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Indigenous Peoples and Type 2 Diabetes: A Discussion of Colonial Wounds and Epistemic Racism

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Key Messages

- Disrupting epistemic racism is a step toward the reconciliation required to revise health-care strategies concerning type 2 diabetes (T2D) among Indigenous peoples.
- By telling Indigenous and biomedical knowledge-based stories of T2D among Indigenous peoples, epistemic racism is revealed.
- Indigenous peoples-led research, in respectful relations with biomedical worldviews, is imperative to address knowledge gaps concerning T2D.

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ABSTRACT

Racism is rooted in historic and ongoing colonial strategies designed to erase, silence and dismiss Indigenous peoples' voices, personhood and worldview. Although within health care today interpersonal racism (discriminatory treatment) is commonly reported on, racism also influences our understanding of health conditions and related treatments. Epistemic racism, the discrimination of how we know, operates through the questions we ask to advance our evidence, and whose knowledge is sought and deemed valid. Epistemic racism is a colonial mechanism that marginalizes and diminishes the power of Indigenous peoples' voices and knowledge bases. In this work, we begin by sharing 2 stories of Indigenous peoples and type 2 diabetes (T2D) from an Indigenous knowledge base and a biomedical knowledge base. Our discussion of epistemic racism, which underlies reported T2D health disparities among Indigenous peoples, includes providing examples of knowledge emerging when the dominance of the biomedical knowledge base is disrupted through centring Indigenous knowledge and peoples. Indigenous-led research, in respectful relations with biomedical worldviews, is imperative. Unsilencing Indigenous peoples' voices and knowledge is necessary when addressing identified T2D health disparities and is truly a health priority. Indigenous revitalization, that is, acceptance of Indigenous knowledge bases, is valid and vital to health and well-being—it is time for ReconciliACTION.

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R É S U M É

Le racisme est enraciné dans des stratégies historiques et coloniales persistantes conçues pour faire disparaître, faire taire et rejeter les voix des personnes autochtones, leur identité individuelle et leur vision du monde. Bien qu'aujourd'hui, dans les soins de santé, le racisme interpersonnel (traitement discriminatoire) soit fréquemment signalé, le racisme influence aussi notre compréhension de l'état de

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santé et des traitements associés. Le racisme épistémique, la discrimination sur ce que nous savons de l'état de santé, se manifeste par les questions que nous posons pour faire progresser nos données, et dont les connaissances sont recherchées et considérées comme valables. Le racisme épistémique est un mécanisme colonial qui marginalise et diminue le pouvoir des voix des personnes autochtones et de leurs bases de connaissances. Dans ces travaux, nous débutons par le partage de 2 récits sur les personnes autochtones et le diabète de type 2 (DT2) établis sur la base des connaissances autochtones et sur la base des connaissances biomédicales. Notre discussion sur le racisme épistémique, qui sous-tend les disparités signalées sur le plan de la santé en lien avec le DT2 au sein des personnes autochtones, s'accompagne d'exemples sur les connaissances qui émergent lorsque la dominance de la base des connaissances biomédicales est perturbée par l'intégration des connaissances et des personnes autochtones. La recherche dirigée par les Autochtones, dans le respect mutuel des visions biomédicales du monde, est essentielle. Il faut donner la parole aux personnes autochtones et lever le voile sur leurs connaissances si l'on veut remédier aux disparités signalées sur le plan de la santé en lien avec le DT2 et en faire une véritable priorité de santé. La revitalisation autochtone, autrement dit, l'acceptation des bases de connaissances autochtones, est valable et indispensable à la santé et au bien-être. Le temps est venu d'aboutir à la réconciliation.

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Racism is rooted in historic and ongoing colonial strategies designed to erase, silence, and dismiss the voice, personhood, and worldview of Indigenous peoples (1,2). Although the impact of over 400 years of colonial imposition has resulted in intergenerational physical, emotional, mental, and spiritual trauma that underlies reported health disparities, colonial strategies have not extinguished Indigenous peoples nor their knowledge systems (1–5). For example, an Ojibway elder spoke of type 2 diabetes (T2D) as an out-of-balance disease, or Windigo, where societal structures split families and enforce new/alien education systems that marginalize and silenced traditional teachings (6). Within health care, various forms of racism reside. Although this includes discriminatory treatment, such as that received by Brian Sinclair (7), epistemic racism underlies the erasure of realities and shapes our collective sight. Epistemic racism operates at the level of our understanding of a health condition through the questions we ask to advance our evidence, and whose knowledge is sought or deemed valid. Thus, this leaves health-care practices, paternalistic attitudes, policies, and research that inherently rely solely on unchallenged biomedical worldviews and perpetuates colonial structures underlying the inadequate delivery of health care within culturally unsafe contexts (8).

In this study, epistemic racism is exposed through the telling of 2 stories of T2D among Indigenous peoples—stories that draw on an Indigenous knowledge base and a biomedical knowledge base. The coauthors of this work each have decades of health-care and research experience, and include a Nēhīnān (Cree) health researcher and food sovereignty community practitioner (M.S.); a Métis physician, who has worked with Indigenous peoples diagnosed with T2D (B.L.); a Métis registered dietitian, who has worked in an urban Indigenous health setting (M.C.); and a Caucasian settler nurse scientist (A.S.). After sharing the stories, we present a thoughtful discussion of the racialized epistemologic context and resolutions. Disrupting epistemic racism is an act of reconciliation imperative to a (re)vision of T2D health-care strategies among Indigenous peoples.

Telling Stories of Indigenous Peoples and T2D

Stories rooted in Indigenous worldviews and knowledge are shared through the voice of Dr Moneca Sinclair, which draw on her experiences from over 40 years of working with Indigenous elders, communities, and health-care practitioners across Turtle Island. As a community nutritionist, food sovereignty advocate, academic student and mentor, artist, educator, and health researcher, she has listened to hundreds of people tell their stories.

These stories resonate with B.L. (Métis physician) and M.C. (Métis registered dietitian) and their experiences within health care. Moneca's sharing of these stories brings life to the voices and relations, and, although echoes of academic literature are heard, the referent source of the stories is not in written words.

"Diabetes is not even a word in our language; it does not speak to us through our land nor does it give us hope," is the type of phrase Moneca has heard uttered by many Indigenous peoples. Often, the story of diabetes is articulated to the public from a biomedical perspective, which continuously cites the staggering numbers and younger age of Indigenous peoples who are getting T2D. Diabetes, a disease Indigenous peoples did not experience until the 1960s, was not like the epidemics of smallpox or the common cold, where one could be treated with medicines; it is a disease that festers as progressively more stress is placed upon a person's body. The stress of ongoing colonialism and this continued ideology of settler racial supremacy dehumanizes and continues to colonize the minds of not only Indigenous peoples but settler colonial peoples. Settlers, especially in the health field, may not be aware of their "unconscious" bias when they are treating Indigenous peoples; the most current example is that of Joyce Echaquan, who died knowing that she was receiving harmful care from health-care workers. The stories of colonialism continue and racism reforms itself with different narratives—rationalizations, such as Indigenous peoples are noncompliant, they want to live in abject poverty, they do not adhere to the policy, and so on. Many individuals and institutions do not wish to acknowledge their colonial or White supremacist or racist bias they have toward Indigenous peoples because it is "messy."

When Indigenous peoples do talk about the disease of diabetes, they are, for me, telling stories of food sovereignty and, most importantly, the loss of their relationship with the land that was once able to feed them. In contrast, when biomedical health researchers tell the diabetes and Indigenous peoples' story, they are inadvertently revealing the ongoing colonial experiment. They are illuminating what happens when colonialism is imposed on a group of people for centuries, and which affects health for generations. Colonialism, legalized through the Indian Act, influences federal and provincial public service programs, and endorses collective and individual unconscious bias, racism, and the refusal to understand that Indigenous peoples view health from a different perspective.

As I listen to the biomedical narrative, I wonder why stories that reflect the loss of relationships with the land, people, and animals are rarely mentioned? If unstated, they are seen as insignificant to

the larger concern of skyrocketing numbers of our people with T2D. The continued assimilation by the dominant settler has resulted in a new “colonial wound” that continues to fester by chronic abject poverty, racism, and unresolved historic trauma, which continues to trouble Indigenous peoples’ minds and hearts from generation to generation. As I walk through the library searching for our voices in the written word in the stacks of journals and books, I do not see our worldviews being represented. I do not see research approaches rooted in Kovach’s conversational research (9), Wilson’s research as ceremony (10), and Tuhiwai-Smith’s decolonizing research (11). These Indigenous methodologies demand that Indigenous voices, stories, people, and ways of being are privileged in health research. I wonder when research will begin to not only address health calls to action from the Truth and Reconciliation Commission of Canada, but also incorporate Indigenous methodologies that demand Indigenous voices, stories, people, and ways of being be privileged and elevated to the same level as biomedical knowledge when making health-care decisions.

Stories rooted in a biomedical worldview reflect a synthesis of relevant academic literature, which draws on written words appropriately cited

Indigenous peoples and T2D is a chronic disease story that began 50 years ago when T2D was almost unknown among Indigenous peoples (5,12). Today, in Canada, Indigenous peoples are 3- to 5-fold more likely to live with a diagnosis of T2D, with higher rates noted among those living closer to urban centres; mounting biomedical evidence demonstrates a growing prevalence, younger age at diagnosis, higher disease rates among women, poorer disease management, and worse health outcomes when compared with the general population (5,12–21). The flourishing of biomedically derived evidence supports the framing of T2D primarily as a physiologic disease with a biomedical therapeutic solution (5,22,23). Solutions focus on individuals, their bodies and behaviours, and how to support behavioural changes (or lifestyle choices), which supports blaming of individuals when treatment plans do not produce the intended results (21,23). During health-care appointments, maintaining or reducing glycated hemoglobin (A1C) levels is a focus. When treatment is ineffective regarding A1C levels, health-care practitioners commonly report experiences of frustration with patients’ inability to manage their health (i.e. blaming) or that there is a lack of resources; curiously, there seems to be minimal consideration beyond those 2 sources of failure (21,23). T2D interventions among Indigenous peoples focus on 1) changes in personal lifestyle choices (e.g. diet, tobacco use, food security, and physical activities) and 2) changes in health-care systems (e.g. primary health-care quality improvements and development of T2D registries and surveillance programs) (21).

One study addressed the role that nonprofit organizations, including Diabetes Canada, played in perpetuating a narrative that T2D is a result of genetics and “lifestyle choices” (24,25), and in silencing Indigenous knowledge. Raphael and colleagues noted that T2D is commonly framed as being the responsibility of individuals. When inequities were briefly mentioned, no insight into the causes or solutions was offered; therefore, with no vision into how inequities could be addressed, the default commonly resides in the blaming or shaming of an individual for this difference. These findings resonate with our considerable experience over the last several decades of hearing similar sentiments within Indigenous community services and frustration with the ongoing marginalization of Indigenous voices and knowledge.

Beckett and colleagues (13) listened to Indigenous peoples discuss experiences of inadequate and culturally unsafe services related to poorer T2D management, which echoes health-care practitioner experiences with treatment challenges (22,26,27).

Family caregivers’ experiences were focussed on 1) juggling between traditional health practices and Western medicine, which requires managing non-Indigenous expectations; 2) lack of accessible and culturally sensitive care, and T2D education; and 3) lack of supports for dealing with the emotional and cultural aspects of managing T2D (8).

Questions and Reflections

As you reflect on each story and accepted truths, notice your responses. Which one is most familiar? How are you able to hear the other, likely contrary story? For most health researchers, health-care practitioners, health-care decision-makers, post-secondary health-care students, and people in general, the second story is likely familiar and confirms long-held ways of understanding health. This example of the result of epistemic racism is upheld through the questions asked, along with whose perspectives and voices are listened to, which then shape our understanding and treatments of T2D among Indigenous peoples. To disrupt this dominance, there is a growing call for holistic health research (12,14,17,28) that incorporates Indigenous knowledge and history. We agree, as Indigenous research methods that privilege Indigenous voices and knowledge will generate evidence to disrupt our reliance on biomedical views driving research, health-care professional undergraduate education, and health-care services.

Disruptions of Epistemic Racism

Epistemic racism is a colonial mechanism that marginalizes and diminishes the power of Indigenous voices and knowledge bases. Biomedical perspectives driving questions asked within health research influence the legitimacy of whose voices are heard and how each voice is understood and becomes validated evidence (29,30). For example, the “thrifty genotype hypothesis” focusses on racialized genetics to explain health disparities; Indigenous scholars challenge the hypothesis and suggest the environmental and sociopolitical contexts be investigated as factors shaping health disparities (31). Indigenous peoples have been, and remain, not silent; resistance continues along with advocating against injustices and racism within health-care contexts—and yet, these voices are not always heard nor afforded the power to inform health-care services (7).

Globally, lower T2D rates are associated with Indigenous populations that have maintained traditional ways compared with those shaped by colonization, global economic, and social forces (14). Similarly, research from western Turtle Island and Aotearoa has shown that Indigenous communities with a stronger connection to their traditional languages also had lower rates of T2D (32,33). These findings are examples of research that ventured beyond lifestyle and genetic factors associated with T2D. In another study, health-care providers’ awareness of the impact of structural racism and historic and ongoing colonialism translated into a patient-centred practice intended to “meet patients where they were at,” rather than expecting treatment adherence (27). Although colonial violence and the biomedical worldview influence health-care delivery, it is promising to read of health-care practitioners stepping away from patient blaming and incorporating personal reflexivity to inform practice decisions.

Recommendations for T2D intervention studies to address Indigenous populations include 1) drawing attention to the historic and ongoing effects of colonialism on Indigenous peoples’ health; 2) breaking intergenerational cycles of disease to promote better health outcomes; 3) culturally based interventions grounded in social, cultural, and historic contexts of health services; and 4) interventions for practitioners to self-reflect on their role in upholding barriers (28). A review of community-based initiatives

suggests the value of holistic health frameworks rooted in Indigenous perspectives and theories (34); thus, we endorse a call for disrupting biomedical dominance within health-care systemic structures and cultivation of space for Indigenous voices, frameworks, and knowledge bases.

Closing Remarks

ReconciliACTION and Indigenous revitalization are imperative for the acceptance of Indigenous knowledge bases as valid and vital to health and well-being, as documented by the Truth and Reconciliation Commission of Canada (30). To challenge biomedical worldview dominance, research governed by decolonizing and Indigenous methodologies is essential. Reclaiming and privileging Indigenous knowledge as a valid way of being/knowing (research) is only possible by following Indigenous protocols (9–11). Issues of power will arise when the intention is to disrupt privileging of biomedical worldviews by creating spaces to elevate Indigenous worldviews as valid evidence to inform health care. Research that represents colonized peoples through a Western lens of understanding is inadequate and disrespectful (9,11). Indigenous-led research, in respectful relations with biomedical worldviews, is imperative to address knowledge gaps concerning T2D. Spaces in which epistemic racism is disrupted are places where evidence will emerge to improve health and health-care practices. Failing to consider historical contexts surrounding health-care, effectively erases our ability to see the impact of present-day colonization and leaving us collectively blind to colonial damage (6). ReconciliACTION is the call to build our capacity to expose and disrupt epistemic racism and to develop sovereign-based approaches to address T2D among Indigenous peoples.

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Author Contributions

M.S. and A.S. took the lead with the first draft of this article, followed by consultations with B.L. and M.C. A.S. was responsible for revising the manuscript based on suggestions of the coauthors. All coauthors reviewed the submitted version and agreed to be accountable for the published version of this work.

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