwyn *et al.*, 2012; Stigglebout *et al.*, 2012), it is not commonly used with persons living with dementia (Miller *et al.*, 2016).

2.3.3 Engaging persons with dementia in service design, delivery and evaluation

The United Nations Convention on the Rights of Persons with Disabilities recognizes that persons with mental disabilities, including those with dementia, must be actively involved in decision-making in terms of the design and delivery of services and supports (Dixon *et al.*, 2018). There are many examples where this has occurred, sometimes as part of a larger research project. For example, persons living with dementia:

- Were involved in service user review panels to assist the work of the UK Alzheimer's Society (Tooke, 2013)
- Assessed the reach and impact of a community-based participatory action research project where persons living with dementia and their family caregivers co-designed and co-delivered educational events (Phillipson *et al.*, 2018)
- Developed a self-management program for persons with dementia and were co-researchers on the research team (Wiersma *et al.*, 2016)
- Developed an Individual Cognitive Stimulation Therapy intervention (Yates, Orrell, Spector, & Orgeta, 2015)
- Helped lead the redesign of an acute care unit (Mann & Hung, 2018)
- Participated on the Advisory Committee for the development of quality standards for persons living with dementia in the community (Health Quality Ontario, 2018)

Such initiatives have positively impacted not only the persons living with dementia who were involved, but also the services they use, according to emerging research. For example, in the study by Mann & Hung (2018), the recommendations developed by persons living with dementia were presented to the hospital board, and the board provided funding for the recommended changes. As well, in the study by Wiersma *et al.* (2016), persons living with dementia determined the content of the self-management program that was developed.

2.3.4 Engaging persons living with dementia in research

There is growing evidence that persons living with dementia can be meaningfully engaged in research as co-researchers or advisors instead of only being involved as research participants (Alzheimer Europe, 2011). For example, Clarke *et al.* (2018) explored an approach to involving persons with dementia in data analysis. Overall, individuals who are engaged as research partners report feeling listened to, valued and empowered (Mann & Hung, 2018). Involvement in research may also result in an increased understanding of their conditions among those who are engaged, and increased ability to manage their conditions (Brett *et al.*, 2014). Dementia research also benefits from this engagement, with researchers having a better understanding of the conditions and selecting more appropriate designs and more relevant measures (see Chapter 7).

2.4 KEY FINDINGS

- a) There is increasing interest in promoting, recognizing and protecting the rights of persons living with dementia. This has taken various forms, including statements of principles in dementia strategies, the designation of dementia as a disability, and the recognition of rights for persons with dementia and their caregivers.
- b) It is becoming more common to engage persons with dementia in their own care, as well as in shaping health services and conducting research. This approach is almost unanimously supported in dementia strategies within Canada and internationally as an emerging best practice.
- c) When engaging those with dementia, consideration should be given to the diversity within this population, recognizing that some groups have unique and additional challenges.

CHAPTER 3

Prevention, awareness and living well with dementia

The charge related to this chapter is “developing and disseminating information to health care professionals and the general public on the importance of prevention and management of, and early intervention in, dementia” (see section 1.3.1). The evidence and best practices related to this charge led the CAHS Expert Panel to conduct a broader examination of how dementia is viewed and the role of health promotion in preventing, delaying and living well with dementia.

The focus of this chapter is the general public. While this includes health professionals, additional targeted approaches are needed for the dementia workforce and are addressed in Chapter 6.

3.1 CHALLENGES

An overriding challenge is that very little has been done to understand, apply and disseminate information about best practices for dementia, prevention and risk reduction.

3.1.1 Adopting healthy lifestyles

It is difficult to realize the changes in behaviour needed to impact the lives of persons living with or at risk of developing dementia (The Lancet Neurology, 2015). We need to better understand what favours the adoption of healthy lifestyles and how to implement effective programs (National Academies of Sciences, Engineering, and Medicine, 2017).

3.1.2 Addressing misinformation and stigma

While basic awareness about dementia may have increased, misinformation, stigma and negative attitudes continue to persist. Globally, public understanding of dementia is limited. Many people still believe that dementia is a normal part of aging (Cahill, Pierce, Werner, Darley, & Bobersky, 2015; Morgan, 2016; Glynn, Shelley, Lawlor, 2017) and do not know about the risk and protective factors that might prevent or delay dementia and its negative effects, or about the risks for and presenting symptoms of depression and stress in caregivers (Bergman, 2009).

A reason for the stigmatization of persons with dementia is the psychiatric nature of the disease, which affects mainly older adults and more women than men (Bergman, 2009). A recent public poll of adult Canadians under 65 found that almost half of respondents admitted that they would feel ashamed or embarrassed if they had dementia and even more feared they might face discrimination (Alzheimer Society of Canada, 2018, January 7).

Much of the common discourse is focused on the negative aspects of dementia, rather than what it means to live well with dementia. We lack a fuller understanding of the dementia experience, including the joys and opportunities that are possible for persons living with dementia (Wolverson, Clarke & Moniz-Cook, 2016).

“There are many small things—one that comes to mind is that our housing estate has put a gate between the houses and the river walkway for security reasons. My husband cannot operate the lock—so he can no longer easily reach the riverside to walk on his own.” — supporter from a suburb

“Shops—I can’t handle it because I am always forgetting my PIN number—well not always, but I am worried in case I inconvenience anyone coming in behind me.” — person with dementia from a rural area

“It is so important to give us time, and not make us feel bad if we are taking time to find our money or pack our bags—it makes all the difference.” — person with dementia from a small town

Innovations in Dementia (2011)

3.1.3 Community barriers for persons living with dementia

Social and physical barriers can make it more difficult for persons living with dementia to get around and feel supported in their communities (Alzheimer Society of Saskatchewan, 2017). For example, geographical isolation, transportation challenges and difficulty in navigating shops and payment have been reported as some of the challenges for persons living with dementia (Innovations in Dementia, 2011).

3.2 PUBLIC POLICY RESPONSES

Though they are not intended to prevent dementia, healthy public policies such as those aimed at tobacco reduction, physical activity, healthy eating and use of helmets for sports activities promote healthy lifestyles and may be contributing to the decreasing incidence of dementia (Livingston *et al.*, 2017). Recognizing the potential benefits, some dementia strategies include health-promoting policies.

Raising awareness of dementia and reducing stigma are top priorities in most provincial, national and international dementia plans (British Columbia Ministry of Health, 2016). Government-led awareness campaigns have been conducted in a number of countries, including Japan and the United Kingdom (World Health Organization & Alzheimer’s Disease International, 2012).

Two provincial strategies (in British Columbia and Alberta) have adopted a broad approach to increasing awareness and are promoting living well with dementia through the development of dementia-friendly communities. While the

Quebec plan does not use this term, it, too, mentions the development of appropriate environments for persons living with dementia.

3.3 CURRENT EVIDENCE AND EMERGING BEST PRACTICES

The InterAcademy Partnership for Health (2018) called for risk reduction strategies for the public to promote healthy brain aging and for the creation of conditions where people can live well with dementia. It emphasized the importance of structural and legislative alterations to support individual actions, recognizing that these broad societal interventions may lead to less inequality by benefiting the less advantaged as well as the more advantaged.

3.3.1 Prevention: protective and risk factors for dementia

Many people are interested in what they can do to prevent cognitive decline and dementia as they age. While the strongest risk factor for dementia, increasing age, is non-modifiable, emerging research suggests that lifestyle factors are potentially modifiable and may have the potential to delay, if not prevent, the onset of dementia (InterAcademy Partnership for Health, 2018). In addition to minimizing factors that heighten risk there are also a number of factors that may protect people against the development of dementia. The International Lancet Commission on Dementia Prevention, Intervention and Care estimated that more than a third of dementia cases might be preventable and identified the following interventions as potentially helpful:

- Prevention, detection and active treatment of hypertension, hyperlipidemia and diabetes;
- Improvement of children’s educational attainment;
- Prevention of head injuries;
- Encouragement of healthy lifestyles, especially increased physical, intellectual and social activity, healthy eating habits, smoking cessation, moderate alcohol consumption and addressing sleep problems (Livingston *et al.*, 2017).

While there is growing agreement on the protective and risk factors for dementia (Livingston *et al.*, 2017; National Academies of Sciences, Engineering, and Medicine, 2017; InterAcademy Partnership for Health, 2018), less is known about the effective implementation of interventions. The consensus report of the USA’s National Academies of Sciences, Engineering and Medicine (2017) felt the evidence in some areas was encouraging but inconclusive, and pointed out a need for further research on larger, more diverse populations with longer follow-up. They did note that many modifiable protective and risk factors for dementia (e.g., hypertension) are also relevant for other chronic conditions, such as stroke and heart disease. Given the other known health benefits for some of these interventions, randomized controlled trials are not appropriate (for instance, because of the known benefits of treatment, it would be unethical not to treat hypertension). It may be difficult or take significant time to develop strong evidence on preventive strategies specifically for dementia, but the presence of other benefits for certain interventions, such as the treatment of hypertension, would reasonably lower the threshold of evidence required before recommending adoption.

Prevention strategies can empower individuals and societies to take action (InterAcademy Partnership for Health, 2018). While much more has to be learned about risk and protective factors for dementia, “if the knowledge already available were properly applied, it might help delay the onset of the disease, possibly slow its progression, and also ensure a better quality of life for people with the disease and their caregivers” (Bergman, 2009 p. 26).

3.3.2 Increasing public understanding of dementia

Increased public awareness is needed about maintaining brain health, the importance of addressing the health and social care challenges of dementia, and engaging persons with dementia and harnessing their abilities (InterAcademy Partnership for Health, 2018). Increasing awareness of the early symptoms of dementia is especially important (World Health Organization & Alzheimer’s Disease International, 2012) because actions can be taken to identify potentially modifiable factors. Memory loss in older adults can be mistaken for a normal part of aging, and the general public is less familiar with other early symptoms of dementia, such as loss of interest.

Increased public awareness and understanding has the potential to reduce the stigma associated with dementia and to encourage persons with dementia and their caregivers to access support at the appropriate time (Nova Scotia Health Research Foundation, 2014). Qualitative research with people who had little or no experience of dementia has revealed that what persons with dementia and their families perceived as stigma was actually fear: fear of dementia itself, of developing the condition or of engaging with persons living with dementia (World Health Organization & Alzheimer’s Disease International, 2012). Still, this fear contributes to stigmatizing and isolating practices such as avoidance or discrimination (Nova Scotia Health Research Foundation, 2014; World Health Organization & Alzheimer’s Disease International, 2012).

There have been many attempts to raise public awareness of dementia, but there appears to be limited evidence on their effectiveness (The Lancet Neurology, 2015). The most common outcome reported on is how many people are reached during public awareness campaigns. For example, in 2004 the Japanese government launched a campaign to raise public awareness and understanding of dementia. Through specialized seminars, over 2.4 million people were recruited within seven years to become “Ninchishō (Dementia) Supporters.” This was more than double their 10-year target (World Health Organization & Alzheimer’s Disease International, 2012). However, there appears to be little evidence on the impact of these supporters on raising awareness and reducing stigma associated with dementia.

Public awareness campaigns are more likely to be effective when they build on what people already know and feel about dementia and address their information gaps (Nova Scotia Health Research Foundation, 2014). Common knowledge gaps related to dementia are:

- Being unaware of risk factors and possible protective factors;
- Confusion on where normal aging ends and dementia begins (e.g., signs and symptoms);
- Belief that there is no benefit to diagnosis because nothing can be done;
- Belief that persons with dementia have no quality of life (Nova Scotia Health Research Foundation, 2014).

Another common knowledge gap is the belief that persons with dementia cannot experience joy, fulfilment and other positive aspects of life and, therefore, cannot live well with dementia. Wolverson, Clarke and Moniz-Cook (2016) undertook a systematic review and synthesis of the qualitative literature on living well with dementia. They identified three superordinate themes related to the positive experiences of those living with dementia: engaging with life in aging, engaging with dementia, and identifying growth opportunities. They concluded that despite the difficult circumstances that dementia presented, persons living with dementia can live well and may even have positive experiences because of their dementia (Wolverson *et al.*, 2016).

The importance of this message is seen in the National Dementia Strategy for England (Department of Health & Social Care [UK], 2009, p. 7), which states:

Our aim is that all persons with dementia and their carers should live well with dementia. There is no doubt that the dementias are a devastating set of illnesses and that they have profound negative effects on all those affected, be they persons with dementia or their carers. However, it is also clear that there is a vast amount that can be done to improve and maintain quality of life in dementia.

According to the Nova Scotia Health Research Foundation (2014), considerations in developing messages to reduce the fear associated with dementia amongst the general public, to provide a more balanced perspective on the experience of dementia and to empower persons with dementia and their caregivers would include:

- Avoiding the use of fear-oriented messages or themes;
- Using realistic and positive images of life with dementia;
- Including information and advice about treatment and available supports.

3.3.3 Making communities work for persons living with dementia

Greater acceptance and inclusion of persons living with dementia within communities is increasingly seen as an important factor in improving their quality of life and minimizing disability (InterAcademy Partnership for Health, 2018). It has been argued that public awareness campaigns need to be part of a broader approach to enhancing the experiences of persons living with dementia, specifically through the creation of dementia-friendly communities (World Health Organization & Alzheimer's Disease International, 2012). In addition to increasing understanding about dementia and reducing stigma, Prior (2012) notes that other key aims of this approach would be to:

- Increase understanding on how to support persons living with dementia to live well;
- Enable persons living with dementia to be active and engaged members of their communities;
- Support persons living with dementia to be independent for as long as possible.

Phillipson *et al.* (2018) examined the impact of involving persons living with dementia in dementia-friendly community projects. They found that over a two-year period community members held reduced negative stereotypes, more positive views of persons living with dementia and their ability to have meaningful involvement in their communities, and more positive perceptions of dementia overall.

Herbert & Scales (2017) examined both dementia-friendly communities and more targeted dementia-friendly strategies including person-centred care, dementia awareness and education, and environmental design to accommodate persons with dementia within hospitals, long-term care homes and the community. Overall, the authors found that “dementia-friendly initiatives broaden the lens from which dementia is viewed” (Herbert & Scales, 2017). More rigorous research is needed, including an examination of the broader range of impacts such as well-being and cost (Canadian Dementia Priority Setting Partnership Steering Committee, 2018; Herbert & Scales, 2017; Shah *et al.*, 2016).

Addressing transportation needs, including access to alternative transportation options, is key to supporting persons with dementia in being active, engaged and independent in their communities (Alzheimer Society of Saskatchewan, 2017). Current research is examining issues such as strategies for creating a dementia-friendly public transportation system (Hyde, 2016) and interventions to help persons with dementia and their caregivers adapt after driving cessation (Sanford, Naglie, Cameron, & Rapoport, 2018).

A number of reports describe the development of dementia-friendly communities across multiple countries (Alzheimer’s Disease International, 2016a; Williamson, 2009). Other publications provide information and recommendations on implementation (Alzheimer Society of Saskatchewan, 2017; Alzheimer’s Disease International, 2016a; Innovations in Dementia, 2011; Prior, 2012). Some have promoted the use of assets-based (Rahman & Swaffer, 2018) and citizenship (Bartlett, 2016) approaches in designing dementia-friendly communities. As argued by Rahman & Swaffer (2018), if dementia-friendly communities are developed based on the deficits rather than the strengths of persons living with dementia, the way society views dementia will never be transformed. Researchers have made three key recommendations regarding the development of dementia-friendly communities:

- Engage persons living with dementia in a meaningful way as integral partners in all aspects of dementia-friendly communities, from development to implementation and evaluation (e.g., Bartlett, 2016;

Green & Lakey, 2013; Heward, Innes, Cutler, & Hambidge, 2017; Phillipson *et al.*, 2018; Rahman & Swaffer, 2018; Swaffer, 2014).

- Prioritize adaptability: there is no one-size-fits-all approach. Determining what aspects to address in developing dementia-friendly communities and how to address these aspects will vary according to the needs and preferences of each community (Prior, 2012).
- Provide opportunities to complement other initiatives, such as age-friendly initiatives as described in the Alzheimer Society of Saskatchewan’s *Dementia Friendly Communities: Municipal Tool kit* (2017) and through the Global Network of Age-Friendly Cities and Communities (World Health Organization, n.d.).

3.4 KEY FINDINGS

- a) There is sufficient evidence to encourage the adoption of health promotion endeavours (improving educational attainment, healthy eating, exercise, smoking cessation, prevention of head injury) and prevention interventions (early detection and treatment of hypertension, hyperlipidemia and diabetes) that address protective and risk factors for dementia.
- b) Public awareness and understanding of dementia is improving, but there are still specific knowledge gaps. Many persons continue to believe that dementia is a normal part of aging and that there is nothing they can do to prevent cognitive decline and dementia as they age.
- c) Public understanding is also needed to address stigma and fear, to show how it is possible to live well with dementia and to empower persons with dementia and their caregivers.
- d) Dementia-friendly communities are emerging as a promising approach to increasing awareness and understanding of dementia while making communities more liveable for persons with dementia. These require local adaptation and the meaningful involvement of persons living with dementia.

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CHAPTER 4

Improving health and social care for persons living with dementia

While the previous chapter addresses issues related to the prevention of dementia, this chapter focuses on the health and social care needs of people after the onset of significant cognitive concerns and through the progression of dementia. The CAHS Expert Panel was charged with commenting on the state of the emerging evidence and best practices related to “developing and disseminating emerging clinical diagnostic and treatment guidelines” and “assessing and disseminating best practices, including greater integration of care, chronic disease prevention and management, and coordination of community support and care” (see section 1.3.1).

Throughout this chapter, we include considerations about care aimed at minimizing dementia’s impact on caregivers; Chapter 5 focuses on this topic specifically. Workforce capacity and training are identified as key drivers for improving the quality of life and care of persons with dementia and their caregivers; these elements are addressed in Chapter 6.

4.1 CHALLENGES

The management of dementia and any associated comorbidities requires a complex combination of health and social care. Though symptoms are not predictable for any individual person with dementia, they typically progress through the stages of cognitive impairment resulting in increased dependency on caregivers and a need for different health and social care in order to optimize quality of life (see Figure 2).

As the condition progresses, persons living with dementia and their caregivers face many challenges related to limited access to services and supports, fragmented care and inappropriate end-of-life care. This section focuses on these issues.

The allocation of sufficient resources to address the increasing demands on the social and health care system is a critical issue that is pervasive in all settings and exacerbates these challenges. Chapter 8 identifies insufficient dedicated resources as a barrier to successful implementation of the measures proposed in dementia strategies.

4.1.1 Limited access

Persons living with dementia and their caregivers experience limited access to health and social care for multiple reasons. Many people are uncertain about where to go for assistance and can experience delays in getting the health care supports they need (Alberta Health, Continuing Care, 2017). Access is also influenced by values, culture and life experiences (Badger & Koehn, 2018; Jacklin, 2018; Le Berre, 2018). The following are some of the areas where persons living with dementia and their caregivers often experience limited access.

Timely diagnosis

This has been defined as communicating an accurate diagnosis at a time when the person living with dementia and their caregivers would benefit from the information (Livingston, *et al.*, 2017). It is an essential step in the provision of good dementia care (World Health Organization & Alzheimer’s Disease International, 2012; Brooker, LaFontaine, Evans, Bray, & Saad, 2014). Unfortunately the making and disclosure of a diagnosis is often too late to allow the person living with dementia the opportunity to plan for their future or benefit from available interventions. An older Canadian study found that 64% of persons living with dementia were undiagnosed (Sternberg, Wolfson, & Baumgarten, 2000) while more recent reports from other economically advantaged countries suggest that approximately a third to half

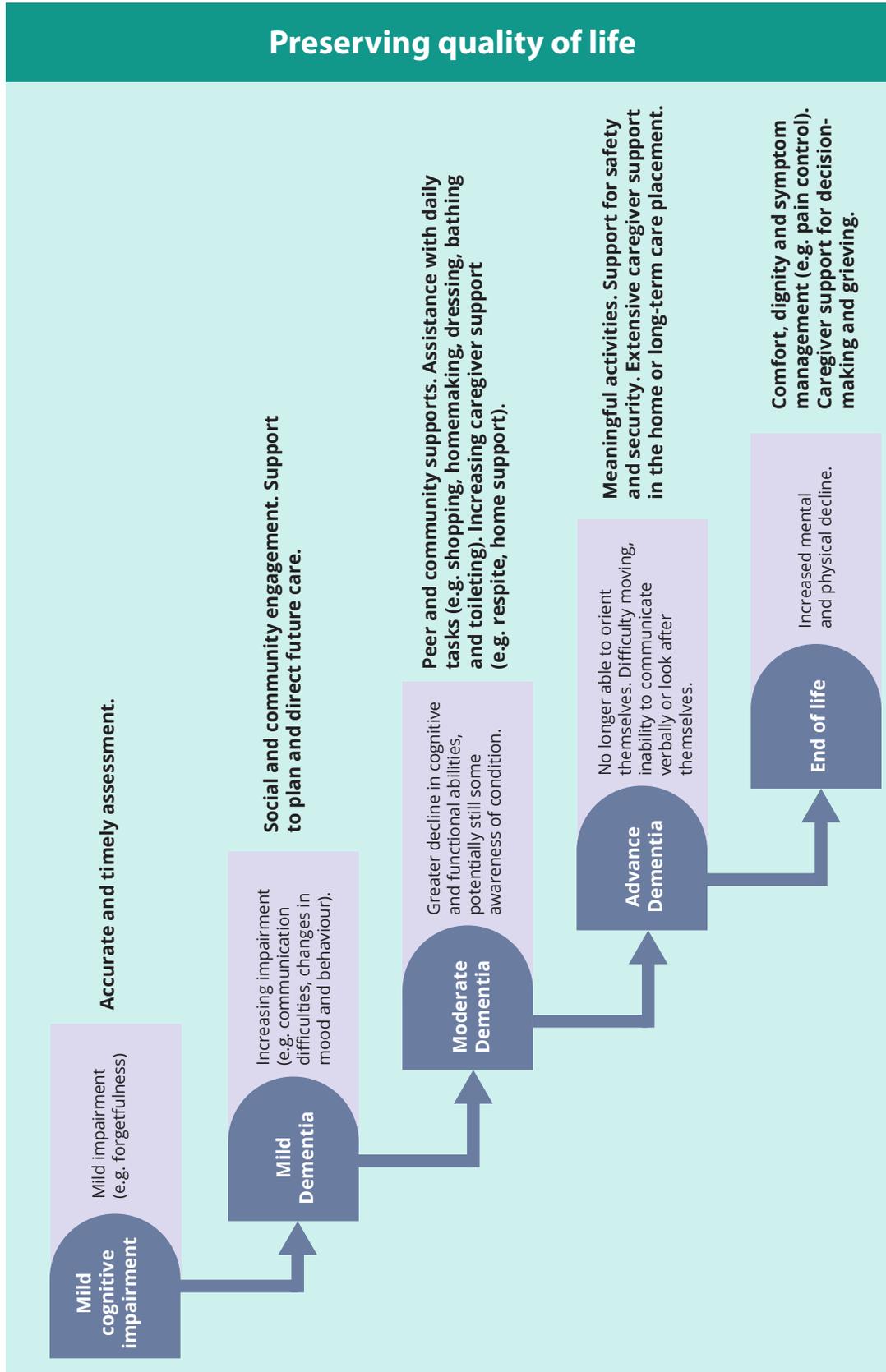


Figure 2: Changing needs as cognitive impairment increases

of persons with dementia are not currently diagnosed (Sava & Arthur, 2015; Mason, Liu, Kasteridis, Goddard, & Jacobs, 2018). Barriers to diagnosis include stigma, denial, fear, normalization of symptoms, inadequate practitioner knowledge and skills, time constraints, uncertainty, and practitioner's reluctance to disclose a diagnosis because of worry about the person's reaction or perceived lack of effective interventions (Dubois, Padovani, Scheltens, Rossi, & Dell'Agnello, 2016). Reliance on specialty services to diagnose dementia could result in avoidable delays in its detection (Alzheimer's Disease International, 2016b). Surveys of persons both with and without cognitive impairment indicate that most (80%+) would want to be told of a diagnosis as early as possible, primarily in order to plan for the future (Van den Dungen, 2014; Khanassov & Vedel, 2016; Watson, Bryant, Sanson-Fisher, Mansfield, & Evans, 2018). Physicians express more uncertainty about the value of communicating an early diagnosis (Dhedhi, Swinglehurst, & Russell, 2014).

Home care

Canadian reports identified the need to make home care more available, accessible and integrated, to achieve better health outcomes and quality of care and to improve the experiences of individuals receiving health care and support (Canadian Healthcare Association, 2009; Canadian Home Care Association, the Canadian Nurses Association and the College of Family Physicians of Canada, 2016). The amount and type of publicly funded home care and support services vary across Canada, as do the criteria for accessing them. Fragmentation in the payment and reimbursement for home-based and institutional care is described as the "single largest obstacle" to the diffusion of innovative models of care for persons with dementia (Samus *et al.*, 2018).

Social care

Supports are often absent for persons living with dementia and their caregivers to help them remain active and engaged members of their communities (Alberta Health, Continuing Care, 2017). In addition, some primary care

practices may lack awareness of existing community support services (Ploeg *et al.*, 2016, Ploeg *et al.*, 2017), making it difficult to manage the broad needs of persons living with dementia and their caregivers (Aminzadeh, Molnar, Dalziel, & Ayotte, 2012).

Management of behavioural and psychological symptoms

Behavioural and psychological symptoms⁵ may include psychosis, depression, aggression, agitation and disinhibition, and will affect up to 90% of persons with dementia at some point over the course of their illness (MacCourt, Wilson, & Tourigny-Rivard, 2011). These symptoms can be most challenging for caregivers and health and social care providers (MacCourt *et al.*, 2011). Because there are limited community-based supports and, when they are available, they are often difficult to access in a timely manner, the emergency room is most often the default resource for caregivers seeking support. In long-term care, antipsychotics are often inappropriately used to reduce behavioural and psychological symptoms. One in four residents throughout Canada are taking antipsychotic medication without a diagnosis of psychosis, whereas the evidence suggests that only 5% to 15% of residents would benefit from these medications (Canadian Foundation for Healthcare Improvement, 2017).

Assisted living

Assisted living⁶ facilities aim to provide residents with secure housing, personal support and limited health care while promoting their choice, autonomy, privacy and independence. Most assisted living residents in Canada require help with one or more activities of daily living. These facilities are viewed as offering an option between fully independent living and long-term care (Doupe *et al.*, 2016). The lower staffing in assisted living, in terms of both numbers and skill levels as compared to long-term care, has raised concerns that more vulnerable residents, such as those with a dementia, may be at an increased risk for poor outcomes in these facilities (Maxwell *et al.*, 2015).

5 Also referred to as behavioural expressions, responsive behaviours, and neuropsychiatric symptoms of dementia.

6 Across Canada, a variety of other terms for assisted living are used. Some of the terms include personal care homes or community care residences (Newfoundland), community care facilities (PEI), special care homes or community residences (New Brunswick), residential care facilities or community-based options (Nova Scotia), résidences pour personnes âgées (Quebec), retirement care homes (Ontario), supportive housing or companion care (Manitoba), enriched assisted living, retirement living or personal care (Saskatchewan), and designated assisted living (if government-funded) or supportive living (Alberta and British Columbia).

Long-term care

When the care requirements of the person with dementia exceed what can be reasonably provided in their community or in assisted living, placement in a long-term care home often becomes necessary (Cepoiu-Martin, Tam-Tham, Patten, Maxwell, & Hogan, 2016; Maxwell *et al.*, 2015; Maxwell *et al.*, 2013).

Extensive variation in safety levels, quality of care and quality of life have been identified in long-term care homes throughout Canada (Canadian Institute for Health Information, 2013; Hirdes Mitchell, Maxwell, & White, 2011). In addition, there are currently a limited number of appropriate long-term care beds available. Mathematical projections suggest that a 400% increase in bed capacity is needed in Canada within 20-30 years. This is of course not realistic and does not take into account the needed and anticipated increase in focus on community-based care (Boissonneault, Décarie, & Légaré, 2018).

Representation of older adults

Adults require a public guardian when they no longer have decision-making capacity, lack an advanced directive and the ability to execute the directive, and have no family or friends who are able or willing to act as their representative (Chamberlain, Baik, & Estabrooks, 2018a). Without family or friend support, they are especially vulnerable to poor quality of care, and yet, there is a scarcity of studies on these older adults, especially on those living in long-term care homes (Chamberlain *et al.*, 2018a).

4.1.2 Fragmented care, transitions and poor quality

Health and social care tend to be fragmented and are difficult to navigate as needs evolve during the course of the dementia and the ability and availability of caregiver support varies (Alzheimer's Disease International, 2016b). This fragmentation of care is especially apparent during transfers of care, which are recognized as high-risk points for care of persons with dementia (Canadian Medical Protective Association, 2018).

Lack of coordination

Persons living with dementia are reliant on a complex array of specialized medical, community and social services (Alzheimer Society of Canada (2010). They require person- and family-centred care that has been described in terms

of a continuing relationship between a care recipient and a practice, where the providers in the practice know the care recipient and the care recipient has a regular source of care (McMurchy, 2009). Healthcare for persons with dementia, however, is often piecemeal, fragmented and uncoordinated, and it can be difficult to tell who, if anyone, is in charge. In short, the system is difficult to navigate (Alzheimer Society of Canada, 2010). There is often a lack of continuity in healthcare systems for persons living with dementia, with little integration or communication between different teams and specialties (Bunn *et al.*, 2016). Some healthcare providers may not be informed that an individual has dementia and so rely on caregivers attending appointments to provide informational continuity and transfer information between specialties (Bunn *et al.*, 2016). Gaps in continuity and poor communication between settings may cause re-hospitalizations and death (Callahan *et al.*, 2015; Sivananthan & McGrail, 2016).

Frequent transitions

Older adults with dementia experience frequent transitions in care, primarily as a result of hospitalization and especially in the year of diagnosis and the year of death (Sivananthan & McGrail, 2016). About one in four long-term care residents experience a transfer to emergency department each year (Robinson, *et al.*, 2012b). A greater number of transitions (i.e., to emergency and hospital) occur in the absence of recommended dementia care and high-quality primary care (Clarke & Pyra, 2006; Sivananthan & McGrail, 2016). Transitions are disruptive, possibly increasing stress and worry for the individual and their caregivers (Alberta Health, Continuing Care, 2017; Jensen *et al.*, 2016). Transfers between long-term care homes and acute care are complex and costly (Robinson *et al.*, 2012b).

Inadequate quality of care leading to poor quality of life

Persons with dementia are less likely to receive the same quality of care or access to services than those without dementia (Bunn *et al.*, 2016). Persons with severe dementia frequently experience uncomfortable medical interventions that lack demonstrable benefit and have poor prognoses (Arcand, 2015; Cummings *et al.*, 2012; Matlow *et al.*, 2017; van der Steen, 2010). Persons with dementia often stay in hospital longer and experience a decline in key functional abilities (e.g., the ability to walk or eat) and overall health (Alzheimer's Disease International, 2016b; Donnelly, McElhane & Carr, 2011).

4.1.3 Inappropriate end-of-life care

Although dementia is considered a life-limiting chronic condition (Canadian Hospice Palliative Care Association, 2015), many families and health and social care providers often still do not view it as a terminal disease (Arcand, 2015; Mitchell *et al.*, 2009) and as a result, they fail to implement a palliative approach with comfort as the primary goal of care (Bergman, 2009; Emecoff, *et al.*, 2018; Livingston *et al.*, 2017). In many jurisdictions of Canada, palliative care does not yet embrace persons with dementia.

The absence of a palliative approach with clear guidelines, along with divergent opinions amongst families and health and social care professionals, can result in poor management of symptoms, especially pain, towards the end of life, causing considerable distress to both the person with dementia and their caregivers (Arcand, 2015; Bergman, 2009; Sampson, Gould, Lee, & Blanchard, 2006).

Decision-making

Persons with dementia are likely to lose cognitive abilities, function and capacity for decision-making, and as a result, are less likely to be able to express their needs and wishes; family and surrogate decision makers are more likely to be required to make complex and difficult ethical decisions, especially at the end of life (e.g., feeding and resuscitation) (Livingston *et al.*, 2017). While most families seem to choose comfort as the primary goal of care, without clear guidelines for a palliative care approach this often does not translate into comfort-focused treatment plans for late-stage dementia (Emecoff *et al.*, 2018).

Symptom management

Relatively little attention has been directed to the complex medical, social and ethical management of physical decline among persons with dementia that leads to death (Alzheimer's Disease International, 2016b). For example, undiagnosed and under-treated pain reduces quality of life, contributes to depression, and might worsen agitation and other behavioural and psychological symptoms (Livingston *et al.*, 2017).

Dying with dementia

The Alzheimers Association in the United States reported that “according to Medicare data, one-third of all seniors who die in a given year have been previously diagnosed with Alzheimer’s disease or another dementia” (Alzheimer’s Association, 2013, p. 218). While all these individuals die with dementia, it is uncertain what proportion of them die *from* Alzheimer’s disease or another dementia. According to Livingston (2017, p. 2),

research on end-of-life care has focused on persons with advanced dementia rather than persons with less severe dementia dying from other conditions. Specifically, it is unknown how persons in the earlier dementia stages with a terminal illness navigate services and make complex treatment decisions, and if they have equitable access to good end-of-life care.

4.2 PUBLIC POLICY RESPONSES

Access to assessment, care and improved care coordination and transitions are themes highlighted in most national and Canadian provincial dementia strategies (Edick *et al.*, 2016; Guillette, 2016; Guillette *et al.*, 2018). In addition, Canadian provincial strategies have an emphasis on person-centred care (Guillette, 2016; Guillette *et al.*, 2018). These stated strategic directions for dementia care are aligned with current public policy initiatives to strengthen primary health care, home and community care, long-term care and end-of-life care.

4.2.1 Increasing the capacity of primary health care

Every provincial dementia strategy in Canada recognizes the need for persons living with dementia and their caregivers to receive timely recognition, diagnosis and clinical management through primary health care teams, supported by specialized services. The anchoring of dementia diagnosis and management in primary health care is less commonly seen outside of Canada (Guillette, 2016; Guillette *et al.*, 2018). In most other countries, dementia care is anchored in specialty care; however, the 2016 World Alzheimer Report (Alzheimer’s Disease International, 2016b) questions the sustainability and appropriateness of this specialized approach to dementia

care in most high-income countries, cautioning that timely access to specialists may not be possible or affordable with the increasing prevalence of dementia.

4.2.2 Enhanced supports at home and in the community

Access to and provision of home care services vary among provinces and territories (Canadian Healthcare Association, 2009). In order to allow persons with dementia to live safely at home for as long as possible, provincial governments are providing clear public policy directives for the provision of community-based supports as care needs increase and become more complex (Alberta Health, Continuing Care, 2017). Generally, provinces acknowledge that “responsive service delivery and flexible care models are needed to allow this vulnerable population to be cared for at home rather than in emergency departments and acute care in-patient beds” (British Columbia Ministry of Health, 2016, p. 6). One strategy specifically recognizes the need for supports at home and in community to help caregivers manage complex behavioural and psychological symptoms (Robertson, 2017).

4.2.3 Assisted Living

The rapid expansion of assisted living in some provinces reflects the convergence of two factors: the preference of older persons and their families for a more home-like environment with more privacy, amenities and choices than a long-term care facility, and the lower cost to government of assisted living compared to long-term care. Access to assisted living, and its regulation, funding (i.e., private pay, government funding for some or all personal care costs) and role in the housing market, vary considerably across the country. In some provinces assisted living is viewed as a substitute for the less intense levels of long-term care.

4.2.4 Long-term care homes

In response to reports on quality problems in long-term care homes, a variety of policy statements have redefined how long-term care is best provided, including:

- Providing a greater variety of regulated and publicly funded facilities and specialized spaces (Alberta Health, Continuing Care, 2017; Bergman, 2009),

- Improving quality through strengthened standards for dementia care in residential facilities (British Columbia Ministry of Health, 2016),
- Enhancing behavioural supports in long-term care homes (Robertson, 2017), and
- Policy changes to reduce the use of restraints (both chemical and physical) wherever possible (Canadian Institute for Health Information, 2018a).

4.2.5 End-of-life care

Appropriate end-of-life planning and care continues to have limited recognition in international dementia strategies (Edick *et al.*, 2016); however, some Canadian provinces seem to be early adopters of this theme, recognizing the need to improve end-of-life care. This is encouraging, as a 2005 report to the Senate, *Still Not There: Quality End-of-Life Care: A Progress Report*, concluded that despite a number of significant advancements, disparities across Canada remained with respect to access to end-of-life care, quality of care and out of-pocket expenses (Carstairs, 2005). Currently some provincial palliative care strategies exist, yet few address dementia.

With regard to end-of-life decisions, federal legislation was passed in 2016 that allows eligible Canadian adults to request medical assistance in dying (Criminal Code [SC 2016, c. 3, 2016]). At the federal government’s request, the Canadian Council of Academies is carrying out an independent review of the evidence concerning advance requests for medical assistance in dying (Council of Canadian Academies, 2018). This review will be of interest for persons living with dementia to the extent that it assesses the issues and evidence related to making end-of-life decisions with capacity-limiting conditions.

4.3 CURRENT EVIDENCE AND EMERGING BEST PRACTICES

With strategic direction provided by public policy, considerable progress has been made across Canada to improve access to services, provide better continuity of care and improve the quality of end of life for persons living with dementia and their caregivers. Current evidence suggests that further development and dissemination of emerging best practices would improve quality of life and care for persons living with dementia.

“I struggle most with knowing that my fiercely proud grandma [with advanced Alzheimer’s disease] would have hated to live this way. There is only a small sliver of relief: knowing she is cared for with the utmost dignity and respect.”

L. Melvin, 2018, p. 1: A physician’s personal reflection on Alzheimer dementia

4.3.1 Person- and family-centred care

Persons with dementia and their caregivers require a complex combination of social and health care that is “tailored to unique individual and cultural needs, preferences and priorities, and should incorporate support for family carers” (Livingston *et al.*, 2017, p. 2673). Because more than 90% of persons living with dementia have at least one other chronic condition and close to 20% have five or more co-morbid conditions (Griffith *et al.*, 2016), an approach that addresses the existence of multiple chronic conditions is essential.

Person-and family-centred care includes focusing on the individual, not on their diagnoses, and building on strengths and abilities rather than losses (Alzheimer Society of Canada, 2011; Nasmith *et al.*, 2010). Some core elements of person-centred care are: comprehensive care, coordination of care, timeliness, functioning e-health, clear and reliable communication, convenience, respect, empathy and understanding, time, continuity, stability and fairness (Lewis, 2009). Relationship-centred care extends person-centred care to include the needs of not only the person being cared for and their family, but also the health and social care provider (de Witt & Fortune, 2017; Nolan, Davies, Ryan & Keady, 2008; Soklaridis, Ravitz, Adler Nevo, & Lieff, 2016).

As with most other chronic conditions, rather than creating a separate, parallel, disease-based system of care, most dementia care in Canada is person-centred and is integrated into existing services with primary care serving as the hub. The Chronic Care Model (Wagner, 1998; Barr *et al.*, 2003) remains the most promising model of care for persons with multiple chronic health conditions, including dementia (Nasmith *et al.*, 2010; Canadian Academy of Health Sciences, 2017). It has been implemented in different ways and to varying degrees in many provinces and in many primary health care practices; however, there is limited evidence on effective implementation, so a comprehensive evaluation should be planned along with the application of the Chronic Care Model (Canadian Academy of Health Sciences, 2017).

4.3.2 Anchored in interdisciplinary team-based primary health care

In the Canadian context, clinical guidelines and provincial strategies assign the responsibility for prevention, promotion, recognition, diagnosis, treatment and coordination of care for most persons with dementia to primary health care, in collaboration with specialized professionals (i.e., geriatricians, neurologists and geriatric psychiatrists) and community-based services. Current evidence supports an interdisciplinary approach to primary health care (Nasmith *et al.*, 2010; College of Family Physicians of Canada, 2017).

Some provinces are co-locating primary care team members (e.g., family health teams in Ontario and family medicine groups in Quebec) and others are creating networks of care (e.g., Alberta) (College of Family Physicians of Canada, 2017). Some teams have a navigator or “pivotal” nurse who develops a close, ongoing trusting relationship with the person with dementia and their caregiver, providing personalized, coordinated services as part of their responsibility on the primary care team (e.g., Alberta, Manitoba, Ontario, Quebec).

Figure 3 highlights some examples of well-supported team-based primary health care, with different approaches to providing comprehensive and coordinated dementia assessment, treatment and care. Although the context and approach differ between and within provinces, they all share the intent to increase the capacity for primary health care to be the hub, where specialized services will support primary health care professionals in managing this complex population. While further evaluation is necessary, these approaches to managing dementia within primary care have shown promising results in terms of feasibility, clinician participation and satisfaction (Lee *et al.*, 2010; Moore *et al.*, 2012; Vedel, Sourial, Arsenaault-Lapierre, & Bergman, 2018).

Figure 3: Various approaches to providing comprehensive and coordinated dementia diagnosis, treatment and care

In Quebec: Within the Family Medicine Group (FMG), the approach is to enable and empower the patient's family physician, nurse, pharmacists and social worker in partnership with the person and their caregiver, using a chronic disease collaborative care approach to detect, diagnose and follow up with dementia patients just as they would with other chronic diseases (Vedel, Monette, & Lapointe, 2012; Azuelos *et al.*, 2014).

In Ontario: Some family health teams refer patients to primary care memory clinics that are run by family physicians and allied health care professionals within that practice. These clinicians, who have participated in an accredited training program, dedicate one to two days a month to assess and manage most persons dealing with cognitive impairment within that practice (Lee *et al.*, 2010; Lee, Hillier, Molnar, & Borrie, 2017).

A task-sharing approach was used in the Kawartha Centre's Neurocognitive Assessment Program (2005–2010). On physician request, trained primary care office staff nurses performed a half-hour analysis of cognitive abilities using standardized tools and supported by a geriatrician-led training and mentoring team (J. Ingram, personal communication, September 18, 2018).

In Saskatchewan: Researchers are collaborating with rural primary health care teams to develop rural-specific strategies for operationalizing dementia best practices in team-based primary health care that are feasible and sustainable in rural settings (Rural Dementia Action Research, 2018). Primary health care teams (which may be made up of a family physician or nurse practitioner, an occupational therapist, a home care nurse, a social worker, a physical therapist and an Alzheimer Society of Saskatchewan First Link Coordinator) have developed and implemented a one-day interdisciplinary memory clinic for initial assessment and follow-up. They adapted visit flow sheets based on Canadian Consensus Guidelines (Seitz, 2012) to a team-based assessment with specific roles for each health care professional. These flow sheets are now embedded in the teams' EMR and accessible to all team members.

Timely and accurate assessments

The initial assessment for memory problems or dementia is recommended to be performed by the person's own primary care team with timely referral to consultants when appropriate (Moore, Frank, & Chambers, 2018; Bergman, Hogan, Patterson, Chertkow & Clarfield, 2003; Clarfield, 1991). This recommendation came from the first Canadian consensus conference in 1989 and has stood the test of time, not changing over the intervening twenty-nine years. Evidence suggests that assessment and follow-up by primary care physicians have similar outcomes to that provided by specialists (Alzheimer's Disease International, 2016b; Meeuwse *et al.*, 2012) and Canadian guidelines recommend that most dementia diagnoses be managed in primary care. Nonetheless, recent studies suggest that most individuals diagnosed with dementia in urban Canadian primary care practices are still referred to a specialist (Warrick, Prorok, & Seitz, 2018).

Standardized referral criteria and processes for specialist consultation have been suggested at previous Canadian Consensus Conferences (Paterson *et al.*, 1999), recognizing that it is important to make these services available in the community and in hospitals when and where needed, with equitable access in rural and remote areas (Bergman, 2009; Alberta Health, Continuing Care, 2017). For example, it is recommended that persons with young-onset dementia (i.e., prior to age 65) and those with rapidly progressing dementia (i.e., dementia that develops within 12 months of the appearance of the first cognitive symptoms) be assessed by specialty services (Gauthier *et al.*, 2012). Innovative approaches are being used to improve access to specialists. For example, in Saskatchewan, an urban-based interdisciplinary one-stop Rural and Remote Memory Clinic provides specialist diagnosis of complex, atypical dementias for individuals living in rural and remote areas of the province (Morgan *et al.*, 2009). Follow-up is provided via telehealth videoconferencing (Morgan *et al.*, 2011).

4.3.3 Evidence-informed care

Evidence-informed clinical dementia care requires current and comprehensive practice guidelines. Between 1989 and 2012, four Canadian Consensus Conferences have produced recommendations on the diagnosis and management of dementia. These recommendations have been used to create clinical practice guidelines (Bergman, *et al.*, 2003; British Columbia Medical Association, Guidelines and Protocols Advisory Committee, 2016; Toward Optimized Practice, 2017) and inform provincial dementia strategies, action plans and frameworks in Canada. Though the recommendations from the Consensus Conferences have evolved over time, the general approach recommended has not changed in a substantial manner.

An emerging clinical and ethical issue is the identification and disclosure of Alzheimer's disease risk based on biomarkers (Johnson & Karlawish, 2015). Though they are not currently recommended for routine clinical use in Canada (Gauthier *et al.*, 2012), it is anticipated that they may become a clinical tool in the coming years.

Behavioural and psychological symptoms of dementia

Behavioural and psychological symptoms of dementia are common among older adults with dementia. Non-pharmacological therapies are usually recommended, yet evidence on effective interventions is not yet widely available (Seitz *et al.*, 2012).

Offering assistance to persons with dementia and their caregivers in managing the behavioural and psychological symptoms of dementia is especially key during transitions, such as from home to hospital (Ray, Ingram, & Cohen-Mansfield, 2015). Intensive geriatric psychiatry case management and outreach programs have been associated with beneficial effects on caregiver stress, total caregiving time and reductions in risks associated with community living (Warrick *et al.*, 2018). A systematic review of psychiatric outreach services for older adults found a substantial evidence base for the effectiveness of home-based mental health treatment in improving psychiatric symptoms (Van Citters & Bartels, 2004).

Specialized geriatric psychiatry outreach teams employ some promising practices in collaborating with primary care and community agencies (Saskatchewan Health

Authority, 2018; Geriatric Psychiatry Community Services of Ottawa, 2011). This task-sharing approach is increasingly seen as a way to provide good quality care.

There are a limited number of large-scale, high-quality studies on managing behavioural and psychological symptoms of dementia in long-term care. The feasibility of some effective and sustainable interventions may be limited in these settings (Seitz *et al.*, 2012). An Ontario study found that while mobile teams provided expertise and shared best practices, an in-home behavioural support model was more effective (Grouchy, Cooper & Wong, 2017).

Concerns about the potentially inappropriate and therefore excessive use of antipsychotics in long-term care, and the associated adverse events, has prompted a number of initiatives to reduce the use of antipsychotics in long-term care homes. The results are promising. For example, early results of an initiative in New Brunswick showed inappropriate antipsychotic use cut almost in half, and among these residents, social engagement, wakefulness and the ability to self-manage care significantly improved without an increase in aggressive behaviours (Canadian Foundation for Healthcare Improvement, 2017). A project in Alberta successfully fostered a shift in health care providers' practices from treating behaviours to using person-centred approaches to manage the causes of the behaviours (Bueckert, 2014) alongside system-wide tracking of changes in medication use, behavioural and other symptom changes (Birney, Charland, Cole, & Arain, 2016).

4.3.4 Home- and community-based care

Most persons living with dementia prefer to continue to live at home, and their caregivers agree (Ogilvie & Eggleton, 2016). Remaining active and preserving their relationships with individuals and the community are critical sources of well-being and coping for persons living with dementia and for their caregivers (World Health Organization, 2015). A recent systematic review suggests that efforts to improve quality of life might focus on supporting relationships, social engagement and everyday functioning, as well as addressing poor physical and mental health and ensuring high-quality care (Martyr *et al.*, 2018).

For persons living with dementia, aging safely at home often requires that a caregiver be available to provide a significant amount of care, as well as to help manage community-based services (Cepoiu-Martin, *et al.*, 2016). This can be overwhelming. Care coordination, peer support and technology have been identified as potential supports for persons living with dementia and their caregivers.

Coordination of care and services

At some points—for example, following diagnosis and during transitions—some persons with dementia and their families require additional support for the coordination of care and services. Case management and care navigation are being used within primary care and other parts of the health system (e.g., acute care, home care) to facilitate person-centred, integrated health and social care (Khanassov & Vedel, 2016).

Case management⁷ has been shown to have a positive impact on care processes, patients, caregivers, use of services and costs (Challis, von Abendorff, Brown, Chesterman, & Hughes, 2002; Godard-Sebillotte, Le Berre, Schuster, Trottier, & Vedel, 2018; Khanassov, Vedel, & Pluye, 2014a,b; Reilly, 2015). Effective case management depends on having a small caseload, regular and proactive follow-up, and transparent communication among health care professionals (Khanassov *et al.*, 2014a,b). Case management can address caregiver needs (Khanassov & Vedel, 2016); some studies show that it contributes to positive outcomes for caregivers (Alzheimer's Disease International, 2016b).

Another approach successfully used by some provinces and regions to facilitate coordination is the integration of community services with primary care. The inclusion of a representative of the Alzheimer Society as a member of a primary care-based memory clinic team resulted in a fivefold increase in the number of referrals to the Alzheimer Society at the time of diagnosis (Lee, Hillier, & Harvey, 2014). This partnership was credited with improving care coordination and integration between primary and community care, and enhancing care provider awareness of available community services (Lee *et al.*, 2014).

Peer and community support

Older adults recently diagnosed with dementia and their caregivers report benefits from peer support (MacCourt *et al.*, 2011). The creation of dementia-friendly communities is an important aspect of creating and maintaining peer support (see Chapter 3). Organized groups also provide more formal approaches to peer support. Successful groups provide opportunities for participants to share feelings and to have these feelings validated by others who understand what they are going through, and provide information about the condition, how to cope with it, and the types of support and services that are available (MacCourt *et al.*, 2011).

Enabling technology

The amount and range of evidence-based technological interventions for dementia is small but growing thanks to the interest in using technology as a way to support independence longer and enable care and monitoring in the home (AGE-WELL, 2018a). While technology is not yet able to support older adults in activities of daily living, such as toileting, bathing and eating, and cannot soothe an agitated older adult, technology and engineering may help some families be more confident that the best care is care in the home (Callahan, 2017). The addendum to this report summarizes the main developments in technology research and product development in dementia and provides information about where to access some online resources for dementia (AGE-WELL, 2018a).

4.3.5 Long-term care homes

Dementia is associated with an increased likelihood of living in a long-term care home (Garner, Tanuseputro, Manuel & Sanmartin, 2018). About 42% of persons 80 and older who have been diagnosed with dementia live in residential care (Canadian Institute for Health Information, 2018a). Supporting individuals to remain at home as long as possible may delay, but not always prevent, placement in long-term care.

Because almost 70% of long-term care residents have dementia (Canadian Institute for Health Information, 2018a), standards are shifting, including toward a more

7 Case management provides follow-up, coordination individual care, liaison with other health care services and collaboration with other providers, in particular family physicians and specialists (Khanassov & Vedel, 2016).

person- and family-centred care approach (British Columbia Ministry of Health, 2016). To that end, a number of organizations and collaborative groups have conducted research to support culture change within long-term care homes, with the aim of spreading dementia-specific standards to all health-care settings (Dupuis, McAiney, Fortune, Ploeg, & de Wit, 2014; Carson, Dupuis, & Arai, 2017; Carson, 2015).

Studies clearly identify the variability in quality of care for persons with dementia, and have formed the basis for increased efforts to improve the quality of dementia care provided in long-term care homes in the last decade (Lourida *et al.*, 2017). The need for additional support and training for direct care providers⁸ is a key enabler and is addressed in Chapter 6. Other leading practices for persons with dementia in long-term care homes include the following three elements.

Dementia-friendly design

Attention to physical design may prevent persons with dementia from becoming more confused or agitated, help them be engaged in activities (Chatha & Wilkinson, 2012; Fleming & Purandare, 2010) and support a person- and family-oriented approach (Keefe *et al.*, 2015).

Minimizing transfers to acute care

Strategies used to decrease transfers to acute care settings to Emergency Department or for hospitalization include the integration of nurse practitioners within long-term care homes (Donald *et al.*, 2013; El-Masri, Omar, & Groh, 2015; McAiney *et al.*, 2008; Stolee & Hillier, 2002), the use of paramedics to deliver care in order to avoid transfer to emergency (Marshall, Clarke, Peddle, & Jensen, 2015), and the use of screening and tracking tools by long-term care staff (Canadian Foundation for Healthcare Improvement, 2014; Cummings *et al.*, 2012).

Improving quality of life through increased and meaningful activities

A strong component of improving residents' quality of life in long-term care is the inclusion of increased and meaningful activities. Often considered the founder of the culture change movement in long-term care, Dr. Bill Thomas, a Harvard-educated physician, is a strong advocate of transforming long-term care homes with the resident's needs at the centre (Baker 2007). In 1991, Thomas developed an approach to what he labeled as the three "plagues" of nursing homes: boredom, loneliness and helplessness (Chapin, 2010). When long-term care facilities integrate living elements, such as outdoor space and gardening and the presence of animals and children, residents have opportunities for meaningful engagement and activity (White-Chu, Graves, Godfrey, Bonner, & Sloane, 2009). In this approach, emphasis is placed on staff-to-resident relationships and providing opportunities to create meaning through activity and care.

4.3.6 Planning for future care

As with other chronic conditions, the goals of care are generally not to cure, but to enhance quality of life and physical, cognitive and social functionality, prevent secondary conditions, and minimize distressing symptoms (Grumbach, 2003). Arcand (2015) recognizes that having clear goals of care, a fully informed family and a common understanding are essential to avoiding possibly unwanted, futile or burdensome interventions, especially with advanced dementia.

Advance care planning in dementia

While there is considerable prognostic uncertainty, dementia shortens life, even after controlling for age and multimorbidity (Livingston *et al.*, 2017). As a result, a well-balanced care pathway for dementia would consider end-of-life care decisions at or soon after diagnosis to enable the greatest chance for the person with dementia to have a real input into these advance directives and decision-making. As British Columbia's Ministry of Health (2016, p. 9) writes:

8 Direct care providers are known by a variety of job titles: home health, hospice or health care aides, nursing assistants or aides, medication aides or technicians, and personal care or support workers. They provide most of the paid care in home and long-term care settings and are unregulated (see Chapter 6).

By planning early and continuously throughout the dementia journey, people with cognitive changes and their families can communicate wishes for their finances, health care and end-of-life care before the decision-making ability is lost.

There often (though not always) comes a point where the person living with dementia loses their ability to make personal decisions. Advance directives provide instructions and identify who can make decisions for the person if they cannot speak for themselves. A recent study found that about two-thirds of Canadians aged 50 and over had thought about what kind of medical treatments they would want if they should become ill. Close to a third had written down their wishes, and half had named someone to be their substitute decision-maker (Howard *et al.*, 2018). How often these discussions occur in the setting of dementia is unknown, but best practice indicates that they should take place on an ongoing basis while the person still retains decision-making capacity, beginning well before the later stages of the illness (Tam-Tham *et al.*, 2016).

Communicating with families

Understanding the family's perspective might help minimize conflicts between the family members and the health care team. According to Arcand (2015), the factors that influence family members' preferences for goals of care are:

- Quality of life;
- The invasiveness of the treatment or investigation proposed;
- Advance directives;
- Cultural and family context;
- Trust or distrust of the health care team.

Various resource materials can inform and support families of persons with dementia, including a booklet developed by Canadian researchers which the World Health Organization recognized as an example of good practice in the field of geriatric palliative care (Arcand & Caron, 2005; Arcand, 2015).

End-of-life care

The *Way Forward National Framework* is built on successful initiatives and identified best practices for quality end-of-life care (Canadian Hospice Palliative Care Association, 2015). It calls for a system-wide shift in practice culture that recognizes that dying is part of living.

There is growing consensus that end-of-life care should be guided by personalized goals of care, rather than attempting to estimate life expectancy and setting criteria for when a person should be able to access palliative care services (Arcand, 2015; Canadian Hospice Palliative Care Association, 2015; Livingston *et al.*, 2017). Withholding or withdrawing life-prolonging treatment does not mean abandoning the person with dementia, but rather signals a shift in focus to active symptom management (Arcand, 2015). For example, this may include refraining from prescribing life-prolonging medications (e.g., prescribing antibiotics for pneumonia) and instead focusing on relieving pain and other distressing symptoms. Persons with dementia might be less able to communicate their needs, so careful assessment and management of pain and other symptoms is paramount to providing good end-of-life care (Livingston *et al.*, 2017).

4.4 KEY FINDINGS

- a) Despite improvements, many persons living with dementia and their caregivers are still experiencing limited access to dementia assessment and services, fragmented care, and inappropriate end-of-life care.
- b) Most persons with dementia have other chronic conditions and require a complex combination of social and health care. A person- and family-centred approach, rather than a disease-centred approach, is essential to providing good care. Relationship-centred care extends this partnership to include health and social care providers and the influences they have on each other.

- c) An integrated care approach positions primary health care to provide more timely diagnosis, earlier access to treatments, improved coordination of care and earlier support for caregivers, which may increase quality of life, reduce caregiver burden, and delay long-term care placement.
- d) Within Canada, there are examples of well-supported primary health care. Various approaches to providing comprehensive and coordinated dementia diagnosis, treatment and care are being implemented. Evidence-informed care requires regular updating of clinical practice guidelines and pathways.
- e) As a person's care needs increase and become more complex, they need a widening web of community-based supports. Technology may play a promising role in supporting individuals to remain at home as long as possible.
- f) The current quantity and quality of long-term care homes may not be adequate to meet the future needs of persons living with dementia, even with increased community-based supports. Incorporating a dementia-friendly approach, including design and meaningful activities, will improve the quality of life of all residents.
- g) Having clear goals of care, advance planning, a fully informed family and a common understanding are essential to having a dignified and respectful death and avoiding possible unwanted, futile or burdensome interventions.

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CHAPTER 5

Education and support for caregivers

The CAHS Expert Panel was charged with examining the evidence and best practices for “care aimed at minimizing familial impacts” (see section 1.3.1). Difficulty obtaining timely access to needed health and social care is often a great source of stress for families, especially when caregiving, so addressing the challenges and adopting the emerging best practices in the previous chapter is essential to minimizing familial impacts. This chapter builds on Chapter 4 and recognizes that caregivers’ needs both overlap with and stand independently of the care needs of the person living with dementia.

5.1 CHALLENGES

About 28% of Canadians, in 2012, provided care to a family member, friend or neighbour who was aged, chronically ill or disabled. Ten percent of these caregivers provided 30 or more hours per week of care (Sinha, 2013). Alzheimer’s disease and related dementias are among the top five health conditions where caregivers reported spending at least 10 hours on care per week.

Most older adults with dementia have a caregiver, primarily an adult child or spouse (Canadian Institute for Health Information, 2018b). Projections, however, suggest that the supply of caregivers will decrease in the future, as the baby boomer cohort tended to have fewer children than earlier generations (Keefe, Légaré, & Carrière, 2007).

In 70% of dementia cases, women, most of them elderly, act as caregivers (Canadian Study of Health and Aging Working Group, 2002). Because most caregivers are women, caregiving is a gender issue. Other gender issues, such as the gap in wages between women and men, further exacerbate the short- and long-term economic consequences of caregiving.

Caregivers of persons with dementia often live through the full progression of the condition from mild cognitive impairment to advanced dementia and end of life (see Chapter 4, Figure 2). The needs of caregivers vary significantly by type of dementia, stage of condition

and situation, and these needs may go unidentified (Keefe, Guberman, Fancey, & Barylak, 2014). While there are positive aspects to caregiving (Lloyd, Patterson, & Muers, 2016; Yu, Cheng, Wang, 2018), the caregiver may experience challenges related to their increasing responsibilities for the person living with dementia, or to their own health, employment and finances. Compared to caregivers for people with other conditions, dementia caregivers are more likely to report negative effects on employment, and to experience stress and burden, leading to higher use of services (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999).

5.1.1 Living with a person who is living with dementia

According to the BC Ministry of Health, “living well with dementia applies not only to persons with dementia but also to their caregivers” (2016, p. 11). Caregivers typically provide an increasing amount of support as cognitive impairment progresses (Prizer & Zimmerman, 2018). As functional capacity declines and in some cases behavioural and psychological symptoms increase, the need for targeted support to caregivers increases. For many caregivers, increasing responsibilities lead to increased stress and negative physical and mental health outcomes (Alzheimer’s Association, 2017; Sallim, Sayampanathan, Cutilan, & Chun-Man, 2015). These caregivers may also experience anticipatory grief as the care recipient declines both cognitively and physically and the relationship between them changes (Holley & Mast, 2009). Moreover, social isolation because of caregiving responsibilities may lead to social consequences, loneliness and mental health consequences.

5.1.2 Health consequences of caregiving

While caregiving is not always a negative experience (Peacock *et al.*, 2010), the personal health impacts of caregiving have been well documented, and include both physical and mental health consequences (Schulz & Sherwood, 2008). For dementia caregivers, compared to

caregivers for persons with other illnesses, the experience of negative health consequences may be even greater. Spousal dementia caregivers are more likely than non-dementia spousal caregivers to experience frailty when caring for their spouse at end of life (Dassel & Carr, 2016). They have also been found to have significantly higher health costs compared to spouses of non-dementia patients (Gilden et al, 2014). Dementia caregivers are at risk for depression (Covinsky et al 2003), which may be related to the behaviours of the care recipient or to the caregiving tasks (O'Rourke & Tuokko, 2000).

5.1.3 Timely access to health and social care

As described in Chapter 4, challenges may arise in accessing adequate and timely care and support at every stage of the condition. Once the progression of dementia has developed to the extent that the person living with dementia needs additional care, caregivers often need to organize these services (Cepoiu-Martin *et al.*, 2016). Home care users living with dementia typically live with a caregiver (77%); their caregivers also provide an average of 26 hours of care each week in addition to that provided by home care services (Canadian Institute for Health Information, 2018d).

As described previously (see Chapter 2, section 2.1.2), the caregiver, health professionals and person with dementia may have different perspectives on whether needs of the person with dementia are being met (Miller *et al.*, 2016; Miranda-Castillo *et al.*, 2013). This can be a source of stress when accessing health and social care.

5.1.4 Financial implications

Caregivers may be unprepared for the financial challenges associated with dementia (Arai, Arai, & Zarit, 2008). They can experience significant out-of-pocket costs for the goods and services required to meet the needs of their care recipient, including costs for home modifications, help with daily activities, recreation, transportation, travel or accommodation expenses related to caregiving

responsibilities, specialized aids or devices, and medications (Keating, Lero, Fast, Lucas, & Eales, 2013; Turcotte, 2013; Turcotte & Sawaya, 2015). Chambers *et al.* (2016) reported that out-of-pocket costs for caregivers caring for persons with dementia alone were \$1.4 billion in 2016. A survey of 163 Canadian caregivers who are part of the baby boomer generation reported that 10% spent more than \$100 a month in caring for a family member (Black *et al.*, 2010). These situations translate into significant financial challenges. A 2012 Statistics Canada survey of all caregivers reported that 20% of spousal caregivers and 7% of adult child caregivers reported financial hardship because of their caregiving responsibilities (Turcotte, 2013).

In addition to out-of-pocket expenses, caregiving can result in lost income or employment consequences (Duxbury & Higgins, 2012; Sinha, 2013; Turcotte, 2013). Approximately 60% of Canadian caregivers are employed (Sinha, 2013). These caregivers may have to reduce hours of work, adjust their work schedule to accommodate their caregiving responsibilities (Sinha, 2013) or leave the workforce entirely (Alberta Health, Continuing Care, 2017; Keating *et al.*, 2013; Longacre, Valdmanis, Handorf, & Fang, 2017; Turcotte, 2013). Balancing work and care provision may be particularly challenging for caregivers of persons with young-onset dementia, as these caregivers tend to be younger, provide more hours of care compared to caregivers of older adults with dementia and have a greater financial need to remain part of the labour force (Canadian Institute for Health Information, 2018d) The impact may occur in the short term as lost or reduced income and in the long term as reduced pension and retirement income (Keating *et al.*, 2013).

Tax policy modifications currently only benefit caregivers who have a taxable income, and these benefits can be difficult to access. According to a recent policy brief (Dunn & Zwicker, 2018), use of the federal Disability Tax Credit is low in Canada, especially amongst older adults. Lack of awareness, perceptions that the tax credit may be of little benefit, out-dated eligibility criteria and a complex application process were identified as key barriers to accessing this benefit.

5.2 PUBLIC POLICY RESPONSES

All Canadian provincial dementia strategies highlight the need to support caregivers, most often through home support, home care, respite, case management and other community supports. Less frequently mentioned in dementia strategies are supports that address the financial implications for caregivers. However, one strategy does recognize that “providing supports that address the financial issues caregivers experience can reduce stress, improve mental and physical health and enable caregivers to continue providing care and support for a longer period of time” (Alberta Health, Continuing Care, 2017, p. 16).

Though they are not specific to caregivers for persons with dementia, the federal government has introduced some income security initiatives, for example the Canada Caregiver Credit and the Compassionate Care Benefit, that recognize caregivers’ important contributions and help compensate for some of the costs associated with caregiving (Canada Revenue Agency, 2018). Some provinces are moving towards direct funding of persons with dementia or their caregivers (i.e., cash transfers), similar to funding programs for people with disabilities. This allows the caregiver to hire people and arrange for services directly. Other provinces have targeted direct payment to the caregivers of eligible home care clients. For example, the Manitoba Primary Caregiver Tax Credit provides a refundable credit (Manitoba Tax Assistance Office, n.d.) while the Nova Scotia Caregiver Benefit supports caregivers of high-need, low-income adults. Nova Scotia’s supportive care program provides financial support to persons with cognitive impairment who have been assessed for home care (Nova Scotia Department of Health and Wellness, n.d.). This type of program indirectly benefits caregivers by supporting the care receiver.

Internationally, some policies exist to support caregivers. For example, certain caregivers in the UK may be eligible for the Carers Allowance, which provides direct funding to low-income caregivers (Yeandle & Buckner, 2017). Other supportive policies in OECD (Organisation for Economic Co-operation and Development) countries include leave for working caregivers, although these vary in duration and may be unpaid (Colombo, Ana, Jérôme, & Tjadens, 2011; Yang & Gimm, 2013). In the UK, “right to request” legislation grants working caregivers the right to request

flexible work arrangements (Yeandle & Buckner, 2017). Canadian legislation pertaining to federally regulated workers was recently enacted to allow any employees (not limited to caregivers) to request flexible work arrangements (Bill C-63, 2017).

5.3 CURRENT EVIDENCE AND EMERGING BEST PRACTICES

While the important contributions of caregivers are widely recognized, their overlapping but separate needs are less well understood. A growing body of literature points to five broad areas:

- Maintenance of physical and psychological health
- Empowerment through knowledge and skills
- Support for work/life balance
- Financial support
- Access to timely and appropriate health and social care

Endeavours to address caregiver needs must take a comprehensive, coherent approach. Interventions with several components (specifically education, training, support and respite) are considered effective and should be made available early (Alzheimer’s Disease International, 2013). Recent research suggests a paradigm shift from reducing stress to optimizing positive experience in developing caregiving support services for dementia (Yu *et al.*, 2018). Some of the interventions with evidence for beneficial outcomes are highlighted below.

5.3.1 Maintenance of physical and psychological health

Respite care is the most common form of support offered to caregivers. It includes in-home respite, which enables the caregiver to leave for a number of hours to go to work or attend to personal matters, adult day programs where the care recipient can participate in activities, and overnight respite where the care recipient is admitted to a long-term care home or other residence for a specific number of days per year allowing the caregiver time to address their psychosocial needs (Colombo *et al.*, 2011). However, timely and flexible services are not always available (Khanassov & Vedel, 2016).

Other supports and services are also needed to address the physical and psychological health of caregivers and prevent burnout (Lilly, Robinson, Holtzman, & Bottorff, 2012). This includes the need for self-care through social engagement and support as well as time for sleep and leisure activities (Waligora, Bahouth, & Han, 2018). The U.K.'s recently updated National Institute for Health and Care Excellence (NICE) guidelines include a recommendation that psychoeducation and skills training interventions be offered to caregivers, including advice on how to look after their own physical and mental health and their emotional and spiritual wellbeing (Pink *et al.*, 2018).

Caregivers are a diverse group of women and men of different ages and with different capacities, availabilities and relationships. Best practices include assessing the needs of the caregiver in addition to the person living with dementia (Health Quality Ontario, 2017). Caregiver assessments are key to more efficiently and appropriately targeting interventions and supports (Keefe *et al.*, 2014; Pink *et al.*, 2018). Case management can be used as a means to support, assess and reassess caregivers' needs (Whitlatch & Orsulic-Jeras, 2018). Interventions are best targeted to these areas in a proactive manner and not only offered when there is a high level of stress.

5.3.2 Empowerment through knowledge and skills

Empowering caregivers with the knowledge and skills to support a person with dementia is important in alleviating stress. Caregivers of persons living with dementia desire access to services and supports that are congruent with the changing needs of the person for whom they are caring (Prorok, Horgan, & Seitz, 2013). They have stressed the importance of support early after the diagnosis is made to help both the caregiver and person with dementia accept change, adjust expectations and obtain social supports (Millenaar *et al.*, 2017). Caregivers often need support in addressing challenges related to care recipient behaviour, planning, decision-making and grief (Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 2013), as well as support and information about transitioning into long-term care (Afram *et al.*, 2015).

Best practices exist in Canada for empowering, educating and supporting caregivers:

- The Alzheimer Society of Canada (2018) provides web-based resources to support caregivers through the full progression of the condition, including information tailored to young and long-distance caregivers, fact sheets on the disease, and information on self-care.
- Provincial and territorial Alzheimer Societies offer programs and services to support caregivers, including in-person caregiver support groups and tele-support groups (Alzheimer Society of British Columbia, 2018a) and tele-workshops (The Alzheimer Society of British Columbia, 2018b) in some locations.
- In many provinces, another Alzheimer Society program called First Link is available and has shown promising results in increasing access to information and supports at the time of diagnosis (Alzheimer Society of Ontario, 2017). An evaluation of the program resulted in program recipients (newly diagnosed persons with dementia and their caregivers) receiving services 11 months earlier compared to clients who accessed the services themselves (i.e., self-directed referrals) (McAiney, Hillier, Stolee, Harvey, & Michael, 2012).
- There are caregiver associations and networks at national and provincial levels that provide information, support and advocacy for caregivers (Carers Canada, n.d.; L'Appui, n.d.), as well as platforms for connecting and sharing (Caregiver Network, 2017).
- Other support services, such as the Reitman Centre CARERS Program in Ontario, give caregivers practical skills and emotional support to deal with the complexities of caregiving. The outcomes of this approach include improvements in caregiver competence, ability to cope with stress and mental well-being (Chiu, Pauley, Wesson, Pushpakumar, & Sadavoy, 2015; Chiu, Wesson, & Sadavoy, 2013).
- Also, an increasing number of online resources are available for caregivers about dementia that provide management strategies and the ability to track their care recipient symptoms over time (AGE-WELL, 2018a).

5.3.3 Support for work-life balance

Workplace policies tend not to be specific to caregivers of persons with dementia. Employers report that they support their staff providing care on a case-by-case basis, often using flexible hours and technology (Government of Canada, 2015). Other approaches include implementing caregiver-friendly workplace policies (Ramesh, Ireson, & Williams, 2017), education or training for supervisors so that they understand the needs of caregivers, flexible work arrangements (e.g. telecommuting and condensed work weeks), and strategic communications that normalize caregiving (Holzapfel, Adelson, & McUlisky, 2015).

Caregiver employees have often been found to be unaware of the supports available to them in the workplace or have not felt comfortable pursuing accommodation due to stigma (Ireson, Sethi, & Williams, 2016). However, once caregivers perceive that employers support them in their care role, they are less likely to quit or look for other work (Greaves Parker, Zacher, & Jimmieson 2015). Ireson *et al.* (2016) caution that rigid policies may exclude caregivers in various situations from needed supports; they suggest a collaborative approach to identifying unique solutions on a case-by-case basis with supports available early on to prevent undue caregiver stress.

5.3.4 Financial support

Avenues to financially support caregivers include direct payments (i.e., cash transfers) and tax policy. Direct payments recognize the significant contributions caregivers make and may allow them to provide care for a longer time (Alzheimer's Disease International, 2013). Evaluations of these direct payment programs and tax policies have not been published and therefore their capacity to support caregivers is unknown. However, caregivers need a simplified approach to accessing eligible benefits (Dunn & Zwicker, 2018).

5.3.5 Access to timely and appropriate health and social care

For the wellbeing of both caregivers and persons living with dementia, it is essential for them to have access to timely and appropriate health and social care for the person living with dementia, as well as supports for navigating what are often fragmented services. Please refer to Chapter 4 for current evidence and emerging best practices.

5.4 KEY FINDINGS

- a) Caregivers want to provide care and they derive positive benefits from their role. Caregivers experience challenges related to their increasing responsibilities for the person living with dementia, which impacts their own health, employment and finances.
- b) It is critical that caregivers be supported in their caring roles. Certain interventions (i.e., education, training, counselling, supportive workplace) may help preserve their quality of life and resiliency and may help sustain or increase their availability as caregivers.
- c) The needs of caregivers vary over time. Ongoing needs assessment is essential to understanding how to support caregivers.
- d) The economic and health consequences of providing care are exacerbated by gender-based expectations. Any policy or program to support caregivers must include a gender-based analysis to assess the intended and unintended consequences for women.
- e) Alzheimer Societies and caregiver associations in Canada play an essential role in empowering, educating and supporting caregivers.

- f) Timely access to needed health and social care for the person living with dementia has a significant impact on caregiving and on the caregiver.
- g) No one policy or practice for providing financial support is a panacea for caregivers. Caregivers are a diverse group and require a flexible range of services and supports applicable to a diverse population.
- h) In-home or in-facility respite is the most common support offered to caregivers through home care programs. However, such services for caregivers can only be accessed if the person living with dementia is a client. Greater efforts must be made to improve access to these programs.
- i) Workplace policies with supportive cultures need to be developed and expanded along with commitment from supervisors and managers to enable caregivers of persons living with dementia to continue to be employed.

CHAPTER 6

Building and supporting the health and social care workforce

The CAHS Expert Panel was charged with examining the evidence on “developing and disseminating information to health care professionals and the general public on the importance of prevention and management of, and early intervention in, dementia.” Chapter 3 addresses this charge with a focus on the general public, recognizing that additional targeted approaches are necessary for health professionals. In reviewing the evidence and emerging best practices on what health professionals need, we noted critically important and related issues. As a result, this chapter provides a broad examination of the evidence on the dementia workforce, which is consistent with the Senate report (Ogilvie & Eggleton, 2016) and with the InterAcademy Partnership for Health’s recent international call for action: “A well trained and supported workforce of the right mix and number to deal with the needs of this emerging population is required” (2018, p. 4).

Defining the dementia workforce

While the previous chapter focused on caregivers, this chapter focuses on those who are paid to provide health and social care. The workforce that supports persons with dementia and their caregivers extends beyond health and social care providers and includes members of the community who may support persons living with dementia and their caregivers, such as service industry workers, bankers, taxi drivers, hairdressers and others (Alberta Health, Continuing Care, 2017; InterAcademy Partnership for Health, 2018). However, the focus of this chapter is on health care professionals and direct care providers.

Health care professionals involved in the complex health and social care of persons living with dementia include nurses, nurse practitioners, physicians, specialists (geriatricians, neurologists, geriatric psychiatrists), social workers, psychologists, pharmacists, dietitians, occupational therapists, physiotherapists, recreation and

music therapists and others. All health professionals have training from accredited university programs and most are governed by provincial legislation that empowers regulatory bodies (i.e. colleges) to establish standards for training, as well as certification and continuing professional development.

Direct care providers represent the vast majority of the dementia workforce, providing most of the paid home-based care and more than 80% of care in long-term care homes (Chamberlain *et al.*, 2018b). They are known by a variety of job titles: home health or hospice or health care aides, nursing assistants or aides, medication aides or technicians, and personal care or support workers. These direct care providers are unregulated, meaning there is no independent accountability, nor are there recognized training and education standards (Chamberlain *et al.*, 2018b).

6.1 CHALLENGES

There is tremendous dedication within the dementia workforce, despite significant challenges. Health and social care providers are frequently managing complex situations in stressful conditions and environments. Their workplace conditions and environment impact their own health as well as the quality of care they are able to provide (Chamberlain *et al.*, 2018b; Hoben *et al.*, 2017). For example, research has suggested a relationship between dementia care and burnout (Duffy, Oyebode, & Allen, 2009). A five-year longitudinal study of direct care providers in Western Canada found no improvements in scores—and in some cases, worsening scores—on work life, health, burnout and job satisfaction (Chamberlain *et al.*, 2018b). Another study of Canadian health care providers found that registered nurses working in long-term care homes were at higher risk for poorer mental health than the general Canadian population (Hoben *et al.*, 2017).

6.1.1 Undervaluing of the workforce and the work

The dementia workforce is predominantly made up of women, in a greater proportion than the health care workforce overall (Alzheimer's Disease International, 2015a). Most direct care providers speak English as a second language (60%), with significant regional differences, according to a recent study of long-term care homes in Western Canada (Chamberlain *et al.*, 2018b).

Direct care providers are often not respected for the physically and emotionally taxing work they do and are not usually included in care decisions (Global Coalition on Aging, 2018). The devaluing of the role of personal support provision has been cited as one of the contributing factors to the wage disparity between home care and facility-based care (Keefe, Knight, Martin-Matthews, & Légaré, 2011). Despite the increasing complexity of care in long-term care homes, a recent study found that registered nurses and allied health care providers in pediatric hospitals tended to be younger, better educated and more experienced than their counterparts in long-term care homes (Hoben *et al.*, 2017).

6.1.2 Barriers in the working environment

The working environment is influenced by organizational factors such as staffing levels, workload, compensation and benefits, leadership, training opportunities, work climate and communication with management (Banaszak-Holl, Castle, Lin, Shrivastwa, & Spreitzer, 2015; Lourida *et al.*, 2017). These organizational factors have been repeatedly identified as a significant barrier to health care providers being able to implement their knowledge into practice (Clarke *et al.*, 2014; Lee, Hillier & Weston, 2014; Spector, Revolta, & Orrel, 2016; Lourida *et al.*, 2017). For example, lack of time and staffing were predictors of lower use of best practices (Estabrooks *et al.*, 2015). Also, while strong evidence is still lacking about which factors cause burnout, key predictors of burnout in direct care providers have been related to the work environment such as time, staffing, space, managing responsive behaviours, unit

culture and structural resources (Chamberlain *et al.*, 2018b), as well as self-efficacy (Duffy *et al.*, 2009). A poor working environment has been shown to affect turnover rates amongst direct care providers (Banaszak-Holl, *et al.*, 2015) and regulated nurses (Chu, Wodchis, McGilton, 2014).

Direct care providers

Direct care providers in long-term care homes often have challenging working conditions, with frequent exposure to responsive behaviours, high workloads, high acuity of residents and little time to perform tasks (Estabrooks *et al.*, 2015). Those working in home care may have safety concerns when working in isolation in private dwellings. Compensation and benefits may not reflect the required skills and responsibilities (Global Coalition on Aging, 2018).

Health and social care professionals

Health and social care professionals also experience a variety of organizational barriers that impact quality of care directly and indirectly. As the first point of contact with the health system for many persons living with dementia (Moore *et al.*, 2018), most Canadian primary care doctors (86%) provide medical care for persons living with dementia (Canadian Institute for Health Information, 2018b); however, some do not feel prepared to manage this care (Boise *et al.*, 2010; Canadian Institute for Health Information, 2018b). Barriers to providing evidence-based care include limited access to and communication with specialists (particularly in rural and remote areas), lack of connection with community-based resources, time constraints, difficulties in coordinating care, inadequate reimbursement and lack of access to interdisciplinary teams (Petrazzuoli *et al.*, 2017; Pimlott *et al.*, 2009; Ploeg *et al.*, 2016; Ploeg *et al.*, 2017; Yaffe, Orzeck, & Barylak, 2009). In long-term care, workload and level of authority have been identified as influencing registered nurses' capacity to effectively fulfill their supervisory responsibilities, which in turn affects residents' experiences and the quality of care they receive from direct care providers (Chu *et al.*, 2016).

6.1.3 Inadequate dementia education and training

International evidence shows that the proportion of health and social care providers receiving training in dementia care is low and that the training provided is of variable quality, even within settings where most clients have dementia (i.e., in long-term care homes) (World Health Organization & Alzheimer's Disease International, 2012). Of great concern are the limited standards for direct care providers and the variable training offered for them across provinces (Estabrooks, *et al.*, 2015).

While efforts have been made in recent years to improve education about dementia for health and social care providers in Canadian university programs, gaps persist in practice-based training for health care professionals. For example, health and social care providers in rural and remote areas lack educational opportunities (Morgan, Innes, & Kosteniuk, 2011).

Efforts to promote evidence-based practices and improve the quality of dementia care are dominated by educational approaches that train professionals through meetings, in-services and the distribution of educational materials (Lourida *et al.*, 2017). Used in isolation, however, these traditional passive didactic approaches appear to have little, no, or undetermined impact on changing practices, improving outcomes (Nova Scotia Health Research Foundation, 2014), or increasing knowledge of and confidence in dementia management (Aminzadeh *et al.*, 2012; Burgio *et al.*, 2001; Gifford *et al.*, 1999).

6.1.4 Insufficient supply of health and social care providers

Dementia workforce planning needs to take into consideration many variables. Projecting future needs is especially complex, given the limited data on the majority of the workforce (e.g., the number of direct care providers) and the time lag involved in training the needed health and social care providers.

The literature and existing dementia strategies note the limited supply of specialists (i.e., geriatricians and geriatric psychiatrists) and direct care providers as particular concerns (Alzheimer's Disease International, 2015b; Hogan *et al.*, 2012; Global Coalition on Aging, 2018). A review of dementia services in rural and remote settings

identified a shortage of skilled staff (Morgan *et al.*, 2011). Some provinces have seen some growth in the number of geriatricians and geriatric psychiatrists over the past six years (Hogan *et al.*, 2012; Canadian Medical Association, 2018); however, this continues to be a challenge in some regions, particularly in rural and remote areas (Morgan, 2018). The demand for direct care providers is especially anticipated to increase, as the number of caregivers may not be sufficient to meet the increasing number of older adults in need of care (Redfoot, Feinberg, & Houser, 2013). Almost 30 percent of direct care providers already work at two or more long-term care homes, according to a study of long-term care homes in Western Canada (Chamberlain *et al.*, 2018b).

Effective health human resource planning for dementia is difficult in Canada without an understanding of the qualifications and number of direct care providers in all provincial jurisdictions (Estabrooks *et al.*, 2015). National data to inform evidence-based planning of health human resources relies on submissions by national professional societies and associations, provincial and territorial regulatory bodies and governments, and educational institutions (Canadian Institute for Health Information, n.d.). In Canada and in other Organisation for Economic Co-operation and Development (OECD) countries, there is no regulatory or other body monitoring or following the labour supply for the direct care workforce, though four provinces are developing mostly voluntary registries of direct care providers (Chamberlain *et al.*, 2018b; Estabrooks, *et al.*, 2015).

6.2 PUBLIC POLICY RESPONSES

All provincial and most international strategies recognize the need to support and strengthen the workforce in response to the projected increase in the number of persons with dementia (Edick *et al.*, 2016; Guillette *et al.*, 2018; Chow *et al.*, 2018). Canada's first provincial dementia strategy was accompanied by a significant annual investment in annual training for direct care providers as well as physician training (Government of Ontario, 1999). At the same time, the Ontario provincial government introduced nurse practitioners into long-term care settings; an evaluation of this practice model found a reduction in hospital admissions and improved staff confidence (McAiney *et al.*, 2008).

Current strategies often include a call for providing targeted education and training coupled with an expansion of the workforce (Chow *et al.*, 2018; Robertson, 2017). Provincial governments are working on understanding the supply and demand of their health and social care workforce to ensure it will be adequate in numbers, training and support in order to provide the care that persons living with dementia will require (Alberta Health, Continuing Care, 2017). The Senate Report on Dementia in Canada (Ogilvie & Eggleton, 2016) recognized the need for a collaborative approach (government, regulatory bodies and educational institutions) to address health human resource capacity, training and education.

6.3 CURRENT EVIDENCE AND EMERGING BEST PRACTICES

Persons living with dementia and their caregivers require both quality care and help with quality of life from a workforce of well-trained and supported health and social care providers.

6.3.1 Valuing the workforce

A relationship-centred care approach recognizes that quality care happens when there are strong reciprocal and interdependent relationships among everyone involved in care, including the person receiving care, their family members and staff (Partnerships for Dementia Care Alliance, n.d.; Soklaridis *et al.*, 2016). Relationship-centred programs and policies have the potential to foster positive dementia care experiences among diverse care partners in community settings, including feeling appreciated (de Witt & Fortune, 2017).

The Global Coalition on Aging (2018) suggests there is a need to change perceptions, to increase awareness of the value of direct care providers. Such efforts would emphasize how direct care provision can be a personally and financially rewarding career and can be the first step toward careers in nursing, geriatrics, other medical fields, social services and business. Engaging direct care providers in decision-making regarding the residents for whom they provide care may better demonstrate a valuing

of their role. For example, Maslow and Fortinsky (2018) suggest that within their scope of practice and training, direct care providers may help to increase the detection of cognitive impairment and encourage older adults with cognitive impairment to obtain a diagnostic evaluation to determine the cause of the condition. A pragmatic clinical trial is underway in Western Canada to assess the impact of coaching and of enabled and empowered teams led by direct care providers to improve care for residents, enhance their ways of working and make their work life better (Cranley *et al.*, 2018). This randomized trial builds on a best practice pilot project in Alberta and BC where half of the teams saw measureable improvements in clinical outcomes as a result of the intervention (Norton, Cranley, Cummings & Estabrooks, 2013).

6.3.2 Supportive work environment

The organizational factors described in section 6.1.2 can foster a supportive work environment. Work environments that improve the physical and mental health of health and social care providers are needed to improve quality of care (Hoben *et al.*, 2017). For example, having effective nurse supervisors and supervisory support fosters improved work environments and the staff's ability to respond to residents' needs in a timely, effective and compassionate manner (Chu *et al.*, 2016; Escrig-Pinol, Corazzini, Blodgett, Chu, & McGilton, 2018).

In the US, the principles outlined in the document *Alzheimer's Association's Long-Term Care Workforce Issues: Principles for Advocacy to Assure Quality Dementia Care Across Settings* (Alzheimer's Association, 2017) have been suggested as best practices supporting the dementia care workforce in long-term care settings (Gilster, Boltz, & Dalessandro, 2018). These principles include recommended staffing levels, sufficient staff training, adequate compensation, supportive work environments, career growth and retention, appropriate licensure and certification, and engagement with family (Alzheimer's Association, 2017). In addition, person-centred care information, interdepartmental communication and teamwork, and ongoing evaluation have been suggested as best practices (Gilster *et al.*, 2018).

Task-sharing approach to care

A task-sharing approach may be part of creating a supportive work environment and has been proposed as the future direction for dementia assessment and management. With this approach, specialists and on-site peers that have developed additional expertise manage dementia care for only the most complex cases, and otherwise focus on training, education and support to build the skills and confidence of other health and social care providers (Alzheimer's Disease International, 2015b).

As described in Chapter 4, a task-sharing approach has been embedded within some primary care clinics in Canada (Lee, *et al.*, 2014). A task-sharing approach in this context should lead to more communication between primary care providers and specialists, fewer but more appropriate referrals from primary care providers, and more timely access to specialists when really needed (Massoud, Lysy, & Bergman, 2010; Lee *et al.*, 2017).

Some provinces and regions have created rapid support mechanisms for family physicians and primary care teams to consult with specialists as they are doing their assessment or ongoing care management. The e-Consult Quebec and the Rapid Access to Consultative Expertise (RACE) telephone service in BC, for example, provide the opportunity for knowledge transfer, further building capacity within primary care.

Task-sharing may also have some application in long-term care homes. A practice model that included access to nurse practitioners in long-term care homes was found to have a positive impact on staff confidence in recognizing and identifying signs and symptoms of potential problems and being able to provide care (McAiney *et al.*, 2008).

6.3.3 Dementia education and training

Given the growing numbers of persons living with dementia and the complexity of their care, there have been calls for specialized education on dementia to be included in the curricula of most health and social care provider programs, especially as roles are evolving. For example, nurses are the largest group of health care providers in Canada and will likely be responsible for a large part of formalized dementia care across all sectors

(Canadian Nurses Association, 2016). Paramedics are increasingly being asked to meet the non-emergency care needs of an aging population (Grosvenor, Hebditch, Daley, Vyvyan, & Banerjee, 2017). There have also been calls for increased standardization in the training of direct care providers (Estabrooks, *et al.*, 2015; Global Coalition on Aging, 2018).

Education and training must go beyond the treatment of dementia as a disease. They need to emphasize that dementia is a chronic, complex condition that can benefit from timely diagnosis, long-term support and management in the context of the person's other conditions (Sivananthan, Puyat, McGrail, 2013; World Health Organization & Alzheimer's Disease International, 2012). Further, training must focus on helping providers at all levels implement person-centred interventions and approaches to enhance the wellbeing and quality of life of persons with dementia at all stages (Jing, Willis & Feng, 2016; Pickett *et al.*, 2018).

Cultural and gender-neutral competency training promote respectful and responsive care (Badger and Koehn, 2018; Jacklin, 2018; LeBerre, 2018). In addition, community-based practice is a competency requiring education and training (Canadian Nurses Association, 2016; Health Quality Ontario, 2017; Morgan, *et al.*, 2016; Nasmith *et al.*, 2010; World Health Organization & Alzheimer's Disease International, 2012).

The World Alzheimer Report 2013 recommended that health and social care professionals be trained to provide person-centred care (Alzheimer's Disease International, 2013). American evidence-based practice recommendations (Fazio, Pace, Flinner & Kallmyer, 2018) and Canadian guidelines for person-centred care of persons living with dementia are available (Alzheimer Society of Canada, 2011). Relationship-centred care approaches are also increasingly being woven into education and training (de Witt & Fortune, 2017; Nolan *et al.*, 2008; Soklaridis *et al.*, 2016).

Novel approaches are starting to emerge within the undergraduate education of health professionals. For example, the Time for Dementia program, which can be delivered to all health care professionals, provides longitudinal and meaningful contact with persons living with dementia and their families (Banerjee *et al.*, 2016).

Evidence-based education and training approaches

Health and social care providers benefit most from problem-based and solution-focused dementia training to support them in applying their learning in practice (Surr *et al.*, 2017; Yaffe *et al.*, 2008). In addition to improving knowledge and skills, educational programs should target the confidence of health and social care providers (Vedel, *et al.*, 2018). Health and social care providers and caregivers alike benefit from practice opportunities, personalized feedback and collaboration with practitioners (Chesney, Alvarado, & Garcia, 2011; Mazmanian & Davis, 2002; Soumerai, 1998).

Having specialists participate in case discussions and as mentors is very well valued by family physicians (Heckman *et al.*, 2016). Specialists have also provided training for long-term care staff on strategies to manage the neuropsychiatric symptoms of dementia with some success. Unfortunately, insufficient resources, such as access to geriatric psychiatrists, have limited the feasibility of implementing such strategies in long-term care (Seitz *et al.*, 2012).

Evidence-based education and training to better understand responsive behaviours is becoming increasingly available. The Physical, Intellectual, Emotional, Capabilities, Environment, Social (P.I.E.C.E.S.) program has demonstrated enhancements in knowledge and confidence; however, changes in practice and health outcomes have not been assessed (McAiney *et al.*, 2007). The Gentle Persuasive Approaches (GPA) is another evidence-based program that has been conducted and evaluated in long-term care and hospitals (Pizzacalla *et al.*, 2015; Schindel Martin *et al.*, 2016).

Evidence-based decision-making supports

Effective dementia education and training for the health and social care workforce includes an underpinning of practice-based learning with theory and the use of a structured tool or guideline to inform practice (Surr *et al.*, 2017). Clinical decision support tools have been shown to improve clinical practice (Bright *et al.*, 2012), including the assessment of dementia (Lindgren, 2011).

As described in Chapter 4, in Canada, four Canadian Consensus Conferences on the Diagnosis and Treatment of Dementia have provided guidance on the diagnosis and

assessment of dementia. The impact of prior consensus statements has not been evaluated in a rigorous manner (Hogan *et al.*, 2001); however, suggestions have been made on how the guideline updates can continue to be relevant. More attention to planning and supporting the implementation of recommendations has been suggested, as well as resources to support dissemination and implementation (Cook & Rockwood, 2013).

The successful implementation of guidelines can be challenging. A critical predictor of success is the presence of an individual or team who serve as a facilitator or “champion,” playing an active role in implementing, supporting and sustaining the use of new knowledge (Gifford *et al.*, 1999; Vedel *et al.*, 2018). Champions recognize the potential benefits of new recommendations and facilitate knowledge dissemination by organizing training sessions and motivating the staff’s use of recommendations (Gifford *et al.*, 1999; Vedel *et al.*, 2018). For example, in Quebec, coaches were used to introduce an interdisciplinary clinical process and care protocol within primary care, along with lectures and case-based practices (Azuelos *et al.*, 2014; Vedel *et al.*, 2018).

Inter-professional education

There is international recognition that inter-professional education contributes to effective collaborative practice, strengthened health systems and improved health outcomes (World Health Organization, 2010). Persons with dementia often have other co-existing chronic conditions and may be affected by other social determinants of health (e.g., issues with housing, poverty). This complexity further supports the need for inter-professional education and inter-professional collaboration.

Inter-professional education is a well-established concept in dementia care, with the emergence of textbooks and formal courses (Forman & Pond, 2017; University of Tasmania College of Health and Medicine, 2018). Providing health professionals with effective evidence-based tools to identify what they could bring to the management of dementia collectively is a possible way to improve inter-professional collaboration and care for persons with dementia and their caregivers (Jackson *et al.*, 2016). However, currently, there is limited evidence of the impact of these initiatives on the care and support of persons with dementia and their caregivers.

Direct care provider training

The establishment of standard sets of core competencies for direct care providers would enable educational programs and employers to develop appropriate continuing education programs and performance expectations of staff who provide dementia care and services across all settings (Alberta Health, Continuing Care, 2017). For example, Ontario and Nova Scotia have established provincial curricula for direct care workers that must be followed by both private and public educators (Nova Scotia Department of Health and Wellness, 2014; Ontario Ministry of Training, Colleges and Universities, 2014). Alberta Health recently released an updated Health Care Aide Competency Profile that lists the ability to “demonstrate appropriate interaction with clients who experience cognitive, behavioural, and psychological impairment (e.g., dementia and/or delirium)” (Government of Alberta, 2018, p. 9). *The American Alzheimer’s Association Dementia Care Practice Recommendations* also outline expectations for direct care providers (Fazio, Pace, Maslow, Zimmerman, & Kallmyer, 2018).

Access to education for rural health care providers

The addendum to this report includes a summary of issues in rural dementia care, including the importance of developing the capacity of rural health and social care providers and increasing their comfort and competency in delivering high-quality care within the context of limited access to specialized dementia services (Morgan, 2018). Remote education and case-based support could improve rural access but evaluation research is limited to date. There are several promising approaches to providing dementia education and support to rural providers:

- Distance learning and in-person training of rural primary care providers resulted in an increase in dementia screening and assessment, a moderate increase in diagnoses, and improved confidence in diagnosing;
- An online tool to guide dementia assessment and diagnosis is currently being evaluated (Morgan, 2018).

6.3.4 Planning for the right number and type of health and social care providers

Building and supporting the health and social care workforce requires that we consider the complexity and progressive nature of dementia, the large number and wide variety of health and social care providers, and the variable capacity and suitability for training within service delivery settings (Bergman, 2009). Attention to issues of sex, gender, ethnicity and poverty are additional important considerations (Badger and Koehn, 2018; Estabrooks, *et al.*, 2015; Jacklin, 2018). Also, population projections—for example, the potential decreased availability of caregivers together with the increasing demand due to the aging population—may result in a significant increase in the number of direct care providers needed in the community (Carrière, Keefe, Légaré, Lin, & Rowe, 2007) and in long-term care facilities (Boissonneault *et al.*, 2018).

The InterAcademy Partnership for Health (2018) calls for the creation and implementation of a national workforce plan. An important part of a workforce plan is to determine strategies to raise staffing levels to meet the quality-of-life and care needs of persons living with dementia and their caregivers. A study of nursing staffing levels in six countries, including Canada, found wide variations in staffing standards and in actual staffing levels within and across countries. Furthermore, it found that nurse-staffing standards have been shown to improve staffing levels (Harrington *et al.*, 2012).

Planning for the health and social dementia care workforce requires innovative approaches. In Ontario, the Dementia Capacity Planning project led by Cancer Care Ontario developed simulation models using administrative healthcare data and a validated dementia algorithm to determine current and future numbers of individuals with dementia and estimate future health resource requirements for this population for services such as home care and respite services (D. Seitz, personal communication, July 31, 2018).

6.4 KEY FINDINGS

- a) All provincial strategies, and most international ones, recognize the need to support and strengthen the workforce. Workforce planning is critical to ensure there are adequate numbers of the needed type of care providers to meet the quality-of-life and care needs of persons living with dementia and their caregivers.
- b) Special attention is needed to address workforce planning and training for the large numbers of direct care providers who provide most of the hands-on care to this highly vulnerable and medically and socially complex population.
- c) Training alone is insufficient to achieve the desired changes in care. Work environments that value and support health and social care providers in providing good dementia care address factors such as time constraints, workload, compensation, leadership and managerial supports. Task-sharing models involving specialists, primary care and other health and social care providers are a key element in workforce planning, training and organization.
- d) It is important to embed dementia care into the curriculum and practice training of all health and social care providers. Case-based or practice-based and solution-focused dementia training is most beneficial to support the application of learning in practice. Used in isolation, traditional didactic and passive strategies (lecture-style meetings, in-services, printed materials and guidelines, and passive materials) are ineffective strategies for increasing knowledge of, and confidence in, dementia management.
- e) Supports for the implementation of evidence-based practice and guidelines are essential for ensuring good quality care.

CHAPTER 7

Research and innovation

The charge to the CAHS Expert Panel included commenting on “investments in all areas of research related to dementia, including biomedical and clinical research, as well as research related to health systems, health services and population health” (see section 1.3.1). A broad perspective was taken, incorporating both research and innovation.⁹

7.1 CHALLENGES

The CAHS Expert Panel believes the strategy should support research on care as well as the search for a cure. To quote Doug Brown (2018), “The need for a cure for dementia is pressing, but practical solutions to benefit those with the condition are also vital.” This research should span all stages of cognitive concerns—from maintenance of brain health in individuals without evident problems to the provision of end-of-life care to those with advanced dementia.

In what follows, we provide brief overviews of a number of the research and innovation challenges encountered with dementia. The Panel purposely did not prioritize research areas, as we felt a more broadly representative group should do this.

7.1.1 Complex etiology of dementia

Dementia is a syndrome with numerous potential causes. In many older persons, it arises from coexisting brain pathologies, not a single condition (Kapasi, DeCarli, & Schneider, 2017). The underlying pathophysiology is complex even when there is a single cause such as Alzheimer’s disease. This means that a one-target, one-drug treatment approach will likely not work (Kumar, Tiwari & Sharma, 2016). Even if hoped-for disease-modifying therapeutic agents are discovered, they will

likely be efficacious in only a minority of persons living with dementia, will require major changes to the health care system in order to be used effectively, and in the short term will increase health care costs (Ritchie *et al.*, 2017). Combination therapy, which may be necessary for dementia, raises specific research, clinical, financial and health system issues (Alzheimer’s Association National Plan Milestone Workgroup, 2014; Hendrix *et al.*, 2016).

7.1.2 Role of biomarkers

Alzheimer’s disease is the most common cause of dementia in older persons. Until recently it was viewed as a clinical-pathological entity, meaning the person both met clinical criteria for dementia in life and showed typical pathological brain changes at autopsy. Current thinking is that a distinction should be made between the clinical symptoms of dementia arising late in the course of the illness and the pathological changes that begin many years before. Biomarkers, such as increased cerebral amyloid plaque burden on amyloid positron emission tomography (PET), can show the pathological changes of Alzheimer’s disease during life. A research framework has been proposed that defines Alzheimer’s disease by the detection of underlying pathological processes at autopsy or during life with biomarkers rather than clinical symptoms (Jack *et al.*, 2018). While the detection of pre-clinical Alzheimer’s disease with biomarkers is now restricted to research, some recommend conducting amyloid PET scanning on those with mild cognitive impairment or dementia to confirm the likely cause, determine prognosis and decide on therapy (Salloway, 2018). Others feel we need to standardize reporting, evaluate performance in detecting early disease, validate diagnostic algorithms based on biomarkers, and create evidence-based guidelines first before widespread adoption (Frisoni *et al.*, 2017).

⁹ Research emphasizes knowledge discovery while innovation is largely concerned with creating useful products from these discoveries and other ideas. To have system-wide impacts, both require successful implementation into practice by means of knowledge translation, defined as “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system” (Straus, Tetroe & Graham, 2013).

7.1.3 Interventions to delay or prevent dementia

Prevention studies pose difficulties because of the long pre-clinical stage of neurodegenerative diseases and the insidious onset and progression of symptoms. This necessitates careful follow-up with large numbers of participants over long periods of time while concurrently considering confounding factors and diverse other potential causes of cognitive and functional decline. Personalized multi-domain interventions that include variable combinations of cognitive stimulation, more social activities, regular exercise, healthy diet, vascular and metabolic risk factor management, and dealing with predisposing psychological features are promising but complex to administer, require long-term changes in behaviour and lifestyle, and still need validation. If such interventions proved to be effective, additional studies would be needed on ways to promote adherence, understand mechanisms, and determine the relative contributions of components as well as their optimal timing and sequencing (Ngandu *et al.*, 2015; Rakesh, Szabo, Alexopoulos, & Zannas, 2017).

There has been a call for a renewed research agenda on loneliness and social isolation (Valtorta & Hanratty, 2012). Loneliness and having fewer close relationships in later life affect quality of life (Rafnsson, Orrell, d'Orsi, Hogervorst, & Steptoe, 2017) and are associated with an increased risk of developing dementia and earlier admission to residential care (Valtorta & Hanratty, 2012). Caregivers of those with dementia are also at risk for loneliness and social isolation.

7.1.4 Behavioural and psychological symptoms

Behavioural and psychological symptoms frequently arise with dementia. Pharmacological therapy is not the first choice for the management of most of these symptoms because its efficacy is modest at best and risks are associated with use. Their employment should be limited to specific symptoms that are not responsive to non-pharmacological interventions and that are severe enough to justify pharmacotherapy (Masopust, Protopopová, Vališ, Pavelek, & Klímová, 2018). Various non-pharmacological approaches are promising. There is evidence, for example, that music therapy, behavioural management, training in communication skills for direct care providers, and

person-centred-care are effective for agitation (Abraha *et al.*, 2017). Larger high-quality studies are required in order to confirm the utility of these interventions (Cikalo *et al.*, 2017), and work must be done on how to effectively disseminate and implement them.

7.1.5 Caregivers

Family, friends and neighbours provide most of the care for persons living with dementia in the community. While caregiving has rewards, this activity can detract from caregivers' quality of life and lead to significant negative health and economic outcomes. Services such as case management and multi-component community programs consisting of a combination of counselling, support groups, education, stress and mood management, and telephone support are beneficial in addressing the needs of caregivers, but further research is required to determine the essential elements of these interventions (Abrahams *et al.*, 2018; Warrick *et al.*, 2018). Longitudinal studies of caregiving have also been proposed to examine how dementia changes relationships and gain a better understanding of the factors that modify caregivers' needs, burden and resiliency. Such studies should be coupled with the rapid translation of findings into practice and policy (Merrilees, 2016).

7.1.6 Health and social care services

The goal of the health and social care system is to optimally deal with the complex and evolving needs of persons living with dementia while supporting and working with their caregivers. This requires a focus on quality of life for people in both groups. The services offered should be easily accessible, timely, commensurate to need, and delivered by a well-trained and supported work force in an efficient manner. Chapter 4 itemizes many of the best practices in this area. Their widespread implementation will require that we engage end users, understand context, strike a balance between fidelity and flexibility, and implement well-informed health policy (Baicker & Chandra, 2017). A scoping review of research on putting evidence-informed dementia care into practice concluded that much work is needed on how to effectively do this (Lourida *et al.*, 2017). Previous chapters in this report have noted a number of quality gaps in this area of practice (i.e., the difference between the care received and what should have been offered). Future research should focus on two key outcomes: the quality of life of those directly

affected by dementia (both persons with dementia and their caregivers) and the quality of care provided. Topics requiring additional research include the provision of end-of-life care (Fox *et al.*, 2018) and managing transitions in care (Hirschman & Hodgson, 2018).

7.1.7 Big data

Big data refers to very large datasets requiring specific technology and methods for analysis. These data holdings can be broad (i.e., routinely collected population-based administrative and clinical data) or deep (i.e., detailed biological and clinical data collected in a research study). Big data approaches to dementia research and care hold promise for improving our understanding of causation, making more timely diagnoses, optimizing resource allocation, predicting outcomes and delivering more tailored treatment. This promise, though, is counterbalanced by a number of technical, research, ethical-legal and regulatory issues that need to be addressed (Ienca, Vayena, & Blasimme, 2018; Anderson & Oderkirk, 2015).

Our publicly funded universal health care system routinely collects and stores a wealth of both administrative and clinical data. The latter includes data collected with interRAI assessment instruments, which are used in many parts of the country. This offers unique opportunities for broad big data research. For example, with interRAI data it may be possible to map health trajectories among persons with dementia who are users of the continuing and long-term care system, compare the relative impact of policies and interventions, and assess the quality of care provided both over time and between sites (Canadian Institute for Health Information, 2013; Hirdes *et al.*, 2011).

7.1.8 Assistive technology and environmental design

Assistive technology for persons with dementia is defined as “any item, piece of equipment, product or system driven by electronics, whether acquired commercially, off-the-shelf, modified or customized, that helps persons with dementia in dealing with the consequences of dementia” (Meiland *et al.*, 2017, p. 2). Potential uses include assisting persons with dementia in everyday activities, providing for their security, and offering opportunities for pleasurable

activities. Technology can also be used for cognitive assessment and training (to date this has focused on the prevention of dementia rather than its treatment), to support caregivers and to improve facility-based care (Piraino, Byrne, Heckman, & Stolee, 2017; Tak, Benefield, & Mahoney, 2010).

The Organisation for Economic Co-operation and Development (OECD) report on dementia (2015) highlights the possibility that technology could improve the lives of persons living with dementia. Notwithstanding this promise, relatively few products were then available, used, reimbursed or evaluated. Recommended actions made in the report included an increased focus on users’ requirements in development, robust independent evaluations of new technologies, and speeding the integration of effective approaches into health and care systems. Meiland *et al.*’s position paper (2017) on technologies to support community-dwelling persons with dementia concludes with a number of recommendations in the areas of development, research, deployment and ethics. The authors include a call for persons with mild to moderate dementia and caregivers to be involved in all projects that aim to develop and test technologies for their ultimate benefit, and state that participating researchers must be knowledgeable about dementia (Meiland *et al.*, 2017). One of the papers commissioned for the work of the CAHS Expert Panel was on *Technology for Dementia* (AGE-WELL, 2018a). The authors provide a number of specific examples of work done in the field but also note that much of the research performed has been limited to pilot or feasibility studies. Much work must still be done; claims of benefit must be confirmed and careful thought must be given to questions of integration and of who will pay for assistive technologies.

Attention to the built environment can have a beneficial impact on the independence and behaviour of persons living with dementia (Marquardt, Bueter, & Motzek, 2014). The key design principles for persons with dementia are surprisingly very straightforward (Fleming & Bennett, 2017). By bundling adherence to these principles, using validated technologies, and providing care from motivated, well-trained and supported staff, we can make substantial improvements in the lives of persons with dementia who need institutional care.

7.1.9 Assessment of the dementia strategy

Evaluation will be needed, both of the overall impact of the dementia strategy as well as specific aspects of it (Greaves & Jolley, 2010). Chapter 8 deals with the overall impact in greater detail. Examples of specific aspects requiring study would include:

- **Public awareness campaigns:** While most strategies recommend them, we know very little about their effectiveness (The Lancet Neurology, 2015). Evaluations to date have focused on process (e.g., counting how many attended an in-person session, watched a video, read a blog, or visited a website). We don't know whether these processes actually lead to positive changes in knowledge, attitudes, behaviour and health outcomes without causing deleterious effects such as instilling fear, desensitization, defeatism or an overly optimistic outlook on the part of the public. Also, while these campaigns should involve persons living with dementia, it is uncertain how best to do this.
- **Workforce studies:** We need to assess how to improve the quality of work life, especially for those providing direct care. We must also assess the effectiveness of educational programs on dementia delivered to the health and social care workforce. See Chapter 6 for additional details.
- **Scaling up successful interventions:** This refers to addressing the system and infrastructure issues that arise during the full-scale implementation of a successful intervention (Nelson *et al.*, 2002). As Feldman and Estabrooks (2017) note, we must move “beyond a series of pilots to a comprehensive and tangible action plan that is immediately actionable.” In Canada a particular challenge is dealing with access issues in rural and remote communities.

7.1.10 Funding

Compared to other major causes of morbidity and mortality, dementia research is underfunded, though this is improving (InterAcademy Partnership for Health, 2018; Luengo-Fernandez, Leal, & Gray, 2015). The anticipated growth in the number of people affected underscores the need to invest in dementia research across all areas of inquiry (InterAcademy Partnership for Health, 2018).

With regard to a specific component of this broad need, there was concern that large pharmaceutical firms would withdraw from dementia drug discovery and early development because of a series of failed clinical trials (Jobke *et al.*, 2018), but this hasn't occurred. This risk may be counterbalanced by changes in the pharmaceutical industry's business model, where more research is now conducted by small- to medium-sized enterprises and contract service providers, often in partnership with larger pharmaceutical firms and venture capital funds.

7.2 PUBLIC POLICY RESPONSES

A call for an increased commitment to research and innovation is frequently included in provincial and international dementia strategies (Chow *et al.*, 2018; Edick *et al.*, 2016; Guillette, 2018). Unfortunately, sufficiently precise performance measures, indicators and targets have generally not accompanied these appeals (Doran, 1981; Wilson *et al.*, 2018).

The *G8 Dementia Summit Declaration* of December 11, 2013 called for greater innovation to improve the quality of life of persons with dementia and their carers while reducing carers' burden. The countries signing the declaration, including Canada, committed to the following (Department of Health and Social Care [UK], 2013):

- Identifying a cure or a disease-modifying therapy for dementia by 2025;
- Significantly increasing the amount of funding for dementia research to reach the preceding goal;
- Developing a coordinated international action plan for dementia research;
- Encouraging open access to all publicly funded research;
- In partnership with the Organisation for Economic Co-operation and Development (OECD), examining current national incentive structures for research coupled with considering what changes could be made to accelerate discovery and implementation.

The Canadian Institute for Health Research (CIHR) Dementia Research Strategy is the research component of the *National Dementia Research and Prevention Plan*

developed by the Canadian federal government in response to the G8 declaration (Ogilvie & Eggleton, 2016). The strategy is co-led by the Institute on Aging and the CIHR Institute of Neurosciences, Mental Health and Addiction. The goals fall into broad themes related to diseases that can affect cognition as we age: primary prevention, secondary prevention and quality of life.

The primary national vehicle for the research strategy is the Canadian Consortium on Neurodegeneration in Aging (CCNA) (Canadian Institute of Health Research, 2017a). The CCNA provides leadership for accelerating progress in age-related neurodegenerative diseases through 350+ clinicians and researchers (CCNA, 2018). It serves as a research hub for a wide range of activities; its researchers are divided into 20 teams that are organized around the three themes with an emphasis on inter-institutional and interdisciplinary collaboration, taking a pan-Canadian approach. They promote the wider inclusion of sex and gender in research on this topic (Tierney, Curtis, Chertkow, & Rylett, 2017) and are working in the areas of prevention, treatment and quality of life. They draw on the data of eight national platforms, and are supported by four crosscutting programs that assist teams in identifying gaps and synergies and in accelerating idea uptake.

At the international level, partnerships have been developed with the Alzheimer's Disease Neuroimaging Initiative in the United States, the European Union Joint Programme – Neurodegenerative Disease Research and others.

Valuable information will also be obtained from the Canadian Longitudinal Study on Aging (Raina *et al.*, 2009), which is following approximately 50,000 Canadians aged 45 to 85 at entry for up to 20 years. The comprehensive data being collected can be used to assess the public health burden of dementia and look for genetic and environmental risk factors for its development (Ma, Thabane, Beyene & Raina, 2016).

One of the currently supported Networks of Centres of Excellence, or NCEs, is AGE-WELL, which is dedicated to the creation of technologies and services that benefit older adults (AGE-WELL, 2018b). A number of the projects supported by AGE-WELL address the needs of persons living with dementia.

7.3 CURRENT EVIDENCE AND EMERGING BEST PRACTICES

To promote dementia research and innovation in a national dementia strategy there is a need to train the next generation of researchers, provide the required research infrastructure for them to do their work, meaningfully engage persons living with dementia and set explicit research priorities.

7.3.1 Development of dementia research capabilities

The scale and complexity of the dementia challenge, including the current and anticipated costs of care, justifies the need for increased dementia research. The Organisation for Economic Co-operation and Development (OECD) report on dementia mentioned earlier also made recommendations to stimulate progress in research and innovation internationally:

- Regulatory and incentive frameworks must be reformed to drive progress in dementia research and care.
- More effective collection and use of data is essential to advancing our knowledge about dementia care and treatment (i.e., big data research).

England's roadmap for advancing dementia research (Pickett *et al.*, 2018) provides additional recommendations on how to stimulate needed research through a ten-point action plan:

- Increase available funding
- Streamline research processes
- Advance public and patient involvement
- Improve research methods
- Enable inclusivity
- Support study recruitment
- Increase data storage and reanalysis
- Increase involvement of practitioners in research
- Enable knowledge exchange
- Create effective researcher networks

We will need to support the training of highly qualified personnel able to conduct the required research through vehicles such as the Canadian Consortium on Neurodegeneration in Aging (CCNA). This will require ensuring career opportunities for them upon completion of their training. We also need to obtain better return on the investments made in investigator-initiated¹⁰ and priority-driven research¹¹ on dementia by drawing upon international best practices and ensuring that research investment is made effectively and efficiently. There are many suggestions for maximizing value and minimizing waste in research by avoiding redundant studies or those using inappropriate methodologies (Chalmers & Glasziou, 2009; Chalmers *et al.*, 2014; Chinnery, Dunham, van der Linden, Westmore, & Whitlock, 2018; Macleod *et al.*, 2014).

7.3.2 Engaging persons living with dementia as partners in research

One of the principles of the CIHR Strategy for Patient-Oriented Research (SPOR) is that persons affected by the condition of interest must be involved in meaningful ways to ensure that the research questions asked and the results obtained are relevant (Canadian Institutes of Health Research, 2011). This holds true for dementia.

A number of studies have described how individuals living with dementia can be involved in research (Giebel *et al.*, 2017; Iliffe, McGrath, & Mitchell, 2011) and can benefit from it (Giebel *et al.*, 2017; Iliffe *et al.*, 2011; Mann & Hung, 2018; Mockfort *et al.*, 2016). Their engagement as co-researchers or project advisors acknowledges the value of their perspective. They can provide important insight across the research process. For example, Clarke *et al.* (2018) explored the involvement of persons with dementia in data analysis. Researchers in studies where persons living with dementia were more fully engaged reported developing a better understanding of the condition and the experiences of those living with it (Mann & Hung, 2018), designing studies more attentive to the needs and preferences of those living with dementia (Brett *et al.*, 2014) and selecting more relevant outcome measures (Domecq *et al.*, 2014).

There are great rewards in working with persons affected by dementia. Researchers need to be open to involving them in meaningful ways and need education on how to do this. Some of the identified issues in co-developing research with persons living with dementia include dealing with anosognosia (Turró-Garriga *et al.*, 2016) and other cognitive deficits that often become more severe as dementia progresses, identifying representative individuals and groups, helping the person living with dementia and caregivers deal with the complexity of research and the research process, assisting them in dealing with certain sensitive topics, protecting the confidentiality of study participants, adapting to shared decision-making, negotiating with research ethics boards, maintaining the interest of the persons living with dementia, and dealing with any additional time and cost requirements (Mockfort *et al.*, 2016; Bethell *et al.*, 2018). Authors emphasize that these are challenges to overcome, not reasons to refuse to try.

Still, more research is needed to better understand how to involve individuals living with dementia as research partners (Gove *et al.*, 2018; Iliffe *et al.*, 2011) and to quantify the impact of their involvement (Bethell *et al.*, 2018). This effort should be guided by the core principles of the Scottish Dementia Working Group Research Subgroup (2014) and the position adopted by Alzheimer Europe (Gove *et al.*, 2018).

7.3.3 Setting priorities

The American *National Plan to Address Alzheimer's Disease* established 65 research milestones to prevent and effectively treat Alzheimer's disease by 2025 (Alzheimer's Association National Plan Milestone Workgroup, 2014). This was updated in 2016 with five additional general target areas identified (Corriveau *et al.*, 2017). A task force of clinicians, researchers, funders, persons living with dementia and caregivers in England came up with five general research goals—prevention, diagnosis, management, workforce, inclusivity—and thirty recommendations (Pickett *et al.*, 2018). The problem

10 Investigator-initiated research includes studies developed and executed under the direction of investigators who typically work within academic institutions.

11 Priority-driven research refers to initiatives created by agencies such as government, foundations and non-governmental organizations to investigate pressing health issues that are of strategic importance to the funder.

isn't identifying potential research targets. Rather, it is deciding on where to focus our limited resources, time and funds.

Research priorities vary according to the stakeholder group consulted. Table 4 shows the top ten dementia research priorities of Canadians affected by dementia (including persons with dementia, their friends, family and care partners, and health and social care providers) that were developed through a process sponsored by the Alzheimer Society of Canada and the Canadian Consortium on Neurodegeneration in Aging (CCNA) (Canadian Dementia Priority Setting Partnership Steering Committee, 2018; Bethell, Pringle, Chambers, Cohen, Commisso, *et al.*, 2018). The table also lists the top ten priorities identified by a group predominantly made up of dementia researchers and clinicians from around the

world (Shah *et al.*, 2016). While both groups considered similar areas, they often assigned divergent priorities to specific topics. As examples, addressing stigma ranked first and research on dementia-friendly communities ranked eighth on the priority list of those affected by dementia, but were 32nd and 26th, respectively, on the researchers' and clinicians' list (Shah *et al.*, 2016). Four of the researchers' and clinicians' top priorities dealt with predicting risk or preventing dementia, but these concerned were ranked 14th and 16th by those with lived experience (James Lind Alliance, 2018). This underscores the importance of respecting diversity when establishing priorities. Promoting inclusivity and equity should be hallmarks of this effort even though melding all perspectives into a common priority list will be a challenging exercise.

Table 4: Top 10 research priorities (listed from highest to lowest ranked) of Canadians affected by dementia and WHO group (researchers and clinicians)

2018 Canadian dementia research priorities (Canadians affected by dementia)	2016 WHO dementia research priorities (researchers and clinicians)
Addressing stigma	Prevention
Emotional wellbeing	Timely and accurate diagnosis
Impact of early treatment	Diversifying therapeutic approaches
Health system capacity	Brain health promotion and dementia prevention communication strategies
Caregiver support	Contributions of vascular conditions
Access to information and services post-diagnosis	Influence and interactions of non-modifiable and modifiable risk and protective factors
Care provider education	Interventions to address risk factors
Dementia-friendly communities	Models of care and support in the community
Implementing best practices for care	Educating, training and supporting formal and informal carers
Non-drug approaches to managing symptoms	Late-life and end-of-life care, including advance care planning

7.4 KEY FINDINGS

- a) An equitable balance in research investment is required across the four research themes (i.e., biomedical, clinical, health services, social, cultural, environmental, and population health) and between creating and translating knowledge.
- b) While international collaborations must be strengthened, the Canadian dementia research agenda needs to address our specific needs and capitalize on our unique advantages.
- c) More research funding is required, along with coordination between the different levels of government, industry and charitable funders in order to maximize benefit and avoid waste.
- d) The engagement of persons living with dementia is critical, but our understanding on how best to do this is at an early stage and should be considered an emerging practice. Examples can be built upon to improve the acceptance and recognition of contributions from persons living with dementia.
- e) Different research priorities have been identified and are best established with broad stakeholder input, which must include persons living with dementia and their families, friends, caregivers, and health and social care providers as well as the research community and funders.
- f) When putting the dementia research and innovation plan into action there is a need to move from abstract, broad goals to specific performance measures, indicators and targets that are quantifiable, accountable and feasible within a predetermined time horizon. There is also a need to support studies on how to effectively scale up evidence-based interventions to large populations.

CHAPTER 8

Implementation

The panel was asked to identify “other aspects of dementia knowledge, prevention and care... that might be included in a national dementia strategy” (see section 1.3.1). An assessment on the state of knowledge about dementia strategies would be incomplete without consideration of the current evidence and emerging best practices on these strategies’ implementation. Each chapter in this assessment has provided examples of the implementation of initiatives aligned with individual elements of dementia strategies. This chapter explores current evidence and emerging best practices on the implementation of dementia strategies.

8.1 CHALLENGES

While there is general agreement on the value of having a national dementia strategy to improve care for persons living with dementia as well as heightening awareness that dementia is a public health priority (InterAcademy Partnership for Health, 2018), there is very little evidence on how to implement dementia strategies successfully and on their impact.

8.1.1 Balancing core direction with flexibility in implementation

It can be a challenge to balance central planning, through a clear direction, vision and coordinated actions, with flexibility for adaptation at the local level (Koch & Iliffe, 2011). Some strategies can be characterized as being too inconsistent, with no common objectives or methods. One potential outcome of an inconsistent approach would be the exacerbation of pre-existing inequities in the provision of care and services across regions (Boyle, 2010). Some of these strategies have involved implementing a plan without a central common core, which may explain why they have shown limited impact (Cahill, 2010; O’Connell *et al.*, 2013).

8.1.2 Dedicated resources

The lack of sufficient dedicated resources has been identified as another issue. Several researchers note that the resources committed in several countries were not sufficient for implementing the measures proposed in the plans (Clarke *et al.*, 2014; Egge, 2014; Hoffman, 2014; Peate, 2016; Pot & Petrea, 2013; Rosow *et al.*, 2011; Williamson, 2009). Even when financial resources were committed, in some countries they were focused on the search for a cure while actions aimed at improving care remained underfunded (Porock *et al.*, 2015; Thornill & Conant, 2018).

8.1.3 Measuring impact

Several governments are evaluating the impact of their strategies, but few have made these results public. Emerging evidence shows that the effective execution of national dementia strategies can lead to improvements in diagnostic rates. The Quebec plan led to a significant increase in the number of dementia diagnoses made within family medicine practice groups as well as to improvements in the quality of care provided (Sourial *et al.*, 2016). The UK recognition rate doubled from one-third to two-thirds following the introduction of their national dementia strategy (Donegan *et al.*, 2017; Mukadam, Livingston, Rantell, & Rickman, 2014). France saw an increase in both diagnoses made and scientific publications (Haefner-Cavaillon, Devos, Ledoux, & Ménard, 2015). This demonstrates that at least certain elements of dementia strategies and action plans can be translated into measurable effects. However, the evaluation focus to date has been primarily quantitative (e.g., the number of new diagnoses) and less on capturing aspects of the quality of care provided or impacts such as raising public awareness and reducing stigma.

8.2 PUBLIC POLICY RESPONSES

Similar to the variations between countries, Canadian provinces are at various stages of development, implementation and evaluation of their dementia strategies. Several provinces have made commitments in their strategies to develop mechanisms for leading and monitoring implementation. In Quebec, the government selected an independent research team to perform continuous evaluations of the implementation of the plan, including the description of barriers and facilitators, and to assess the impact on the care provided (Godard-Sebillotte, Vedel, & Bergman, 2016).

8.3 CURRENT EVIDENCE AND EMERGING BEST PRACTICES

There is limited evidence on the impact of dementia strategies, though recommended best practices have emerged (Alzheimer's Disease International & World Health Organization, 2012; Vedel & Couturier, 2016). The following best practices have been identified:

- Strong leadership, broad collaboration and defined roles
- Long-term commitment with the allocation of appropriate resources to achieve the identified priorities
- Flexibility: one size does not fit all
- Quality improvement, standards of care and accreditation
- Evaluation and evolution of the strategy

In what follows, we explore these key elements of success in some detail, and then summarize the potential role of national dementia standards in quality improvement.

8.3.1 Strong leadership, broad collaboration and defined roles

Setting up a strong intersectoral leadership group with clearly defined roles and responsibilities is a determinant of the effective implementation of national dementia strategies (Alzheimer's Disease International & World

Health Organization, 2012). Hoffman (2014) argues that a mechanism to ensure efficient coordination and collaboration across and within organizations is a vital component of action plans. Strong leadership will ensure effective and consistent implementation, appropriately address issues that arise, monitor effectiveness, and make changes to the plan as needed.

8.3.2 Long-term commitment with the allocation of appropriate resources to achieve identified priorities

It is better to focus on fewer achievable targets than to set too many and achieve only a few, if any (Pot & Petrea, 2013). We must balance the need for widespread change with the risk of trying to do too much too quickly (Alzheimer's Disease International & World Health Organization, 2012). An implementation schedule (Alzheimer's Disease International & World Health Organization, 2012) incorporating a long-term approach is required (Pot & Petrea, 2013).

In addition, sufficient and stable funding is critical (Alzheimer's Disease International & World Health Organization, 2012; Egge, 2014; Guillette *et al.*, 2018; Rosow *et al.*, 2011; Stone, 2001). A long-term commitment makes it possible to scale up to system-wide changes that are based on evaluation. For example, the Quebec dementia strategy (Bergman, 2009) started with 42 family medicine groups followed by a comprehensive evaluation before moving on to province-wide dissemination (Sourial *et al.*, 2016). Similarly, in France, the results of 17 pilot projects were used to inform widespread dissemination of the plan to the whole country (Somme *et al.*, 2014). A similar approach was taken in England (Clarke *et al.*, 2014; Iliffe & Wilcock, 2009; Koch & Iliffe, 2011).

8.3.3 Flexibility: one size does not fit all

While most existing dementia strategies are designed around common themes based on current evidence and best practices, each country or region has unique characteristics that require consideration. Successful strategies allow for flexible operationalization that takes into account local needs and context while maintaining key attributes of the national plan (Pot & Petrea, 2013).

Interventions that are implemented in ways compatible with the current health and social care structure are more likely to be well received by healthcare professionals (Khanassov *et al.*, 2014a). Factors to consider in tailoring implementation include the current practices of potential adopters, the time available (and time required) to learn the intervention and put it into effect, and the capacity for adopters to adapt practices (Khanassov *et al.*, 2014a). Mobilization of support from local stakeholders is crucial, as is basing changes on local realities (Bloch & Hénaut, 2014; Truswell, 2011; Koch & Iliffe, 2011).

8.3.4 Quality improvement, standards of care and accreditation

Any dementia strategy should support the use of evidence and best practices. In this regard, quality improvement strategies at the practice level (Irwin, Stokes, & Marshall, 2015) are very promising approaches. Quality improvement is usually described as a “continuous effort to improve processes that include identifying a problem, examining and applying solutions and monitoring for improvement” (Irwin *et al.*, 2015). Audit and feedback, computerized advice, point-of-care reminders, practice facilitation, educational outreach and processes for patient review and follow-up have all demonstrated evidence of a quality improvement effect (Irwin *et al.*, 2015).

One tool that can be used in quality improvement is national standards of care to support organizations in delivering best practices for patients with dementia. Such standards do not currently exist in Canada (Health Standards Organization, 2018). The Health Standards Organization (2018) has proposed the development and introduction of an all-settings approach to support condition-based care journey integration. This would acknowledge the need to:

- Address every stage of care (prevention and early identification to end of life),
- Use an inter-disciplinary focus and
- Include patients and caregivers.

This direction for national standards would be consistent with taking a person-oriented approach as described in Chapter 4.

Integrated standards of care can be operationalized and measured at the organizational level through accreditation and other health quality mechanisms that help ensure implementation in the provision of care. This needs to be done within an improvement culture and not a blame culture (Armstrong *et al.*, 2018). As such, integrated standards of care may encourage the implementation of some priorities of a dementia strategy, particularly related to health and social care.

8.3.5 Evaluation and evolution of the strategy

Alzheimer’s Disease International and World Health Organization (2012) recognize the need to put in place an evaluation plan to assess impact and inform course adaptations (Egge, 2014; Pot & Petrea, 2013).

Dementia strategies evolve over time, as has occurred with the Canadian provincial strategies (see Table 1, Chapter 1). The evaluation and updating of plans provides the opportunity to:

- Integrate new evidence,
- Build on what works,
- Respond to changes in context such as shifts in funding, and
- Identify future research priorities.

The evaluation of dementia strategies requires innovative and diverse quantitative and qualitative methods. These range from simple pre and post studies to more complex approaches such as stepped wedge trials (Prost *et al.*, 2015).

Developmental evaluation (Fagen *et al.*, 2011) is particularly well suited for evaluating dementia strategies because it supports social innovations and change through a continuous process of real-time information exchange, continuous development, adaptation and experimentation (Patton, 2011). It necessitates monitoring the actions performed (e.g. number of training sessions) to assess outcomes (e.g. quality of life for persons living with dementia, quality of care, attitudes of workers) (Lilford *et al.*, 2010).

The selection of outcomes requires input from all stakeholders. The indicators and outcomes developed by Health Quality Ontario's *Dementia Care for People Living in the Community* (Health Quality Ontario, 2017) and the evaluation of the Quebec plan (Vedel & Couturier, 2016) provide valuable lessons.

8.4 KEY FINDINGS

- a) Strong government leadership with broad stakeholder collaboration and clearly defined roles is critical to leading, inspiring and evaluating change.
- b) A dementia implementation action plan requires:
 - i. A compelling central vision and direction balanced with flexibility to adapt to local needs and contexts,
 - ii. A long-term commitment and appropriate resources to achieve identified priorities, as well as research and evaluation,
 - iii. A concrete action plan with targets and timelines,
 - iv. Consideration of the various approaches to implementation that have been used, including both widespread and phased implementation, and
 - v. Planning, at the outset, for continuous evaluation of the dementia strategy to inform implementation and modifications as needed,
- c) The introduction of national dementia standards of care along with an accreditation process will complement quality improvement efforts that are aligned with dementia strategy priorities.

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