

OVERCOMING BARRIERS TO CULTURALLY SAFE AND APPROPRIATE DEMENTIA CARE SERVICES AND SUPPORTS FOR INDIGENOUS PEOPLES IN CANADA

Regine Halseth



National Collaborating Centre
for Indigenous Health



Centre de collaboration nationale
de la santé autochtone

CHRONIC AND INFECTIOUS DISEASES

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For further information or to obtain additional copies, please contact:

National Collaborating Centre for Indigenous Health (NCCIH)
3333 University Way
Prince George, BC,
V2N 4Z9 Canada

Tel: (250) 960-5250
Fax: (250) 960-5644
Email: nccih@unbc.ca
Web: nccih.ca

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Indigenous people have higher rates of many of the risk factors for dementias, including diabetes, midlife hypertension and obesity, physical inactivity, lower levels of education, and smoking

(Petrasek MacDonald, Barnes, & Middleton, 2015; Warren, Shi, Young, & Borenstein, 2015).

INTRODUCTION

Memory loss can sometimes occur as people age. This may be the result of the natural aging process or some medical conditions like Alzheimer's disease and other dementias. In these cases, memory loss can often be progressively degenerative and irreversible, affecting an individual's daily functioning. While dementias can occur in younger individuals, they more typically occur in seniors¹ (Alzheimer Society of Canada, 2017).

While little is known about dementias among Indigenous² populations in Canada, they are recognized as an emerging health issue within Indigenous communities (Jacklin & Walker, 2012; Jacklin, Walker, & Shawande, 2013; Jacklin, & Warry, 2012a/b). The Indigenous seniors population has been growing rapidly, more than doubling between 2001 and 2011 (O'Donnell, Wendt, & the National Association of Friendship Centres, 2017). Of the approximately 82,690 Indigenous seniors in 2011, 46% identified as First Nations, 45% identified as Métis, and 3% identified as Inuit (O'Donnell et al., 2017). Indigenous people have higher rates of many of the risk

factors for dementias, including diabetes, midlife hypertension and obesity, physical inactivity, lower levels of education, and smoking³ (Petrasek MacDonald, Barnes, & Middleton, 2015; Warren, Shi, Young, & Borenstein, 2015). As a result, the rates of dementias are expected to increase more rapidly for Indigenous people compared to non-Indigenous people. Further, Indigenous people face a host of barriers in accessing health care related to poverty, cultural and linguistic differences, racism and discrimination, and geography. These barriers affect their ability to access dementia care services and supports.

This paper aims to identify the challenges and barriers Indigenous people in Canada face in accessing culturally safe and appropriate dementia care services and supports, and suggest ways of overcoming them. Specifically, it will begin by providing an overview of the general challenges Indigenous seniors face in accessing health services. It will then summarize the literature on Indigenous perspectives of aging well and on caring for

loved ones with dementia, as an understanding of these perspectives is essential for developing programs and services that are responsive to Indigenous peoples' needs. The paper will conclude by identifying key elements of a culturally safe framework for dementia care in Indigenous communities and highlighting some examples of innovative dementia care services for Indigenous populations.

This paper draws on literature identified through a search of Pubmed, Medline and Google Scholar, 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 January 2017. However, because there is limited research in this area, information from Australia and the United States may occasionally be included. 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.

* On May 30, 2019, the National Collaborating Centre for Aboriginal Health (NCCA)H) officially became the National Collaborating Centre for Indigenous health (NCCIH).

¹ For the purposes of this paper, seniors are defined as anyone age 65 and older. However, it is important to recognize that age-related risk factors/health effects associated with dementia are evident in a significant proportion of the Indigenous population by midlife.

² 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.

³ For more information about the risk factors for dementias among Indigenous peoples in Canada, please refer to the NCCIH's companion paper, Alzheimer's disease and related dementias in Indigenous populations in Canada: Prevalence and risk factors (Petrasek Macdonald, Ward, and Halseth, 2018).

CHALLENGES AND BARRIERS TO DEMENTIA ASSESSMENT, DIAGNOSIS AND CARE IN INDIGENOUS COMMUNITIES

The literature identifies a number of challenges and barriers Indigenous people with dementia and their families face in accessing services related to dementia assessment, diagnosis and care. These include poorer health status, geographic isolation, socio-economic inequities, racism and discrimination, and jurisdictional issues. Many of these challenges are intimately connected with colonialism and its impacts (Petrasek MacDonald, Ward, & Halseth, 2018).

Health status

Indigenous seniors generally have poorer health than non-Indigenous seniors. The lasting impacts of colonization and residential schools, including a shift from a healthy traditional diet to a less healthy market-based one, a more sedentary lifestyle, mental health issues, addictions, poverty and family violence, have left Indigenous seniors with higher rates of chronic diseases and other conditions than non-Indigenous seniors. This includes diabetes, hypertension and obesity, which are

risk factors for the development of dementias (Health Council of Canada, 2013; Beatty & Weber-Beeds, 2012).⁴ Of Indigenous seniors participating in the 2012 Aboriginal Peoples' Survey (APS), 88% of women and 86% of men reported being diagnosed with at least one chronic condition, with high blood pressure and diabetes being the most commonly reported conditions (O'Donnell et al., 2017). While no single comprehensive assessment of obesity exists for Indigenous seniors, research suggests that obesity is more prevalent among Indigenous people compared to the general Canadian population, with estimated prevalence among adults aged 55 and over ranging from 27.2%-31.9% for selected Indigenous groups across multiple data survey tools (Public Health Agency of Canada & Canadian Institutes for Health Information, 2011). This poorer health status means that Indigenous seniors are more likely to have complex healthcare needs that must be met.



Geographic isolation

Indigenous seniors often live in regions where it is more challenging and expensive to provide care and address their health needs (Health Council of Canada, 2013; Jacklin & Warry, 2012b). While an increasing proportion of Indigenous seniors are living in population centres,⁵ they are less likely to do so (52% compared to non-Indigenous seniors (80%) (O'Donnell et al., 2017). Health services and programs are more limited in rural and remote locations, requiring many Indigenous seniors to travel to urban centres to access any health services beyond basic care, with significant disruption to their lives and at great costs, including financial burden, increased stress or anxiety, and/or physical discomfort (Morgan et al., 2009, 2011). A lack of local access to physicians and specialists, coupled with poor knowledge about dementia symptoms, the progression of the disease and how to care for individuals who have it among general practitioners and community members, can

⁴ For more information about the risk factors for dementias among Indigenous peoples in Canada, please refer to the NCCIH's companion paper, Alzheimer's disease and related dementias in Indigenous populations in Canada: Prevalence and risk factors (Petrasek Macdonald, Ward, and Halseth, 2018)

⁵ Defined as having at least 1000 people and no fewer than 400 persons per square kilometre (O'Donnell et al., 2017).

also result in a delayed diagnosis, poorer quality care, and impacts to the health of individuals and their quality of life (Cammer, 2006; Dal Bello-Haas, Cammer, Morgan, Stewart, & Kosteniuk, 2014; Pace, 2013). Accessing health services in urban centres may also be more challenging due to the elimination of, or cutbacks to, public modes of transportation in rural and remote areas.⁶ Additionally, communication and coordination barriers between community healthcare providers and urban healthcare services may result in a failure to share potentially pertinent knowledge with clients and families, impacting the smooth transition of Indigenous dementia patients from one healthcare setting to another (Dal Bello-Haas et al., 2014; Finkelstein, Forbes, & Richmond, 2012; Health Council of Canada, 2013).

Socio-economic, cultural and jurisdictional barriers and challenges

Formal senior care services and facilities are underutilized by some Indigenous seniors because of unique barriers such as lower levels of education, language and cultural differences, experiences with racism and discrimination in the health system, jurisdictional ambiguities over who pays for services accessed off reserve, and lack of affordability. Indigenous

Healthcare providers who lack an understanding about the historic experiences or the practical realities of Indigenous peoples' everyday lives may make inaccurate assumptions about Indigenous peoples' abilities to care for themselves or access services and resources, leading to ineffective, insensitive or poor quality care

(Alcock, 2014; Health Council of Canada, 2013).

seniors may have literacy and language barriers which affect their understanding of their health conditions and their willingness to seek help from service providers, making it difficult for them to navigate complex care systems and government bureaucracies on their own (Beatty & Weber-Beeds, 2012; Health Council of Canada, 2013). They may fear or mistrust western systems or healthcare personnel because of prior experiences with racism and discrimination within the healthcare system (Cammer, 2006; Finkelstein et al., 2012). Healthcare providers who lack an understanding about the historic experiences or the practical realities of Indigenous peoples' everyday lives may make inaccurate assumptions about Indigenous peoples' abilities to care for themselves or access services and resources, leading to ineffective, insensitive or poor quality care (Alcock, 2014; Health Council of Canada, 2013). The health system may also fail to

provide Indigenous seniors with opportunities to communicate in their own languages or to participate in ceremonies and eat traditional foods, activities which are seen as critically important social supports for maintaining Indigenous seniors' health and well-being (Health Council of Canada, 2013). Jurisdictional issues over who pays for health services has restricted access for some Indigenous people to specific programs, as Métis and off-reserve First Nations do not have access to the unique healthcare programs and services available to First Nations on reserve and Inuit (Health Council of Canada, 2013). Finally, poverty restricts Indigenous peoples' ability to pay for home services or better quality long-term care facilities (Andrews, Morgan, & Stewart, 2010; Health Council of Canada, 2013), as well as impacts the quality of care received from family caregivers (Beatty & Berdahl, 2011; Health Council of Canada, 2013).

⁶ Recently, Greyhound announced plans to pull passenger services out of parts of rural British Columbia, which has since been expanded to include loss of bus services to Alberta, Saskatchewan and Manitoba, cancelling all but one route in British Columbia.

THE CURRENT HEALTH SERVICES ENVIRONMENT FOR INDIGENOUS SENIORS WITH DEMENTIA



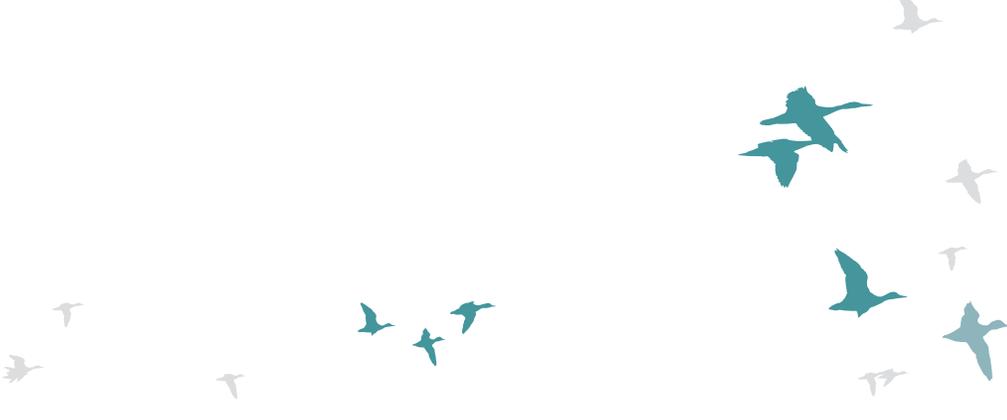
The services and programs currently available to assist Indigenous people with dementia and their caregivers vary widely across Canada. Jacklin and Warry (2012a) note that the historically low rates of dementias among Indigenous people have meant that their specific needs are often overlooked by mainstream service providers and by government funding agencies that provide services on reserve. In their research assessing dementia care in First Nations communities across Ontario, they found a “high degree of medical system involvement in public education, diagnosis and care for people with dementia” in southern communities, but more limited access in remote and northern communities (see also Jacklin, Warry, & Blind, 2014a/b; Pace, Jacklin, & Warry, 2013). Further, the services in remote and isolated communities tended to focus on primary health care rather than on the involvement of physicians and specialists, and towards seniors in general rather than accommodating the unique needs of dementia patients.

Consistent with this finding, the federal government offers three general programs that can provide some assistance to Indigenous people with dementias and their caregivers. The First Nations and Inuit Home and Community Care (FNIHCC) program, funded by the First Nations and Inuit Health Branch (FNIHB) of Health Canada, provides funding for home care services, including non-medical personal care services such as meal preparation, light housekeeping, respite care and minor home maintenance, as well as for institutional care for individuals living on a reserve or north of 60 degrees in a First Nations or Inuit community (Banerjee, 2007). Indigenous and Northern Affairs’ Assisted Living/Adult Care program plays a limited role in seniors care by providing institutional support and extended care for individuals requiring 24 hours of medical or nursing support. Additionally, the Non-Insured Health Benefits (NIHB) Program provides coverage to registered First Nations and Inuit for a range of medically necessary items and services

not covered by other plans and programs, including some medical supplies and equipment, drugs and pharmacy products, medical health counselling, and medical transportation to access medically necessary health services not available within the community.

Funding for these programs and services, however, has been thinly spread, resulting in numerous gaps in health care services with respect to the specialized care needs of older Indigenous adults and individuals with dementia, especially in more rural and remote Indigenous communities (Health Council of Canada, 2013). Not all rural and remote communities have continuing care or homecare services, and there is a lack of culturally appropriate and safe palliative care,⁷ with no funding available for end-of-life care through either the FNIHB or FNIHCC programs for palliative clients and their families (Beatty & Berdahl, 2011; Health Council of Canada, 2013). Individuals who are diagnosed with dementia before they are considered to be seniors face additional challenges such as

⁷ A palliative approach, which “focuses on comfort and quality of life for those affected by progressive, life threatening illness” is now considered to be best practice in the care of patients with advanced dementia (Alzheimer Society, New Brunswick, 2018, para. 1). The goal of palliative care is not only to control pain, but also to support the emotional, spiritual and cultural needs of the patient and maximize functioning.



lack of access to financial assistance for dementia care services and inappropriate services that do not consider the day-to-day realities of these patients' lives (Alcock, 2014). Chronic underfunding and excessive restrictions and bureaucratic processes with the NIHB program have resulted in denials and delayed approvals for health benefits and medical transportation, placing Indigenous seniors, many of whom live in poverty, at risk of worsening illness, admission to hospital, and reduced quality of life (Health Council of Canada, 2013). There is a lack of round-the-clock care or rehabilitation, respite, crisis support, emergency, and mental health services in Indigenous communities (Beatty & Berdahl, 2011; Finkelstein et al., 2012; Pace, 2013). While most Inuit living in Inuit Nunangat⁸ have access to culturally safe long-term care facilities in or near their communities, offering a familiar language and culture and allowing them to connect with their families and communities with relative ease, only approximately 1% of First Nations

reserve communities have access to such facilities (Health Council of Canada, 2013). Additionally, culturally appropriate dementia care resources that incorporate Indigenous knowledge are lacking (Finkelstein et al., 2012).

These gaps in service have meant that healthcare providers in underserved areas have had to develop adaptive strategies to deal with shortages in staff and other barriers to dementia care, such as working to overcome any mistrust clients and community members may have about mainstream health professionals and health systems, and developing their own resources (Finkelstein et al., 2012). Such measures are needed to encourage community members to become better educated about dementias and the importance of accessing care, as well as cope with the stresses of working in a poorly resourced health care environment.



⁸ Inuit Nunangat refers to the Inuit homeland, consisting of the four Inuit regions of Nunavut, Nunatsiavut (northern coast of Labrador), Nunavik (northern Quebec), and Inuvialuit (northern Northwest Territories) (Indigenous and Northern Affairs Canada, 2016).





In the case of Indigenous peoples with dementia, the development of culturally appropriate and safe models of care requires an understanding of Indigenous perspectives of aging well, as well as their preferences for caring for their loved ones with dementia.

CULTURALLY APPROPRIATE AND SAFE DEMENTIA CARE SERVICES AND SUPPORTS



It has become well recognized that the health care system has not been meeting the unique needs and priorities of Indigenous clients and, as a result, continues to contribute to ongoing health disparities. In recent decades, the concepts of culturally appropriate and safe care have emerged to address some of these health system shortcomings. While not yet universally adopted, the application of these concepts has the potential to reduce health disparities by addressing any barriers that may prevent Indigenous people from engaging in their care. This includes minimizing existing power imbalances between healthcare professionals and their Indigenous patients, fostering respectful and trusting relationships, and incorporating patients' values and perspectives into their care plans (Journal of Obstetrics and Gynaecology Canada, 2013; Truong, Paradies, & Priest, 2014; Yeung, 2016). Culturally appropriate and safe services acknowledge cultural differences and consider “the cultural identities, histories, and sociopolitical contexts of Indigenous people within their care” (Yeung, 2016, p. 2). In the case of Indigenous peoples with dementia, the development of culturally appropriate and safe models of care requires an understanding of Indigenous perspectives of aging well, as well as their preferences for caring for their loved ones with dementia. This section summarizes the literature on Indigenous peoples' perspectives of aging well and their preferences for dementia care.



Indigenous perspectives on aging well

Understanding how populations perceive aging well is important for understanding their health, healing and wellness needs (Abonyi & Favel, 2012). While perspectives of aging well differ among Indigenous peoples across Canada, there are several crosscutting themes. For many Indigenous people, aging well is not necessarily associated with having good health, but is shaped by beliefs related to the medicine wheel,⁹ including balancing physical, mental, emotional and spiritual realms (Abonyi & Favel, 2012; Collings, 2001; Edge & McCallum, 2006; Pace, 2012; Somogyi, Barker, MacLean, & Grischkan, 2015). Indigenous perceptions of aging well encompass elements of individual, family and community health, and highlight the importance of history, culture, language, and the successful transmission of knowledge to new generations (Abonyi & Favel, 2012).

The research exploring Indigenous perspectives on aging well is generally limited and focuses primarily on First Nations. A group of researchers associated with the Indigenous Cognition and Awareness Research Exchange (I-CAARE) have been exploring perspectives of



aging well among First Nations from diverse communities across Ontario. In their studies, First Nations seniors highlighted the importance of seeking spiritual, emotional, physical and mental balance in preventing dementias and empowering individuals to live a healthy life (Jacklin et al., 2014a/b; Pace, 2012, 2013; Pace et al., 2013). This includes: participating in cultural activities, speaking Indigenous languages, healing from current and historical trauma, maintaining meaningful relationships, using humour to diffuse stress and tension, having a positive attitude and willingness to accept changes to health and abilities, continuing to be engaged in community and social life, and

maintaining a sense of purpose in one's life. Additionally, the Seven Grandfather teachings of wisdom, love, honesty, respect, humility, bravery and truth played a central role in their perceptions of aging well. Elders expressed that these beliefs helped them accept the changes that occurred as they grew older. However, they noted that cultural changes affecting seniors' roles and relationships in their communities have had an impact on their health and their ability to age successfully (Pace, 2013; Pace et al., 2013). An outmigration of youth to urban centres has resulted in fewer caregivers, increasing the risk of loneliness and isolation for seniors (Health Council of Canada, 2013). Loneliness and isolation

⁹ While the 'medicine wheel' is typically associated with First Nations populations, its focus on the holistic health, including physical, mental, spiritual, and emotional dimensions, is shared widely across Indigenous cultures.

were seen as one of the biggest factors for ill health in old age, with both related to depression and cognitive decline (Jacklin et al., 2014 a/b).

Similar perspectives on aging well were echoed by First Nations Elders in regions across British Columbia. In this case, Elders indicated that being a cultural mentor, passing on wisdom and knowledge, eating healthy, having positive attitudes, living clean, family time, keeping active, mental stimulation, participating in cultural gatherings and traditional activities, staying involved in community activities, being considerate of others, and treating people kindly were the secrets to aging well (First Nations Health Authority [FNHA], 2014, p. 2).

There has been a dearth of research exploring the perceptions of aging well among Indigenous peoples, especially among Inuit or Métis. Only two studies could be identified which focused on Inuit and Métis perceptions; however both revealed similar perceptions of aging well as First Nations.

Successful aging was characterized not necessarily as the absence of ill health, but rather as the ability to successfully manage declining health (Collings, 2001; Edge & McCallum, 2006). Central to this was having positive attitudes in later life, ongoing contributions to community life, and a willingness to transmit accumulated wisdom and knowledge to successive generations.

Indigenous models and preferences for the care of seniors and individuals with dementia

There is little research on Indigenous models and preferences for the care of seniors and individuals with dementia and what exists is primarily focused on First Nations. Nevertheless, given that Inuit and Métis share similar holistic perspectives of health and well-being, it is likely that many of the core tenets of the First Nation approach may apply in other Indigenous contexts as well. These core tenets include respect for

Elders, incorporation of culture and language, a preference for informal models of care, and utilization of a shared caregiving approach based on fostering what Beatty and Weber-Beeds (2012) define as “mitho-pimatisiwin” (a northern Woodland Cree term meaning ‘the good life’) for seniors. This approach is holistic and strengths-based, and involves interventions at the level of the individual, the family and the community.

Elders are highly respected in Indigenous communities and informal caregiving is considered a cultural obligation (Andrews et al., 2010; Cammer, 2006; Collings, 2001; Edge & McCallum, 2006, FNHA, 2014; Jacklin, Pace, & Warry, 2015; Stevenson et al., 2015). Many Indigenous seniors prefer cultural approaches to care based on family and community caregiving models (Jacklin et al., 2014a; Jacklin & Warry, 2012b; Pace, 2016; Stevenson, et al., 2015). In a qualitative study exploring caregiving and models of care in First Nations communities across Ontario, underlying Indigenous values of



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...First Nations seniors highlighted the importance of seeking spiritual, emotional, physical and mental balance in preventing dementias and empowering individuals to live a healthy life

(Jacklin et al., 2014a/b; Pace, 2012, 2013; Pace et al., 2013).

respect for Elders and family, and community responsibility for caregiving “created a consistent family caregiving model across the Indigenous cultures and geographic contexts” (Jacklin et al., 2015, p. 106). Participants in this study viewed families and caregivers as best able to help individuals with dementia by keeping them in a familiar environment and supporting them with household tasks as well as social events and cultural activities. These perspectives were shared by Tahltan and Secwepemc participants in two separate studies (Hulko et al., 2010; Stevenson et al., 2015). Likewise, in the absence of accessible health care and support services, Inuit from a southern Labrador community perceived social networks and family support as especially important sources of strength in coping with dementia (Pace, 2016). Family caregiving is also seen as important for cultural continuity

for First Nations, Inuit and Métis, through the maintenance of Elder’s roles as transmitters of knowledge and wisdom to younger generations (Collings, 2001; Edge & McCallum, 2006; Jacklin & Warry, 2012b; Jacklin et al., 2015; Pace et al., 2013; Somogyi et al.; Stevenson et al., 2015).

For Indigenous seniors and individuals with dementia, history, culture and language are important sources of strength and resilience. In several First Nations studies, participants spoke about how culture helped them cope with and care for family members with dementia, including the supportive role of family, the value of humour, and the use of Indigenous languages (Bourassa, Blind, Dietrich, & Oleson, 2015; Jacklin & Warry, 2012a; Pace 2013). For some First Nations dementia patients in Ontario, traditional medicine use was another important aspect of culture. While

few study participants knew about any traditional medicines used specifically for dementia and memory loss, a number of participants, especially in the more remote communities, used traditional medicines for other ailments and for overall health (Jacklin & Warry, 2012b; Jacklin et al., 2014a).

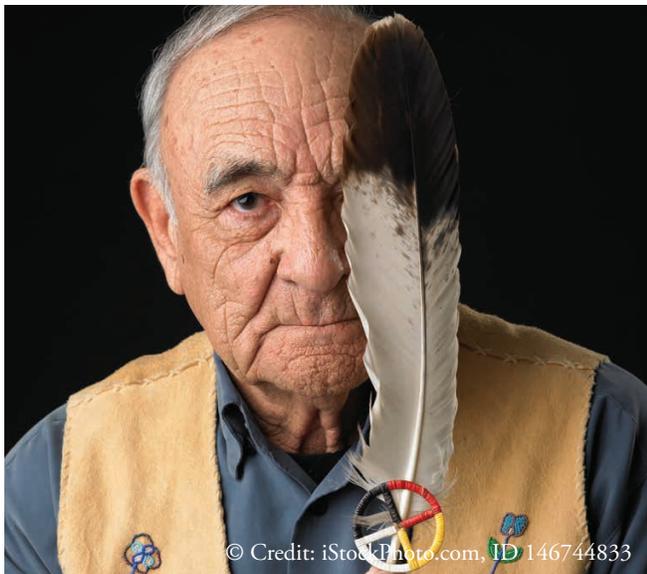
History, culture and language also provide the foundation for cognitive and physical stimulation, which plays a role in improving quality of life for dementia patients and preventing age-related cognitive decline and neurodegenerative diseases (Bherer, Erickson, & Liu-Ambrose, 2013; Potter, Ellard, Rees, & Thorogood, 2011; Woods, Thorgrimsen, Spector, Royan, & Orrell, 2006). Some First Nations seniors in Jacklin and colleagues’ cross-Ontario study exploring perceptions of dementia spoke about how listening to Indigenous

For Indigenous seniors and individuals with dementia, history, culture and language are important sources of strength and resilience....participants spoke about how culture helped them cope with and care for family members with dementia, including the supportive role of family, the value of humour, and the use of Indigenous languages

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History, culture and language also provide the foundation for cognitive and physical stimulation, which plays a role in improving quality of life for dementia patients and preventing age-related cognitive decline and neurodegenerative diseases

(Bherer, Erickson, & Liu-Ambrose, 2013; Potter, Ellard, Rees, & Thorogood, 2011; Woods, Thorgrimsen, Spector, Royan, & Orrell, 2006).

music or language tapes, speaking their Indigenous language, storytelling, and participating in ceremony helped keep their minds healthy (Jacklin & Walker, 2012; Jacklin & Warry, 2012a). Likewise, Hulko's (2014) exploration of the relationship between nature and dementia for Secwepemc Nation Elders found that bringing back a traditional lifestyle, whether it be through participating in traditional food gathering or harvesting activities, nature-based ceremonies, eating traditional foods, walking in the woods, holding storytelling sessions with youth outdoors, or gardening activities, was not only a way of reviving culture and preventing the onset of dementia, it also provided a form of nature-assisted horticulture therapy for dementia patients. Hulko argues that culturally relevant programming would be therapeutic for dementia patients and well received by First Nations Elders.

Lastly, land and connection to place can also be considered as important sources of strength and resilience for Indigenous people with dementia and their caregivers. Stevenson et al. (2015) found that land and place provided spiritual connection for Tahltan First Nations with Alzheimer's disease, as remaining in a familiar place allowed them to maintain social connections and engage in traditional activities. They also found that being in the community facilitated a sense of belonging, safety and accessible help for caregivers, helping them cope with their loved ones with dementia. Their study highlighted that cultural factors, such as receiving care on traditional territories, maintenance of connection to place and community, and revitalization of intergenerational knowledge transfer, played a "significant role in Tahltan experiences, wellness,

and understandings of diagnosis, care and prevention surrounding the disease" (p. 25).

While there are likely differences across Indigenous cultures, the limited evidence suggests that First Nations, Inuit and Métis peoples prefer shared caregiving models and holistic approaches to caring for individuals with dementia. There are many benefits to caring for dementia patients at home and in the community, including: familiarity of place, culturally appropriate care, the ability to speak in one's own language, continuity in families, and the maintenance of Elders' roles in the community. However, informal caregiving can also cause emotional strain on caregivers in the absence of family and community supports.



Key elements of a culturally safe dementia caregiving framework in Indigenous communities

A culturally safe framework for health services and dementia care is needed for Indigenous communities (Jacklin, Warry, Pitawanakwat, & Blind, 2016). This framework must incorporate Indigenous perspectives of aging well, their preferences for care, and the current barriers to dementia care services and supports in Indigenous communities. Further, it must be focused on keeping Indigenous people with dementia cared for by their families and within their communities for as long as possible, and if they must interact

with the healthcare system, ensuring that these interactions are respectful and that individuals are well supported in accessing services. This section provides recommendations and highlights initiatives and strategies that can facilitate culturally safe dementia care services and supports for Indigenous peoples. While the process of providing care for Indigenous patients requires two elements – a care delivery element and a knowledge element (Finkelstein et al., 2012) – this section focuses primarily on the care delivery element. The section is organized into two general areas: 1) fostering healthy and supportive family and community environments; and 2) reducing health system barriers to dementia care and support.

Fostering healthy and supportive family and community environments

In her research with Secwepemc Elders, Hulko (2014) discusses differences between underlying assumptions behind Indigenous and mainstream approaches to addressing health issues and their implications for accessing community and health services. She argues that because Indigenous approaches emphasize shared caregiving rather than focusing on the individual and his/her health seeking behaviours (the assumption on which mainstream approaches are predicated), attention must shift towards the well-being of communities and collective health action to promote and maintain



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Policies, services and structures supporting Indigenous people with dementias must be tailored to the unique cultural contexts and everyday lived realities of Indigenous peoples and communities.

holistic health. Strategies and initiatives are thus needed to foster healthy and supportive families and communities to enhance the quality of care and supports for Indigenous people with dementias and promote holistic health and well-being. The types of interventions or strategies that might contribute to a healthier and supportive family and community environment are wide-ranging. They might include strategies or initiatives that: address poverty and socio-economic marginalization within Indigenous communities; help reduce the stigma and fear of dementias and build local care capacity; aim to improve mental health and wellness within communities; encourage youth to stay in their communities; support the ability of individuals with dementia to remain in their homes with the support of families and communities for as long as they can; and provide opportunities for social, mental and physical stimulation.

Policies, services and structures that enable Indigenous seniors with dementia to stay in their communities

Currently, there is little research, and few initiatives, being undertaken with respect to fostering healthy and supportive families and communities to enhance care for Indigenous people with dementias. At the national level, the Government of Canada has recently identified the need for a national strategy for dementia-friendly communities, with key elements involving “reducing or eliminating the stigma associated with dementia through increased awareness and education campaigns, as well as the uptake of specific initiatives by business operators and other service providers to deliver dementia-friendly interactions” (Standing Senate Committee on Social Affairs, Science and Technology [SSCSAST], 2016,

p. 14). However, Indigenous input into this report has been minimal, with only one Indigenous organization consulted (the Assembly of First Nations) and only one of the 29 recommendations focusing specifically on Indigenous populations.¹⁰

Policies, services and structures supporting Indigenous people with dementias must be tailored to the unique cultural contexts and everyday lived realities of Indigenous peoples and communities. While not specifically focused on caring for individuals with dementia, the Sioux Lookout Meno Ya Win Health Centre’s “Aging at Home” strategy could be considered an example of a locally tailored initiative. This strategy involves a collaboration among multiple partners to ensure that a comprehensive set of seniors care services, from within and outside the health system context,

¹⁰ This recommendation called for an expansion of the FNIHB’s Home and Community Care Program.

is available for First Nations in this northern Ontario Health Services area (Fukushima, Cromarty, & Linkewich, n.d.). These services include home and community care services, patient and family support services, support service coordination, respite services, community supportive housing, physician and hospital services, regional long-term care homes, education, transportation and nursing services.

Building local capacity through education and training

Reducing or eliminating the fear and stigma associated with dementias in Indigenous communities could help strengthen the process of accessing dementia care and build local capacity to deliver formal dementia care and support informal caregivers. Fear and stigma may prevent individuals from seeking an assessment, delaying appropriate care, as well as inhibit the development of community awareness of dementia and the sharing of knowledge about ways to cope with it (Bourassa et al., 2015; Cabera, Beattie, Dwosh, & Illes, 2015; Cammer, 2006; Stevenson et al., 2013, 2015). The literature calls for the development of culturally appropriate and holistic dementia resources which incorporate cultural practices, values and beliefs to explain dementia

symptoms, risk factors, and disease progression, as well as coping and care strategies that ensure respectful care (Jacklin et al., 2016; Pace, 2013). While countries like Australia have been actively developing culturally-grounded education tools for some time, targeted at both health practitioners and at Aboriginal families and communities, these types of tools are just starting to be developed for Indigenous people in Canada. Two groups are taking the lead in this endeavor – the Indigenous Cognition and Aging Awareness Research Exchange (I-CAARE) for First Nations communities in Ontario and the Illes Group of the National Core for Neuroethics for the Tahltan in British Columbia. However, much more work needs to be done to develop culturally appropriate education tools for the diverse Indigenous cultures across Canada, as they have the potential to improve dementia health literacy and increase cultural safety (Webkamigad, Jacklin, Cote-Meek, & Pianosi, 2016).

Strategies, programs and services to enhance quality of life

There is also a need for strategies, programs and services that aim to enhance the quality of life and the physical, mental, spiritual, and emotional health and well-being

of Indigenous seniors, including those with dementia. Strategies have been developed at multiple levels to foster healthier and safer places for seniors to live and thrive. For example, in 2006, the Age-Friendly Communities initiative was initiated in 36 Canadian cities, as well as ten rural and remote communities across Canada,¹¹ however, it was primarily targeted at the general population, with limited consideration for Indigenous populations. As part of this strategy, communities across Canada worked to develop guides to enable their communities to become more age friendly. The special guide developed for rural and remote communities, for example, provided tips for becoming more age-friendly with respect to outdoor spaces and buildings, transportation, housing, respect and social inclusion, social participation, communication and information, civic participation and employment opportunities, and community support and health services.¹² However, only the ‘social inclusion and respect’ category included any consideration for Indigenous populations. The lack of attention to the unique needs and circumstances of Indigenous populations is problematic given the well-recognized and critical need for substantial investments to improve housing, health services access, transportation, and community social and recreational facilities and infrastructure in Indigenous communities.

¹¹ The Federal, Provincial, Territorial Age-Friendly Rural and Remote Communities Initiative was implemented in 10 communities with populations less than 5000. This included Alert Bay, BC, Lumby, BC, High Prairie, AB, Turtleford, SK, Gimli, MB, Bonnechere, ON, Port Hope Simpson, NL, Clareville, NL, Alberton, PEI, and Guysborough, NS (Federal/Provincial/Territorial Ministers Responsible for Seniors, 2007a).

¹² See Federal/Provincial/Territorial Ministers Responsible for Seniors. (2007b). *Age-friendly rural and remote communities: A guide*. Ottawa, ON: Authors. Retrieved September 20, 2017 from http://www.health.gov.bc.ca/library/publications/year/2007/AFRRRC_en.pdf

More programs and services are needed to enhance quality of life for Indigenous seniors, including those with dementia, and their physical, mental, spiritual and emotional health and well-being. This may include programs and services that allow Indigenous people to remain in their homes and live as independent a life as they can, such as more home-based care, personal care workers and/or home care workers (Jacklin, Warry, & Dietrich, 2013). It may include programs that promote social interaction to ward off loneliness, such as support groups, community groups, and other initiatives to get Indigenous seniors out of the house and away from the television. It may also include programs and services which promote mental and physical stimulation, including “supports that encourage and enable [Indigenous] seniors to participate in activities that reflect their cultural values or traditional

ways of life” (Pace, 2013, p. 115), as well as “culturally sensitive ways to incorporate ‘mind always going’ so that Indigenous people can make lifestyle choices that reduce dementia risks” (Hulko, et al., 2010, p. 335). As noted by Jacklin and Warry (2012b), since cognition is culturally constructed, cognitive stimulation must be culturally relevant. Examples may include programs that: enhance the role of Elders in intergenerational knowledge transfer and revitalize Indigenous cultures; provide transportation services to facilitate the participation of Elders in local community activities; provide Indigenous people with opportunities to communicate in their own languages, participate in ceremonies and eat traditional foods; and keep Indigenous people connected to their lands and communities. These types of programs would provide

opportunities for social and cognitive stimulation, and help facilitate “a sense of belonging, safety, and accessible help” (Stevenson et al., 2015, p. 22).

Supporting caregivers

Additionally, there is a need for better and more consistent supports and resources for caregivers and care recipients to address challenges associated with an outmigration of youth to urban centres, resulting in fewer family caregivers, as well as limited caregiving resources and caregiver burnout (Andrews, et al., 2010; Beatty & Berdahl, 2011; Lanting, Crossley, Morgan, & Cammer, 2011; Pace, 2013). This includes better support for respite, adult day service programs, friendly visiting programs and after-hour care services (Beatty & Weber-Beeds, 2012; Finkelstein et al., 2012; Jacklin et al., 2014b; Pace et al., 2013).



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As noted by Jacklin and Warry (2012b), since cognition is culturally constructed, cognitive stimulation must be culturally relevant.





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Reducing health system barriers to dementia care services and supports

As dementia symptoms worsen, interactions with the healthcare system become more frequent. In order to optimize the quality of care and quality of life of Indigenous people with dementia, innovation and flexibility are required to address unique barriers they face in accessing health care. This section focuses on health system initiatives or strategies that have the potential to address barriers to culturally appropriate dementia care services and supports.

Overcoming geographic barriers to assessment, diagnosis and care

In many Indigenous communities, the lack of knowledgeable specialists to provide early diagnosis and treatment is a significant barrier to accessing dementia care services. Telehealth has been used successfully to address the challenges of providing dementia care services for Indigenous people in rural and remote communities (Morgan et al., 2009). For example, a rural and remote

interdisciplinary memory clinic in northern Saskatchewan, which has been operational since 2006, has improved access to diagnosis and management of early stage dementia. The integrated one-day weekly clinic provides assessment by a neurologist, neuropsychology team, geriatrician, neuro-radiologist, and physical therapist, as well as follow-ups at 6 weeks, 12 weeks, 6 months, one year and yearly (Morgan et al., 2011). It adopts a family-centred approach, with assessment in the patient's Indigenous language if desired. Caregivers are encouraged to attend to provide information on patient history and daily functioning, as well as receive information on how to care for their loved ones with dementia. Evaluations have shown that the memory clinic has significantly reduced participants' travel time, and both patients and caregivers are comfortable during these sessions. They appreciate the coordinated one-stop approach to assessment and diagnosis, and prefer telehealth to in-person appointments because of their convenience. However, while these studies have shown a general satisfaction with telehealth services, a systematic review identified some barriers to acceptance of telehealth

for Indigenous people, including a lack of cultural competence on the part of healthcare professionals, inadequate communication technologies, lack of cultural safety, and/or loss of connection and relationship with healthcare professionals (Fraser et al., 2017). These barriers highlight the need for cultural safety training as a prerequisite for health professionals working in these contexts. Nevertheless, telehealth has improved access to specialist dementia services in rural and remote Indigenous communities and should be supported through additional funding and technical support.

Greater flexibility with regard to health system and service rules could also potentially help overcome some of the geographic and financial barriers Indigenous people face in accessing dementia care services in rural and remote communities. Cammer (2006) highlights several examples of bending health system rules within the context of First Nations from a northern Saskatchewan community, such as not denying services due to financial hardship, admitting older adults with dementia to the hospital's long-term care for 'social reasons' or 'respite' rather than for



‘dementia’, and allowing family to visit patients outside normal visiting hours. The Government of Canada acknowledged the need for greater flexibility to adapt to local and regional contexts in its recent call for a national dementia-friendly strategy. Specifically, they recommended an expansion of the FNIHB’s Home and Community Care Program to reflect current Indigenous population levels, and permit and encourage innovative approaches to program delivery (SSCSAST, 2016).

Jurisdictional and bureaucratic considerations

Jurisdictional and bureaucratic barriers to accessing dementia care services and supports must also be addressed. This includes who pays for services if they are accessed off-reserve; the lack of programs and services available for Métis and non-status Indians that are available to First Nations on reserve and Inuit, like home care and continuing support programs; as well as delays or denied approvals for medicine, supplies and medical travel due to underfunding, excessive restrictions, and highly bureaucratic processes associated with the NIHB program. The

Supreme Court of Canada’s (2016) landmark decision that Métis and non-status Indians are the responsibility of the federal government and the Truth and Reconciliation Commission’s (2015) Calls to Action facilitate a reconsideration of existing policies and requirements for these programs. In the meantime, some barriers can be reduced by incorporating some flexibility into programs. For example, the pre-approval requirement to cover the travel costs of ‘non-medical’ escorts – usually a family member or friend – to accompany Elders who have chronic health problems or need a translator can be changed such that pre-approval is only required to be obtained once a year rather than for each trip (Health Council of Canada, 2013). Having Indigenous controlled models of managing the NIHB program or using NIHB navigators would also help Indigenous seniors overcome some of these challenges (Health Council of Canada, 2013).

Shared caregiving and multi-collaborative approaches

Lack of access to health programs, services and resources can also

be addressed through shared caregiving approaches where resources are pooled between families, health care providers and community services to meet the full range of Indigenous seniors’ needs. There are several examples of shared caregiving approaches in First Nations communities across Canada, including the Peter Ballantyne Cree Nation’s innovative integrated shared caregiving model of seniors care services and the Siksika Nation’s integrated health services (Health Council of Canada, 2013). These approaches typically involve the development of partnerships with other health service providers and governments to offer a wide range of culturally appropriate dementia care services and supports. They incorporate Indigenous values, beliefs and preferences around family and community caregiving, holistic health, and the inclusion of traditional and cultural programming. They also work to overcome specific barriers around accessing dementia care services, such as providing an integrated continuum of care through enhanced collaboration and communication among health providers and institutions and assistance with navigating complex health systems.

Holistic and culturally grounded healthcare

Indigenous people are often reluctant to utilize mainstream health services and programs as a result of previous experiences with racism and discrimination in healthcare settings, mistrust of mainstream healthcare professionals, cultural and linguistic communication differences, and the fact that mainstream services do not address the holistic needs of Indigenous patients. These are significant barriers to culturally safe dementia care (Jacklin et al., 2013, 2014a/b). To address these barriers, researchers have called for the use of culturally grounded healthcare, including assessment tools and experiences with the healthcare system (Lanting et al., 2011; Cattarinich, Gibson, & Cave, 2001; Pitawanakwat et al., 2016). This includes enhancing cross-cultural communication between healthcare providers and their Indigenous clients; incorporating cultural traditions and values into direct care; and building trusting and therapeutic relationships. Table 1 provides tips, derived from the literature, for health care professionals in providing culturally grounded healthcare.

Healthcare providers require additional training and education so they can respond to the needs of Indigenous patients with dementia and their caregivers in a more sensitive and respectful manner. This includes training on the colonial history of Indigenous peoples and their impacts on health and well-being, including how they

experience dementia and dementia care (Jacklin et al., 2016); education and awareness training to address institutional racism and systemic barriers to health care (Alcock, 2014; Bourassa et al., 2015; Cammer, 2006); as well as culturally relevant training related to dementia and dementia care approaches, so that patients and caregivers have more timely access to relevant information and resources (Dal Bello-Haas et al., 2015; Finkelstein et al., 2012).

Culturally appropriate long-term care facilities

Additionally, there is a need to address the lack of culturally appropriate long-term care facilities both in Indigenous communities and in urban centres. Jacklin and Warry (2012b) argue that the provision of services for Indigenous people with dementia are best delivered locally to minimize culture and language barriers. Community-based services address communication barriers Indigenous seniors may have with non-Indigenous health professionals, as well as feelings of loneliness and isolation (Beatty & Weber-Beeds, 2012). They also reinforce Elders' important role within the community as transmitters of knowledge and address the holistic needs of Indigenous patients. As noted earlier, there is a lack of seniors' care facilities in First Nations and Métis communities. The federal government must change current funding policies to support the construction of, and ongoing operational costs for, long-term care homes on reserves so that Elders can access specialized services in a culturally and linguistically familiar environment, as well as their social support networks (Beatty

& Weber-Beeds, 2012; Jacklin et al., 2013). While there are some facilities, such as Tsawaayuus (Rainbow Garden Eldercare Home) in Port Alberni, BC, and Westbank First Nation Pine Acres, which are guided by holistic perspectives of wellness and aim to promote an active and meaningful life for residents in ways grounded in Indigenous ways of being (FNHA, 2014; Hernandez & Kyahatte, 2015), most do not have the capacity to handle dementia patients.

At some point dementia symptoms may become so severe that there is no other option but to transfer rural Indigenous people with dementia to long-term care centres in neighbouring urban centres because none exist within their home communities. While urban-based long-term care facilities do provide access to the specialized services Indigenous dementia patients may require, they are often difficult for Indigenous seniors to access due to high costs or residency requirements (Beatty & Weber-Beeds, 2012). They may also not address the social aspects of care well, including feelings of isolation or cultural alienation that Indigenous seniors may experience within unfamiliar urban environments (Carstairs & Keon, 2007). These challenges could be better addressed through the establishment of Indigenous long-term care facilities within urban centres, the provision of subsidies for Indigenous seniors so they can better access the long-term care facilities of their choice, and by implementing culturally responsive programming and employment in healthcare systems (Beatty & Berdahl, 2011).

TABLE 1: TIPS FOR CULTURALLY GROUNDED HEALTHCARE

Enhance cross-cultural communication between healthcare practitioners and their Indigenous clients	Incorporate cultural traditions and values into direct care	Build trusting and therapeutic relationships
<ul style="list-style-type: none"> • use culturally safe and fair assessment instruments to improve the assessment experience (Hulko et al., 2010) • use Indigenous languages and translation services whenever possible (Cattarinich et al., 2001) • use plain language rather than medical jargon (Jacklin et al., 2013) • use communication assistance from other members of the family or an Aboriginal navigator within the healthcare system (Jacklin et al., 2013) • use humour to create comfort in the health care environment (Cattarinich, et al., 2001) • replace direct question-answer type questions with storytelling techniques (Cattarinich et al., 2001; Hulko et al., 2010) • use active listening about an Elder’s social, cultural and historic context (Hulko et al. 2010) 	<ul style="list-style-type: none"> • respect Elders and Indigenous peoples’ values and beliefs (Hulko et al., 2010) • adopt a holistic client and family-centred approach that recognizes the importance of spirituality and the historical significance of residential schools, including having a supportive network between patients, caregivers and community members; using culturally sensitive client and family-centred approaches in health care (Forbes et al., 2013) 	<ul style="list-style-type: none"> • resolve conflict (Forbes et al., 2013) • ensure continuity of care through enhanced collaboration and communication with other health professionals and institutions (Alcock, 2014; Beatty & Weber-Beeds, 2012; Forbes et al., 2013; Jacklin et al., 2014a/b) • be aware of, and knowledgeable about, community programs (Forbes et al., 2013) • be respectful and friendly to clients (Bourassa et al., 2015; Finkelstein et al., 2012) • take time to work with clients and discuss medications and treatment plans with caregivers in order to help connect them with appropriate services (Finkelstein et al., 2012; Jacklin et al., 2014a) • have an open door policy and be available for crisis support (Finkelstein et al., 2012) • attend community events and seek out the expertise and support of Elders and Chief and Council (Finkelstein et al., 2012) • educate community members about dementias and the benefits of being assessed (Finkelstein et al., 2012)





The Indigenous seniors population is growing rapidly and due to higher prevalence of many of the risk factors for dementias, the prevalence of dementias in this population is expected to increase considerably.

CONCLUSIONS



There is an urgent imperative to proactively plan for and implement strategies, programs and structures to support Indigenous people with dementias and their caregivers. The Indigenous seniors population is growing rapidly and due to higher prevalence of many of the risk factors for dementias, the prevalence of dementias in this population is expected to increase considerably. Indigenous seniors have complex health needs and they face multiple barriers and challenges to accessing dementia care services within their communities. In order to address their dementia care needs, programs and services must reflect their preferences for dementia care as well as the practical realities they face within their communities.

The literature highlighted Indigenous seniors' preferences for holistic, strengths-based, and shared care-giving models of dementia care that incorporated Indigenous cultural and linguistic programming as well as the involvement of families

and communities in dementia care. It also highlighted the many gaps faced by Indigenous seniors with dementia and their caregivers in accessing health care services, particularly in reserve communities. In order to address their dementia care needs effectively and in a culturally safe way, programs and services must be tailored to the unique local and cultural context and focus on ensuring Indigenous seniors with dementia are able to remain in their homes and communities as long as possible, with the support of friends and family. This will entail: building community capacity through culturally appropriate health information and training; adopting greater health system and service flexibility, as well as local community and inter-agency communication and collaboration to overcome gaps in resources; providing holistic dementia care services that address socio-economic barriers to health care, enhance the quality of life and well-being of

Indigenous seniors with dementias and their caregivers, as well as focus on direct health needs; and utilizing innovations that allow Indigenous seniors with dementia to access specialized care, diagnostic and treatment services closer to home. In cases where there is no other option but to relocate Indigenous patients with dementia to urban centres to access more comprehensive services, interventions are needed to ensure they receive culturally safe health care, including respectful and caring interactions with healthcare providers, use of Indigenous languages and translators, inclusion of traditional activities and practices, and supportive family and community environments. While these features would more typically be present in urban Indigenous long-term care facilities, they can also become present in non-Indigenous facilities through transforming the ways in which health care is provided in such settings, and through cultural safety training for non-Indigenous health care providers.



RESOURCES



Policies/strategies

Federal/Provincial/Territorial Ministers Responsible for Seniors. (n.d.). *Age-friendly rural and remote communities: A guide*. Ottawa, ON: Public Health Agency of Canada. Retrieved July 5, 2017 from http://www.phac-aspc.gc.ca/seniors-aines/alt-formats/pdf/publications/public/healthy-sante/age_friendly_rural/AFRRC_en.pdf

Fukushima, H., Cromarty, H., & Linkewich, B. (n.d.). *The Meno Ya Win Elder care continuum: Applying the "Aging at Home" strategy to meet northern First Nations' needs*. Sioux Lookout, ON: Sioux Lookout Meno Ya Win Health Centre. Retrieved June 15, 2017 from http://www.slmhc.on.ca/assets/files/traditional-healing/the_meno_ya_win_elder_care.pdf

Standing Senate Committee on Social Affairs, Science and Technology. (2016). *Dementia in Canada: A national strategy for dementia-friendly communities*. Ottawa, ON: Author. Retrieved June 15, 2017 from https://sencanada.ca/content/sen/committee/421/SOCI/Reports/SOCI_6thReport_DementiaInCanada-WEB_e.pdf

Promising practices

Health Council of Canada. (2013). Providing integrated services to elders on reserve: Siksika Nation, Alberta. In *Canada's most vulnerable: Improving health care for First Nations, Inuit, and Metis seniors* (pp. 40-41). Ottawa, ON: Author. Accessed October 15, 2018 from http://publications.gc.ca/collections/collection_2013/ccs-hcc/H174-40-2013-eng.pdf

Health Council of Canada. (2013). Shared caregiving in the community: Peter Ballantyne Cree Nation, Saskatchewan. In *Canada's most vulnerable: Improving health care for First Nations, Inuit, and Metis seniors* (pp. 42-43). Ottawa, ON: Author. Accessed October 15, 2018 from http://publications.gc.ca/collections/collection_2013/ccs-hcc/H174-40-2013-eng.pdf



Culturally-grounded education tools

For health practitioners:

Rural Dementia Action Research. (2015). The Northern Cultural Assessment of Memory (N-CAM): A protocol designed to detect cognitive change in Indigenous Peoples. (webinar), <https://vimeo.com/144396136>

For Indigenous families and communities:

Indigenous Cognition & Aging Awareness Research Exchange, Dementia factsheets (What is Dementia? Indigenous perspectives and cultural understandings; Signs and symptoms of dementia: An Indigenous guide; Preventing dementia in Indigenous peoples by aging well: Advice from older Indigenous peoples; What to expect after a diagnosis of dementia: An Indigenous person's guide), <https://www.i-caare.ca/dementia-factsheets>

Framst, L.S. (n.d.). *The mind thief: A kid's guide to Alzheimer's disease*. Vancouver, BC: National Core for neuroethics. <http://neuroethics.med.ubc.ca/res/kt/books/adbooks/>

Stevenson, S., Illes, J., Beattie, B.L., Dwosh, E., Vedan, R., and Bruce, L. in collaboration with the Community Members of the Tahltan First Nation and the University of British Columbia Research Team. (2015). *Wellness in early onset familial Alzheimer Disease: Experiences of the Tahltan First Nation*. Vancouver, BC: University of British Columbia. Retrieved May 8, 2011 from <http://med-fom-neuroethics.sites.olt.ubc.ca/files/2015/08/GTP-Wellness-in-EOFAD-s.pdf>

Alcock, D. (2017). Oral narratives of female Indigenous caregivers for loved ones diagnosed with alcohol-related dementia, YouTube video, https://www.youtube.com/watch?v=dkSf_cIyxYs

Paikin, S. 2017). Dementia in Indigenous communities, YouTube video, <https://www.youtube.com/watch?v=gA6t1xCIQec>

Organizations

Alzheimer Society of Canada, provides information about available programs and services, brochures and publications on Alzheimer's disease for health practitioners, caregivers, community members and individuals with dementias, <https://alzheimer.ca/en/about-dementia/indigenous-peoples-and-dementia>

Alzheimer's Association, provides information on a range of dementia related topics, including types, symptoms, disease progress, caring for individuals with dementia and activities, <https://www.alz.org/>

Indigenous Cognition & Aging Awareness Research Exchange, resources for families, communities and health professionals working with Indigenous populations, <http://www.i-caare.ca/>

Illes Group, National Core for Neuroethics, University of British Columbia, Faculty of Medicine, website provides access to a variety of resources on dementias, including resources for families and communities, <http://neuroethics.med.ubc.ca/res/kt/books/adbooks/>



REFERENCES

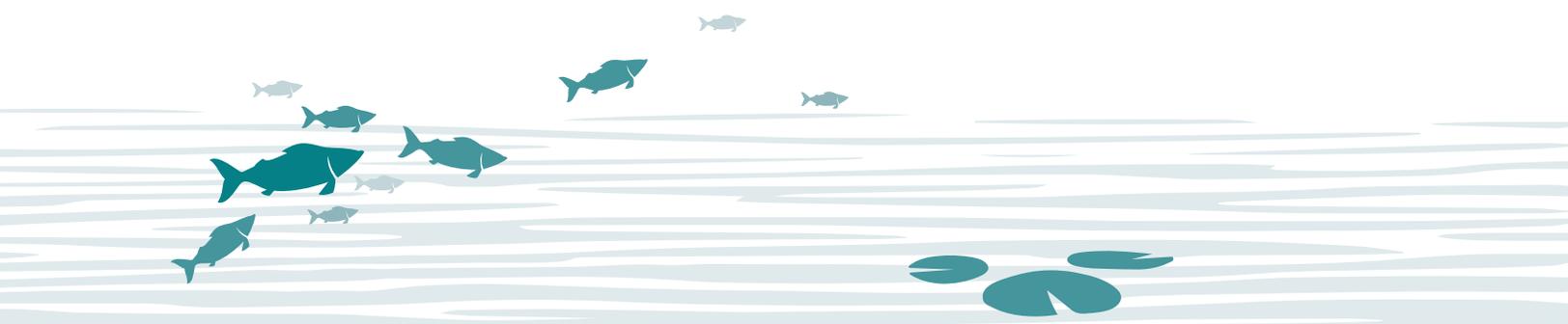


- Abonyi, S., & Favel, M. (2012). Marie's story of aging well: Toward new perspectives on the experience of aging for Aboriginal seniors in Canada. *Anthropology & Aging Quarterly*, 33(1), 11, 20.
- Alcock, D. (2014). "Write my story before I forget": An auto-ethnography of Aboriginal alcohol dementia. Unpublished MA thesis, University of Western Ontario, London, Ontario, Canada.
- Alzheimer Society of Canada. (2017). *Shattering the myths*. Toronto, ON: Author. Retrieved September 20, 2017 from http://www.alzheimer.ca/en/About-dementia/What-is-dementia/Shattering-the-myths#DynamicId_4
- Alzheimer Society – New Brunswick. (2018). Importance of palliative care. *Dementia and end-of-life care*. Fredericton, NB: Author. Retrieved January 8, 2018 from <http://www.alzheimer.ca/en/nb/Living-with-dementia/Caring-for-someone/End-of-life-care/Importance-palliative-care>
- Andrews, M.E., Morgan, D.G., & Stewart, N.J. (2010). Dementia awareness in northern nursing practice. *Canadian Journal of Nursing Research*, 42(1), 56-73.
- Banerjee, A. (2007). *An overview of long-term care in Canada and selected provinces and territories. Women and health care reform*. Toronto, ON: Women and Health Care Reform Group. Retrieved May 13, 2017 from http://femmesreformesante.ca/publications/banerjee_overviewLTC.pdf
- Beatty, B.B., & Berdahl, L. (2011). Health care and Aboriginal seniors in urban Canada: Helping a neglected class. *The International Indigenous policy Journal*, 2(1), 10.
- Beatty, B., & Weber-Beeds, A. (2012). Mitho-pimatisiwin for the elderly: The strength of a shared caregiving approach in Aboriginal health. In D. Newhouse, K. FitzMaurice, T. McGuire-Adams, & D. Jetté (eds.), *Well-being in the urban Aboriginal community* (Chapter 6). Toronto, ON: Thompson Educational Publishing.
- Bherer, L., Erickson, K.I., & Liu-Ambrose, T. (2013). A review of the effects of physical activity and exercise on cognitive and brain functions in older adults. *Journal of Aging Research*, 657508. Retrieved June 19, 2017 from <https://www.hindawi.com/journals/jar/2013/657508/abs/>
- Bourassa, C., Blind, M., Dietrich, D., & Oleson, E. (2015). Understanding the intergenerational effects of colonization: Aboriginal women with neurological conditions – their reality and resilience. *International Journal of Indigenous Health*, 10(2), 3-20.
- Cabera, L.Y., Beattie, B.L., Dwosh, E., & Illes, J. (2015). Converging approaches to understanding early onset familial Alzheimer disease: A First Nation study. *SAGE Open Medicine*, 3: 2050312115621766.
- Cammer, A.L. (2006). *Negotiating culturally incongruent healthcare systems: The process of accessing dementia care in northern Saskatchewan*. Unpublished MSc thesis, University of Saskatchewan, Saskatoon, Saskatchewan, Canada.
- Carstairs, S. (Hon.), & Keon, W.J. (Hon.). (2007). *Embracing the challenge of aging*. Ottawa, ON: Special Senate Committee on Aging First Interim Report. Retrieved July 5, 2017 from <https://sencanada.ca/content/sen/committee/391/agei/rep/repintfeb07-e.htm>
- Cattarinich, X., Gibson, N., & Cave, A.J. (2001). Assessing mental capacity in Canadian Aboriginal seniors. *Social Science & Medicine*, 53(11), 1469-1479.
- Collings, P. (2001). "If you got everything, it's good enough": Perspectives on successful aging in a Canadian Inuit community. *Journal of Cross-Cultural Gerontology*, 16(2), 127-55.
- Dal Bello-Haas, V., Cammer, A., Morgan, D., Stewart, N., & Kosteniuk, J. (2014). Rural and remote dementia care challenges and needs: Perspectives of formal and informal care providers residing in Saskatchewan, Canada. *Rural and Remote Health*, 14, 2747.
- Edge, L., & McCallum, T. (2006). Métis identity: Sharing traditional knowledge and healing practices at Métis Elders' gatherings. *Pimatisiwin: A Journal of Indigenous and Aboriginal Community Health*, 4(2), 83-115.
- Federal/Provincial/Territorial Ministers Responsible for Seniors. (2007a). *Age-friendly rural and remote communities: A guide*. Ottawa, ON: Public Health Agency of Canada. Retrieved July 5, 2017 from http://www.phac-aspc.gc.ca/seniors-aines/alt-formats/pdf/publications/public/healthy-sante/age_friendly_rural/AFRRC_en.pdf

- Federal/Provincial/Territorial Ministers Responsible for Seniors. (2007b). *Age-friendly rural and remote communities: A guide* Ottawa, ON: Authors. Retrieved September 20, 2017 from http://www.health.gov.bc.ca/library/publications/year/2007/AFRRRC_en.pdf
- Finkelstein, S.A., Forbes, D.A., & Richmond, C.A.M. (2012). Formal dementia care among First Nations in southwestern Ontario. *Canadian Journal on Aging, 31*(3), 257-270.
- First Nations Health Authority [FNHA]. (2014). *Spirit: Sharing First Nations Health and Wellness Magazine. Winter (The Elders Issue)*. First Nations Health Authority. Retrieved July 4, 2017 from http://www.fnha.ca/SpiritMagazine/Spirit_Winter2014.pdf
- Forbes, D., Blake, C., Thiessen, E., Finkelstein, S., Gibson, M., Morgan, D.G., Markle-Reid, M. et al. (2013). Dementia care knowledge sharing within a First Nations community. *Canadian Journal on Aging, 32*(4), 360-74.
- Fraser, S., Mackean, T., Grant, J., Hunter, K., Towers, K., & Ivers, R. (2017). Use of telehealth for health care of Indigenous peoples with chronic conditions: A systematic review. *Rural and Remote Health, 17*, 4205.
- Fukushima, H., Cromarty, H., & Linkewich, B. (n.d.). *The Meno Ya Win Elder care continuum: Applying the "Aging at Home" strategy to meet northern First Nations needs*. Sioux Lookout, ON: Sioux Lookout Meno Ya Win Health Centre. Retrieved June 15, 2017 from http://www.slmhc.on.ca/assets/files/traditional-healing/the_meno_ya_win_elder_care.pdf
- Health Council of Canada. (2013). *Canada's most vulnerable: Improving health care for First Nations, Inuit, and Métis seniors*. Toronto, ON: Author. Retrieved May 11, 2017 from http://www.metisnation.org/media/422632/senior_ab_report_2013_en_final.pdf
- Hernandez, J., & Kyahatte, R. (2015). All-aboriginal seniors home in BC highlights the need for more space. *Reporting in Indigenous Communities*. Vancouver, BC: UBC Graduate School of Journalism. Retrieved July 5, 2017 from <http://indigenousreporting.com/2015/all-aboriginal-seniors-home-in-b-c-highlights-the-need-for-more-space/>
- Hulko, W. (2014). Digging up the roots: Nature and dementia for First Nations elders. In M. Marshall (ed.), *Creating culturally appropriate outside spaces and experiences for people with dementia: Using nature and the outdoors in person-centred care* (pp. 96-104). London, UK: Jessica Kingsley Publishers.
- Hulko, W., Camille, E., Antifeau, E., Arnouse, M., Bachynski, N., & Taylor, D. (2010). Views of First Nation elders on memory loss and memory care in later life. *Journal of Cross-Cultural Gerontology, 25*(4): 317-42.
- Indigenous and Northern Affairs Canada. (2016). *Inuit Nunangat map*. Ottawa, ON: Author. Retrieved July 5, 2017 from <http://www.aadnc-aandc.gc.ca/Map/irs/mp/index-en.html>
- Jacklin, K., Pace, J.E., & Warry, W. (2015). Informal dementia caregiving among Indigenous communities in Ontario, Canada. *Care Management Journals, 16*(2), 106-120.



- Jacklin, K., & Walker, J. (2012). *Trends in Alzheimer's disease and related dementias among First Nations and Inuit*. Ottawa, ON: Health Canada. Retrieved May 11, 2017 from http://media.wix.com/ugd/6e29de_05ec1795a75a41b08a0119a561221420.pdf
- Jacklin, K.M., Walker, J.D., & Shawande, M. (2013). The emergence of dementia as a health concern among First Nations populations in Alberta, Canada. *Canadian Journal of Public Health*, 104(1), e39-44.
- Jacklin, K., & Warry, W. (2012a). Forgetting and forgotten: Dementia in Aboriginal seniors. *Anthropology & Aging Quarterly*, 33(1), 13, 21-22.
- Jacklin, K., & Warry, W. (2012b). "They knew who she was": Toward an understanding of diagnosis and care of people with dementia in Aboriginal communities [Abstract for paper presented at the Alzheimer's Association International Conference]. *Alzheimer's & Dementia*, 8(4), SP431.
- Jacklin, K., Warry, W., & Blind, M. (2014a). *Perceptions of Alzheimer's disease and related dementia among Aboriginal peoples in Ontario: Sudbury community report*. Sudbury, ON: Northern Ontario School of Medicine I-CAARE project. Retrieved May 9, 2017 from http://media.wix.com/ugd/6e29de_9423c1d1a4154fd0a1bbead3bfb74e.pdf
- Jacklin, K., Warry, W., & Blind, M. (2014b). *Perceptions of Alzheimer's disease and related dementia among Aboriginal peoples in Ontario: Six Nations Community report*. Sudbury, ON: Northern Ontario School of Medicine I-CCARE project. Retrieved May 9, 2017 from http://media.wix.com/ugd/6e29de_6f06af37bcd04640a7347e33c43e88e4.pdf
- Jacklin, K., Warry, W., & Dietrich, D. (2013). *Perceptions of Alzheimer's disease among related dementias among Aboriginal peoples in Ontario: Thunder Bay community report*. Sudbury, ON: Northern Ontario School of Medicine I-CCARE project. Retrieved May 9, 2017 from http://media.wix.com/ugd/6e29de_c89dd0b81e5c4786b86c295cfbada740.pdf
- Jacklin, K., Warry, W., Pitawanakwat, K., & Blind, M. (2016). Considerations in culturally safe care for Indigenous people with dementia in Canada [Abstract Supplement]. *Alzheimer's & Dementia*, 12(7), 270-271.
- Journal of Obstetrics and Gynaecology Canada. (2013). Chapter 8 - Changing outcomes through cultural competent care. *Health professionals working with First Nations, Inuit, and Métis consensus guideline*, 35(6), S38-S41.
- Lanting, S., Crossley, M., Morgan, D., & Cammer, A. (2011). Aboriginal experiences of aging and dementia in a context of sociocultural change: Qualitative analysis of key informant group interviews with Aboriginal seniors. *Journal of Cross-Cultural Gerontology*, 26(1), 103-117.
- Morgan, D.G., Crossley, M., Kirk, A., D'Arcy, C., Stewart, N., Biem, J., Forbes, D. et al. (2009). Improving access to dementia care: Development and evaluation of a rural and remote memory clinic. *Aging & Mental Health*, 13(1), 17-30.
- Morgan, D.G., Crossley, M., Kirk, A., McBain, L., Stewart, N.J., D'Arcy, C., Forbes, D. et al. (2011). Evaluation of telehealth for preclinic assessment and follow-up in an interprofessional rural and remote memory clinic. *Journal of Applied Gerontology*, 30(3), 304-331.
- O'Donnell, V., Wendt, M., & the National Association of Friendship Centres. (2017). *Aboriginal Peoples Survey, 2012: Aboriginal seniors in population centres in Canada*. Ottawa, ON: Statistics Canada, Catalogue 9-653-X.
- Pace, J. (2012). Understanding aging: Culture, cognitive health and contemporary Aboriginal peoples' experience with dementia. *Anthropology & Aging Quarterly*, 33(1), 14.
- Pace, J.E. (2013). *Meanings of memory: Aging and dementia in First Nations communities on Manitoulin Island, Ontario*. Unpublished PhD, McMaster University, Hamilton, Ontario, Canada.
- Pace, J.E. (2016). Focusing on dementia: Using photovoice to document southern Labrador Inuit experiences of cognitive decline [Abstract]. *Alzheimer's & Dementia*, 12(7), 259.



- Pace, J.E., Jacklin, K., & Warry, W. (2013). *Perceptions of Alzheimer's disease among related dementias among Aboriginal peoples in Ontario: Report for Manitoulin Island First Nations*. Sudbury, ON: Northern Ontario School of Medicine I-CCARE project. Retrieved May 9, 2017 from http://media.wix.com/ugd/6e29de_6551ccf787094ac9a9844b1f10405063.pdf
- Petrasek MacDonald, J., Barnes, D.E., & Middleton, L.E. (2015). Implications of risk factors for Alzheimer's disease in Canada's Indigenous population. *Canadian Geriatrics Journal*, 18(3), 152-158.
- Petrasek MacDonald, J., Ward, V., & Halseth, R. (2018). *Alzheimer's disease and related dementias in Indigenous populations in Canada: Prevalence and risk factors*. Prince George, BC: National Collaborating Centre for Aboriginal Health.
- Pitawanakwat, K., Jacklin, K., Blind, M., O'Connell, M., Warry, W., Walker, J., McElhaney, J. et al. (2016). Adapting the Kimberley Indigenous cognitive assessment for use with Indigenous older adults in Canada [Abstract Supplement]. *Alzheimer's & Dementia*, 12(7), 311.
- Potter, R., Ellard, D., Rees, K., & Thorogood, M. (2011). A systematic review of the effects of physical activity on physical functioning, quality of life and depression in older people with dementia. *Geriatric Psychiatry*, 26(10), 1000-1011.
- Public Health Agency of Canada and the Canadian Institute for Health Information. (2011). *Obesity in Canada*. Ottawa, ON: Author. Retrieved September 20, 2017 from <https://www.canada.ca/content/dam/phac-aspc/migration/phac-aspc/hp-ps/hl-mvs/oic-oac/assets/pdf/oic-oac-eng.pdf>
- Somogyi, B.K., Barker, M., MacLean, C., & Grischkan, P. (2015). Inuit elderly: A systematic review of peer reviewed journal articles. *Journal of Gerontological Social Work*, 58(5), 484-502.
- Standing Senate Committee on Social Affairs, Science and Technology [SSCSAST]. (2016). *Dementia in Canada: A national strategy for dementia-friendly communities*. Ottawa, ON: Author. Retrieved June 15, 2017 from http://www.alzheimer.ca/-/media/Files/national/Advocacy/SOCI_6thReport_DementiaInCanada-WEB_e.pdf
- Stevenson, S., Beattie, B.L., Vedan, R., Dwosh, E., Bruce, L., & Illes, J. (2013). Neuroethics, confidentiality, and a cultural imperative in early onset Alzheimer disease: A case study with a First Nation population. *Philosophy, Ethics, and Humanities in Medicine*, 8, 15. DOI: 10.1186/1747-5341-8-15
- Stevenson, S., Illes, J., Beattie, B.L., Dwosh, E., Vedan, R., and Bruce, L. in collaboration with the Community Members of the Tahltan First Nation and the University of British Columbia Research Team. (2015). *Wellness in early onset familial Alzheimer Disease: Experiences of the Tahltan First Nation*. Vancouver, BC: University of British Columbia. Retrieved May 8, 2011 from <http://med-fom-neuroethics.sites.olt.ubc.ca/files/2015/08/GTP-Wellness-in-EOFAD-s.pdf>
- Supreme Court of Canada. (2016). *Daniels v. Canada (Indian Affairs and Northern Development)*, SCC 12, [2016] 1 S.C.R. 99. Ottawa, ON: Author. Retrieved September 21, 2017 from <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/15858/index.do>
- Truth and Reconciliation Commission of Canada. (2015) *Truth and Reconciliation Commission Calls to Action*. Winnipeg, MB: Author. Retrieved September 21, 2017 from http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Calls_to_Action_English2.pdf
- Truong, M. Paradies, Y., & Priest, N. (2014). Interventions to improve cultural competency in healthcare: A systematic review of reviews. *BMC Services Research*, 14, 99.
- Warren, L.A., Shi, Q., Young, K., & Borenstein, A. (2015). Prevalence and incidence of dementia among Indigenous populations: A systematic review. *International Psychogeriatrics*, 27(12), 1959-1970.
- Webkamigad, S.C.M., Jacklin, K., Cote-Meek, S., & Pianosi, B. (2016). Dementia health literacy among First Nations people in Ontario: Integrating western and Indigenous understandings [Abstract supplement]. *Alzheimer's & Dementia*, 12(7, Suppl.), 1006-07.
- Woods, B., Thorgrimsen, L., Spector, A., Royan, L., & Orrell, M. (2006). Improved quality of life and cognitive stimulation therapy in dementia. *Aging & Mental Health*, 10(3), 219-226.
- Yeung, S. (2016). Conceptualizing cultural safety: Definitions and applications of safety in health care for Indigenous mothers in Canada. *Journal for Social Thought*, 1(1), 1-13.

