Indigenous Peoples and Diabetes

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Indigenous Peoples and Diabetes
Community Empowerment and Wellness
Mariana Leal Ferreira and Gretchen Chesley Lang



Indigenous Peoples and Diabetes

Community Empowerment and Wellness

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To all our relations!

and

To the Seven Generations!

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Foreword

Diabetes and Genocide— Beyond the Thrifty Gene

Nancy Scheper-Hughes*

"To say I am Native American means I am or will be diabetic."

"That's what the doctor told me. We Indians have bad blood. See, that's why I drank so much all my life. It's in me, in my blood. So there's not much I can do about it, either."

Yurok individuals to Mariana Ferreira, this volume

"The tradition of the oppressed teaches us that the state of emergency in which we live is not the exception but the rule. We must attain to a conception of history that is in keeping with this insight. Then we shall clearly recognize that it is our task [as intellectuals] to bring about a real state of emergency, and this will improve our position in the struggle against Fascism. One reason why Fascism has a chance is that in the name of progress its opponents treat it as a historical norm."

Walter Benjamin, "Theses on the Philosophy of History"

There are different ways of imagining, 'reading,' and interpreting history: bio-evolutionary history; social or collective history; individual/biographical/personal history. While all of these can offer essential insights toward understanding and responding to the particular vulnerabilities of Indigenous Peoples and communities world wide to adult onset (i.e., type 2) diabetes, this collection emphasizes the impact of social history—colonial histories and their sequelae, to be exact—on the etiology and epidemiology of diabetes today in Indigenous communities in North America, Latin America, the Arctic, Australia and the Indian Ocean.

Walter Benjamin,¹ writing on the eve of World War II, recognized an invisible feature of social and political life, which while appearing in a more exaggerated form under fascism, obtains in most societies and under various forms of governance and

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^{1.} Walter Benjamin. 1968 [1940]. Illuminations: Essays and Reflections, edited by Hannah Arendt. New York: Schocken.

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governmentality: the tendency to 'normalize' suffering, disease, and premature death among certain excluded or marginalized classes and populations. This is what Michael Taussig² (reflecting on Benjamin) calls "terror as usual" and what I have called "every-day violence,"³ though we do not usually associate disease with violence and terror, except perhaps when diseases are linked to biological warfare and other forms of blatant bio-terrorism. But violence and disease are linked in more ordinary way in social and bureaucratic indifference toward the excess morbidity and mortality of certain populations under the assumption that alarming statistics are not to be seen as alarming at all but rather as 'normal' to the population and therefore 'to be expected.' Another, is in the rush to biologize and racialize gross differences with respect to vulnerability to disease. Thus, alcoholism, depression, and suicide, obesity and diabetes in Indigenous communities have been normalized and racialized, consciously or not, in etiological theories.

To date, the prevailing medical model of diabetes etiology focuses on the 'faulty genes' of Indigenous Peoples combined with their faulty diets and other unhealthy behaviors, victim-blaming hypotheses that only serve to trap the sick person inside a cage of disease that is seemingly of their own making. Thus, some of the chapters of this new collection hark back to Susan Sontag's angry and visionary broadsheet, *Illness as Metaphor*, and refer to diabetes as symbol, as metaphor, even to diabetes as myth, in an effort to contest the view of diabetes as a plain thing, a natural fact, as disease itself.

This innovative book, a paradigm-breaking endeavor, is a creative assemblage of chapters by medical anthropologists, health professionals, nurses and doctors, Indigenous Peoples and community workers. It shifts the medical gaze from the diseased body to a diseased colonial and post-colonial history of genocide, the collective experience of trauma reproduced in the many 'small wars and invisible genocides' practiced against Indigenous Peoples to this day.

This volume is a bold attempt to reframe the meaning of diabetes as a socio-political pathology and to place the disease outside and beyond the body of the individual sufferer and to see it as the consequences of genocide and its aftermaths and in the signature that these collective losses have left on the bodies and even the physiologies and chemistries of Indigenous Peoples in the past and today. To say that diabetes is a socio-political pathology is not to deny the medical model of disease but rather to search for ultimate, rather than immediate causes and to recognize that what medical anthropologist Margaret Lock calls 'local biologies' (with reference to her comparative study of menopause among Japanese and North American women) emerge out of distinctive and collective experiences and histories of embodiment and risk producing local

^{2.} See Michael Taussig. 1992. "Terror as Usual: Walter Benjamin's Theory of the History as State of Siege." In *The Nervous System*, esp. pp. 11–16, and 195–96. New York: Routledge.

^{3.} See Nancy Scheper-Hughes. 1992, *Death without Weeping: The Violence of Everyday Life*. Everyday violence encompasses everything from the routinized, bureaucratized, and utterly banal violence of young children dying of hunger and maternal despair in Northeast Brazil to elderly African-Americans dying unnecessarily of heat stroke in suffocating apartments in inner city Chicago during the heat wave of 1995. See Eric Klinenberg, 1999, "Denaturalizing Disaster: A Social Autopsy of the Chicago Heat Wave," *Theory and Society* 28: 239–92.

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and even culture bound symptoms and experiences of supposedly universal illnesses and disease. These papers look at the social context of diabetes within Indigenous experiences of colonial expansions and occupation that disrupted Indigenous ways of being-in and living-in the world and of living in and experiencing their bodies.

Several chapters discuss how socio-inequality, traumatic experiences and psychosocial stress produce observable changes in the neuroendocrine system, affecting the production and circulation of hormones, including cortisol, glucagons, catecholamines and insulin itself. In the absence of protective factors, the leading symptom of diabetes mellitus, hyperglycemia or high blood sugars, sets in and its persistence brings terrifying problems for the body: blindness, poor circulation of hands and feet leading to gangrene and amputations, sexual impotence and other serious afflictions. Strong family ties, networks of social support, generosity, solidarity and love can produce what the authors here call emotional liberty. In their absence, the ability to grieve, to feel pain, and to suffer is impaired, generating intense emotional pain and suffering which pave the way for diabetes mellitus to set in.

Genocide, trauma, emotion, food, the loss of and return to hunting and gathering as cultural and biological survival are generative themes of this collection. Contributors contend that the prevailing research focusing on obesity, nutrition, and individual health behavior—although undeniably contributors to health outcomes obscures social and historical issues that are even more fundamental to the etiology of the disease. The link between diet and diabetes is a robust one, of course, but these authors and clinicians argue from a political and human rights perspective that recognizes the devastating effects of colonization on Indigenous health and on access to abundant and nourishing food. Ferreira and her associates argue that "access to quality, nutritious food has become a human rights issue for Indigenous Peoples globally since everyone has the right to be free from hunger and undernutrition." This new civil right—a 'right to *good* food'—is enshrined in various international statutes including the Rome Declaration on World Food Security (1996), the International Covenant on Economic, Social and Cultural Rights (1966) and the Universal Declaration of Human Rights (1948). The authors note that there are profound contradictions between prevailing economic and clinical visions of what a "healthy diet" is, and the hunger and scarcity that prevails in Indigenous communities, as documented in Part 2 of this book (chapters 6 by Omura; 7 by Roy; 8 by Smith Morris; 9 by Lang; and 10 by Korn and Ryser). The healing power of traditional forms of food gathering and preparation, its highly ritualized and communal dimensions requires not only equitable and sustainable food systems, but rights to the security of Indigenous livelihoods, meaning rights to land, to labor, and to social and political security, all of which are presently lacking for most of the world's Indigenous Peoples.

I recall a visit in 1995 to a dispossessed band of Kung San people originally of the Kahahari Desert, who had resettled, for a price, on the private estate of an Afrikaner entrepreneur in the Northern Cape of South Africa. In exchange for the right to live on the estate, which was turned into a nature reserve and living cultural museum for tourists, the resident Kagga Kama had to dress traditionally in animal skins and entertain wealthy tourists with their display of traditional tools and weapons, story-telling and boasts of their hunting prowess. Back stage, however, the Kagga Kama lived in

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wretched pre-fabricated huts, a veritable slum in the wilderness. They were prohibited from hunting the plentiful springbok deer, rabbits and other small animals and from digging up and gathering the roots, berries, melons and eggs that had once been the mainstay of their diets. All their 'hunting and gathering' was now limited and contained to the estate-owned company store where dried corn meal, coffee, sugar, lard, flour and canned foods were the only food available to these 'faux' hunters who entertained the white tourist tribes with their displays of blow guns, darts, and digging sticks which they were prevented from using. A dietician supplied by a local university was conducting a study of the effects of 'poor dietary' habits on the Kaga Kama San who suffered inordinately from respiratory infections, tuberculosis, and, of course, diabetes. The Afrikaner student of nutritional science saw no irony in her empirical studies recording the daily caloric intake and nutritional analyses of the 'deficiencies' of Kagga Kama diets.

In this important and innovative collection the authors situate diabetes inside history rather than outside it, as in the shadowy, mythological and certainly myth-making anthropological and bio-evolutionary models of the prehistory of hunting and gathering peoples. James Neel, the controversial human geneticist of Yanomami fame, contributed a particularly dangerous view of Indigenous genetics around his hypothesized "thrift gene" theory of genetically-transmitted propensity to diabetes. Neel imagined Indigenous Peoples as camel-like beasts with an inherited ability to over-eat during times of plenty so as to produce a storage pouch of abdominal fat that could be drawn on during times of famine and food scarcity. Like many such hypothetical and imaginative theories ("just so stories") of bio-evolutionary and physiological adaptations, the inherited traits become liabilities and risks under new or rapidly changing circumstances. Thus, the 'thrifty gene' (a gene that has yet to materialize in the age of modern genomics) is seen as an evolutionary mechanism that back-fired once hunting and gathering peoples 'evolved' toward more 'civilized' and sedentary lives complete with cash stores and McDonalds and Kentucky Fry take-outs on or in easy reach of every reservation, not to mention every inner city neighborhood. Hunting and gathering amidst alternating periods of fast and famine disappeared, but (according to the 'thrifty gene hypothesis' the propensity to store fat lives on in Indigenous Peoples causing them to sicken from overweight and diabetes-prone sedentary habits.

The notion of the 'thrifty gene' (and the way it has been interpreted by health workers) suggests that "Indigenous blood" carries a taint—the threat of passing on an inherited risk of diabetes for which the only solution, paradoxically, is the dilution of Indigenous blood through racial intermarriage, another form of 'invisible genocide.' Thus, bad genetics combines with bad anthropology to produce a theory that put Indigenous People in their place—that is, on the margins as bio-evolutionary holdovers and deviants only capable of reproducing cycles of medical and social pathology. Despite this, the thrifty gene hypothesis has been adopted not only by doctors and other biomedical practitioners but by Indigenous Peoples themselves looking for an explanation for the ills that disproportionately beset their communities.

Like all reductionist theories, the 'thrifty gene' is nothing if not a 'thrifty'/nifty hypothesis, one that simplifies and excludes the complexities, the bio-social interactions,

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and the intervening variables like social class, gender, and the impact of colonial and post-colonial experiences of dispossession, forced migrations, and resettlement, chronic malnutrition, segregation and social exclusion. As Ferreira notes, the thrifty gene hypothesis erodes self-knowledge and turns sufferers into their own worst enemies as they adopt the idea that they are the heirs of faulty genetics and faulty behaviors (junk-food eaters, alcoholics, etc.) This, too, is another dimension of invisible genocide.

This volume is, therefore, more than a conventional medical anthropological presentation of illness narratives to balance the medical model of disease. Rather, the authors are engaged in taking at face value what Indigenous Peoples say, and feel, and do about the diabetes 'epidemic.' The goal is to move away from the purely medical model of diabetes and toward Indigenous models and understandings, an effort that was spearheaded not by physicians and social scientists but also by Indigenous Peoples themselves who chose to invite collaborations with clinicians, social scientists and researchers, but on their own terms. New efforts, such as the Kahnawake Schools Diabetes Prevention Project described by Ann Macaulay et al., confront the ethics of research and present a model for new partnerships among scholars, activists and community members.

The invention of new therapies in some communities include successful projects of culture restoration and rebuilding, including music therapy and relaxation, language and oral history workshops, bike paths, walking trails, summer camps for young people, providing social support and the emergence of new social movements to build solidarity. Acknowledging the role of mind-body interactions in stress reduction therapies, the editors have included a provocative chapter discussing evidence of the positive effects of relaxation techniques on the production of insulin.

Indigenous Peoples and Diabetes makes an eloquent case for a new and enlarged model and understanding of a modern epidemic on behalf of those who are doubly stigmatized by a disease that is seen as hopelessly mired in faulty adaptations (biological and cultural) to modern life. The book is inspired by a strong commitment to a liberation medicine and to the belief that access to good food, respect for cultural traditions, and integrative therapies are basic human rights.

Series Editors' Preface

Pamela J. Stewart and Andrew Strathern

We are pleased to see the present set of essays included in the *Ethnographic Studies in Medical Anthropology* Series. This collection is a unique set of essays that address a serious and significant medical problem, i.e., type II (also referred to as Adult Onset) diabetes. This form of diabetes is becoming an increasing problem around the world, both among wealthy populations who can buy whatever sorts of foods they wish, including healthy foods, and also among populations who may not be able to purchase, do not wish to, or do not have available to them healthy food supplies.

The approaches to the management of the Type II diabetes that are discussed in the collection could profitably be applied to contexts in many geographic areas among peoples living in diverse economic situations. Diet, exercise, emotional well-being, and family support have proven to be significant factors in the proper management of chronic disease states, including diabetes. Education of the individual with diabetes and their family is vitally important. Doctor-patient / health-care worker-patient communication is an important part of treatment. Since the management of diabetes is complex, requiring continuous vigilance, it is important that health-care workers and patients have an easy means to exchange information and that they rely on each other in a relationship of communication and mutual understanding (see discussions in Strathern and Stewart 1999).

The essays in this volume each have their individual strengths and the book will certainly take its place in the literature on medical anthropology. We read and commented on the Introduction and Chapters 1–20 during 2004. The topics in the essays are such that the work could be used in many different contexts and set for a variety of courses, e.g. those on critical medical anthropology, cultural identities, patient-physician communication, epidemiology, and nursing awareness, also in community educational centers and in training programs for healthcare practitioners.

The ways that Indigenous Peoples deal with health, diet, and disease are of particular interest to many scholars as they are also to ourselves in our research. In two of our recent books, *Curing and Healing: Medical Anthropology in Global Perspective* (Strathern and Stewart 1999) and *Humors and Substances: Ideas of the Body in New Guinea* (Stewart and Strathern 2001), we set out to explore how the peoples we work with in Papua New Guinea see their physical bodies and the sicknesses that influence their bodily functions as a part of their larger world-view or emplacement of themselves within their indigenous cosmology.

It is also always interesting and important to learn about how people build up their bodies through food and how they think their bodies are constituted in healthy or unhealthy ways. Here we will take an example from the Mount Hagen people of Papua New Guinea, among whom we have worked for many years and published on widely (e.g., A.J. Strathern 1971; Strathern and Stewart 2000). Historically they have had definite ideas about food and the body. For them, the sweet potato (*Ipomoea batatas*) was their staple, the focal member of a class of food sources called *röng* in the local language. This also included taro, yams, green vegetables of many kinds, bananas, sugarcane, edible ferns, shoots, and inflorescences. All of these foods were appreciated and many were planted together in complex garden areas known as *pana*, a term which later came to signify "year" in colonial times after the 1930s.

Sweet potatoes, an introduced crop, nevertheless had become, in the several hundred years after its arrival in New Guinea, the staple crop for the peoples of the Highlands region, because of its ability to grow well in mountainous conditions. For Hageners, then, sweet potato was the quintessential "food", which they even described in the 1960s, using a term from the lingua franca Tok Pisin, as their "merasin" (medicine), i.e., a food that could keep them feeling well. Taro, although a much more ancient crop, was not described in this way, but people did say of it *kun pei na petem*, "there is no hunger in it", it was very satisfying to eat and staved off the pangs of hunger.

All categories of *röng* were contrasted, and paired, with the category of *kng/kung*, "pork", which in colonial times was expanded to include beef and mutton, introduced forms of meat. The provision, for special occasions, of *kng röng rakl*, "pork and vegetables", was seen as an important marker of hospitality; and what pork especially added to foods in general was *kopong*, "grease". In turn "grease" was a general marker of vitality, prosperity, and fertility. To have *kopong* was therefore to be vital, alive, healthy, and even influential. A body lacking *kopong* was not seen as healthy.

Hageners' ideas about bodily composition, therefore, led them to associate "fatness" with "health", a supposition that can further lead to problems for them in contexts where their dietary intake has changed. Pork was rarely eaten in the past and consumed only at special ceremonies along with vegetables, which were daily staples; the availability of fatty meat and fried food in urban stores has changed this situation radically. This observation underlines the importance of studying diet as an integral part of a people's whole set of historical and adaptive circumstances and their own ideas of ideal bodily and mental states. In Hagen a good *noman* or "mind" was also said to be reflected in a "healthy" body, i.e., one with *kopong* (grease/fat).

In thinking about the body in sickness one must also consider the body and its place within the social system at large. Many discussions on the body in anthropology have tended to oscillate between a stress on the body as a passive marker and the body as a locus of agency. Mary Douglas in her writing distinguished clearly between different social environments and their effects on perception and experience (Douglas 1966) and spoke of the "social body" as constraining the perceptions of the "individual body" (Douglas 1970: 68). Thomas Csordas, by contrast, has emphasized embodied experience as the foundation of culture (e.g. Csordas 1994).

But if one starts with a different set of propositions, i.e., looking at the emplacement of the individual body within a cosmological world-view, this opposition is itself mediated. To say that the body is a part of the cosmos implies already that it has its place in the cosmos and that the cosmos, in a sense, runs through it as well as viceversa. To be a part of the cosmos, however, is also actively to experience life within it and to experience change and stress that evoke active and energetic responses. When disjunctions occur between a sense of "proper" cosmological emplacement it is more difficult for individuals to place their bodily well-being into a cycle of day-to-day health maintenance. This is true for those peoples classified as "indigenous" and those that are not classified in that way. Issues of this kind are explored in thoughtful, practical, and concerned ways by the contributors to this volume.

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