

# ALZHEIMER'S DISEASE AND RELATED DEMENTIAS IN INDIGENOUS POPULATIONS: *Knowledge, Needs, and Gaps*

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Centre de collaboration nationale  
de la santé autochtone

CHRONIC AND INFECTIOUS DISEASES



© 2022 National Collaborating Centre for Indigenous Health (NCCIH). This publication was funded by the NCCIH and made possible through a financial contribution from the Public Health Agency of Canada (PHAC). The views expressed herein do not necessarily represent the views of PHAC.

## Acknowledgements

The NCCIH uses an external blind review process for documents that are research based, involve literature reviews or knowledge synthesis, or undertake an assessment of knowledge gaps. We would like to acknowledge our reviewers for their generous contributions of time and expertise to this manuscript.

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Halseth, R. (2022). *Alzheimer's Disease and related dementias in Indigenous populations: Knowledge, needs, and gaps*. National Collaborating Centre for Indigenous Health.

La version française est également disponible au [ccnsa.ca](http://ccnsa.ca) sous le titre : *La maladie d'Alzheimer et les démences apparentées chez les populations autochtones : connaissances, besoins et lacunes*.

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ISBN (print): 978-1-77368-332-4  
ISBN (online): 978-1-77368-333-1

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# INTRODUCTION



Canada's population is rapidly aging, with the seniors population expected to grow by 68% over the next 20 years (Canadian Institute for Health Information, 2021). This process is being accompanied by a corresponding growth of age-related conditions such as Alzheimer's disease and related dementias (Jacklin et al., 2013a; Jacklin & Walker, 2020; Public Health Agency of Canada [PHAC], 2017). The term dementia refers to a set of symptoms of progressive deterioration of cognitive functions that affect daily activities. The most common types of dementia are Alzheimer's disease, which accounts for 60-80% of cases, as well as vascular dementia, lewy body dementia, front-temporal dementia, and mixed dementia (Centres for Disease Control and Prevention [CDCP], 2019). These neurodegenerative dementias, herein referred to collectively as 'dementias,' are caused by damage to or loss of nerve cells and their connections to the brain. To date, there are no cures for these types of dementia, though medication may help protect the brain or

manage specific symptoms of dementia such as anxiety (CDCP, 2019). However, sometimes the symptoms of dementia may be reversible with treatment if they are caused by factors such as a side effect of medication, increased pressure in the brain, vitamin deficiency, and thyroid hormone imbalance. Dementias are common among older adults (65 years or more) but are not considered a normal part of aging because not all adults will develop dementia. Some of the risk factors for developing dementias include age, family history, race/ethnicity, poor heart health, and traumatic brain injury. While many of these risk factors are beyond an individual's control, leading a healthy lifestyle can reduce the chances of developing chronic diseases and thus the number of people with dementia (CDCP, 2019).

Historically, rates of dementias have been low among Indigenous<sup>1</sup> Peoples in Canada (Hendrie et al., 1993; Jacklin & Warry, 2012a; Warren et al., 2015). However, the rate is expected to increase more

rapidly among this population compared to the general Canadian population because of the higher rates of many of the risk factors for dementias among Indigenous Peoples, including diabetes, midlife hypertension, obesity, physical inactivity, lower levels of education, and smoking (de Souza-Talarico et al., 2016; Petrusek MacDonald et al., 2015; Walker et al., 2020; Warren et al., 2020).<sup>2</sup>

Indigenous people face considerable barriers to optimal dementia care. Some of these barriers are related to socio-economic marginalization stemming from colonization; reduced access to health services and specialized healthcare providers; a lack of cultural safety in mainstream health systems; a mistrust of mainstream healthcare providers; and stigma associated with dementias (Bourassa et al., 2015; Cabrera et al., 2015; McAtackney et al., 2021; Stevenson et al., 2013, 2015). Other barriers are related to a lack of knowledge about, or access to, appropriate and culturally relevant information

<sup>1</sup> The term 'Indigenous' is used throughout this paper to refer to First Nations, Inuit, and Métis peoples inclusively. When not referring to all three groups of Indigenous people, the terms for the specific group(s) being referred to will be used. It is important to note, however, that almost all of the research related to dementia is focused on First Nations populations living on reserve.

<sup>2</sup> For more information about the risk factors for dementias among Indigenous Peoples in Canada, please refer to the National Collaborating Centre for Indigenous Health's (NCCIH) report, "Alzheimer's disease and related dementias (ADRDs) in Indigenous populations in Canada: Prevalence and risk factors" (Petrusek MacDonald et al., 2018).

*There is a need to raise awareness about dementias, reduce associated stigma, and build local capacity to care for individuals with these diseases in Indigenous communities, especially in rural and remote regions where access to resources may be lacking.*



about dementia and available supports. Collectively, these types of barriers can prevent individuals from seeking timely health care, thus delaying diagnosis, care, and treatment. This, in turn, can lead to poorer quality of life and health outcomes for individuals with dementia and their caregivers (Morgan et al., 2009, 2011). There is a need to raise awareness about dementias, reduce associated stigma, and build local capacity to care for individuals with these diseases in Indigenous communities, especially in rural and remote regions where access to resources may be lacking (Jacklin et al., 2016; Forbes et al., 2013; Pace, 2013; PHAC, 2019, 2020).

In recognition of the growing impact of dementias in Canada, especially on certain populations, including Indigenous Peoples, the federal government released

a national dementia strategy in 2019 which includes principles for creating “a Canada in which all people with dementia and caregivers are valued and supported, quality of life is optimized and dementia is prevented, well understood, and effectively treated” (PHAC, 2019, p. ix). The strategy identifies the need to address specific knowledge needs and gaps related to dementia, and articulates key principles and priorities for the development of information resources. These priorities include, among others, a respect for and value of diversity, with a focus on those most at risk or with distinct needs; a respect for human rights to support autonomy and dignity; and engagement in evidence-informed decision-making that considers traditional knowledge, the experiences of those living with or caring for someone with

dementia, as well as scientific evidence. The strategy emphasizes the need to engage with First Nations, Inuit, and Métis governments, organizations, and communities in order to develop distinction-based solutions appropriate for the unique contexts of communities, as well as resources that are culturally appropriate, safe, and accessible across cultures, languages, and different geographic areas to help care providers deliver quality care and enhance understanding of the disease among all Canadians.

This paper summarizes what is known about the knowledge, needs, and gaps of Indigenous Peoples and healthcare practitioners working in Indigenous communities related to dementias. Specifically, it begins by providing a review of First Nations, Inuit, and Métis understandings of dementias,

perceptions of healthy aging, and preferences for care, as this information is important for situating the knowledge needs of Indigenous Peoples with respect to dementias. It then provides an overview of barriers and facilitators of knowledge translation and exchange about dementia care and management in Indigenous communities, followed by a summary of the knowledge needs and gaps related to dementia care in Indigenous settings, including for Indigenous dementia patients and informal care providers, healthcare providers, Indigenous communities, policy makers, and

program developers. The paper concludes with a discussion of some considerations for developing culturally appropriate dementia resources in Indigenous communities, and examples of existing dementia education, tools, and resources.

The paper draws on both peer-reviewed and grey literature identified through a search of PubMed, Medline, Google and Google Scholar, and using the search terms ‘First Nations’, ‘Aboriginal’, ‘Native’, ‘Indigenous’, ‘Inuit’, ‘Métis’, ‘Indian’, AND ‘Alzheimer’, ‘Dementia’, and ‘Memory

Loss.’ Searches were narrowed, wherever possible, to include literature from Canada alone, published up to July 2021. However, because there is limited research in this area, information from Australia, the United States, and New Zealand may occasionally be included where relevant. While this literature review was not systematic, and therefore may not have identified all relevant literature, it is reasonably comprehensive and likely a good representation of current knowledge in this field.



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# FIRST NATIONS, INUIT, AND MÉTIS UNDERSTANDINGS OF DEMENTIAS, PERCEPTIONS OF HEALTHY AGING, AND PREFERENCES FOR CARE

Culture can influence how diseases are perceived and experienced by individuals, which in turn can affect health seeking behaviours, diagnosis, and treatment (Jacklin & Walker, 2012). For example, non-Indigenous people generally understand dementias from a Western biomedical perspective as “disease processes happening in the brain of the individual for which, at present, there is no specific cause or effective treatment;” as a result, they tend to seek out a diagnosis sooner than other cultures that may view dementias as a natural part of aging (Gray et al., 2009, p. 3). Understanding cultural perceptions and the experiences of individuals with dementia and caregiving processes are critical for providing adequate and culturally appropriate health services and information (Lanting et al., 2011). This section presents what is known about Indigenous Peoples’ understandings of dementias, their perceptions of healthy aging, and their

preferences for care. Most of the focus of research in this area is on First Nations understandings and perceptions, though some research with Inuit populations is beginning to emerge (see for example Pace, 2020).

One of the factors that can affect how dementias are understood by Indigenous people is the translatability of dementia and related terms to Indigenous languages. The existing body of research indicates that no words exist for dementia or dementia-related diseases in First Nations languages, though there are words that describe symptoms or a state of mind associated with these diseases (Cammer, 2006; Hendrix & Swift Cloud Lebeau, 2006; Jacklin et al., 2014a, 2014b; Indigenous Cognition & Aging Awareness Research Exchange [I-CAARE], 2015a; Webkamigad et al., 2020a). For example, rather than referring to dementias directly, Anishinaabe community members and healthcare providers on

Manitoulin Island described the symptoms of dementias as being forgetful, having a bad memory, being senile, having a senior’s moment, or ‘Oldtimer’s disease’ (Pace, 2013). They also mentioned certain Ojibwe words describing these symptoms as “the knowledge a person had is buried within,” or “telling stories in circles.” No similar research has been undertaken among Inuit or Métis populations, though some symptoms were described for Inuit in relation to aging poorly and mental health issues in aging. These included “mind changes,” (Collings, 2001), withdrawal and melancholy (Vallee, 1966, as cited in Kirmayer et al., 2009), “quajimaillituq,” an Inuktitut word that applies to rabid dogs and conveys the sense of doing foolish things and not knowing what one does (Kirmayer et al., 2009), and “isumaqanngtiq,” which translates into English as being “without thoughts” (Kirmayer et al., 1994). In the absence of specific terms for

dementia, there may be multiple perspectives of what it is and how it is experienced by Indigenous individuals.

There is a dearth of knowledge about Indigenous understandings of cognitive impairment and dementia (Jacklin & Walker, 2020; Racine et al., 2020). The existing body of research suggests that Indigenous Peoples may hold different understandings of dementias, ranging from traditional to biomedical understandings, with variations within and across communities. Many First Nations considered memory loss and dementias as a normal part of aging, of coming full circle in one's life cycle, or as a phase of moving "closer to the creator," rather than as something that is thought to be problematic (Dudley et al., 2019; Hulko, 2014; Hulko et al., 2010; Hulko et al., 2019; I-CAARE, 2015b; Jacklin et al., 2013; Jacklin et al., 2014a, 2014b; Lanting et al., 2011; Pace, 2012, 2013, Pace et al., 2013; Sutherland, 2007). This process was viewed in a respectful and positive manner, with individuals with dementia being accepted for the way they were (Pace, 2013).

Some First Nations people held perceptions of dementias that were steeped in spirituality and tradition. An American Indian family interpreted some of the symptoms of dementia as "supernormal," representing communications



with the supernatural world or with ancestors (Henderson & Henderson, 2002). Some First Nations in Ontario viewed behaviours that were considered by westerners as "hallucinations" to be visions that brought individuals closer to the creator (Jacklin & Warry, 2012a; Jacklin et al., 2013b). Older members of a Tahltan First Nations community in British Columbia (BC) described dementia as a mysterious sickness, a hex, bad medicine, or witchcraft (Stevenson et al., 2015). Despite these different traditional understandings of dementia, dementias were not often considered a major health concern in these communities, either because symptoms and behaviours associated with the disease aligned with cultural understandings of aging, or because individuals were facing other more pressing health conditions (Jacklin & Warry,

2012a; Pace et al., 2013). Among southern Inuit, dominant understandings related to perceptions that individuals with dementia were experiencing loss of self, identity, and connection to place, with a search for "home" as a recurring theme (Pace, 2020).

Most studies highlighted a mix of both traditional and biomedical understandings of dementias within Indigenous communities. For example, Secwepemc Elders from one community in BC spoke of two views of memory loss and dementia; a few held the traditional understanding of "going through the full circle" (of life), but most held the shémé (White) way of understanding dementia, and considered it a "White disease" problematized by "White settlers" (Hulko et al., 2010). In most of the existing studies, dementia was seen as a new disease brought



about through lifestyle changes stemming from contact with White settlers rather than resulting from physiological changes. For example, Cree grandmothers in one study identified a faster-paced lifestyle, increased consumption of junk food, and less physical exercise as causes of memory loss and dementia (Lanting et al., 2011), while Secwepemc Elders from another study identified a change in diets, accidents, age, alcohol and drugs, loss of oral culture, medications, pollution, and trauma (including residential schools) as root causes of dementia (Hulko, 2014; Hulko et al., 2010). Likewise, First Nations from diverse communities in Ontario identified changes to traditional ways of life, including sedentary lifestyles, environmental contamination, and reliance on store-bought foods as contributing to poor health and increases in dementias (Jacklin & Warry, 2012a; Pace, 2013; Pace et al., 2013). They also identified the changing roles of Elders in the community, whereby they were no longer keeping their minds active, as well as psychosocial factors such as grief, historical trauma, substance abuse, depression, and loneliness as contributing factors, in addition to genetics and physiology (Jacklin & Warry, 2012a; Pace et al., 2013).

The research suggests that geography and age may influence the degree to which either biomedical or traditional understandings predominate

within Indigenous communities. In their study assessing perspectives of dementias among diverse First Nations in Ontario, Jacklin and colleagues found that communities that were more isolated placed greater importance on traditional understandings of dementia as a natural part of aging, with few individuals recognizing it as a genetic, vascular, or brain disease (Jacklin et al., 2014a; Jacklin & Warry, 2012a; Pace, 2013; Pace et al., 2013). In contrast, greater emphasis was placed on physiological explanations of causation and medicalized explanatory models in the more accessible southern communities (Jacklin et al., 2014b). This may be due, in part, to the differential access that some communities had to resources and the degree to which physicians and specialists were involved in public education, diagnosis, and care for people with dementia (Jacklin & Warry, 2012a). Stevenson and colleagues (2015), in their research on perceptions and understanding of early onset familial Alzheimer's disease (EOFAD) among members of a large Tahltan First Nations family in BC found that older community members had more traditional understandings of dementias, while younger community members based their understanding on Western biomedical frameworks. While Western biomedical understandings of EOFAD predominated in the community, traditional concepts about

maintaining and promoting wellness were upheld simultaneously (Cabrera et al., 2015; Stevenson et al., 2015).

The diverse understandings that Indigenous Peoples hold about dementias may have impacts on the degree to which stigma is associated with these diseases. However, while stigma presented some challenges in the treatment or diagnosis of some First Nations dementia patients, especially among those with substance abuse issues (Alcock, 2014; Bourassa et al., 2015; Cabrera et al., 2015; Health Council of Canada, 2013; Stevenson et al., 2013, 2015), other studies indicated that the disease was not highly stigmatized among First Nations (Jacklin & Walker, 2020; Jacklin et al., 2013b). As noted by Olson and Albensi (2020), no stigma was associated with the disease until it was labelled as 'dementia.'

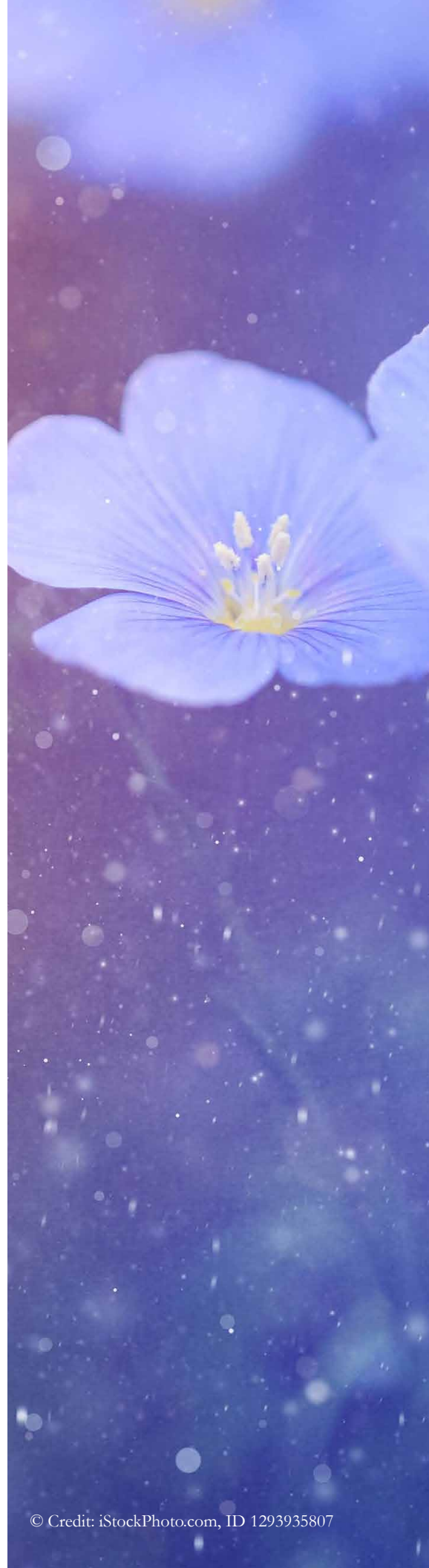
There is also a dearth of research on Indigenous understandings of healthy aging (Hillier & Al-Shammaa, 2020); however, this limited body of research indicates that First Nations, Inuit, and Métis peoples viewed health holistically, emphasizing physical, mental, emotional, and spiritual components as well as relationships at multiple levels. Key components of healthy aging for First Nations included: continued ability to participate in social and cultural events and maintain meaningful

relationships with others (Jacklin et al., 2014a, 2014b; Jacklin et al., 2013b; Pace 2013); meaningful intergenerational social engagement and social roles (Cornect-Benoit et al., 2020; I-CAARE, 2017); participation in land-based cultural activities (Jacklin et al., 2014a); being respected (Pace, 2013); imparting wisdom, mentoring youth, and supporting youth healing (Abonyi & Favel, 2012); as well as good overall health, positive attitude, sense of purpose, keeping busy, and staying engaged in life (Pace et al., 2013; Jacklin et al., 2013b). Healthy aging also incorporated elements of autonomy, control, and adaptability (Pace, 2013). First Nations on Manitoulin Island viewed the process of growing older as shaped by beliefs related to the Medicine Wheel and the Seven Grandfather Teachings<sup>3</sup>, which collectively emphasize balance, acceptance, and maintaining purpose in one's life by being socially, physically, spiritually, intellectually, and emotionally engaged (Pace, 2012).

Inuit and Métis peoples held similar views on what constituted healthy aging. Key components of healthy aging for Inuit included: 1) intergenerational transmission of knowledge (Collings, 2001); 2) low probability of disease and

related disability, high cognitive and physical functional capacity, and active engagement with life (Rowe & Kahn, 1997 as cited in Somogyi et al., 2015); 3) positive attributes often associated with Elder status (i.e., wisdom), good emotional health, and respect in the community (Somogyi et al., 2015); 4) family relationships, social support, adequate housing conditions, having safe community conditions that promote physical activity and well-being, having access to health services locally, attending community events, and being on the land (Baron et al., 2020); as well as 5) engagement, activity, good health, positive attitude, and social connection (Pace, 2020). Culture was seen as contributing to healthy aging for Inuit by protecting against cognitive decline and supporting the maintenance of identity for people with dementia (Pace, 2020). Among Métis, Edge and McCallum (2006) identified ongoing contributions to community life, intergenerational knowledge transmission, and maintaining social relationships as important for aging well (Edge & McCallum, 2006), while Owusu (2020) highlighted the importance of land and attachment to place in supporting wholistic health and wellness and fostering resiliency

<sup>3</sup> The Seven Grandfather Teachings area set of teachings on human conduct towards others based on wisdom, love, respect, bravery, honesty, humility and truth. For further information on how each of these teachings emphasize holistic health, please refer to <https://nhbp-nsn.gov/seven-grandfather-teachings/>





among elderly Métis living in Île-à-la-Crosse, Saskatchewan.

Just as culture influences Indigenous people's perceptions of dementia, cultural perspectives on healthy aging and social relationships also influence their perceptions of caregiving. In existing studies, First Nations, Inuit, and Métis individuals expressed a preference for aging in place, with the support of family, friends, and community members (Alcock, 2019; Jacklin et al., 2014a; Jacklin et al., 2015a; Jacklin & Walker, 2012; Pace, 2013; Jacklin & Walker, 2020, Pace, 2020). Aging in place has benefits for both the individual and the community, including improving quality of life, preventing traumatic removal to a care facility, maintaining some independence and control, and enhancing cost-effectiveness (Vanleerberghe et al., 2017 as cited in Bourassa et al., 2021, p. 208). It also confers protective benefits related to cognition in that individuals have access to well-established social networks and familiar places (Pace, 2020). However, significant pressures and barriers exist at family, community, health system, and social policy levels to aging in place, including out-migration of youth, lack of family caregivers, shortage of healthcare providers

and programs, changing community values, limited access to provincial health services and culturally relevant and safe care, financial constraints, and a lack of educational resources and supports for caregivers (Habjan et al., 2012; PHAC, 2019).

Studies also indicate strong expectations of care within Indigenous communities, and a preference for informal caregiving over institutionalized caregiving. In studies with First Nations communities in Ontario, caregiving was perceived as rooted in cultural values such as empathy, compassion, love, patience, and acceptance, and thus was viewed by many family members in positive ways, as a responsibility (Habjan et al., 2012; Jacklin & Chiovitte, 2020; Jacklin et al., 2015a; Pace, 2020). For example, Jacklin and Walker (2012) found that among First Nations study participants in Ontario, informal caregivers were culturally valued and had a positive view of their roles and responsibilities. They perceived institutionalized caregiving as problematic because it interrupted intergenerational knowledge transmission and undermined the important role of Elders in their community. Jacklin and Warry (2012b) found a strong preference for cultural approaches to care,

including family and community care models, respect for Elders, and use of traditional medicine among dementia patients, caregivers, and healthcare providers in First Nations sites in Ontario. First Nations and Métis caregivers in another study

emphasized the importance of family, intergenerational kinship and caregiving, and viewed institutionalized caregiving as problematic due to issues related to continuity of care, cultural safety, and discrimination (Alcock, 2019). Strong cultures

and expectations of care within community and preferences for cultural approaches to care can influence the type of information that care providers will need (Stevenson et al., 2015).



# BARRIERS AND FACILITATORS OF KNOWLEDGE TRANSLATION AND EXCHANGE ABOUT DEMENTIA CARE AND MANAGEMENT IN INDIGENOUS COMMUNITIES

Knowledge systems and knowledge sharing play important roles in delivering effective dementia care (Finkelstein et al., 2012). Four key stakeholder groups are typically involved in the knowledge sharing process – healthcare providers, clients, family care providers, and community members (Finkelstein et al., 2012). Stakeholders hold varying levels of knowledge related to dementias in Indigenous contexts. The different knowledge that each stakeholder has must be shared across groups, and any knowledge needs and gaps must be addressed to achieve effective and culturally appropriate dementia care and management in Indigenous communities. Forbes et al. (2013) present a culturally sensitive model for sharing dementia care information that shows the directions in which knowledge must flow between the various stakeholder groups in First Nations communities. The model is prefaced on the

assumption that persons with dementia should have a right to have a voice and be enabled to participate in decisions that are important to them. It is based on three broad themes: 1) developing trusting relationships to provide the essential foundation for the sharing of knowledge; 2) overcoming barriers to accessing the information by adapting it to the local context; and 3) applying the information in ways that capitalize on cultural and contextual opportunities.

Efforts to enhance knowledge exchange in Indigenous settings can be challenged by several unique barriers, including cultural/linguistic, geographic, and educational barriers (Beatty & Berdahl, 2011; Bottenberg, 2021; Bourassa et al., 2021; Jernigan et al., 2020; Webkamigad et al., 2020a, 2020b). These barriers can result in an underutilization of elderly care services and facilities, reduced access to dementia-related resources and

information, as well as reduced understanding and uptake of dementia information by Indigenous people. In turn, knowledge exchange can be facilitated by undertaking diverse actions for overcoming these types of barriers through building relationships, enhancing communication and coordination, and incorporating culture into services and educational initiatives. This section discusses the barriers and facilitators of knowledge exchange that have been identified in Indigenous communities.

## Barriers to knowledge translation and exchange

Several cultural and linguistic factors were identified as barriers to knowledge translation and exchange. There may be a lack of dementia resources and information available for individuals who speak and understand only an Indigenous language, or there may be

*Lack of knowledge and awareness about dementia within Indigenous communities may lead to stigma associated with the disease, which in turn can pose a significant barrier to seeking health information and services for individuals experiencing symptoms.*

difficulty translating words related to dementia and dementia care into Indigenous languages, making it more challenging to share knowledge about dementia effectively to Indigenous clients (Butler et al., 2011; Cammer, 2006; Cattarinich et al., 2001). Failures on the part of health educators to account for cultural attitudes towards health, dementia, or the nature and effect of complex familial relationships in dementia care, can affect the ability of health messaging related to dementia prevention and management to resonate with Indigenous audiences (Andrews et al., 2010; Butler et al., 2011). Additionally, there may be cultural differences in communication styles, acceptable word usage, and preferences for communication modes that health communicators should be aware of to increase the effectiveness of messaging (Jacklin et al., 2014b; Webkamigad et al., 2020a).

Geographical location may pose challenges for health communication between dementia patients, their caregivers, and healthcare providers. Many Indigenous people live in remote, isolated,

or northern locations, which often experience a high turnover of nurses, resulting in reduced familiarity with older members of the community (Andrews et al., 2010), as well as inequitable access to health services and healthcare providers. This limits opportunities to access dementia information and resources (Forbes et al., 2013; Jacklin & Warry, 2012a; Jernigan et al., 2020) and maintain in-person contact (Butler et al., 2011). The geographic distribution of the population in these locations can make comprehensive outreach difficult (Stevenson et al., 2013). Additionally, challenges associated with ensuring patient confidentiality in small communities, where everyone knows each other, can also present barriers to knowledge exchange (Butler et al., 2011; Stevenson et al., 2013). In contrast, Indigenous individuals living in more centrally located communities may have better access to dementia information and resources because they are within the service region of local Alzheimer Societies, which play a major role in public education efforts related to dementia (Jacklin et al., 2014b).

The varying levels of education and degrees of knowledge that each of the various stakeholders in the knowledge exchange process have, and the failure to share that knowledge among other stakeholders also presents a barrier to knowledge exchange in Indigenous contexts. Local physicians and nurses may lack specialized knowledge about dementia or about resources that might be available that they can refer their patients to (Andrews et al., 2010; Bourassa et al., 2021). They might also lack knowledge about how to provide culturally appropriate dementia care (Hulko et al., 2021; McAtackney et al., 2021). Differences in levels of education between Indigenous patients and caregivers compared to healthcare providers may pose literacy barriers and challenges related to communicating highly technical concepts effectively (Butler et al., 2011; Cattarinich et al., 2001; Pace et al., 2019). Lack of knowledge and awareness about dementia within Indigenous communities may lead to stigma associated with the disease, which in turn can pose a significant barrier to seeking health information and services for individuals experiencing symptoms (Alcock, 2014; Bourassa et al., 2015; Cabrera et al., 2015; Health Council of Canada, 2013). Caregivers and older Indigenous adults may not know there are specific dementia supports and services available that they can access, including



how to access culturally safe geriatric care and dementia diagnosis, and how to access traditional medicines, healing, and practices (Alcock, 2019; Shrestha et al., 2020). There may be failures to share knowledge among parties involved in the knowledge transfer process resulting from a lack of collaboration and coordination among and between the various health providers (Alcock, 2014; Beatty & Weber-Beeds, 2012; Dal Bello-Haas et al., 2014; Finkelstein et al., 2012; Health Council of Canada, 2013; Stolee et al., 2020). The legacy of colonialism, including mistrust in mainstream health care services and providers and experiences of racism and discrimination encountered in healthcare systems, is also a significant barrier to accessing health services and information in Indigenous settings (Bottenberg, 2021; Bourassa et

al., 2015; Cammer, 2006; Olson & Albensi, 2020; Webkamigad et al., 2016).

### Facilitators of knowledge translation and exchange

Facilitators of knowledge translation in Indigenous communities include building relationships between patients, caregivers, and healthcare providers; enhancing communication and coordination across stakeholders; and incorporating culture into the provision of dementia care services and dementia health education initiatives. Developing trusting and therapeutic relationships with patients, caregivers, and healthcare providers is central to the knowledge exchange process (Abram et al., 2012; Forbes et al., 2013). Some ways of developing meaningful relations

and interactions include taking time to explain medications and discuss treatment plans, connecting in a deeper and spiritual way, considering the impact of trauma on clients, and having a respectful, caring, and supportive approach (Forbes et al., 2013; Webkamigad et al., 2020b). Developing relationships also entails learning how to address communication barriers among the various stakeholders.

Several elements of enhancing communication and coordination across stakeholders were identified. Communication can be enhanced between healthcare providers and Indigenous clients by improving cross-cultural communication skills (Valle & Cook Gait, 1998; Webkamigad et al., 2020a, 2020b). For example, Webkamigad et al. (2020a) highlighted the importance of using a two-eyed seeing approach



and consulting with Elders to ensure that dementia resources use terms that are considered acceptable to particular groups of First Nations, Inuit, and Métis peoples, and that language is supportive of peoplehood and understanding of relational care. It can also be enhanced by: maintaining consistency of care and care providers; ensuring sustainability of community programs; bringing services and information closer to home by shifting resources from acute care to the community and long-term care; having a supportive network between patients, caregivers and community members; and resolving any disagreements in how people with dementia are cared for and who has power of attorney (Forbes et al., 2013). Better integration of health services can also enhance communication between on-reserve health practitioners and off-reserve health institutions (Finkelstein et al., 2012).

Since culture shapes Indigenous people's perspectives on dementia, healthy aging, and preferences for caregiving, incorporating culture into health services provision and

the development of dementia resources can help facilitate knowledge exchange. This can include:

- using a culturally sensitive, holistic, client- and family-centred approach that recognizes the importance of spirituality (Forbes et al., 2013);
- understanding cultural attitudes towards health and dementia and incorporating these into dementia resources in addition to biomedical understandings of the disease (Butler et al., 2011; Cabrera et al., 2015; Hulko et al., 2010; Jacklin & Warry, 2012a; Jacklin et al., 2015b; Lanting et al., 2011);
- decolonizing health information by prioritizing Indigenous knowledge in the development of health promotion materials (Webkamigad et al., 2020a);
- using language that accounts for literacy and education levels (Korhonen, 2006; Jacklin et al., 2015b; Webkamigad et al., 2020b);
- incorporating the client's cultural practices, beliefs, values, and language into knowledge sharing approaches (Forbes et al., 2013; Jacklin & Chiovitte, 2020; Stevenson et al., 2013);
- emphasizing Indigenous Peoples' relationship-centred concepts and approaches to dementia care, which prioritize family and community involvement over person-centred care and focus on connections between health and place, the spirit world, tradition and culture (Hulko et al., 2019; Pace, 2020);
- utilizing First Nations, Inuit, and Métis or distinctions-based preferences of communication styles and modes (Webkamigad et al., 2020b);
- utilizing strategies that are community-based and draw on the strengths of First Nations, Inuit, and Métis communities, including the role of Elders (Goldberg et al., 2018; Johnston et al., 2019; McElhane et al., 2021); and



- acknowledging the cultural and linguistic diversity between and amongst First Nations, Inuit, and Métis communities (Browne et al., 2017; Johnston et al., 2019; Goldberg et al., 2018).

Additionally, actions to overcome First Nations, Inuit, and Métis people's mistrust in mainstream health services is also central to communicating health information effectively. Ensuring that Indigenous people experience cultural safety in their encounters with the mainstream healthcare system has been identified as critical to addressing this mistrust and improving their knowledge about dementias (Bottenberg, 2021). Cultural safety means providing an environment that is spiritually, socially, emotionally, and physically safe for patients and clients (Williams, 1999).

Some examples of actions that can foster cultural safety include:

- reflecting on how healthcare providers' own cultures, attitudes, and beliefs about others affect their practice (Curtis et al., 2019; Faculty of Health, 2013);
- ensuring clear, open, and respectful two-way communication, developing trust and respect, treating clients with dignity, and recognizing there is more than one way of doing things (Faculty of Health, 2013; Greenwood et al., 2017; Williams, 1999);
- ensuring that the health services delivery environment is culturally appropriate and welcoming (Williams, 1999; Greenwood, 2019);
- using culturally appropriate prevention and diagnosis protocols (Bottenberg, 2021; Bourassa et al., 2021);

- emphasizing client empowerment, patient self-determination, and active participation in health care decision-making (Williams, 1999; Smith et al., 2021); and
- paying attention to the roots of health and health care inequities, such as the impacts of colonization on socio-economic marginalization, intergenerational trauma, and ongoing racism and discrimination to improve quality of care and health outcomes (Alcock, 2014; Bourassa et al., 2015; Forbes et al., 2013; Jacklin & Chiovitte, 2020).

Collectively, these types of actions can reduce barriers that influence health care seeking behaviour, improve health literacy, and facilitate uptake of health information.

# KNOWLEDGE NEEDS AND GAPS RELATED TO DEMENTIA CARE IN INDIGENOUS SETTINGS

Alzheimer's disease and age-related dementia resources and health promotion materials tailored to meet the needs of Indigenous populations are often requested by caregivers, older adults, nurses, personal support workers, and researchers (Jacklin et al., 2014a, 2014b, Pace et al., 2013); yet, culturally appropriate resources are often lacking, especially in more isolated and remote locations (Finkelstein et al., 2012; Forbes et al., 2013; Jacklin & Chiovitte, 2020; Webkamigad, 2017). Addressing gaps in knowledge can help build caregiver capacity and enhance responses to dementia at various potential intervention points in the disease's development, including preventing dementia, promoting healthy aging, encouraging early diagnosis, improving dementia literacy, delaying the progression of symptoms, enhancing quality of care and life, supporting caregivers, and preventing caregiver burnout (Jacklin & Chiovitte, 2020). This section discusses the knowledge needs of Indigenous dementia patients and caregivers, healthcare providers, community members,

and program developers and policy makers identified in the literature. While some of the knowledge needs span multiple target audiences, others are unique to specific groups. This section also discusses any existing gaps in knowledge that need to be addressed through research to improve optimal care and the development of culturally appropriate dementia education resources and programs.

## Knowledge needs and gaps of Indigenous dementia patients and informal care providers

Given Indigenous Peoples' preference for informal family care for individuals experiencing cognitive decline, and their holistic perceptions of aging well, more culturally appropriate education and training resources are needed with respect to dementia and dementia care to provide optimal care and promote health and well-being. Lack of knowledge about dementia and available supports and services in Indigenous communities can result in late interventions

for dementia patients and underutilization of available supports by caregivers who may not know that supports exist (Alcock, 2019; Finkelstein et al., 2012).

The literature review identified a paucity of studies that explicitly aimed to identify knowledge needs and gaps of First Nations, Inuit, and Métis dementia patients and their caregivers, and the few that did so focused on the knowledge needs of First Nations only. For example, Abram et al. (2012) aimed to assess the health information needs of healthcare practitioners, caregivers, and dementia patients in one on-reserve First Nations community; the work of Jacklin and colleagues (see for example, Jacklin et al., 2014b) examined the knowledge needs of several First Nations communities in Ontario; and Stevenson et al. (2015) examined the knowledge needs of informal caregivers and family members with EOFAD in one Tahltan community in BC. In the "Living with Dementia in Rural First Nations Communities: A Health and Wellness Project," students

from the University of Manitoba's physical and occupational therapy program visited Pinaymootang First Nations to conduct research on the types of programs that might benefit those living with dementia, resulting in the creation of a dementia toolbox of educational resources for caregivers (Bolt, 2021). While Abram et al. (2012) found that stakeholders in one First Nations community in southwestern Ontario were receiving culturally appropriate information, services and supports, enabling dementia patients to remain largely in their homes with the support of family and friends, the degree to which First Nations, Inuit, and Métis dementia patients and informal care providers are able to access culturally appropriate dementia resources and information remains largely unknown. Nevertheless, a number of studies did suggest areas where knowledge could be improved among Indigenous patients and their caregivers related to dementias.

Collectively, a wide variety of knowledge needs were identified for First Nations, Inuit, and Métis peoples across the various stages of the dementia care journey. Prior to a dementia diagnosis, culturally appropriate information about dementia prevention is needed (Jernigan et al., 2020). At the beginning of the dementia journey, Indigenous patients and caregivers need information to help them recognize they need assistance to facilitate

earlier diagnosis and care. This includes information to enhance awareness of dementia, the types of dementia, and symptoms (Finkelstein et al., 2012; Jacklin & Walker, 2020; Pace, 2013; Webkamigad et al., 2020b); Indigenous models of explaining dementia (Jacklin et al., 2016); the process and availability of predictive genetic testing for EOFAD (Stevenson et al., 2015); where to go for referrals (Forbes et al., 2013); and how to approach primary care practitioners about symptoms or concerns and assist someone receiving news of a diagnosis (PHAC, 2019).

Following a diagnosis, caregivers require access to different types of resources and education to help them care for someone living with dementia and optimize quality of life. This includes information about:

- the trajectory of the disease, how to slow its progression, and how to plan for the needs of loved ones across the various stages of the disease (Finkelstein et al., 2012; Jacklin & Chiovitte, 2020; Jacklin & Walker, 2020; Jacklin et al., 2014b; Pace, 2013; Webkamigad et al., 2020b);
- how to navigate the healthcare system and other in-community and external supports (McAttackney et al., 2021; PHAC, 2019);

- how to provide care for dementia patients, including culturally responsive caregiver interventions (Browne et al., 2017) and better resources and tools to assist with daily living and therapies (PHAC, 2019);
- how dementia will impact individuals with the disease mentally, emotionally, physically, and spiritually (Webkamigad et al., 2020b);
- strategies to maintain memory, improve well-being, and enhance quality of life for dementia patients (Abram et al., 2012), including eating healthy foods, engaging in physical activity, engaging in activities dementia patients enjoy, maintaining a purpose in life, having social contact, and reducing stress, as well as resources that are tied to traditional teachings, spirituality, and Indigenous cultural values and promote holistic health (Alcock, 2019; Pace, 2013; Webkamigad et al., 2020b);
- the benefits of cultural activities and languages to improve quality of life, improve mental and physical health, ground individuals in their place and time, and stimulate memories and reminiscence of dementia patients (Pace, 2020; Starblanket & Legare, 2019);

- strategies for coping with symptoms and behaviours to ensure respectful care (Pace 2013), and responding to and preventing challenging or violent behaviour (PHAC, 2019);
- how to determine competency of the patient to make life and legal decisions (Forbes et al., 2013; Jernigan et al., 2020);
- the latter stages of the dementia care journey, including care options once the disease progresses to the point of needing 24-hour care, and end-of-life decisions (Forbes et al., 2013); and
- how to support transitions to long-term care (PHAC, 2019).

Caregivers of individuals with alcohol-related dementia may have unique knowledge needs given that this form of dementia is caused by past excessive alcohol use and typically leads to earlier onset of dementia (Cheng et al., 2017; Ridley et al., 2013). As a result, these patients may not be eligible for specific services and resources available to seniors' populations and require information about how to manoeuvre the healthcare system in this context (Alcock, 2014).

*Additional information and resources are needed to protect caregiver well-being and promote self-care. This information must be made available early in the dementia care journey so that caregivers can potentially access it sooner.*



Additional information and resources are needed to protect caregiver well-being and promote self-care. This information must be made available early in the dementia care journey so that caregivers can potentially access it sooner (Alcock, 2019; Cammer, 2006). This includes information on where to go for help, when to seek out extra supports, types of supports available locally and how to access or use them, including adult day programs, respite programs, and education programs (PHAC, 2019); as well as coping strategies to help deal with caregiver burnout (Alcock, 2019; Finkelstein et al., 2012). Since the majority of caregivers are female,<sup>4</sup> information about how to access financial supports and programs is also needed (Alcock, 2019).

### Knowledge needs and gaps of healthcare providers

Health services delivery in rural, remote, and Indigenous

communities is often characterized by differential access to and use of family physicians, a need to travel to larger urban centres for specialty services, and a reliance on health care provided by nurses (NCCIH, 2019). The level of knowledge and skills that the various healthcare providers who work in these settings may have to provide high quality and culturally-relevant dementia care may vary widely, affecting their ability to provide optimal care (Finkelstein et al., 2012; Hulko et al., 2021). This section focuses on the knowledge needs of healthcare providers working in Indigenous communities identified in the literature. Again, few studies explicitly aimed to assess the knowledge needs of healthcare providers working in northern, remote, and Indigenous settings (Abram et al., 2012; Dal Bello-Haas et al., 2014). The few that did focused on enhancing the knowledge of health practitioners working with First Nations clients.

<sup>4</sup> Women and men live in different structural contexts, with women generally experiencing an unequal distribution of opportunities, constraints, and responsibilities, including additional childcare and household responsibilities, reduced personal wealth and less likelihood of having full-time employment (Alpass et al., 2013). When coupled with a cultural expectation of informal caregiving, this context can result in greater emotional and financial stresses for women with reduced access to fewer personal and social resources to cope with those stresses, leading to lower levels of psychological and physical health compared to male caregivers (Alpass et al., 2013; Ibáñez et al., 2021).



One study assessed the knowledge needs of healthcare providers in rural and remote areas of Saskatchewan, including two First Nations communities, and found that one-third of physicians were not comfortable diagnosing and managing patients with dementia (Dal Bello-Haas et al., 2014). This finding hints at a potential lack of capacity within Indigenous communities to diagnose and manage patients with dementia, especially in the context of insufficient access to physicians and specialists. Several studies highlighted the need for resources, education programs, and training opportunities to enhance the knowledge and skills of local health practitioners to better prepare them for providing optimal dementia care. This included the following:

- additional training on dementias for healthcare staff working in Indigenous communities, especially for workers offering respite care (Bourassa et al., 2021; Jacklin et al., 2014b; Pace et al., 2013);
- enhanced knowledge and skills to assist with early identification of clients with dementia to improve quality of life and facilitate access to appropriate services and supports (Alcock, 2019), including: culturally appropriate guidelines on how to diagnose dementia; evidence-based best practices and standards for care; and assessment tools (including for non-English speaking individuals and their families); as well as knowledge about dementia across the care pathway from diagnosis through to end of life to reduce stigma and improve the quality of care (Bradley et al., 2020; Dal Bello-Haas et al., 2014; Jacklin et al., 2020; PHAC, 2019);
- continuing education opportunities on topics related to dementia (Dal Bello-Haas et al., 2014);
- information and education to help practitioners assess the needs of the family and the ability of caregivers to continue in this role, as well as identify, recognize, and offer supports to families (Alcock, 2019; Blind, 2017; Forbes et al., 2013);
- information about services and supports available to Indigenous dementia patients with substance abuse issues (Alcock, 2019);
- information about unsafe behaviours so that family members can be alerted and encouraged to address safety issues (Forbes et al., 2013);
- information on how to integrate services to enhance communication between on-reserve health practitioners and off-reserve health institutions (Finkelstein et al., 2012); and
- information on how to provide culturally appropriate dementia care within specific Indigenous communities (Hulko et al., 2021; McAtackney et al., 2021).

Additionally, healthcare practitioners require educational and training opportunities to overcome some of the barriers to accessing health care services and information that are rooted in lack of trust and lack of cultural

safety in health care encounters. This includes:

- information about Indigenous social determinants of health and colonial histories to facilitate understanding about the root causes of dementia and foster empathy (Alcock, 2014, 2019; Jacklin et al., 2016);
- training on how to develop effective communication with dementia patients in cross-cultural contexts, including cultural etiquette and respect for informal roles of communication such as storytelling (Cattarinich et al., 2001; Gaspard et al., 2021; Hulko et al., 2021), working with knowledge brokers,<sup>5</sup> culturally attuning dementia-care messages, intercultural outreach and networking, and intercultural engagement<sup>6</sup> (Valle & Cook Gait, 1998; Webkamigad et al., 2020a);
- cultural safety training specific to the communities being served to ensure healthcare providers develop trusting relationships with their clients and overcome stigma associated with substance use among healthcare providers (Alcock, 2019);

- cultural awareness training to address racism and systemic barriers to care and facilitate respectful communication between patients and healthcare providers (Bourassa et al., 2015; Cammer, 2006); and
- information to ensure people feel welcomed and well-cared for when hospitalization or admission to long-term care is necessary (PHAC, 2019), including best and promising practices for integrating cultural norms and traditions into long-term dementia care (Alcock, 2019; Browne et al., 2017).

## Knowledge needs and gaps of Indigenous communities

Indigenous communities may feel unprepared and poorly equipped to deal with individuals who have dementia (Hulko et al., 2010; Sutherland, 2007, as cited in Jacklin & Walker, 2020). Research has highlighted the importance of community-based dementia education programs and resources in the prevention and management of dementia in Indigenous communities (Johnston et al., 2019). Such

programs and resources can help reduce the stigma and stress associated with dementia because community members will know what to expect and the focus will be shifted from dealing with dementia once symptoms become worse, to reducing the risk of dementia through health promotion (Alcock, 2019). These should be developed based on each community's understanding of dementia and include suggestions for how to modify risk factors and care for community members with dementia, with consideration of their unique cultures, values, strengths, assets, and priorities (Goldberg et al., 2018; Johnston et al., 2019). The specific knowledge needs of Indigenous communities identified in the literature focus on both prevention and management aspects of dementia. These include:

- increased awareness of the disease among all age groups in public education materials to help reduce stigma associated with the disease, improve access to care, delay the progression of the disease, improve health outcomes, and optimize quality of life. Topics of education include the various types of dementia, the

<sup>5</sup> Knowledge brokers are individuals who assist in the knowledge translation and exchange process by promoting interaction between researchers and end users. They help develop a mutual understanding of goals and cultures, collaborate with end users to identify issues and problems that require solutions, and facilitate the “identification, access, assessment, interpretation, and translation of research evidence into local policy and practice” (Dobbins et al., 2009, p. 1).

<sup>6</sup> Intercultural outreach, networking, and engagement here refer to various processes used by researchers and health educators to solicit input and feedback from relevant individuals, organizations, and communities in order to tailor communication and messaging to be culturally appropriate for those specific audiences.

symptoms of dementia, what causes it, and the progression of the disease (Alcock, 2019; Cammer, 2006; Pace, 2012; PHAC, 2019; Stevenson et al., 2015);

- public health education on strategies to reduce the risk of developing dementia, including information on how lifestyle choices influence risk, how to make supportive environments to pursue healthy living (PHAC, 2019), and the use of traditional teachings and spirituality to promote holistic health (Pace, 2013);
- resources to support community caregiving (Jacklin & Chiovitte, 2020);
- strategies for ensuring active engagement of those with dementia to maintain dignity and autonomy (PHAC, 2019);
- resources tailored to youth so as to bridge the knowledge gap between older and younger generations (Stevenson et al., 2015);
- public health education on predictive genetic testing for EOFAD (Stevenson et al., 2015); and

- how to make communities age friendly and ensure individuals and businesses interacting with people with dementia do so with compassion, ease, and confidence (PHAC, 2019).

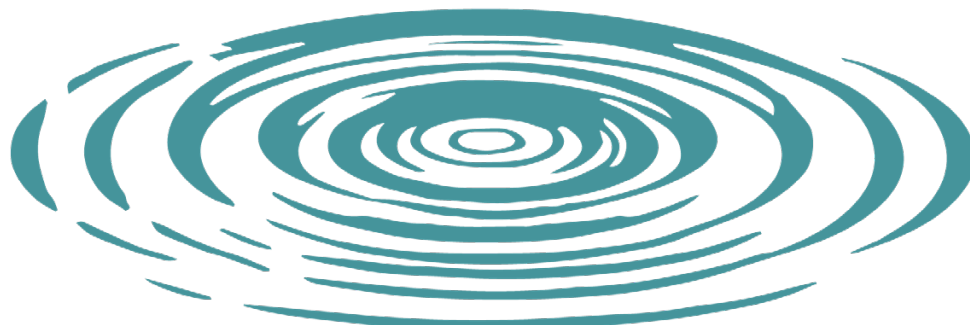
## Knowledge needs and gaps of policy makers and program developers

In addition to the knowledge needs identified above, the literature also identified a diverse range of knowledge gaps for policy makers and program developers related to dementia in Indigenous communities. Many of these knowledge gaps require additional research; however, research priorities should be established with broad stakeholder input, including those with dementia and their caregivers (PHAC, 2019) and Indigenous communities (Jacklin & Bourassa, 2017). Addressing these knowledge gaps will inform not only the development of dementia policies, programs, and services, but also the development of culturally

appropriate and evidence-based resources for Indigenous persons with dementia, their informal caregivers, health professionals, and community members.

Incorporating culturally grounded understandings of dementia into dementia resources can help reduce stigma and promote familial and community caregiving, yet there is a paucity of research examining Indigenous interpretations and understandings of dementia beyond the perspectives of some First Nations (Jacklin & Walker, 2020; Racine et al., 2020). Addressing this knowledge gap is important for formulating distinctions-based responses and services for First Nations, Inuit, and Métis peoples and communities.

Program developers and policy makers need information about developing effective dementia prevention and intervention activities. There is a paucity of research evaluating the effectiveness of prevention and intervention activities (Jacklin & Walker, 2012), with none focused on Indigenous interventions.

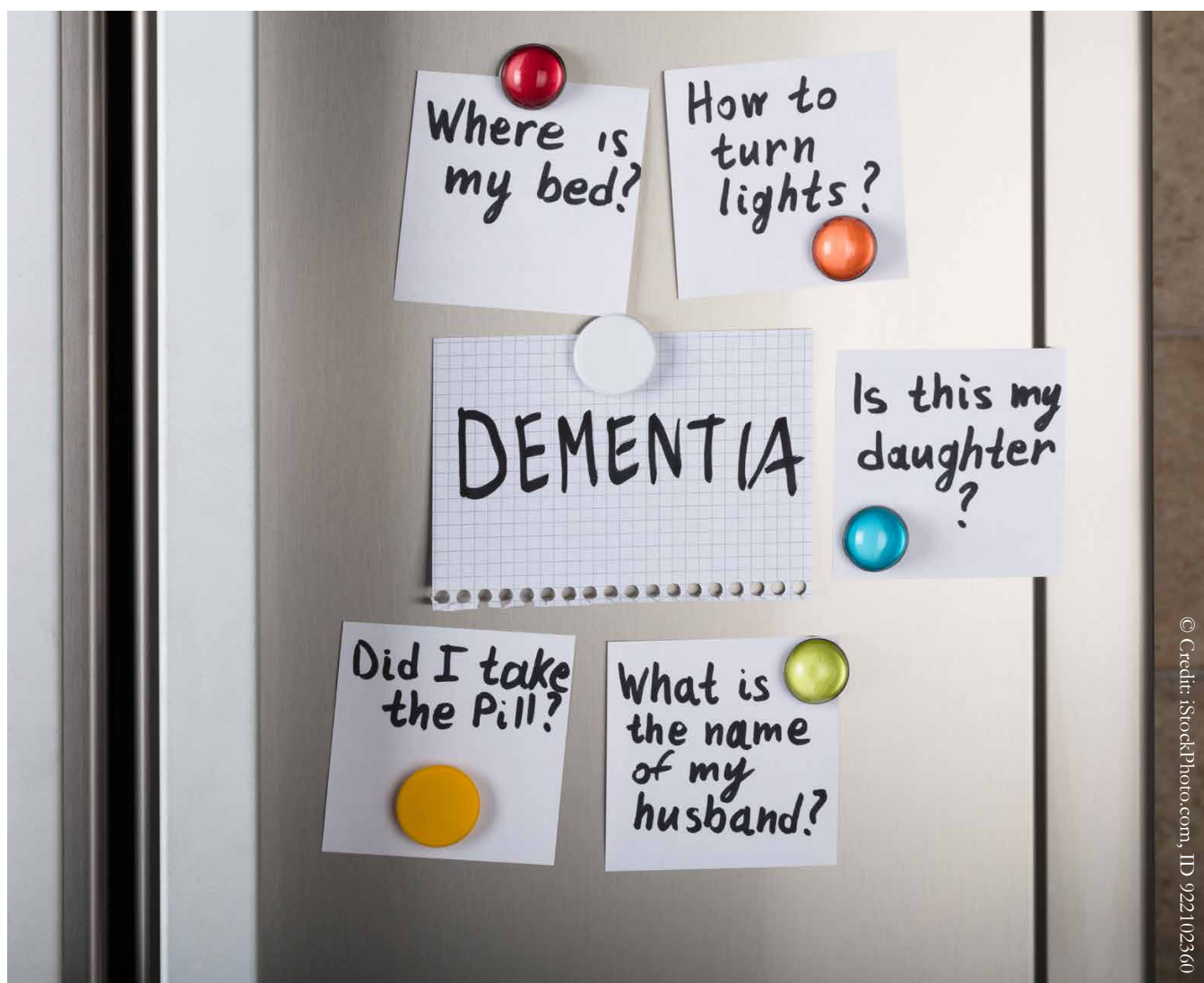


Browne et al. (2017) identified the need for research on culturally responsive caregiver interventions that address dementia care, while Jacklin and Walker (2020) recognized the need for research on how to include Indigenous medicine and ceremony in care. The shortage of evidence-based dementia interventions, best practices, and therapies as well as effective interventions to support quality of life for those living with

dementia and their caregivers were also identified as research priorities by the Public Health Agency of Canada (2019).

With the recent development of a national dementia strategy, research will also be needed to track progress on the strategy, assess the impacts of activities, and plan future dementia policies, programs, and services (PHAC, 2019). This includes

better surveillance and data on groups that are differentially impacted by dementia and at risk of developing the disease, including where they are located and whether trends are increasing or decreasing. It also includes research on the effects of dementia in communities and evaluations of the impact of community-based projects that seek to optimize the well-being of patients and caregivers.



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# CONSIDERATIONS FOR DEVELOPING CULTURALLY APPROPRIATE DEMENTIA RESOURCES



Communicating health information in culturally appropriate ways is an important aspect of delivering culturally safe dementia services. By considering the diversity of Indigenous Peoples' languages, cultures, health literacy levels, experiences, and preferences in health communication, intended messages can be conveyed in ways that better resonate with First Nations, Inuit, and Métis audiences, thus increasing uptake and effectiveness of that information within those populations (Gould et al., 2012; Maar et al., 2016; Smylie, 2018). This section focuses on considerations for improving health literacy in First Nations, Inuit, and Métis contexts.

One of the key considerations for health communication relates to where individuals prefer to seek out information. Their preference may depend on a number of contextual factors, including the nature of the information needed, the intended audience, the remoteness and size of communities, and the availability of diverse knowledge resources within communities.

Several studies found that First Nations preferred a face-to-face approach to receiving dementia education, from someone they had developed a trusted connection with (Alcock, 2019; Forbes et al., 2013; Webkamigad et al., 2016). Webkamigad et al. (2016) found that Anishinaabe caregivers and older adults in the Sudbury, Ontario region preferred dementia education to be carried out by means of family-centred group sessions, supplemented by dementia health promotion material situated within the framework of the Medicine Wheel, which draws upon the Seven Grandfather Teachings to exemplify how individuals can live a healthy life. Forbes and colleagues (2013) found that in a small First Nations community in southwestern Ontario, a face-to-face approach to knowledge sharing with someone who is trusted in the community was more effective than attendance at support groups due to the stigma associated with dementia. They also found that informal care providers tended to seek out information about dementia from local healthcare providers and physicians or

from family members with health care experience rather than from internet and print resources. Webkamigad et al. (2020b) suggested that general information, such as health promotion resources related to dementia, should be widely available at the community level – in doctors' offices, at the Alzheimer Society, in the Health Unit, and at Indigenous organizations such as the Aboriginal Peoples' Alliance of Northern Ontario and Aboriginal health centres. Given the diverse nature of health information, effective health promotion requires a mix of both human and material resources (Webkamigad, 2017; Webkamigad et al., 2020b).

To be culturally appropriate, communication tools must account for any potential cultural, geographic, social, educational, and linguistic factors that might affect Indigenous people's understanding about dementia (Lanting et al., 2011). They must be sensitive to a person's readiness and capacity to accept and understand the information, with information tailored to the



*Utilizing a two-eyed seeing approach in the development of dementia education resources, one that gives equal consideration to both Indigenous and biomedical knowledges, is advocated as a way of decolonizing dementia education.*

specific needs of the patients and their care providers (Forbes et al., 2013). This includes consideration of Indigenous cultures and language, education levels, protocols around rules and social behaviours, and preferred communication styles (Cattarinich et al., 2001). Information should be provided in the patient's language to ensure it is accurately conveyed and achieves a level of patient comfort (Jacklin et al., 2014a). It should be presented in an engaging and accessible format (Webkamigad, 2017, Webkamigad et al., 2020b). Communication about dementias in Indigenous communities may be more effective if it is in shorter presentations, in understandable

plain language or in alternative mediums with more culturally appropriate content (Jacklin et al., 2014a, 2014b; Stephenson et al., 2015). Written resources in Indigenous languages may be more useful for individuals who are fluent in those languages, but many Indigenous people prefer verbal communication (Webkamigad et al., 2020b). Cross-cultural barriers can also be overcome by using rich visual images<sup>7</sup> from local Indigenous cultures or culturally effective styles of education, such as visiting, sharing, teachings, and storytelling methods (Lanting et al., 2011; Webkamigad et al., 2020b).

Mackie and colleagues (2012) and Cabrera et al. (2015) highlighted the importance of blending both Indigenous and Western knowledge about risk, diagnosis, and care for people with dementia into the design of resources. In their research that aimed to develop resources to aid First Nations individuals and families in a northern BC community in making decisions about EOFAD, Cabrera et al. (2015) found that biomedical knowledge around the disease shaped people's knowledge and understanding of the disease and helped decrease stigma in the community by fostering more open discussion around the disease and strategies.

<sup>7</sup> Rich visual images are graphical tools that use images and cartoons to tell a story that conveys information. Research has shown that such images can help enhance learning and understanding of information among target audiences (Sheldon et al., 2017; Song & Turner, 2010).

Traditional knowledge, values, practices, and beliefs were more important for approaches to wellness and caregiving, especially the importance given to family and community care and to the land as a source of healing. For example, a biological definition of family might be central to determining who might be at risk of EOFAD, but this definition might undermine Indigenous Peoples' identity and social structures that support EOFAD care. Traditional and biomedical knowledge complemented each other to maintain wellness among Indigenous dementia patients. The authors noted that it was important to seek guidance from Elders and community members on how to incorporate both biological and social definitions of family into these resources. Utilizing a two-eyed seeing approach in the development of dementia education resources, one that gives equal consideration to both Indigenous and biomedical knowledges, is advocated as a way of decolonizing dementia education (Alcock, 2019; Blind, 2017; Jacklin & Chiovitte, 2020; Webkamigad et al., 2020a).

Since oral methods of communication have been identified as the preferred mode of communication for some First Nations (Alcock, 2019; Forbes et al., 2013), public outreach and awareness campaigns may be effective ways of increasing awareness about dementia, its symptoms, and progression to the general public and informal caregivers. However, if awareness campaigns are to be useful, adequate support services must be in place to meet the needs of communities (Alcock, 2019; Bourassa et al., 2019). This emphasizes the importance of community consultation in the development of education strategies and communication tools for ensuring they are appropriate for meeting community needs. To be effective, oral methods of communication also require improved cross-cultural communication, built on establishing connections at a deeper cultural level through relationship building, trust, respect, listening, humour, storytelling, and offerings (Alcock, 2019; Webkamigad, 2017; Webkamigad et al., 2020b).

The very limited research suggests that healthcare providers serving in Indigenous communities may prefer to access their information from different sources than Indigenous families and community members. Webkamigad et al. (2016) found that employees of the Home and Community Care Centre accessed their information through continuing education opportunities, either through formal education or workshops. In a study assessing dementia care needs among formal and informal care providers residing in rural and remote areas of Saskatchewan, Dal Bello-Haas et al. (2014) found that the majority of physicians (83%) and non-physician healthcare providers (80%) indicated they would like more continuing education opportunities. Physician respondents preferred these opportunities to be provided in workshop format, with approximately one-third indicating they would like these opportunities to be provided locally. Non-physician healthcare providers preferred these opportunities to be provided in either workshop or telehealth format, offered locally.

# EXAMPLES OF EXISTING DEMENTIA EDUCATION, TOOLS, AND RESOURCES

This section focuses on existing dementia education, tools, and resources that may be useful in Indigenous contexts in Canada. Currently, few culturally appropriate tools and resources related to dementias and Indigenous Peoples have been developed, though likely more will be developed in the near future to respond to the federal government's national dementia strategy. This section also explores general Canadian dementia tools and resources, as well as some international Indigenous-specific examples.

## Culturally appropriate dementia education and resources in Canada

In Canada, dementia education, tools, and resources that are culturally appropriate and/or tailored to meet the needs of Indigenous populations have been developed by Indigenous and non-Indigenous research groups, various Alzheimer's Associations, provincial and territorial governments, and non-Indigenous health organizations. These include resources for Indigenous dementia patients,

caregivers, and healthcare providers, available in both written and video formats, as well as dementia resource repositories and training programs.

The Canadian Consortium on Neurodegeneration in Aging (CCNA), launched in 2014 by the Canadian Institutes for Health Research as a national network of researchers focused on enhancing understanding of dementias and improving quality of life for dementia patients, includes a research focus on issues in dementia care for Indigenous populations. This team of researchers is focused on improving diagnosis and surveillance of dementia in Indigenous populations; developing culturally safe, trauma-informed approaches to addressing dementia; understanding connections between cultural and societal factors that influence wellness in the progression and expression of dementia; and building capacity for Indigenous dementia research (CCNA, 2021).

Researchers associated with the Indigenous Cognition and Aging Awareness Research Exchange (I-CAARE) group, also part of

the CCNA, undertook research with Indigenous communities on dementias in Ontario and Saskatchewan. They explored aspects of Indigenous cultures, knowledges, spirituality, and ceremony related to quality of life; adapted the Kimberley Indigenous Cognitive Assessment (KICA) tool for use by Canadian healthcare providers to diagnose dementia in Indigenous contexts in Canada; determined how many Indigenous people had dementia and where and how they got help; and investigated the use of technology tools for managing dementia among older Indigenous adults. Their findings informed the development of a number of culturally appropriate health information resources on dementias, including: presentations on community-based dementia research; fact sheets on dementia signs and symptoms, First Nations perspectives of dementia, dementia prevention, and dementia care; a fact sheet on aging well; training modules for health professionals working with Indigenous people and their families; practice tools; as well as reports and published articles from research undertaken by the I-CAARE team in First Nations



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communities on dementias. These resources can be accessed at <https://www.i-caare.ca/>. The adaptation of the KICA tool resulted in the development, testing and clinical validation of a new Canadian Indigenous Cognitive Assessment tool (Jacklin et al., 2020; Walker et al., 2021).

A series of YouTube videos are available on dementia and dementia care in Indigenous contexts across North America and Australia. These can be accessed from [https://www.youtube.com/results?search\\_query=Indigenous+%26+dementia](https://www.youtube.com/results?search_query=Indigenous+%26+dementia)

The Rural Dementia Action Research (RaDAR) group from the University of Saskatchewan provides access to a range of resources on dementia care, within both Indigenous and non-Indigenous contexts.

These include resources to help support caregivers and health professionals, such as on detecting cognitive change in Indigenous people and dementia management, as well as clinical guidelines and a protocol designed to detect cognitive change in Indigenous people. These can be accessed at <https://cchsa-ccssma.usask.ca/ruraldementiacare/RaDAR%20Publications.php> and <https://cchsa-ccssma.usask.ca/ruraldementiacare/research-and-projects/RaDAR%20Projects.php>

The *BrainXchange*™ is a network of researchers, educators, caregivers, policy workers, and people with lived experience who are dedicated to improving the quality of life for people with or at risk of brain-health issues related to dementia, mental health, and neurological

conditions associated with aging. They have an online Resource Centre, which provides access to presentations and resources related to dementia and culturally safe care in Indigenous communities, as well as dementia resources for the general population. Indigenous resources can be accessed at <https://brainxchange.ca/Public/Resource-Centre-Topics-A-to-Z/Indigenous-Communities>

The Illes Group of the National Core for Neuroethics, University of British Columbia Faculty of Medicine, has undertaken several projects related to dementia in Indigenous populations, including cross-cultural understandings of aging and dementia, and ethical issues in dementia care for Indigenous populations. Their website provides access to a variety of resources on these topics, including presentations, publications, and resources

for families and communities (<https://neuroethics.med.ubc.ca/res/>). They also produced “The Mind Thief: A kid’s guide to Alzheimer’s disease,” a comic book about dementia to raise awareness among young children about the disease (<https://med-fom-neuroethics.sites.olt.ubc.ca/files/2015/08/GTP-The-Mind-Thief-s1.pdf>) and “Wellness in early onset familial Alzheimer Disease: Experiences of the Tahltan First Nation,” a report presenting findings from a study exploring the experiences of the Tahltan First Nation about early onset familial Alzheimer Disease (<https://med-fom-neuroethics.sites.olt.ubc.ca/files/2015/08/GTP-Wellness-in-EOFAD-s.pdf>).

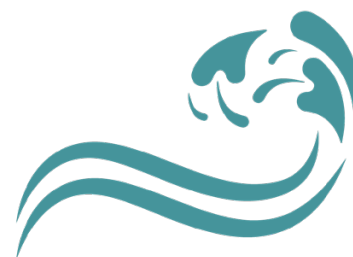
Several provincial and territorial governments have released information handbooks for Indigenous seniors about services they qualify for and how to access them. This includes the Government of Nunavut’s *Seniors Information Handbook* (<https://www.gov.nu.ca/eia/documents/nunavut-seniors-information-handbook>) and the First Nations Health Authority & Seniors BC’s *BC Elders’ guide, 1<sup>st</sup> edition* ([https://www.fnha.ca/WellnessSite/WellnessDocuments/BC\\_EldersGuide.pdf](https://www.fnha.ca/WellnessSite/WellnessDocuments/BC_EldersGuide.pdf)).

Cancer Care Ontario has developed a *Palliative care toolkit for Indigenous communities* (<https://www.cancercareontario.ca/en/guidelines-advice/treatment-modality/palliative-care/toolkit-aboriginal-communities>), with information and resources for First Nations, Inuit, and Métis families and communities to help support people with palliative care needs. While targeted specifically at individuals with cancer, the toolkit provides some information that may be useful in the context of advanced dementia, including Indigenous definitions of palliative care, personal stories and resources to develop capacity in palliative care and cope with grief and loss, information to support decision-making and planning, and information to help caregivers care for their loved ones.

The Native Women’s Association of Canada (NWAC) has produced several resources related to dementia. It released findings from a 2010 study that aimed to fill gaps in knowledge about how Indigenous people conceptualized neurological conditions, the impacts on their families and communities, and the resources and supports needed to provide culturally safe and appropriate care (NWAC,

2013). They also released two fact sheets related to dementia: 1) Caregiver Dementia Fact Sheet, which provides information for maintaining caregiver wellness; and 2) Dementia Fact Sheet, which provides information on what dementia is, its symptoms, what causes it, risk factors, and Indigenous views on dementia. These can be accessed at: <https://nwac.ca/knowledge-centre>.

Several other Indigenous-specific dementia resources also exist. The First Nations Health Authority produced a video on Gitksan understandings of dementia and caring for a family member living with the disease to help educate First Nations audiences ([https://www.youtube.com/watch?v=0XqYd1wo\\_Uw](https://www.youtube.com/watch?v=0XqYd1wo_Uw)). The Ontario Caregiver Organization has developed resources for Indigenous caregivers, including resources on Indigenous health services providers, links to resources and websites with information on health conditions, mental health resources, and Canadian caregiver organizations (<https://ontariocaregiver.ca/resources-for-indigenous-caregivers/>).



## General Canadian dementia resources

Other dementia-related tools and resources have been developed for the general Canadian population. While these are not necessarily tailored to the needs of Indigenous populations, they can nevertheless be useful to Indigenous populations or tailored to their contexts. These include resources for dementia patients and caregivers, training resources for care providers, and resources for the development of dementia policies and programs.

### Resources for dementia patients and caregivers

*Alzheimer's Association – Canada Division*

This website provides access to a wide range of resources on dementias for people with dementia, caregivers, family members and healthcare practitioners, including information about symptoms, types of dementias, risk factors, diagnosis, treatment and support, caregiving, and tips for living well. <https://www.alz.org/ca/dementia-alzheimers-canada.asp>



*Alzheimer Society of Canada, First Link® Program*

The First Link program provides information and referrals for individuals who receive a diagnosis of Alzheimer's disease, linking them to relevant health and social resources in their community, and raising awareness and understanding about dementia. <https://alzheimer.ca/en/help-support/programs-services/first-link>

*Dementia Connections*

This website provides access to resources related to dementia prevention, maintaining well-being for patients and caregivers, interventions to improve quality of life, and access to services and resources in the Calgary area. <https://dementiaconnections.ca/>

*Alzheimer Society of Alberta and the Northwest Territories' Community Dementia Ambassador Program*

This program connects persons with dementia living in rural and remote areas and their families and caregivers to various services, supports, and resources. Ambassadors receive training related to dementia and use this knowledge and skills to build capacity among caregivers, build connections and relationships in communities, and address cultural values about dementia and community norms at the local level (PHAC, 2020). The program has been active in three communities, with four dementia ambassadors, two of whom are Indigenous language speakers (PHAC, 2020). Information about the program can be accessed at [https://alzheimer.ca/ab/en/help-support/programs-services#Community\\_Dementia\\_Ambassador\\_Program](https://alzheimer.ca/ab/en/help-support/programs-services#Community_Dementia_Ambassador_Program)



## Training resources

### *Shine a Light on Dementia*

Offered in the Yukon, this free training program aims to enhance knowledge and skills of caregivers to provide quality care for people with dementia. It focuses on topics related to the onset, development, and progression of dementia; approaches and strategies for caregivers; grief management and self care for caregivers; legal and financial matters; and palliative care. Information about accessing the program can be found at <https://www.yukonu.ca/programs/courses/just-ce100>

### *ALZeducate, Online Dementia Care Training Program for Health Care Professionals*

Offered by the Alzheimer Society of Toronto, this online course aims to enhance knowledge and skills and improve quality of care for people with dementia among personal support workers and other frontline healthcare providers. This includes skills pertaining to person-centred care, aspects of aging, Alzheimer's disease and dementia, the impacts of dementias on a person's life, how to respond to challenging behaviour, supportive care strategies, and communication strategies when working with someone with dementia. <http://www.alzeducate.ca/>

### *City of Vancouver and the Alzheimer Society of BC. (n.d.). Dementia-friendly city train the trainer workbook*

The Train the Trainer program aims to provide facilitators who offer training to frontline staff information they need to more effectively serve people living with dementia. This tool provides a model for delivering the Dementia-Friendly City Train the Trainer program. <https://vancouver.ca/files/cov/cs-social-policy-dementia-friendly-city-train-the-trainer-workbook.pdf>

## Policy resources

### *Canadian Caregiver Coalition. (2013). Canadian Carer Strategy*

This document outlines a vision for addressing the needs of family caregivers in Canada, guided by principles of respect, choice, and self-determination. The strategy is based on five key elements: 1) safeguarding the health and well-being of family caregivers; 2) minimizing their financial burden; 3) enabling access to user friendly information and education; 4) creating flexible workplaces and educational environments for caregivers; and 5) investing in research on family caregiving as a foundation for evidence-informed decision-making. [https://www.homecareontario.ca/docs/default-source/Family-Caregiving/cc-caregiver-strategy\\_v4.pdf](https://www.homecareontario.ca/docs/default-source/Family-Caregiving/cc-caregiver-strategy_v4.pdf)

### *Alzheimer Society of British Columbia. (2016). Dementia-friendly communities local government toolkit*

This toolkit provides local governments with actions for making their communities more supportive of people with dementia. It describes what dementia is, what makes a dementia-friendly community, and why it is important to do so. It then outlines the process for implementing a dementia-friendly community strategy, and provides some urban and rural case study examples and other resources. <https://alzheimer.ca/bc/en/take-action/dementia-friendly-communities/become-dementia-friendly-municipality/local-government>

### *Government of Alberta, Alberta Dementia Strategy and Action Plan*

This document outlines the Government of Alberta's priorities and actions for improving dementia diagnosis and care and enhancing supports for families, caregivers, and communities. <https://www.alberta.ca/alberta-dementia-strategy-and-action-plan.aspx>

### *Ministry of Health, Government of British Columbia. (2016). Provincial guide to dementia care in British Columbia: Achievements and next steps*

This document sets the BC Provincial Government's direction for planning dementia care services and supports in the



province. It outlines priorities and deliverables for reducing the risk of dementia and improving quality of life for dementia patients, their families, and caregivers. <https://www.health.gov.bc.ca/library/publications/year/2016/bc-dementia-care-guide.pdf>

*Federal/Provincial/Territorial Ministers Responsible for Seniors. (n.d.). Age-friendly rural and remote communities: A guide*

This document is intended for individuals and groups in rural and remote locales who are interested in making their communities more age-friendly. It describes what is meant by “age-friendly” and helps communities identify common barriers and assets to becoming age-friendly, with the aim of fostering dialogue and action towards this goal. [https://www.phac-aspc.gc.ca/seniors-aines/alt-formats/pdf/publications/public/healthy-sante/age\\_friendly\\_rural/AFRRC\\_en.pdf](https://www.phac-aspc.gc.ca/seniors-aines/alt-formats/pdf/publications/public/healthy-sante/age_friendly_rural/AFRRC_en.pdf)

*Public Health Agency of Canada. (2019). A dementia strategy for Canada: Together we aspire*

This document outlines the federal government’s vision, principles, priorities, and actions for a national dementia strategy that focuses on optimizing quality of life for people living with dementia and their caregivers and facilitating prevention

and effective treatment of the disease. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html>

The Public Health Agency of Canada is required to report annually on progress. Their first progress report, *A dementia strategy for Canada: Together we achieve – 2020 annual report*, highlights initiatives to date focused on dementia education, public awareness, and improving quality of life for both patients and caregivers. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy-annual-report-parliament-june-2020.html>

*Standing Senate Committee on Social Affairs, Science and Technology. (2016). Dementia in Canada: A national strategy for dementia-friendly communities*

This document reports findings from the Standing Senate Committee’s examination of the issue of dementia in Canadian society, as heard from a broad range of experts, including First Nations. The report discusses the impact of dementia on Canada and globally; the types, symptoms, diagnosis, and progression of dementia; and current efforts to address dementia. [https://sencanada.ca/content/sen/committee/421/SOCI/Reports/SOCI\\_6thReport\\_DementiaInCanada-WEB\\_e.pdf](https://sencanada.ca/content/sen/committee/421/SOCI/Reports/SOCI_6thReport_DementiaInCanada-WEB_e.pdf)

*Canadian Academy of Health Sciences. (2019). 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*

This report reviews existing evidence and emerging best practices and gaps relevant to dementia in Canada to inform national dementia strategic priorities. The report discusses six overarching themes: 1) promoting research, initiatives, and best practices related to dementia; 2) recognizing the centrality of respectful engagement with persons with dementia and their caregivers; 3) addressing dementia as a determinants of health issue; 4) ensuring the availability of an adequately trained and supported dementia workforce; 5) balancing research investments across multiple domains equitably; and 6) utilizing evidence to implement a dementia strategy. <https://cahs-acss.ca/wp-content/uploads/2019/04/REPORT.pdf>

An addendum to this assessment includes a series of commissioned papers focusing on *Improving the quality of life and care of persons living with dementia and their caregivers*. <https://cahs-acss.ca/wp-content/uploads/2019/04/Addendum.pdf>

## International Indigenous dementia resources

While not many Indigenous dementia health promotion/ education training resources exist in Canada, other countries, such as Australia and the United States, have devoted considerable effort to developing Indigenous health promotion, education, and training resources related to dementias for Indigenous people with dementia, family members, and caregivers, as well as frontline health and community workers. Many of these incorporate physical, mental, emotional, spiritual, and cultural components and might be useful in the Canadian context, including activities for patients with dementia to improve quality of life, tips for reducing the impact of behavioural and psychological symptoms for caregivers, information about the disease and its progression, as well as prevention and mitigation information.

### **Australian Indigenous HealthInfonet, Dementia resources**

This website includes culturally appropriate resources focused on dementia awareness, support guides for caregivers, symptoms as the disease progresses, prevention and mitigation, as well as guidelines for dementia diagnosis and care, learning resources, and an Indigenous

cognitive assessment tool. <https://healthinfonet.ecu.edu.au/learn/health-topics/dementia/resources/>

**Alzheimer’s Association – North Carolina Chapter**, North Carolina American Indian Health Board, Wake Forest School of Medicine, and University of North Carolina School of Medicine, (n.d.). Memory loss and Alzheimer’s disease in Native People

This booklet aims to help American Indian people understand more about Alzheimer’s disease and recognize the early signs of memory loss, drawing from the personal experiences of individuals who have been affected by the disease. The booklet emphasizes the importance of early detection. <https://alz.org/media/Documents/Memory-Loss-and-Alzheimer-s-Disease-in-Native-People.pdf>

### **National Ageing Research Institute, Inc., Dementia**

This website provides access to culturally appropriate resources for healthcare providers for improving the quality of dementia care for Indigenous people, including an Indigenous cognitive assessment tool, information for e-interpreting during dementia assessments, and dementia prevention resources. <https://www.nari.net.au/pages/search.aspx?q=indigenous>

### **National Indian Council on Aging, Inc.**

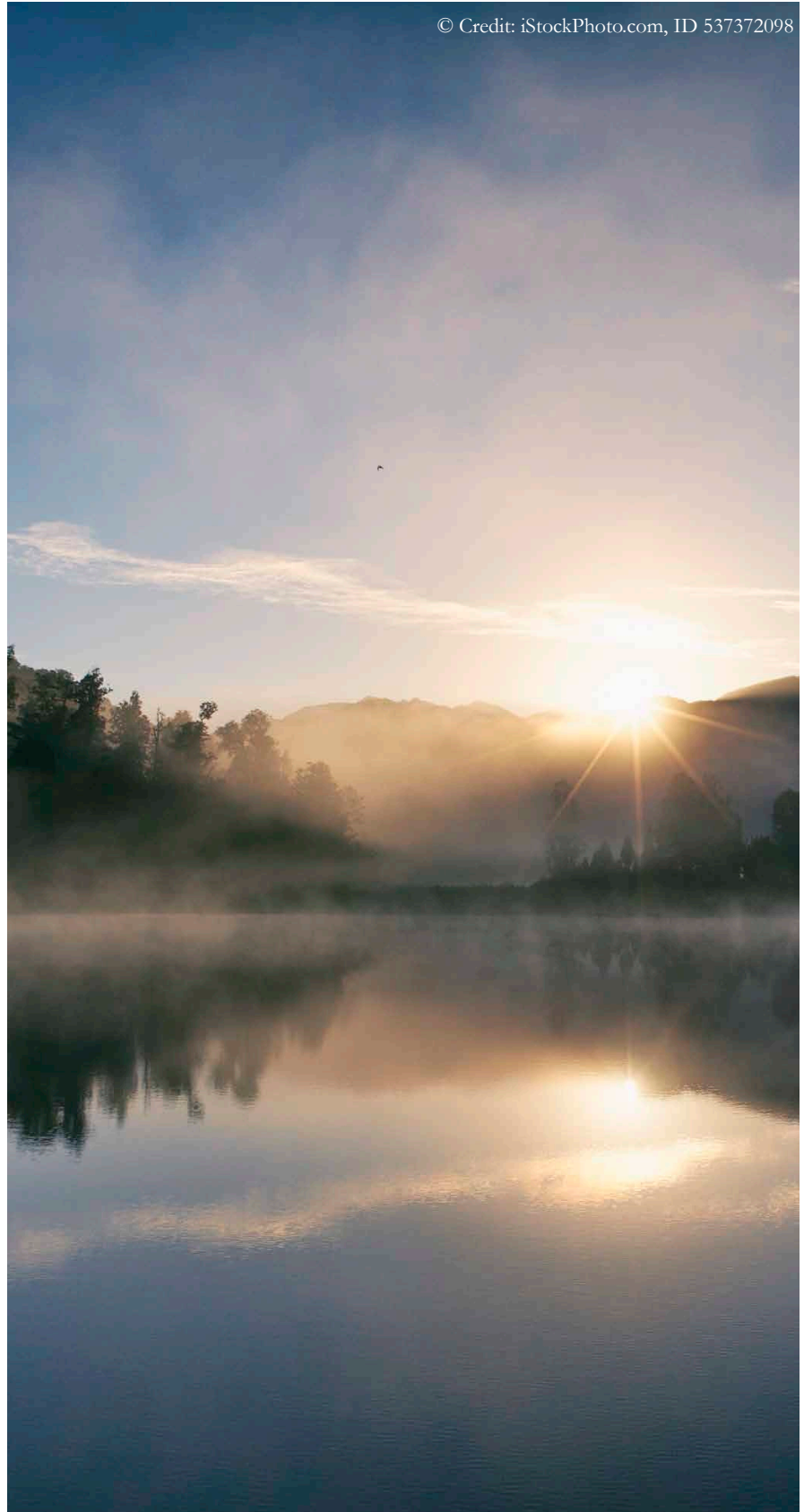
The National Indian Council on Aging is a nonprofit organization focused on the needs of aging American Indian and Alaska Native Elders. Their website (<https://www.nicoa.org/>) provides access to several Elder resources, including information on Alzheimer’s disease and access to related resources, as well as the *Savvy caregiver in Indian country trainer’s manual, Part One* (<https://nicoa.org/wp-content/uploads/2014/04/Savvy-Caregiver-Part-1.pdf>) and *Part Two* (<https://nicoa.org/wp-content/uploads/2014/04/Savvy-Caregiver-Part-2.pdf>).

### **National Resource Center on Native American Aging, *Native Elder Caregiver Curriculum***

The National Resource Center on Native American Aging is a nonprofit organization that provides education, training, and technical assistance for individuals and organizations working to improve the quality of life and delivery of related support services to the Native aging population. They developed The Native Elder Caregiver Curriculum to support families and community members, especially informal caregivers, in caring for aging members of their community in ways that support quality of life. <https://www.nrcnaa.org/native-elder-caregiver-curriculum>

## International Indigenous Dementia Research Network

The IIDRN aims to enhance knowledge about Indigenous Peoples' understandings and experiences with dementia and impacts of the disease on individuals and communities, with the aim of improving the quality of dementia care. Their website provides access to a diverse range of resources and publications produced by members of the network, reporting on issues related to dementia and caregiving, and other factors that influence the health of Indigenous seniors. <https://memorykeepersmdt.com/international-indigenous-dementia-research-network-iidrn/>





# CONCLUSION



Dementia is an emerging health issue in Indigenous communities that is expected to place increasing stress on families, caregivers, local healthcare providers, and community members. Knowledge sharing is considered a key component of delivering effective dementia care, yet many caregivers and health practitioners working in Indigenous communities in Canada have reported feeling they lacked knowledge, skills, and capacity to provide optimal care for individuals with dementia. Enhancing knowledge related to dementia can help build caregiver capacity and enhance dementia prevention and management responses in Indigenous communities. The federal government has recognized the differential impact that dementias are having on certain populations, including Indigenous populations. It has committed to addressing knowledge needs and gaps related to dementia through engaging with Indigenous governments, organizations, and communities to develop dementia

care solutions and culturally appropriate information resources that are distinctions-based, prioritize human rights, and incorporate all types of evidence, including traditional knowledge and the experiences of those living with or caring for someone with dementia.

Many of the existing dementia knowledge resources are developed for the general population. Of the few resources that are tailored to meet the needs of Indigenous populations, almost all are focused only on First Nations, leaving a paucity of resources tailored to meet the unique needs and local contexts of other Indigenous populations, especially Inuit and Métis, and the needs of healthcare providers working in those communities. The existing resources do not account for the different understandings that First Nations, Inuit, and Métis people have of dementia, their perceptions of healthy aging, their preferences for cultural approaches to dementia care, or

their demographic, geographic, socio-economic, or health system contexts. It is also imperative that the diverse knowledge needs and gaps related to dementia experienced by the various stakeholders in the knowledge sharing process – Indigenous persons with dementia and their caregivers, local healthcare providers, community members, program developers, and policy makers – are addressed. Improving access to culturally appropriate dementia information is a key aspect of facilitating health equity. Communicating health information to Indigenous people in culturally appropriate ways can lead to more effective knowledge translation, and thus to reduced health inequalities for Indigenous Peoples (Webkamigad et al., 2020b). Additionally, to improve knowledge about dementia among Indigenous populations, broader system level changes are required to address current system level barriers to accessing health services and information for Indigenous people, including lower levels of education, inequitable access to health services and resources, lack of cultural safety, lack of trust in non-Indigenous health services and practitioners, and lack of integration and coordination across health institutions and services.

*Of the few resources that are tailored to meet the needs of Indigenous populations, almost all are focused only on First Nations, leaving a paucity of resources tailored to meet the unique needs and local contexts of other Indigenous populations, especially Inuit and Métis, and the needs of healthcare providers working in those communities.*

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