Book Review


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With Indigenous Peoples and Dementia: New Understandings of Memory Loss and Memory Care (2019), editors Wendy Hulko, Danielle Wilson, and Jean E. Balestrery aim to provide the first significant synthesis of the nascent scholarship on Indigenous understandings of dementia and memory loss. The book not only includes contributions by Indigenous researchers but also stories (19-22) and conversations between researchers and Elders (146-177). For example, in the segment titled “A Fecund Frontier,” an Alaskan Inupiaq Elder and a social worker dialog about their years-long collaboration, including the frustrations that accompany co-presenting at conferences and their struggles to communicate across a cultural divide. In the end, the social worker asks, “Do you think what we are doing is going to help at all?” to which the Elder replies, “Oh yes, it will. If it helps even just one person, it has all been worth it” (175). The dialogic nature of the piece and the hope for possible futures is but one of the decolonizing efforts of this volume. Chapter 6, for example, is a highly reflective essay on memory loss among the Māori, written by Mere Kēpa. This Indigenous author takes meaningful steps toward decolonizing dementia scholarship by skillfully blending the epistemic value of a traditional prayer with current research literature and her personal experiences of her father getting dementia while she was pursuing her doctoral degree. Kēpa’s piece includes use of several Māori words and a glossary at the end, but is also a decolonial endeavor in less region- or Nation-specific ways: the personal stories and conversations that are not often a major component in the broader dementia literature are here included and lend credibility to this book toward the stated goal of decolonizing academic writing and research. The volume consists of three sections, each encompassing three chapters. The first section covers the prevalence, causes, and discourse around memory loss and memory care among Indigenous peoples. The second section details more specific Indigenous perspectives on care and dementia prevention. The third and final section addresses ways to apply current theory and knowledge to the practice of dementia care.

Focusing mostly on Canadian First Nations peoples, with a chapter each on the US and New Zealand, this work does not include research with Indigenous peoples of Australia, Central or South America, or other world regions. Instead, the editors privilege the perspectives of First Nations peoples with whom they have the most experience collaborating to guide this book. For example, the editors state that their participatory research with Secwepemc people revealed the important use of storytelling to teach many aspects of life and culture to the younger generation. Their work, however, revealed that the Secwepemc
have no stories on memory loss, so the team worked with local peoples to create a culturally-grounded story centered around memory sharing and loss of the coyote (80-83). Other dementia practitioners have done similar work to situate memory loss in specific locations and storytelling traditions, such as The River Story among the Ojibwe (Dementia Friends Wisconsin 2018). These examples illustrate how conducting research about, and working to support the consequences of, memory loss requires a clear understanding of how memory work is done by and for different peoples.

Indigenous Peoples and Dementia presents the importance of Indigenous research methods and knowledge translation back to communities in decolonizing dementia research and care. For example, the editors emphasize in the introduction the role of relationship-centered care among Indigenous populations rather than the Eurocentric “patient-centered” model of care for Elders (7). However, despite repeated calls for decolonizing methodologies in the text, there were a few places where the editors could have strengthened this point. For example, in Chapter 2, J. Neil Henderson, Linda Carson, and Kama King provide an example of how persons classified as having 100% Indigenous genes may have a smaller “genetic load” partially due to the practice of Native peoples raiding Anglo families and stealing their children (50). This passage left me wondering if there wasn’t a better example that could have been provided for such “admixture.” The same authors also provide a syndemic dementia model for American Indians and Alaska Natives that was a bit confusing (54), since it was primarily based on the realities of “reservation life” (55), which may not fully apply to Alaska Native peoples who do not hold reservations (ANCSA Regional Association 2020). Their syndemic dementia model suggests an interplay between several constructs, but due to the directionality of the arrows depicted in the model on page 54, it appears to lack an understanding of the complex interrelationship between depression and diabetes, smoking, blood pressure, and cardiovascular disease. However, Chapter 7, written by these same three authors, presents a biocultural model of depression, diabetes, and dementia that better explicates these relationships.

Chapter 3, written by Suzanne MacLeod, provides an analysis of how Indigeneity and dementia are often portrayed in the media, taking the example of Canadian Elder, Joe. This reflexive poststructural piece truly attempts to decolonize the discourse around dementia by elucidating the ways in which Joe, who had advanced Alzheimer’s Disease, is portrayed as a violent criminal. News coverage stripped Joe of his personhood as journalists focused on Joe’s indigeneity and aggression as his defining characteristics, whereas other (white) individuals in these stories were often depicted with fuller, richer lives with mention of their military service or work ethic (67-68). For example, Joe is repeatedly referred to as an “aggressive Alzheimer’s sufferer” while mention of his past career as a Canadian National Railway worker is given short shrift. This contrasts with how Frank (a white man) is depicted in these articles; his career and military service is mentioned nearly twice as often across the 24 newspaper articles analyzed by MacLeod. This chapter concludes with ways researchers and practitioners can utilize Indigenous perspectives to provide culturally-appropriate solutions for senior care.

Chapters 8 and 9 present specific examples of collaborating with Canadian First Nations experts to create or improve educational storytelling materials for dementia care. Although Barbara Purves and Wendy Hulko’s chapter 8 presents a project with a very narrow scope and analysis of only four participants, this work demonstrates how Indigenous peoples may conceptualize the loss of their culture and traditional stories as being related to individual memory loss, a thread that runs throughout several chapters and is discussed in depth in the book’s conclusion.

There are a few places of redundancy in this edited volume, especially around projected dementia prevalence and the “modifiable” risk factors for Indigenous people like hypertension, obesity, and diabetes. These same risk factors are covered in several chapters (Ch 1, 2, 4, and 5) but this repetition...
could have been reduced by inserting references to other chapters within the book. Additionally, the authors and editors note in several different chapters that Indigenous populations simultaneously view memory loss and age-related confusion as a normal part of the aging process while holding negative stigma surrounding dementia diagnosis. Although it is unclear if this is true across all Indigenous populations (especially ones not covered in this book), such redundancies in the text could have been reduced with citations.

Despite this, the book makes clear the tension between emic understandings of memory and aging and those commonly held in the medical community. Biomedical understandings of aging suggest that cognitive decline, confusion, and significant memory loss are signifiers of abnormal aging that can be partially modified given timely intervention. Given that Indigenous populations may not agree with this assessment, it is unclear from this text if the dementia practitioner can (or should) attempt to change such culturally-grounded perceptions of aging and memory loss. Instead, the book focuses on how to incorporate Indigenous perspectives of acceptance into eldercare and applying dementia research to Indigenous populations in culturally-safe ways. This may leave the reader wondering if (and how) they should attempt to dispel the idea that memory loss and confusion are a normal part of aging that need not be diagnosed or addressed among Indigenous populations. Chapters 4 (written by Pace, Jacklin, Warry, and Pitawanakwat) and 5 (written by Bourassa, Blind, Jacklin, Oleson, and Ross-Hopley) do clearly demonstrate this conundrum, as caregivers share their stories in which lack of information and denial of dementia led to increasingly problematic symptoms and caregiver burden with little to no support that strained family relationships.

Nonetheless, this work is a comprehensive synthesis of the burgeoning scholarship of First Nations perspectives of dementia. With small contributions from New Zealand and the US, this book will have value for scholars working in Canada and the Northern US. The scope of the book is best suited for researchers and graduate students because the book’s focus on the complicated social determinants of health may be too abstract for the typical undergraduate student. Additionally, the authors and editors touch upon a wide variety of viewpoints, often without giving many specifics, which may be difficult for the practitioner to synthesize and act upon. For example, the editors state in the conclusion that trauma-informed policy, practice, and research changes need to occur, leaving people working in the field wondering how to realize such changes. This is likely also due to the nature of the book’s topic; Indigenous dementia spans many different cultural groups across several nations with very different policy-making structures and different ways of remembering. Overall, this book is an informative read that calls for increasing research into the perspectives of Indigenous peoples and memory loss.

References
