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<CH HEAD>Chapter 1

<CH TITLE>The Hidden Embodied Stories Behind Diabetes as Racialized Health Disparities

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<A>Learning Objectives

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1. To describe how the concepts of whiteness and racialization can influence interpretations of health and disease.
2. To outline the DOHaD model and discuss how the concept of embodiment can better reflect the lived experiences of oppression.
3. To explore historic examples of racialized views of diabetes and reflect on factors that can influence the high rates of diabetes among Indigenous peoples in Canada today.

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<A>Introduction

Indigenous peoples in Canada suffer disproportionately from health disparities, such as higher rates of Type 2 diabetes, and a variety of causes of these disparities has been proposed. Indigenous health, however, has historically been viewed through a colonial lens inscribing meanings on Indigenous bodies as primitive, as thrifty, or as simply non-compliant. With the biomedical focus on the individual body, and on health as a somatic (bodily) state, these inscribed meanings promote a view that it is something about the Indigenous body itself that is responsible for the higher rates of diabetes and informs a view of Indigeneity itself as risk. The

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body, however, according to Nancy Scheper-Hughes and Margaret Lock, "is simultaneously a physical and symbolic artifact, naturally and culturally produced, [and] anchored in a particular historical moment" (Scheper-Hughes and Lock 1987: 6). By considering various socio-historic views of the body, or of the bodies of particular groups of people, the connections of health to broader social, political economic, and historic conditions may be revealed. Through the lens of embodiment, this chapter explores the intersection of the biological and social by reviewing shifting rates of diabetes among ethnic groups within different socio-historic locations. As with the contemporary view of Indigeneity as risk, differing historic rates of diabetes among different ethnic groups or "races", such as Irish or Jewish immigrants in the late 19th to early 20th centuries, have often been considered to reflect a race-based or genetic predisposition, something in the racialized body. However, this view geneticizes the social and political economic inequities and oppressions underlying health disparities and renders the the connections of health to broader social, political economic, and historic conditions invisible. By framing diabetes as developmental in origin, I argue that the shifting historic rates of diabetes among various ethnic groups, as well as contemporary rates among Indigenous peoples in Canada, reflect lived experiences of oppression that have been embodied in unequal bodies, made visible as health disparities. Through the lens of embodiment, I reveal how health disparities reflect hidden embodied stories of inequity.

<A>Biomedicine and the Body

The contemporary biomedical approach to diabetes is based in nutritional health and focuses on the individual and, more importantly, on individual compliance with dietary and lifestyle recommendations to ensure bodily health. If an individual consumes a "balanced" diet of

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adequate levels of essential nutrients and body measures (e.g., Body Mass Index) are within appropriate ranges, the nutritional status of the individual is presumed to be good. Poor nutritional health, on the other hand, is seen as reflecting individual non-compliance with dietary recommendations and/or poor lifestyle choices, and it is inscribed on the physical body (e.g., obesity). This view further informs the traditional understanding of diabetes as a "disease of affluence" with the obese body as a feature of overconsumption and lack of activity. Further, the biomedical approach focuses on normal versus abnormal physiological functioning (i.e., pathophysiology), and on a part of, or process within, the body. The two basic components of the pathophysiology of diabetes, for instance, are impaired insulin secretion and increased insulin resistance. The focus on health as somatic (bodily) and on the individual body, as well as on a part or process within the body (pathophysiology), shifts emphasis away from the social and political economic forces acting on bodies and influencing health. A lack of consideration of social and political economic forces shaping health can lead to views of underlying genetics or a genetic susceptibility as the cause of poor health, most notably among specific groups of people.

James Neel's (1962) thrifty genotype hypothesis was instrumental in informing a view of the Indigenous body as "thrifty" or genetically susceptible to developing diabetes. In short, Neel argued that Indigenous bodies had evolved to be thrifty to survive times of famine and, when exposed to agriculture, their "primitive" bodies clashed with "civilization". Such views of genetic susceptibility further create a subsequent view of "race" or ethnicity as a risk factor. Indeed, one of the key risk factors identified on the Diabetes Canada website (2019) is being of African, Arab, Asian, Hispanic, Indigenous, or South Asian descent, therefore, essentially not "White" or of European descent. In other words, by virtue of descent, one is defined as "high risk". Within this perspective, health is not only seen as somatic but also as white; the white

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body is the biomedical normal. This is further evident in C. Chaufan and R. Weitz's (2009) discussion on the "invisibility of poverty" in diabetes research, where the authors note there is a paucity of research on poor whites and that this gap in the literature inadvertently reinforces the idea that something about "whiteness protects poor whites" while something about minorities, and their bodies, causes diabetes. Is it something about whiteness that protects whites, or is it something about white privilege?

White privilege can best be understood through the fundamental concept of whiteness. As Paul Kivel (1996) explains, the concept of **whiteness** is a persuasive fiction enforced by power and violence: it is a constantly shifting boundary separating those who are entitled to have certain privileges from those whose exploitation and vulnerability to violence is justified by their not being white. It is a fluid concept as who is considered white changes over time; the meaning of whiteness is historical and has shifted across time periods. For example, during the 19th and early 20th centuries, the "Irish race" was not seen as white. Whiteness can further be conceptualized as a "dominant cultural space with enormous political significance, with the purpose to keep others on the margin because 'white' culture is the dominant culture that sets the norms. Everybody else is then compared to that norm" (Estable et al. 1997: 21). It is through whiteness that categories of Other are created and further create lived experiences of Otherness involving a variety of oppressions, such as racism and discrimination, in contrast to white privilege involving the advantages and entitlements experienced by being white. In a biomedical perspective, these categories of Other are often labelled in terms of ethnicity or "race" and can be considered to reflect genetic difference or genetic susceptibility. When this is applied to biomedical understandings of disease, the racialized Other, and their bodies, becomes the risk factor for a given disease.

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Historically, it has been white people who have held power and typically people of colour and Indigenous peoples who have been deemed not white and racialized. **Racialization** is the "process of manufacturing or utilizing the notion of race in any capacity" (Dalal 2002: 27), and it is the process by which a group of people is defined by their alleged "race" and meanings are assigned to their identity. For example, higher rates of incarceration or poverty of a group are seen as a product of their "race", or genetic predisposition, rather than the inequities and inequalities embedded in social structures and systems. Although the concept of "race" is a social construct with no biological basis, through the process of racialization, identified groups of people face lived experiences of oppression (e.g., racism and discrimination). Many of these oppressions directly relate to the social determinants of health and reflect an intersection of the social and the biological; different lived experiences lead to different health risks for different bodies. Assuming race or ethnicity is the underlying cause of diabetes among Indigenous people or people of colour positions diabetes as a part of the racialized body and geneticizes the social, political economic, and historical inequities acting on non-white bodies and renders these oppressions invisible. Through a developmental rather than genetic lens, the mechanisms through which oppression can inform high diabetes rates, and challenge views of diabetes as a disease of affluence, may be explored.

<A>Embodying the Social Origins of Disease

In contrast to genetic predispositions or race-based views of health and disease, acknowledgement of the inequities and inequalities embedded in society's social structures and systems has led to a focus on the social origins of health and disease and a different understanding of what is informing disparities in health, such as higher rates of diabetes. The

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social determinants of health refer to the conditions in which people are born, grow, live, work, and age, and how these circumstances are shaped by the distribution of money, power, and resources within a society (WHO 2020). It is the social determinants of health that are mostly responsible for the social and political inequities that underlie **health disparities** or the preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health experienced by socially disadvantaged populations, often defined by race or ethnicity (CDC 2018). However, the social determinants informing differential outcomes in health and disease also reflect lived experiences of privilege and oppression (see McGibbon 2012 for a critical health discussion of oppression as a determinant of health); lived experiences that can be physiologically embodied and transmitted intergenerationally.

More recent hypotheses regarding the cause of diabetes suggest a developmental origin. The Developmental Origins of Health and Disease (**DOHaD**) model proposes that the physiology and structure of the developing body (e.g., a fetus) may be adapted in response to adverse environmental conditions (e.g., maternal undernutrition), thereby predisposing it to a variety of chronic diseases, including obesity and diabetes, later in adult life. This hypothesis has been confirmed by many research findings over the past decades (see Vaiserman 2017 for a review of evidence for the DOHaD model). A traditional focus of the DOHaD model has been on poor maternal nutritional environments, such as famines, and their impact on fetal development. A commonly cited example of such early life metabolic adaptations in response to environmental cues is the Dutch Famine (~1944-1945) and its effects on maternal nutrition and the adult health of the exposed offspring. At the peak of the wartime "hunger winter" in the Netherlands, food rations were severely cut (< 800 calories per day) leading to severe undernutrition for pregnant women. A comparison of the individuals exposed to the famine *in*

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utero and individuals not exposed (gestated before or after the famine) revealed an association with numerous health problems for the exposed cohort; e.g., glucose intolerance, obesity, stress sensitivity, coronary heart disease, and breast cancer (Roseboom, de Rooij, and Painter 2006). Further, these "programmed" effects in a fetus can be transmitted across generations causing an intergenerational effect (Gentner and O'Connor Leppert 2019). However, the timing has been broadened to include events prior to conception as well as after birth and early childhood thus initiating new measures focusing on both maternal and paternal influences and environments, as well as early childhood experiences.

One study, for instance, found a father's Civil War lived experiences as a prisoner of war (POW) seemed to impact his sons' longevity. During the Civil War, there were periods when prisoners were frequently exchanged between sides. However, at times these exchanges were halted leading to increased prison populations and severe hardship (e.g., harsher treatment and inadequate nutrition) among the prisoners. In their study, Dora Costa, Noelle Yetter, and Heather DeSomer (2018) found that the longevity of sons born to soldiers who underwent more severe conditions as POWs was shorter than for sons of fathers who were not POWs or who were part of the exchange programs. The authors further found that maternal nutrition factored in. When maternal nutrition was inadequate, the sons of ex-POWs who experienced severe hardship were more likely to die earlier than the sons of non-POWs and ex-POWs who fared better in captivity. As the observed effect was sex specific (only sons were affected) the researchers speculate that an epigenetic effect working through the Y chromosome is responsible.

As well, there are new understandings of the relationship of adverse childhood experiences in infancy and early childhood, namely trauma, and the subsequent development of chronic diseases. Maura Gentner and Mary O'Connor Leppert (2019) sum up new findings and

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outline a variety of emotionally traumatic stressors considered, including physical, psychological, and sexual abuse; neglect; violence in the home or community; parent mental illness or substance abuse; natural disaster; war; death or separation of caregivers; serious illness or injury; and bullying. Toxic stress or extreme, prolonged, or multiple stress exposures in childhood has been clearly associated with higher rates of adult diseases, including diabetes. Further, cumulative childhood adverse experiences increase the risk of adult disease, which increases with each added adverse childhood experience.

These insights into paternal influences and of childhood adverse experiences broaden our understanding of environmental conditions impacting physiological development and subsequent risk of disease in adulthood. However, despite these connections between lived experiences and the development of chronic disease conditions, biomedical discussions often focus on physiological terms such as the "maternal environment" rather than a pregnant woman. Similarly, these environmental (i.e., not genetic) conditions can be better understood as lived experiences of individuals or groups. It is the impact of lived experiences, whether famine or trauma, on the body. There is a need to move beyond a part or process within the pathophysiological body and to emphasize the social determinants of health. The DOHaD model reveals how lived experiences become physiologically inscribed within the body. When the body is racialized, lived experiences of oppression can be embodied and manifest as health disparities.

The concept of **embodiment,** or the process by which people "literally incorporate biologically, the social and material world in which we live" (Krieger 2001: 672), allows for an understanding of the body as both biological and social, as well as a site of difference within which the stories (lived experiences) of inequity may be inscribed. Through the lens of embodiment, the individual body becomes a person, and factors impacting the health of an

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individual body can reflect the lived experiences of inequity and marginalization. A developmental origins framework provides insight into how the adverse lived experiences of racialization become embodied and manifest as health disparities. "Race" can be seen a collection of phenotypically or culturally similar individual bodies, as well as a social body reflecting those bodies' unequal relationship to society, inscribed with difference and facing the lived experiences of oppressions and inequities. But when considering whiteness, one must consider who is white. By exploring shifting constructions of whiteness and rates of diabetes in different socio-historic locations, the hidden embodied stories in racialized bodies can be revealed.

<A>Racialized Bodies, Racialized Diseases

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I am haunted by the human chimpanzees I saw along that hundred miles of horrible country … [To] see white chimpanzees is dreadful; if they were black one would not see it so much, but their skins, except where tanned by exposure, are as white as ours.

(Kingsley III cited in Martin 2014: 52)

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The above quotation comes from an infamous letter written by Charles Kingsley to his wife after his visit to Ireland in 1860. Kinsley explains, in Darwinian terms, how his "assessment of these people as racially inferior and non-human sat uncomfortably with the whiteness of their skin" (Martin 2014: 52). Amy Martin (2014: 52) discusses how Kingsley's description revealed how

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the Irish "stood at the intersection of two contemporaneous racial formations – one relying on the epidermal logic of whiteness emerging primarily in North America and the other founded on a more fluid understanding of racial hierarchy that justified the British empire". Anti-Irish racism was inseparable from anti-Catholicism, and "the impoverished conditions of the Irish both at home and abroad [were] frequently understood as a product of their culture and race". Indeed, racialized bodies have often been historically seen as more than distinct physical or physiological types but are also considered to represent inferior values, behaviours, and cultural practices.**<1>** However, by considering history, and in particular histories of inequity, through the lens of embodiment, the shifting rates of diabetes across ethnic groups and over time gives insight into shifting whiteness and the racialization of disease. Interpretations of the body, and of pathophysiology, are shaped by social and scientific discourse, and during the late nineteenth and early twentieth centuries, a racialized scientific discourse saw biomedical interpretations intersecting with views of white supremacy and leading to racialized interpretations of bodies, health, and disease: Interpretations that silenced the stories behind the disparities.

Differing rates of diabetes among ethnic groups or "races" have often been considered to reflect a race-based or genetic predisposition, something in the racialized body. In the United States, for instance, some of the highest contemporary rates of diabetes are found among African Americans. However, at the turn of the 20th century African Americans were not considered to be susceptible to the disease; as stated by Pancoast (1898: 41), "Diabetes is a rare disease in the colored race". In contrast, the highest rates of diabetes were seen among European immigrants, Jewish immigrants from eastern Europe and Irish immigrants in particular. Of course, and noted in the above 19th century quotation about the Irish, at that time different European ethnic and religious groups were not seen as white but rather as different races, and indeed, their bodies, as

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well as high rates of diabetes, were racialized.

Racist views and stereotypes, as well as societal tensions about a given issue, informed interpretations of higher rates of diabetes among different "races". Views of the "Irish race" and high rates of diabetes in the early 20th century were informed by societal anxieties regarding immigration, and indeed, the lived experiences of racism and discrimination as immigrants, if not as disease carriers, were disregarded (see Reitmanova et al. 2015 for a critical discourse analysis of the racialization of immigrant health in Canadian media). Austin O'Malley (1918: 628) argues that the Irish in the United States have by far the poorest resistance to diseases in general of all the immigrants from Europe, and "in diabetes the Irish are in second place". In an author's note at the end of his article, O'Malley (1918: 632) compares the death rate of Irish in the United States to the death rate in Ireland and discourages further immigration: "I merely wish to inform the Irish in Ireland, in friendly spirit, that their death rate at home is normal, but in America is horrible; that they should remain at home, where they ought to be, and try to save Ireland with mind and hand – and not mouth alone … Keep the young men at home". However, the majority of Irish immigrants in the mid-19th century was escaping the Great Famine, and mass immigration continued throughout the late 19th and early 20th centuries due to religious discrimination by Great Britain and the "troubles" in Ireland. It is these lived experiences of oppressions, through the lens of embodiment, that likely influenced the high rates of diabetes among Irish immigrants.

Similarly, high rates of diabetes among Jewish immigrants at the turn of the century were racialized erasing embodied lived experiences.**<2>** As W. H. Thomas (1904: 358) states, "There is no race which is so subject to diabetes as the Jews". Attempts to explain the higher rates of diabetes among Jews in the early 20th century varied from personal failures to hereditary defects

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to urban life, albeit always based within the racialized Jewish body. Wilson (1912: 663) claimed that "some hereditary defect" made Jews prone to develop diabetes, whereas E. P. Joslin (1924: 727) focused on overindulgence stating, "The Jew, in my opinion, is not prone to diabetes because he is a Jew, but rather because he is fat". R. Saundby (1897 cited in Tuchmann 2011: 25), conversely, argued that "modern life is in itself a cause of diabetes" and that Jews, "well-to-do Jews" in particular, developed diabetes not because they were Jewish but rather because they lived in the city and ate too much, exercised too little, and strained the nervous system. However, this represented a stereotype of Jews as "the vast majority of Jews in the United States in the early 20th century were poor immigrants from Eastern Europe, yet the 'Jew' most often portrayed in the diabetes literature was the affluent Jewish urbanite" (Howe 1976 cited in Tuchmann 2011: 26). The fact that Jewish immigrants were escaping antisemitism fueled by white supremacist views, and the ghettoization and violent pogroms of the mid-19th to early 20th centuries in Europe, was not considered but would have led to cumulative adverse lived experiences. Indeed, a concurrent view of Jews at the time, informed by white supremacy and nationalism, was of a conspiracy theory of Jewish world economic domination (Levy 2005), a view that very well may have encouraged the stereotype of the "affluent Jewish urbanite" in discussions of diabetes.

Clearly racial distinctions in diabetes rates were evident in the early 20th century, even when the diabetes rate was low. As Isaac Lemann (1911: 466) stated, "The negro certainly possesses no predisposition such as that of the Jews so well known, nor on the other hand, can he be known to enjoy any immunity. His carefree life of hard manual labor, with a minimum of physical strain, might lead us to think an immunity probable". Framing diabetes as a disease of affluence, Lemann (1911) highlights class distinctions in diabetes rates. Higher rates of diabetes

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are found among the "well-to-do overfed" who live a life of "great nervous tension", whereas African Americans "belong so overwhelmingly to the poorer classes" (Lemann 1911: 462). This class distinction revealed the view of the day that diabetes was a disease of upper classes because of the strain on their bodies due to leadership, a view informed by Social Darwinism (see Shane O'Donnell 2015 for a discourse analysis of historic views of the causes of diabetes).

However, rates of diabetes among African Americans began to rise during the 20th century leading to a reinforced view of race-based differences in health. In a comparison of diabetes among the "colored race" and the "white race," Harold Bowcock (1928: 994-995) noted an "extremely high comparative incidence of the disease among colored females" as opposed to the higher rate seen among white males, as well as an earlier age of onset in that "diabetes appears about ten years earlier in the negro than the white race". Highlighting these unique characteristics of diabetes further racializes the disease within the African American body and ignores the embodied violence and oppressions brought about by a history of slavery followed by segregation and the Jim Crow laws. Bowcock highlights a view of racial inferiority in the conclusion of his study on "Diabetes Mellitus in the Negro Race", stating that the "disease is usually mild and the greatest handicap to adequate control is poor cooperation, due to poverty and lack of intelligence" (Bowcock 1928: 999).

The racialization of Irish and Jewish immigrants during the 19th to early 20th century and the shifting rates of high levels of diabetes reflect the fluidness of whiteness and who could access white privilege and who would face oppressions. Through the lens of embodiment, the lived experiences of the racialized bodies of Irish and Jewish immigrants became embodied stories of anti-Semitism, famine, and conflict manifest as disparities in diabetes rates. Health disparities among different ethnic groups, however, shift over time, as unequal histories are

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created, and today it is Indigenous peoples who experience the highest burden of diabetes globally.

Rates of diabetes among Indigenous peoples in Canada are 3 to 5 times that of non-Indigenous Canadians and, similar to diabetes among African Americans in the early 20th century discussed above, reveal an earlier age of onset and higher rates among Indigenous women. These differences in disease presentation inform a causal interpretation of the Indigenous body and inform the view of Indigeneity as a risk factor for diabetes. However, in the mid-20th century, diabetes was for the most part non-existent among Indigenous peoples; as stated by L. A. Chase (1937: 369), “Indians are not subject to diabetes”. Through the lens of embodiment, the histories of colonization that have led to intergenerational trauma must be considered in discussions of diabetes among Indigenous peoples today. The demise of the fur trade economy of the 19th century, the confines of the newly created reserve system, broken treaty promises, and the cultural genocide of the residential schools not only set the stage for extreme poverty and severely high levels of malnutrition coupled synergistically with infectious diseases but also inform historic trauma that has been transmitted across generations. The lived experiences of the residential schools would have represented numerous cumulative adverse childhood experiences, experiences that would have been inscribed in the body and transmitted across generations. From a developmental origins perspective, diabetes is not due to Indigeneity but rather reflects the embodied stories of the lived experiences of colonization and ongoing settler colonialism made visible as health disparities.

<A>Notes

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1. An example of a late 19th century depiction of the Irish can be found on Wikimedia https://commons.wikimedia.org/wiki/File:Scientific_racism_irish.jpg. The image and associated text propose an African origin of the Irish, as well as an associated inherent inferiority, and reflect the scientific racism of the day.

2. You can explore specific histories, and find images, of late 19th – early 20th immigrants to Canada through the Library and Archives Canada website https://www.bac-lac.gc.ca/. To locate images, conduct a Collections Search with the search term "immigrants" and select "images" in the drop-down menu. Use the advanced search feature for a specific time-period and/or ethnic group.

<A>Critical Thinking Questions

1. How may the concept of whiteness influence biomedical interpretations of disease? What may be made invisible with the racialization of diseases?

2. What does the developmental origins of health and disease (DOHaD) model emphasize? How can the concept of embodiment expand understandings of disease beyond the pathophysiological body?

3. In your own words, describe how health disparities can reflect embodied lived experiences (provide examples).

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