

INDIGENOUS PEOPLES AND DEMENTIA

New Understandings of Memory
Loss and Memory Care

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INTRODUCTION

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DEMENTIA IS ON THE RISE among non-Indigenous and Indigenous populations around the world.¹ In Canada, approximately half a million people have dementia, and the Alzheimer Society of Canada (2010) reports that this number will more than double over the next thirty years. In the United States, more than 5 million Americans have dementia, and another 15 million have been identified as family caregivers (Lindberg 2014). And even though only approximately 48,000 New Zealanders were living with dementia in 2011, the Ministry of Health reported in 2013 that this number is expected to increase by over 60 percent by 2026.

Dementia has real costs that have prompted action plans by governments around the world. It has been estimated, for instance, that half a million Americans die each year of dementia, resulting in more than \$140 billion spent annually in excess Medicare and Medicaid payments by the federal government (Lindberg 2014). A national plan to address dementia came together in 2011, when Congress passed the National Alzheimer's Project Act. This legislation supported the National Alzheimer's Project, one major goal of which was to decrease "disparities in Alzheimer's for ethnic and racial minority populations" and to "coordinate with international bodies to fight Alzheimer's globally" (U.S. Department of Health and Human Services 2014, 3; see also National Quality Forum 2014).

New Zealand's Ministry of Health followed suit in 2013, with its New Zealand Framework for Dementia Care. The framework explicitly acknowledged that dementia care must "consider the needs of Maori and other

ethnicities” (Ministry of Health 2013, 3). In June 2017, Canada passed its own legislation, becoming the thirtieth country to create a national dementia strategy (Alzheimer Society of Canada 2017).² Seven provinces, including Ontario and Quebec, had previously developed and implemented province-wide plans to respond to the projected increase of people with dementia, and the Alzheimer Society of Canada and the Alzheimer Society of B.C. had commissioned a major study, completed by RiskAnalytica in 2009.³

This study concluded that system navigators – people or agencies who see the health system as a whole – could reduce the “economic burden of dementia.” Unfortunately, it and other social policy studies employed what Anne Robertson (1990) refers to as “apocalyptic demography” to advance their cause.⁴ They placed little emphasis on persons with dementia as citizens who had rights to dignity and care (Bartlett and O’Connor 2010) and instead added to the crisis discourse that has made dementia the most feared diagnosis (George and Whitehouse 2014; Whitehouse and George 2008). Though we recognize that rising rates of dementia pose a challenge to provinces, states, and nations, we wrote this book in response to a need – expressed by communities and practitioners – for information on how best to address memory loss and memory care in Indigenous communities in the context of efforts to achieve health equity. For example, a needs assessment conducted by the Alzheimer Society of B.C. in 1998 identified a lack of awareness of dementia and a desire for more information on the part of local First Nations (Alzheimer Society of B.C., Central Interior Region 1998). The New Zealand Framework for Dementia Care (Ministry of Health 2013, 3) recognized that Māori have “a higher rate of risk factors for dementia” than other New Zealanders. In Ontario, Indigenous health organizations began to report an increase in dementia in their communities in 2007 (Sutherland 2007). These demands for information coalesced with the United Nations Declaration on the Rights of Indigenous Peoples, which states that “Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health” (United Nations 2007, Article 24.2). The product of more than thirty years of activism by the global Indigenous movement, the declaration aims to ameliorate health disparities among Indigenous peoples around the world.

Although dementia in Indigenous populations is a relatively new area of research, the rates have been increasing among Indigenous people everywhere. And we know that the types and causes of dementia in Indigenous communities differ from those in other populations. Whereas policy makers

and service providers have only recently taken up Indigenous people and dementia as an area of concern, epidemiological research on this topic began more than twenty-five years ago, when it was discovered that Alzheimer's was rare among Cree people in Manitoba (Hendrie et al. 1993). Over the next few decades, anthropologists and other social scientists focused their research on the meanings that Indigenous people, particularly Elders, ascribe to memory loss in later life and identified issues related to assessment and care.⁵ The contributors to this volume build on this knowledge base and are collectively committed to honouring knowledge translation and Indigenous research methodologies and working in collaboration with Indigenous communities and nations (Kovach 2009; Tuhiwai Smith 2012; Wilson 2008). Most adopt a decolonizing approach and recommend culturally safe care, a stance that reflects the changing landscape of Indigenous health research.

To decolonize something is to call into question the existence and legitimacy of the settler colonial state and to mobilize Indigenous people and their allies to work toward the demise of settler colonialism in all its forms (Simpson and Smith 2014; Tuck and Yang 2012). This means dismantling structures and processes that were put in place to monitor, control, and oppress Indigenous peoples. As Eve Tuck and Wayne Yang (2012, 1) so eloquently put it, decolonization “brings about the repatriation of Indigenous land and life; it is not a metaphor.” In the fields of child welfare and health services, decolonization entails devolving responsibility to Indigenous communities, thereby promoting their self-determination. Decolonization is best achieved by working in collaboration, and settlers are integral to the process. Following Tuck and Yang, our definition of “settlers” goes beyond people of white European descent to encompass racialized people, including those from other colonial contexts: “settler colonialism and its decolonization implicates and unsettles everyone” (Tuck and Yang 2012, 7). Decolonization is not simply about returning to the past or romanticizing it but about combining its lessons with current realities (Cardenas Aguilar 2015; see also Hulko et al. 2010).

A decolonizing approach underpins the concept of culturally safe care. Developed by Irapeti Ramsden, a Māori nurse, in 1990, the concept of cultural safety has been adopted by nurses across Canada, particularly those working with Indigenous people, and by other health disciplines, including social work. Researchers and practitioners of culturally safe care acknowledge the power imbalances that are inherent in relationships between service

providers and service users, and they shift the power toward the latter. They recognize cultural safety as both a process and an outcome of giving and receiving care or doing research in collaboration with Indigenous people.⁶

Our research is grounded in the knowledge translation and exchange paradigm, a critical framework for collaborative research.⁷ The Canadian Institutes of Health Research (CIHR 2012, 1) defines knowledge translation as “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system.” Since 2005, networks have formed to foster dementia knowledge transfer – with its emphasis on “partnership and multidirectional communication” to address changing or varied definitions of dementia – at the local, national, and international levels (Illes, Chahal, and Beattie 2011). These include the Alzheimer Knowledge Exchange in Ontario, Canadian Dementia Knowledge Translation Network, a US-based coalition called Leaders Engaged in Alzheimer’s Disease, and the International Indigenous Dementia Research Network; the membership of the latter encompasses researchers and decision makers from across Canada, the United States, New Zealand, and Australia, many of whom contributed to this book.

However, as Janet Smylie, Michelle Olding, and Carolyn Ziegler point out in “Sharing What We Know about Living a Good Life: Indigenous Approaches to Knowledge Translation” (2014), the CIHR definition of knowledge does not recognize that “knowing” and “doing” are intertwined and indistinguishable in Indigenous knowledge systems. Intended to encourage Canadian health researchers to take up the knowledge translation challenge, the definition fails to suggest that Indigenous knowledge translation strategies and protocols are “dynamic, participatory, integrated into family and community activities, repeated or cyclical, and intergenerational” (Smylie, Olding, and Ziegler 2014, 18). They should be pursued and adhered to throughout the research process, not merely at the end of a project.

We recognize that relationship-centred care and other recent approaches to dementia care that emphasize family and community involvement align more closely with Indigenous principles than does person-centred care; however, the latter is still “considered the gold standard” by the Institutes of Medicine (World Health Organization and Alzheimer’s Disease International 2012). The person-centred approach recognizes the inherent dignity of the person living with dementia – that is, that they are a person

first – and strives to limit ill-being and maximize well-being in dementia care (Kitwood 1997; Love and Pinkowitz 2013). But its Eurocentric focus on and lionization of the individual may not align well with Indigenous approaches to Elder care. Individuality stands in sharp contrast to Indigenous principles of relationality and interconnectedness (see Hulko and Stern 2009; Jenkins 2014).

Although the contributions to this volume are grounded in the knowledge translation and exchange paradigm, we emphasize that research and practice should ultimately be shaped by Indigenous worldviews rather than by the simplistic application of models of dementia care to Indigenous people. As Leroy Little Bear (2000, 77) succinctly states, “one of the problems with colonialism is that it tries to maintain a singular social order by means of force and law, suppressing the diversity of human worldviews.” For Indigenous people, energy is central to life, and the world is in constant motion. This belief underpins a holistic and cyclical view of the world, which is encapsulated in the medicine wheel and the circle of life. Though some scholars (see Hart 2009, 35) assert that Indigenous cultures share certain core concepts such as wholeness, balance, harmony, growth, and healing, Little Bear emphasizes that Indigenous worldviews are always firmly rooted in a particular place. The concept of relationality – one’s connection to land and space and all that lives on and within it – is integral to Indigenous worldviews and explains why many Elders refer to “all my relations” when they pray to the Creator (Hulko 2014, 97).

Indigenous worldviews have only recently been taken into account in the naming and diagnosis of dementia and Alzheimer’s disease. The umbrella term “dementia” applies to various forms of cognitive impairment that affect mostly older adults, the primary symptoms of which are memory loss, word-finding difficulties, disorientation, and impaired judgment (Alzheimer Society of Canada 2015). Alzheimer’s disease is a specific type of dementia, which was identified by Alois Alzheimer in 1906. Except for the genetic type of Alzheimer’s, the disease can be conclusively diagnosed solely by the postmortem identification of the plaques and tangles that it produces in the brain. Dementia is predominantly associated with older people today, and the word itself is often used interchangeably with Alzheimer’s disease in everyday discourse. But there is a case for avoiding it altogether. In many ethnocultural and Indigenous communities, the word may not exist or hold any meaning in their language, or it may have uniformly negative connotations. Secwepemc Elders recommend using “memory loss” and “memory

care” (Hulko et al. 2010). We recognize that these terms privilege memory and its loss over other symptoms of dementia, but memory loss is the hallmark of dementia and perhaps a more easily recognizable feature of impaired cognition than disorientation or language difficulties, for example. And, as Barbara Purves and Wendy Hulko demonstrate in Chapter 8 of this volume, memory holds special meaning for Indigenous people.

Indigenous worldviews have likewise influenced diagnosis. The diagnosis of dementia – by a physician or a psychiatrist, in a doctor’s office or a memory clinic – often involves the Mini-Mental State Examination (see Beard 2016). However, this test has been criticized for being a culturally relative (and hence unreliable) assessment tool. Researchers and clinicians have sought to develop “culture fair” alternatives that can enable more accurate diagnoses of cognitive impairment in certain ethnocultural groups. For Indigenous people, these tools include the Kimberley Indigenous Cognitive Assessment (KICA), created for use in the Kimberley region and the Northern Territory of Australia; the Grasshoppers and Geese test, developed for Cree people in Saskatchewan; and the Canadian Indigenous Cognitive Assessment, adapted from the KICA by Ontario researchers.⁸ A key feature of these new screening protocols and assessment tools is the incorporation of visual images that reflect the culture and territory of the person being assessed. They are welcome additions to the clinician’s diagnostic skill set, but we need more tools that reflect the uniqueness of Indigenous people. The developers of the KICA note that “Indigenous people are heterogeneous and there is a need to trial tools with people from different areas, language groups, ages and levels of cognitive impairment” (Smith et al. 2007, 118).

With these new approaches and methods in mind, *Indigenous Peoples and Dementia* opens with “We Call It Healing.” This is one of two stories (the other being “Coyote: Keeper of Memories”) crafted during a story creation workshop for the Culturally Safe Dementia Care (CSDC) project conducted in collaboration with Elders of the Secwepemc Nation (see Hulko et al. 2014). Secwepemc people traditionally used stories to teach future generations about their environment, social structures, and beliefs, but there are no stories about memory loss or memory care in existence (Hulko et al. 2010). As a team, the workshop participants created new stories originating from community-based research with Secwepemc Elders. Jean William, Cecilia Dick DeRose, and Estella Patrick Moller are the keepers of this new knowledge, and the stories appear in this book with the permission of the CSDC Elders. “We Call It Healing,” “Coyote: Keeper

of Memories,” and a third story or teaching interlude, “A Fecund Frontier” (not connected to the workshop), set the stage for the thematic discussions in the volume’s three parts by demonstrating how working and researching in collaboration with Indigenous people and communities can be embodied within a knowledge translation and exchange framework. These stories teach us that the act of sharing – whether it be personal experience or traditional values or while working together – requires deep listening. The Secwepemc Elder in “We Call It Healing” imparts an important lesson for us all: “The past carries forward into the future,” and “If the emotional bruises are healed – through sweats, smudging, love, and the Creator – then the dementia can be healed or the impact of living with it lessened.” The Coyote story similarly showcases storytelling as medicine among Indigenous people and a powerful way to pass traditional values, principles of living, and knowledge about memory loss and memory care to future generations. The final story, “A Fecund Frontier,” by Jean Balestrery and Sophie “Eqeelana Tungwenuk” Nothstine, reveals the productive possibilities for colearning that can emerge when two people of differing worldviews and cultural backgrounds come together.

Part 1, “Prevalence, Causes, and Public Discourse,” includes three chapters that directly address the complexities of memory loss and dementia in Indigenous communities. We know that prevalence rates vary from community to community and are trending upward, but we do not fully understand why. For example, dementia is on the rise among First Nations people in British Columbia due to the aging of the Indigenous population in Canada and the prevalence of risk factors linked to colonization such as obesity, diabetes, poverty or low socioeconomic status, low levels of formal education, and cardiovascular disease (British Columbia Provincial Health Officer 2009). Risk factors, which vary from population to population, are generally categorized as modifiable or non-modifiable. The former include external causes such as lifestyle, place of residence, and income. The latter, which cannot be altered, include genetic or hereditary traits. As the BC example suggests, Indigenous people, as an oppressed group, often experience numerous modifiable risk factors that are barriers to health equity and services (Greenwood et al. 2015). Hereditary factors are less common among Indigenous populations than non-Indigenous ones, and to date, only two families are known to have been diagnosed with early onset familial Alzheimer’s in Canada (B. Butler et al. 2010; B. Lynn Beattie, pers. comm., August 2010).

In Chapter 1, Jennifer Walker and Kristen Jacklin discuss current and projected rates of dementia prevalence in Canada, noting that the demographic pressures and risk factors encountered by most Indigenous populations are similar to those for First Nations in British Columbia. In Chapter 2, Neil Henderson, Linda Carson, and Kama King continue the discussion by exploring modifiable and non-modifiable risk factors and by proposing what they call an Indigenous Syndemic Dementia Model. The section concludes with Suzanne MacLeod's "A Story about Joe in the News Media," a fascinating analysis of the "crisis" discourse that prevails in contemporary media accounts of persons with dementia. MacLeod argues that these news stories represent ongoing colonizing practices because they cast the Indigenous person as dangerous and the white person as an innocent victim. They are devoid of history and context.

Part 2, "Indigenous Perspectives on Care and Prevention," includes three chapters that bring lived experiences, traditional knowledge, and community insights to bear on memory loss and memory care. Recognizing that the language of biomedicine does not resonate well with many Anishinaabe people, Jessica Pace and her colleagues explore Anishinaabe traditional knowledge about dementia prevention by using the medicine wheel. Similarly, in Chapter 5, Carrie Bourassa and her colleagues employ Indigenous research methods and draw on interviews and focus groups with Indigenous caregivers to delineate the unique challenges of caring for persons with dementia in an Indigenous context. They also make recommendations for support services that foster culturally safe care. In Chapter 6, Mere Kēpa presents a Māori view on aging and memory loss and advocates for whānau-based care, a humanizing form of care centred on Māori principles.

Part 3, "Applying Theory and Knowledge to Practice," focuses explicitly on the application of research to practice. In Chapter 7, Linda Carson, Neil Henderson, and Kama King apply their Indigenous Syndemic Dementia Model to depression and diabetes, highlighting the need to historicize and contextualize these chronic health conditions in order to develop more culturally relevant and safe treatments. In Chapter 8, Barbara Purves and Wendy Hulko explore representations of Indigenous people in a computer-based reminiscence program and its usability with Elders. They argue that we need to proceed cautiously when we use visual imagery that refers to painful historical events. But we should not sanitize the past. Finally, Wendy Hulko, Jessica Kent, and Danielle Wilson reveal what happened when a knowledge translation and exchange framework was applied to the develop-

ment and evaluation of a storybook and a video for children and youth of the Secwepemc Nation. Incorporating traditional Secwepemc views on aging, the authors produced the book and the film through iterative cycles of community engagement. This method and their evaluation of it indicates that these learning tools can strengthen intergenerational relationships and understanding of memory loss and memory care from a Secwepemc perspective.

Indigenous Peoples and Dementia presents the current state of knowledge on Indigenous people and dementia within a decolonization framework. Our volume promotes culturally safe research and care as settler colonial states and Indigenous communities move toward health equity. Given the recent push for early diagnosis and treatment in dementia care, we need to ask whether this is – or should be – “best practice” with Indigenous people, given their differing worldviews and focus on holism and interconnectedness. Indigenous communities are grappling with tough questions: Is the current (biomedical) approach to dementia at odds with a more holistic view of and response to memory loss in later life? If it is, which approach should we follow, or should we try to reconcile the differences? What does this ultimately mean for Elders living with dementia?⁹ We hope that this book provides guidance for nations and communities as they determine the way forward.

As we pass through life, multiple factors influence our physical, spiritual, mental, and emotional health and well-being. Indigenous people throughout Turtle Island share a collective history of oppression, but they also share a history of resilience. This book explores the causal links between this history of oppression and health outcomes such as dementia. Its authors and the researchers – Indigenous people and their allies – contribute new knowledge, or new “cultural narratives” (Zeilig 2014), in support of calls for action to promote and improve dementia-related health outcomes for Elders. Elders are the knowledge keepers of this generation and the valued members of a declining cohort, yet they and their health needs have received little attention in academic research or public policy (Rosenberg et al. 2010). Any measure to protect their health is a step toward rectifying health inequities to better serve generations to come.

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