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Author

Howard, Heather

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Politics of Culture in Urban Indigenous Community-Based Diabetes Programs

Heather A. Howard

INTRODUCTION

Diabetes has repeatedly been identified as a top health concern for indigenous peoples.¹ Although most indigenous people in North America today live off-reservation, diabetes research has for the most part neglected urban indigenous communities and the significance of urbanization for indigenous peoples' health.² Urban indigenous health programs draw on broad funding strategies and resources that are largely developed and contingent on reservation-based experience and research results, even though reservation-based experiences are not analogous to those of indigenous peoples living in urban areas. In the urban setting, the social determinants of indigenous peoples' health are elaborated by a multiplicity of health care structures, knowledges, and practices; unique urban-adapted kinship and social networks; and demographic variables such as socioeconomic status and cultural diversities. These factors are particularly significant to urban indigenous peoples' experiences of diabetes and have not been thoroughly investigated. Moreover, diabetes education materials and

HEATHER A. HOWARD is an assistant professor of anthropology at Michigan State University and affiliated faculty with the Centre for Aboriginal Initiatives at the University of Toronto. She has coedited Aboriginal Peoples in Canadian Cites: Transformations and Continuities and Keeping the Campfires Going: Native Women's Activism in Urban Communities. Her research is also published in the journals American Indian Quarterly and Medical Anthropology: Cross-Cultural Studies in Health and Illness.

programs aimed at prevention and management which are based on local, participatory social research and experiences have been slow to develop in indigenous communities overall.³ However, community-based approaches to diabetes have been in place for more than three decades within the urban indigenous community of Toronto, Canada.⁴ This provides an opportunity to take a long view on the historical transformation of the politics of culture in the production of knowledge and practice within indigenous community-based diabetes programming in an urban setting.

Pierre Bourdieu's theory of cultural capital, as reconceived and popularized in health promotion, emphasizes the function of cultural resources in the production of health.⁵ To move beyond a functional representation of culture in addressing health inequalities, I offer a critical perspective of the concept of cultural capital in health promotion by situating programs within the social relations and political contexts of the overall complex history of Toronto indigenous community-building and social service delivery.⁶ Bourdieu described the processes of socialization, embodiment, and distribution of cultural resources in the production of social value and power relations within society, and emphasized that the "social world is accumulated history." In the context of urban indigenous community production, and in Toronto particularly, accumulated plural histories intersect in heterogeneous economic, social, and cultural capital producing and divesting processes.⁸ Those intersections are illustrated in the transformations of indigenous community-led discourse and action in diabetes education and support programs.

The socioeconomic and political dynamics that shape the production, investment, and divestment of cultural capital in the history of indigenous community-based diabetes intervention in Toronto have greatly impacted programs. As Bourdieu describes, changes in the "the structure of the distribution of [cultural] capital ... i.e., the set of constraints inscribed in the very reality of that world, which govern its functioning in a durable way, determine the chances of success for practices."9 In Toronto, programs were initiated in the mid-1970s as models of indigenous self-determination, cultural engagement, and attention to broader decolonization struggles. However, over time, diabetes education accessed by indigenous people became increasingly standardized to universal biomedical perspectives and to reified concepts of culture and tradition. Rather than move toward increased community involvement and development, targeted and designed to meet local urban needs and conditions, programs instead tended to become homogenized and based on broader regional and national initiatives. James Waldram argues that the "reification of Aboriginal culture as a treatment model is clearly intertwined with broader concerns over identity, themselves a product of an emerging Aboriginal consciousness in reaction to a colonial legacy."10 As this article demonstrates, it

is additionally important to consider ongoing political processes and structural relations of oppression as these may both inspire and limit the possibilities for culture-based approaches to health promotion for indigenous peoples. I conclude with a presentation of critical reflection that occurs within the Toronto indigenous community today, as the complexities of the meaning and application of indigenous culture in diabetes prevention and management programs are being reassessed.

BACKGROUND AND CONTEXT FOR INDIGENOUS DIABETES PROGRAMS IN TORONTO

The indigenous population in Toronto is very diverse culturally, linguistically, and economically. This diversity precedes the existence of the contemporary settler city that occupies lands recognized as those of the treaty-signatory Anishinabek as well as Wendat and Haudensaunee peoples.¹¹ Indigenous peoples have lived continuously in the area for thousands of years; however, their numbers declined significantly with disease, removal, and settler pressures until the twentieth century.¹² Among the reasons indigenous peoples moved to Toronto, particularly after World War II, are conditions on reservations that were caused by government tutelage and impediment to economic development; assimilation programs including removal to residential schools; the seeking of educational and labor opportunities; and participation in military service. 13 As in many other cities throughout North America, a vibrant indigenous community has grown and flourished.¹⁴ Today, it is estimated that seventy thousand indigenous people live in Toronto. 15 Culturally, while indigenous peoples from within the general boundaries of the province of Ontario dominate these numbers, Toronto has attracted indigenous peoples from across the Americas. A 2002 report prepared by the Native Canadian Centre of Toronto (NCCT) asserted that its membership included indigenous people from 115 First Nations. 16 The particular diversity of educational and economic opportunity in Toronto, combined with the sociopolitical history of indigenous/non-indigenous relations in Canada, led to class stratification within this urban indigenous community, which also generated a significant middle class.¹⁷ There is no specific indigenous enclave or neighborhood in Toronto, and therefore the community is most visibly defined by a relatively large network of indigenous social service organizations. 18

The Aboriginal Peoples Survey that was conducted by the Canadian government in conjunction with the 2001 census indicates that 30 percent of the off-reservation population reported having a disability, and 60 percent reported at least one chronic condition such as arthritis, high blood pressure,

or diabetes. The survey identified 24,910 Aboriginal people in Toronto, of which 51.5 percent reported a chronic condition, and nearly 12 percent reported having diabetes, compared to Aboriginal people in the province of Ontario overall, which had 9 percent reporting diabetes. ¹⁹ Complications from diabetes are also more frequent and severe for indigenous peoples, including blindness, limb amputation, and organ failure. ²⁰ While more recent and accurate data for urban indigenous populations is needed, the Canadian Diabetes Association reported in 2010 that 20 percent of the indigenous population overall in Canada has diabetes. ²¹ Visible complications, as well as living with diabetes or caring for a person with diabetes, make diabetes a predominant feature of urban indigenous community life, and are experiences to which many indigenous people relate. Although these issues have been examined in rural contexts, the growing population of indigenous peoples in urban environments makes it urgent to begin to examine these experiences from urban indigenous points of view. ²²

Indigenous persons with diabetes access prevention and management education in Toronto in basically two ways: as individual patients in the health care system and as voluntary participants in community-based services and support groups. With the exception of those who utilize the indigenous community health center, Anishnawbe Health Toronto (AHT), where allopathic and traditional medical practitioners work together, indigenous diabetes patients often access medical professionals through emergency care, and as such the delivery of diabetes management education is usually standardized. There is little or no cultural sensitivity or relevance in the materials or approaches used, despite increased efforts in the last decade to improve cultural competency education for health professionals. Anecdotal evidence suggests that indigenous people encounter degrees of racism, stereotypes, and patronizing approaches from mainstream health care providers. For example, they might be asked if they abuse alcohol or are homeless, questions that indigenous patients suspect are not asked of non-indigenous persons with diabetes. Speeches made about adhering to the Canadian Diabetes Association's recommendations on daily intakes of starches, proteins, and carbohydrates may be meaningless and overwhelming. Further, stereotypical beliefs about indigenous people's irresponsibility for personal health care, inability to comply with doctors' orders, and over-presentation in service-seeking may contribute to indigenous patients' sense of a lack of control and self-determination.²³

These dynamics constitute non-indigenous institutional forms of cultural capital shaped by the broader historical, political, and social relations between the Canadian state and indigenous peoples. When manifested in encounters between indigenous patients and non-indigenous providers within the health care system, the power dynamics that are generated impact health status and

health inequalities and have, in part, motivated indigenous community organizations to determine, lead, and control health care delivery to indigenous community members, including diabetes services. These dynamics contextualize the way that indigenous cultural capital is operationalized in diverse ways over time.

TORONTO INDIGENOUS COMMUNITY-BASED DIABETES PROGRAMS IN HISTORICAL PERSPECTIVE

Table 1 provides a timeline of the organizations and programs discussed throughout this article. The earliest indigenous community-based diabetes program in Canada is usually identified as The Native Diabetes Program initiated at the NCCT in 1980.²⁴

Table 1
Timeline of Indigenous Organizations and Programs

| Name of Organization or Program | Timeline |
|---|--------------|
| Native Canadian Centre of Toronto (NCCT) | 1962-present |
| Native Diabetes Program | 1980–1983 |
| Aboriginal Circle of Life Services (ACOLS) | 1989-present |
| Anishnawbe Health Toronto (AHT) | 1989-present |
| Southern Ontario Aboriginal Diabetes Initiative (SOADI) | 1993-present |
| SOADI Toronto branch office | 2009-present |
| Reztore Pride | 2011-present |

The collaborative work of Rebecca Hagey, an anthropologist and nursing professor at the University of Toronto, with that of indigenous community leaders on the development of this program, is often cited as an exemplary model of community empowerment and highlights how indigenous cultural perspectives structured the program.²⁵ Brooke Olson described Hagey's work as a rare example of "comprehensive explorations of how cultural beliefs affected the ways in which people conceptualized diabetes and responded to intervention programs."²⁶ In Marianne Ferreira and Gretchen Lang's 2006 volume *Indigenous Peoples and Diabetes*, Dennis Weidman describes Hagey's work as successful because "In addition to collaboration and consultation with small groups of diabetes patients and their families, Native political organizations and spiritual leaders were involved and Native staff collaborated with community services agencies."²⁷

To fully appreciate the processes that structured the distribution of cultural capital in the establishment, operation, and transformation of the Native Diabetes Program, consideration should be given to the historical context and

social role of the Native Canadian Centre of Toronto itself within processes of the production of urban indigenous community infrastructure. The NCCT, formally established in 1962, is the oldest indigenous community organization in Toronto. Many see it as the centerpiece or metaphorical town square of the community. Described symbolically as the "heart" or "mother" of organizations, many other indigenous organizations in the city were initiated as a program or committee at the NCCT. This includes Anishnawbe Health Toronto, which evolved from the Native Diabetes Program into a fully accredited community health center that today offers a full range of allopathic and traditional healing services.²⁸

The Native Diabetes Program originated from within the structure of counseling programs offered at the NCCT in the 1970s. These programs included employment, housing, nutritional and alcoholism counseling, and information and referral, which were established under the leadership of the late Joe Sylvester, Rebecca Hagey's key collaborator.²⁹ Based on the Centre's alcoholism counseling program, Sylvester led the establishment in 1974 of Pedahbun Lodge, an organization mandated with providing a unique, culture-based, grassroots, community-run approach to addiction problems and recovery.³⁰ Pedahbun Lodge served as a model for the development of several similar centers in other indigenous communities in Canada and the United States until it was dissolved in 2000 in the context of considerable community division. In her published reports on the diabetes program, Hagey noted a debate among indigenous participants over correlations between both diabetes and alcoholism as "problems due to white man's food and environment."³¹

Emerging from the thick of indigenous activism in the 1970s, both Pedahbun Lodge and the Native Diabetes Program reflected an explanatory model for illness grounded in a critique of colonial experience. Led by Sylvester, other community members, and leaders who worked closely with Hagey, these community-based health initiatives framed preventative, recovery, and disease management strategies within decolonizing discourses. That is, as Jennie R. Joe and Robert Young have described, diabetes is explained as a "disease of civilization" in which the oppressive historical processes of land dispossession, non-indigenous settlement, forced removal to reservations, and other policies aimed at cultural destruction and assimilation are central to the processes that brought about disease. Transformations in indigenous dietary and physical activity resulting from these aggressive colonial policies and actions generated the conditions that have resulted in the high prevalence rates of type 2 diabetes among indigenous peoples.³² Indigenous leaders in Toronto defined and explained diabetes as a health problem that articulated indigenous inequities in terms of ongoing colonial relations. For example, the original name of the Native Diabetes Program included the word "education,"

but this was dropped, according to Hagey, because it "was seen to represent the coercive education tactics of the white schooling system" and reflected the aggressive assimilative purpose of Canadian education policy aimed at indigenous cultural destruction.³³

The Native Diabetes Program included several forms of intervention paired with research. It delivered individual counseling and a series of full-day workshops open to persons with diabetes and interested family members. The workshops were led by Sylvester and involved ceremony, storytelling, and activities offered by other "resource people," who included "nutritionists, nurses, student volunteers, Native diabetics . . . and any prominent Indian leaders who may be hosting the event."³⁴ Anishinaabe (Ojibway) traditional knowledge was privileged in the explanatory model for understanding, preventing, and managing diabetes in the material resources that emerged from the program, such as pamphlets and other handouts. As Hagey describes it, rhetorical strategies employed by these diabetes education materials were not only culturally familiar, but also critical of the colonial contexts that gave rise to diabetes. For example, integrated into the workshop presentations were stories about Windigo, who symbolizes a lack of spirituality or being out of control.³⁵ In her analysis of the use of Windigo in the diabetes program, Hagey writes that

Some of the older Ojibway from northern areas intuitively classified diabetes as out-of-balance or Windigo disease. That is there may be a connection between diabetes and an external overpowering influence repaying the misdeeds of ancestors who sold land and water to the white man, which resulted in many native people now living in poverty situations. Windigo is starvation personified.³⁶

Hagey adds that:

Windigo . . . can represent the scourges of capitalism, which have been experienced so negatively by native people: private ownership has taken their land, profit motivation has depleted resources belonging to all humans and future generations, corporate productivity has split families and enforced a new and alien education with the abandonment of old stocks of knowledge, and so forth.³⁷

A pamphlet produced by the program titled "Nanabush and the Stranger" presents trickster narratives in a manner that addressed individual and community mechanisms for coping with diabetes through a number of metaphors. Nanabush (or Nanabozho) is a central figure in Anishinaabe traditional storytelling. He represents archetypes of both hero and trickster, and is best described as a reflection of the people's "conception of what constitutes human nature and human character." Invoking Nanabush in a contemporary story in which he struggles with the complexities of diabetes exemplifies a deployment of cultural capital that raises broader questions about indigenous health

inequality, while promoting behavioral change grounded primarily in indigenous self-determination. Like Windigo figuring as "the stranger," diabetes literally and metaphorically represents the forces of non-indigenous invasion of indigenous bodies. More than merely culturally relevant, the story's redistribution of power to indigenous control represents a transformation in the production and distribution of cultural capital that perhaps best explains the Native Diabetes Program's success.³⁹

This storytelling content is foundational to the Native Diabetes Program and represents investments of cultural capital by leaders in the indigenous community. Hagey, however, did not directly discuss the politics embodied in their practice and thus did not analyze the program in these terms. Instead, she framed her discussion of the program for academic audiences as discourse analysis, focusing on the contrasts between the expressive forms of indigenous culture in the Native Diabetes Program and the "bureaucratized" frameworks for understanding diabetes privileged in biomedical perspectives. ⁴⁰ At the time the work assumed an opposition between indigenous community-based structures and bureaucratic ones, read as exclusively Euro-Canadian. However in the early 1980s the NCCT itself was undergoing significant bureaucratization; as it moved from reliance upon volunteers, activists, and social movement perspectives to a professionalized structure progressively dependent upon government-funded programs, tensions rose over bounded concepts of culture, and the application of tradition became increasingly contested.

Here Bourdieu's conceptualization of practice—as political dynamics which underscore social and cultural capital (symbolic capital) emergent from accumulated history—is useful for understanding how, subsequent to Sylvester's and Hagey's initial program at the NCCT, the Toronto indigenous community-based diabetes programs continued to develop. 41 At this time, in response to community demand and amidst frictions generated by evolving social, economic, and power inequalities within the community, a movement of traditionalization of indigenous social services occurred.⁴² As the NCCT competed with a rising number of other indigenous social service delivery agencies, it sought to redefine itself at the heart of authoritative representations of indigenous culture. As it does now the NCCT then operated partly in response to social problems, but also as a nexus of community production in which it asserts authority over urban indigenous cultural production. Drawing on its long-standing history in the community and its distinctive identity as a sacred space, the NCCT generated cultural models utilized by its programs, models that other indigenous organizations in the city as well as individual community members elaborated upon or challenged.⁴³ Moreover, as I have written elsewhere in more detail, the NCCT attempts to generate unity of

representation in serving as an ambassador to non-indigenous people who are curious and interested in indigenous people in ways that create

a politically charged space of complex competing discourses that reify, reinvent, and adapt concepts of Native "traditions" in the urban context. Urban Native people confront and often resist the ways in which their identity is relegated to a homogenized, romanticized, and static past by non-Natives. Yet, "the past" is precisely the cultural capital drawn upon to build community for current and future generations. Asserting urban Native culture counters stereotypes and shapes power relations between Native and non-Native people, while also attempting to empower a distinct sense of community.⁴⁴

Within these sociohistorical contexts of community politics and processes in the production of culture, the Native Diabetes Program operated at the NCCT amid a wide array of programs, including recreational activities and a number of programs based on traditional teachings. By 1984, the NCCT's membership, volunteer and community involvement were rapidly diminishing and the Board of Directors made the controversial decision to lay off the entire staff and completely reorganize. This led to community protests in the street in front of the NCCT that lasted for weeks. The NCCT only reopened after a tempestuous annual general meeting and the administration was replaced.⁴⁵ Out of the ashes of this controversy, diabetes services relocated and Anishnawbe Health Toronto was established by 1989.⁴⁶

An oral history recorded with Joe Sylvester in 1982 provides some indication of the tensions that surrounded the fragmentation of the NCCT in the early 1980s, the resulting surge in development of new organizations, and the increased professionalization of indigenous Toronto social services. This shift also highlights transformations in the production and "structure of the distribution of [cultural] capital" by means of increased incorporation of traditional knowledge frameworks for urban indigenous people living with diabetes.⁴⁷ Sylvester's oral history relates numerous traditional stories with the common theme of indigenous foods, including Nanabozho's battle with corn, the Anishinaabe migration story in which wild rice and cranberries are central (foods that grow in water), and how the Anishinaabe found maple syrup. Sylvester stated that he felt it was his sacred duty to pass on these stories:

If I don't pass on the things that I have learned during this lifetime, I will die a very selfish death. . . . I have never been sorry that I am getting old. I'm glad I don't have to go through what the young people are going through now. . . . It's my turn to tell them if they want to listen. I can't go out and run after them — they have to come to me. I cannot force anything on anyone that doesn't want it. . . . I started to write some of it in a newsletter and I've got a lot of flak from the old people here in the community. And I stopped . . . because I was getting so much flak — that

I should not write those sacred things in the paper. But somehow we must pass these things on 48

Described as the "vision of the late Elder, Joe Sylvester," the official history of AHT records the clinic's origins with a "diabetes research project, which acknowledged that a more comprehensive approach to health care was needed by the Aboriginal community." A key original objective of AHT, which continues today, is to:

recover, record and promote Traditional Aboriginal practices where possible and appropriate.... Today, AHT not only promotes Traditional Aboriginal practices but has affirmed and placed them at its core. Its model of health care is based on Traditional practices and approaches and is reflected in the design of its programs and services.⁵⁰

The establishment of AHT marked an important shift in the value and distribution of cultural capital in indigenous community-based health promotion and is reflective of broader transformations in the political dynamics of the Toronto indigenous community infrastructure that was growing at the time. This shift in the circulation of indigenous cultural capital also interfaced with new state-sponsored regional and national diabetes initiatives in the early 1990s, which responded to emerging awareness of significantly higher rates of diabetes in indigenous communities. These non-indigenous institutional forms of cultural and economic capital exerted additional pressures on the shape and dynamics of indigenous community approaches to diabetes. Competition for funding was increasing, and programs began responding to funder-driven evaluative criteria that revolved around non-indigenous biomedical approaches to diabetes. As a result, these changes were to have an important effect on programs at the NCCT and shifts in the balance of cultural capital in the evolution of indigenous diabetes programs more broadly.

RECONFIGURATIONS OF INDIGENOUS CULTURAL CAPITAL IN DIABETES PROGRAMS AT THE NCCT DURING THE 1990S

A needs assessment that the NCCT conducted in 1989 found a large gap in services to the growing population of indigenous senior citizens living in the city. This population included many of the generation who were active in the establishment of the contemporary urban indigenous community after World War II, as well as recent arrivals who in their elder years had to move to the city to access vital health care services that were not available in or near their reservation communities. With funding from the federal government, the Aboriginal Circle of Life Services program (ACOLS) was established to serve

this constituency of the urban indigenous community, and it continues to be a significant program provided by the NCCT. It serves a concentration of older indigenous persons who live in an independent living apartment complex next door, as well as others throughout the greater Toronto metropolitan area. The program provides personal support, accompaniment to doctors' appointments, transportation and shopping, a lunch program, and various educational and recreational activities.⁵¹

From its inception, the ACOLS program continued to deliver diabetes education and services at the NCCT, but these were provided outside its regularly funded services. These diabetes-related services included both biomedical and cultural approaches. Glucose and hypertension screening, foot care, and dietary education, for example, were provided mainly by hospitalbased outreach and research programs such as the Diabetes Clinical Research Unit of Mount Sinai Hospital or the Tri-hospital Diabetes Education Centre. Occasionally, a pharmacist delivered workshops on medications, and herbalists presented material on herbs said to reduce blood sugar levels, increase immunity, or regulate insulin. A nursing student from the University of Toronto compiled a review of diabetes education seminars at the NCCT and reported that handouts on diabetes resources were distributed because participants appeared to know little about diabetes or where to get help. These handouts based on standardized biomedical understanding of diabetes replaced the culture-based pamphlets of the earlier Native Diabetes Program, although AHT later developed its own set of pamphlets which reproduces in part the "Nanabush and the Stranger" story.⁵² This period is also marked by a transition in non-indigenous organizations that attended to the urban indigenous community such as hospitals and other health services. While probably well intentioned, this also aligned with emerging policy and funding strategies that recolonized understanding of diabetes by means of non-indigenous cultural capital and served to diminish indigenous self-determination in this area of health care.

In 1993, the Ontario government established the Southern Ontario Aboriginal Diabetes Initiative (SOADI) to serve both on and off-reserve populations over a vast territory of about 175,000 square miles. SOADI services are focused on prevention of diabetes and its complications. The program employs indigenous staff and has developed a wide range of materials used in its workshops which initially were based largely on the translation of biomedical approaches using pan-cultural terms, images, and references. From the mid-1990s, SOADI was called upon regularly to deliver workshops at the NCCT. However, while numerous SOADI branches were established throughout its vast service area, a Toronto-specific office was not opened until 2009. Diabetes programming aimed primarily at clients in the ACOLS

program remained voluntary, ad hoc, or irregular. During the 1990s the ad hoc, yet diverse nature of diabetes programming at the NCCT reflected a process of acquiescence to dominant biomedical models for diabetes care because these were increasingly available and freely offered by non-indigenous institutions. As the following example illustrates, attempts to deliver programs grounded in decolonizing approaches became difficult to sustain in the context of evolving funding priorities that increasingly privileged dominant biomedical cultural models for diabetes prevention and management.

In 1998, Ruth Cyr assumed the directorship of the ACOLS program. Cyr, an indigenous person and registered nurse, designed and delivered a once-per-month support group for persons with diabetes and for caregivers that attempted to balance indigenous cultural perspectives and allopathic approaches with an emphasis on physical activity. Until her departure from the program in 2004, hers was the most regular and consistent diabetes program delivered at the NCCT, although it had little direct funding. Cyr's common directive intentionally used a double-entendre to avoid the "five white foods" sugars, salt, milk, lard, and flour—that reaffirmed and situated the eradication of diabetes within decolonization efforts. This perspective complemented that of the late Rodney Bobiwash, the NCCT's executive director from 1998 to 1999, who spearheaded a bio-regionalist food program based on these principles and in collaboration with AHT. Bobiwash, who was an Anishinaabe historian, indigenous rights, and anti-racism activist, was also the nephew of Lloyd Bobiwash, who had worked with Joe Sylvester and Rebecca Hagey on the earlier Native Diabetes Program. Both uncle and nephew passed away in their early forties due to complications from diabetes. Bobiwash and Cyr consciously operationalized cultural capital as a tool of decolonization. In this model, cultural revitalization is not in and of itself the complete goal, but is fundamental to the broader strategy of asserting indigenous rights and sovereignty vis-à-vis the nation-state and historical relations of oppression. In other words, indigenous health is produced not only through an investment of cultural capital, but also through its operationalization in light of the embodiment of historical relations of power as well as self-determined practice.

The link between illness among indigenous people and the colonial encounter also re-emerged as important in the 1990s because of the exposure of the extensive sexual and physical abuse suffered by the survivors of residential schools and increased attention to that abuse. The Royal Commission on Aboriginal Peoples formally recognized in 1996 the collective trauma inflicted upon survivors of residential schools and their descendants. As a result the Aboriginal Healing Foundation was established to disburse funds to community programs aimed at addressing the legacy of physical and sexual abuse in the schools. These efforts centered on mental health and addictions treatment

and prevention, perhaps because these areas of illness were seen as more readily linked to sexual and physical abuse. However, based on her personal experience as a residential school survivor and a person living with diabetes, Ruth Cyr saw broader connections between residential school experiences and the health status of indigenous community members. She was particularly concerned with how the schools left a legacy of obstacles to preventing and managing diabetes. Many of those who accessed the ACOLS programs were residential school survivors living with diabetes who exhibited behaviors that Cyr and ACOLS staff saw as possibly connected to their experiences in the schools.

I also worked at the NCCT at this time as the coordinator of the Toronto Native Community History Project. Cyr and I developed a project to explore this further through an oral history project and eventually convinced the Aboriginal Healing Foundation to support it. The project focused on testimony about diet, food, and the dining environment in the schools and integrated the results of this testimony into a pilot intervention that repositioned survivors as teachers whose experiences could empower indigenous community control over processes that caused and exacerbated diabetes. In the first phase of the project, oral histories were recorded of residential school survivors' reminiscences of diet and eating behaviors instilled while attending residential schools. In the second phase, diabetes education workshops called "Tribal Kitchens" were formulated to apply knowledge gathered in the first phase. Throughout the project, residential school experience of punishment, the legacy of deprivation, the association of morality and food, and the possibilities for reclaiming food traditions were structurally linked to the development of unhealthy physical, mental, spiritual, and emotional conditions which put indigenous peoples at risk for diabetes. These included the loss of a relationship with food grounded in indigenous social life, parenting, family, and community, which framed diabetes within a critique of colonial disempowerment, and the prevention, management, and eradication of diabetes within a decolonizing approach.⁵³

Within the changing context of competition for government funding, however, interventions emphasizing critique and analysis of historical and contemporary forms of colonization like this program proved difficult to sustain. After the pilot project ended, funding was sought to renew a longer-term program that would incorporate a complete overhaul of the food services delivered by the NCCT based on the research and approach of the residential school project. A proposal was submitted but turned down by the Métis, Off-reserve Aboriginal and Urban Inuit Prevention and Promotion (MOAUIPP) that had been established in 1999 under the federal Aboriginal Diabetes Initiative. Not surprisingly, the objectives of the MOAUIPP were not defined by decolonizing or holistic approaches to diabetes, which address the structural and political-economic determinants of health, but instead were

more narrowly framed in biomedical and individuated behavioral approaches. While the program invited "innovative" proposals that ensured "Aboriginal/Inuit ownership of diabetes primary prevention and health promotion programs," the funded projects were required to "raise awareness of diabetes, its risk factors, and the value of healthy lifestyle practices . . . [and] promote effective management of diabetes." The resulting success of the program has been evaluated in terms of biomedical knowledge transfer based on, for example, the numbers of indigenous people trained in biomedical-based prevention and management practice. Programs like those initiated at the NCCT, which contextualized explanations for diabetes within the historical structural relations of oppression and its prevention and treatment within decolonizing, culture-based, self-determined approaches, were at odds with the individuated, behavioral focus of the biomedical explanatory model that drove the Health Canada initiative.

In 1999, the Southern Ontario Aboriginal Diabetes Initiative published its first newsletter aimed specifically at urban indigenous populations in the "horseshoe" around the western shores of Lake Ontario, which includes Toronto. The SOADI newsletter defined as one of its purposes to "develop and distribute culturally appropriate education, promotion and prevention resources based on community needs."56 Indeed, SOADI has generated a vast array of resources, including a diversity of prevention workshop materials, toolkits, videos, personal care items, and games provided by their staff members who travel throughout the organization's vast service area. SOADI was instrumental in the development of an Ontario Ministry of Health and Long-term Care diabetes education policy aimed at indigenous people as one based on a "holistic vision of health." The policy was intended to "address and incorporate the physical, mental, emotional, and spiritual needs of individuals, families, and communities living with or affected by Diabetes."57 However, there are limited mechanisms to deliver advocated, local participatory methods or to address structural issues within this framework. To accommodate its extensive reach, SOADI's materials were developed for a relatively general audience of indigenous peoples that did not reflect the local, participatory research-informed approaches characterizing earlier Toronto programs that were framed in critical anticolonial analyses.⁵⁸

CONTEMPORARY CRITICAL REFLECTIONS

More recently, the trajectory described above is being critically reassessed. Indigenous health practitioners and youth in particular are emphasizing historically situated, sociopolitical determinants of illness, health, and well-being in

community-based diabetes prevention and management programs, signaling further shifts in the circulation of indigenous cultural capital. At AHT, diabetes services have continued and include individual consultations with both traditional healers and biomedical staff at the clinic, talking circles, and prevention and management education that combines culture-based approaches with biomedical standards of care. The professionalization and biomedical qualifications of AHT indigenous staff are as much a source of pride as the continued emphasis on traditional cultural approaches.⁵⁹ Regular testing of blood glucose, examining eyes and feet, mastering cravings, getting exercise, and sometimes counting calories are urged, along with principles of balance, spiritual connection, and natural world approaches glossed as indigenous perspectives and ways of life.⁶⁰ Examples have been described by the AHT Diabetes Team in several issues of the newspaper published by the NCCT. Reporting on a "Drumming for Diabetes" event held in May 2010, for instance, AHT Diabetes Team member Brad Stone wrote:

Through our cultural way of life, we enjoyed each other's company and sang songs not only to each other, but to our ancestors in the spirit world who continue to help and watch over us in life. Songs of healing, honor and well-being were sung to help our people and the fight in this diabetes epidemic which continues to have high rates amongst our people all across the nation. . . . When we come together as a community, we can heal as a community (emphasis in original).⁶¹

Stone also described a one-day Diabetes Camp organized by the AHT team at a park located outside the city, in which the goal was:

Integrating the traditional teachings and medicines into diabetes education.... Everyone enjoyed the trip and the opportunity to reconnect with Mother Nature. New teachings and reminders were shared to the group of the various ways they can help to manage their diabetes and prevent complications – through healthy eating, regular activity, traditional medicines, as well as keeping up with regular blood work and annual foot and eye exams.⁶²

Sometimes, attempts to pair the biomedical and indigenous explanatory models for diabetes highlight a paradox, such as that illustrated in another report titled "Think Traditionally," in which a genetic risk argument—"having family members with diabetes and being of Aboriginal descent—you can't change your blood family!"—is presented alongside the assertion that "Our ancestors did not have diabetes." The point is to translate the philosophy underlying ancestral practice into contemporary urban indigenous community habits.

The omission of reference to colonization or dispossession discourses in favor of emphasis on holistic perspectives and the possibilities of living traditionally in the city reflects the transformations of cultural capital I have

described throughout this article. These include those catalyzed within the historical and contemporary politics of indigenous community-based health and service delivery, as well as by means of dialectical engagement with dominant non-indigenous institutional forms of cultural capital that privilege depoliticized and biomedical measures of success for diabetes programs. These power relations must also be contextualized by the historical transformations of economic capital within indigenous health care politics. For example, in a recent move towards reversal of these dynamics, AHT's leadership on the Urban Aboriginal Diabetes Research Project represents a landmark in examining the experience of indigenous people living with diabetes in the urban context by means of processes grounded in indigenous community-based methods and philosophy, including an overt assertion of indigenous community sovereignty. Rather than serving as a community partner to a university or hospital-driven study, AHT assumed autonomous control of the government funding and administration for the project, and located it within AHT facilities and thus within indigenous community space.64

Pushback to the colonization of indigenous cultural capital in understanding and acting on diabetes is further palpable in the voices of indigenous youth participants in the recent SOADI hip-hop project, Reztore Pride, a collaboration conducted with indigenous rap recording artist Rex Smallboy and the group War Party. Cultural capital is produced at the intersection of ancestral practice, past suffering, and future empowerment, as is described in the words of John Waylon Marvin Henhawk, aka John Henny Jack (Mohawk), who spearheaded the project:

I remember the struggles our ancestors had to face in order for us to be here on Turtle Island today. I remember the massacres our people faced. I remember that this land was once all Indian country. I remember that our ancestors accepted all non-natives to share and live on this land through the Two-Row Wampum Belt. . . . I remember those kids who were forced to live in the Residential Schools and were beaten for speaking their language, raped, molested, tortured, and killed. I remember that it was once illegal for our people to live our ways in this country. . . . We must remember those spirits from the past, and to think about the future generations when making any decisions. . . . Being involved in this project has given me so much hope for our youth. . . . I remember my grandma had diabetes. . . . It hurts my heart to think about my grandma and all my people who live with diabetes. It hurts me so much because I know that my people did not ask to be put in this situation with diabetes or any of the issues our people face, and that so many of my people do not have any knowledge about such a serious disease. I have hope that this album might help change some of that. 65

Henhawk's references to personal, family, community, and broader indigenous experience are inextricably interwoven to infuse the contemporary struggle against diabetes with those of indigenous peoples' battles against land and cultural dispossession, broken treaty promises, massacres, assimilation policies, residential school abuses, and other violences that he, his grandma, and "our people" did not ask for. The lyrics of "The Plague" by MC Sage, below, further illustrate the stark realities of embodied suffering lived by the young songwriters and squarely reposition cultural capital as decolonizing discourse and practice in the production of health:

I miss my fam who was taken by this plag. Lost thay toes and lost thay lags. Then they passed away dang, Its probably in are blood, Running through are vains. So if we don't change. Then well be gone the same way, same way, same way. Diabetes is a problem that effects us all.... It's a struggle to servive in this shoganosh world. Especially wne the food will make you clinically SICK.... I gotta yell when I talk. Gotta scream when I talk. Cuz the government don't want the truth to be told. Diabetes is a pandemic. And the government knows that us nishnobs just cant take it.... We gotta speak and let these lyrics run deep. To the souls of the youth and the people in the streets.... From diabetes to the lies in your treatys, everywhere u look you see the people in the city... no buddy wants to hear the truth up in a song.66

As these perspectives show, critical reflection is emerging from the grounded experience of living with, and witnessing the escalation of, diabetes at the personal level situated intersubjectively within historical and political relations of power. These indigenous youth open possibilities to revise Bourdieu's analysis where it fails to explore fully the processes by which consciousness and agency mobilize the circulation of cultural capital. They offer opportunities to shift practice in indigenous community-based diabetes programs in which the limitations of the homogenizing approaches and materials produced in the context of social service bureaucratization are becoming recognized. Ultimately the practice of a new generation of community-based health care and service providers is informed by a passionate, personally based understanding of diabetes, by a sense of urgency, by consciousness of structural violence, and by the recognition of the possibilities of unity across cultural, gender, and age diversity in urban indigenous community life.

CONCLUSION

Toronto indigenous health activist/practitioners have long shared an understanding of indigenous peoples' poor health status as the embodiment of a collective colonial experience. As noted throughout this article, the production of health knowledge and practice is positioned in relation to broader decolonization as well as to indigenous rights discourse and action. The construction of illness as an inscription on the body of colonial experiences continues to figure in lay discourse among indigenous community members and is particularly conspicuous among youth, which is a trend that deserves further research and attention. Indigenous youth constitute the fastest growing demographic in Canada and the increasingly earlier onset of type 2 diabetes among indigenous youth is a rapidly growing international concern.

Exploitation and oppression have had direct roles in sustaining inequity and in explaining the loss of well being for indigenous peoples. Diseases, especially those classified as "white" diseases, are read as ongoing colonialism.⁶⁷ However, since the 1990s this explanatory model has increasingly been diluted in indigenous community-based diabetes programs into one more focused on past traditional healing and ancestral practices with less emphasis on the political-economic conditions from which these past approaches are to be recovered. The transformation from indigenous social movements into professionalized social and health service delivery organizations has been marked by a shift in the form of cultural capital from one more openly centered on anticolonial discourse as an explanatory model to a less politicized focus on reified concepts of culture, tradition, and the past, an institutionalizing process that Taiaiake Alfred and John Corntassel caution may further embed indigenous people "in the colonial institutions they set out to challenge." ⁶⁸

This transition, in which an anticolonial analytical framework appears sparingly in the content of diabetes education and services delivered at the community level, reflects an accumulated history in the urban indigenous community programs influenced by the structural politics that mediate the distribution of government-controlled resources. Programs like the MOAUIPP, along with the Ontario Aboriginal Diabetes Strategy (OADS) implemented by the Ontario Ministry of Health and by Long-term Care in 2006, have significantly transformed the dominant discourse of the explanatory model for diabetes expressed in indigenous prevention and management programs. As the OADS explains, the "dramatic increase in type 2 diabetes in Aboriginal communities is due to a combination of sedentary lifestyles, diet and genetic susceptibility." The strategy therefore addresses education, research, community capacity-building, and coordination of services based on biomedical and behavioral approaches. It recognizes that "Improving the social, economic and physical environments will contribute to significant gains in Aboriginal health status"; however, the strategy does not situate these factors in historical context.⁶⁹ The hierarchical power dynamics that mediate the relationship between the state and indigenous peoples serves to silence politically framed, decolonizing, and sovereignty-based approaches to the eradication of diabetes, highlighting the limitations of government-led initiatives.

In this context, there is danger that homogenizing assumptions about the sociohistorical experiences, parameters, membership, and participation of community, as well as essentialist reifications of indigenous traditional culture, may dominate the design and delivery of indigenous diabetes interventions and broader indigenous health initiatives. This process is occurring despite a growing body of indigenous research and practice that emphasize local conditions, control, and participation and is also critical of models that assume the authority of biomedical knowledge and "add indigenous culture and stir." Recent indigenous cultural or traditional approaches need to be considered as dynamic in relation to how community programs are embedded in a politics of intergovernmental relations of power and control over resources. These are factors that may contribute to differential uptake of diabetes prevention and management information by indigenous community members, and in turn impact the sustainability and dissemination of interventions.

Finally, this article illustrates the value of pairing social research with the development of diabetes interventions with indigenous peoples, a practice so often characterized as exemplary in descriptions of the founding Native Diabetes Program at the NCCT. Carolyn Smith-Morris cautions that community-based diabetes interventions can only be properly assessed if the concept of "community" is itself critically defined with consideration for "political and social structures, alliances, and rivalries . . . and intercultural relations," to which extended, participatory, ethnographic research can contribute significantly.⁷⁰ I have situated community-based diabetes programs within the layered contexts of an overall complex history of Toronto indigenous community-building and social service and health care delivery. I have also briefly highlighted some aspects of these contexts as they relate to the regional and national bureaucratization of indigenous resources, which are important to understanding the production of indigenous health knowledge and practice. Longer-term research needs to continue to examine links between health interventions and the complexities of cultural, social, and economic capital. The politics of the multitribal and socioeconomically diverse dynamics of contemporary urban indigenous communities are significant considerations for present and future community-based diabetes initiatives if our goals include the eradication not only of the disease, but also of the colonial structures of power reproduced within these initiatives.

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NOTES

- 1. The term *indigenous* is used throughout this article because it is generally preferred and used to describe the collective identity of and within the community that is the subject of this article. Although *Native* and *aboriginal* continue to be used by organizations, it is used less frequently by individuals. Aboriginal is considered a colonial legal category rarely used by individuals to self-identify, and they usually prefer to personally identify with their specific national and/or cultural heritage. Although *First Nations* is sometimes used interchangeably with indigenous, some regard this term as exclusive of some indigenous peoples and therefore is an inadequate collective term. Reference to diabetes throughout this article generally refers to type 2 diabetes, formerly referred to as adult-onset or non-insulin dependent diabetes mellitus, although type 1 and gestational diabetes are also present. Type 2 diabetes is most prevalent, constituting 95 percent of diabetes diagnoses, has unclear genetic causation, and is considered relative to and preventable through lifestyle or environmental conditions (Lynn Lavallee and Heather Howard, *Urban Aboriginal Diabetes Research Report* (Anishnawbe Health Toronto, 2011): 6–7; Centers for Disease Control and Prevention, "2011 National Diabetes Fact Sheet," last modified May 23, 2011, http://www.cdc.gov/diabetes/pubs/estimates11.htm.
- 2. In Canada, statistics on urban indigenous populations vary widely, and ranges from as high as 73 percent of all indigenous people living off-reservation and/or in urban areas reported by the Royal Commission on Aboriginal Peoples in 1993, to as low as 49 percent based on the federal census conducted in 2001. For details, see Royal Commission on Aboriginal Peoples, *Aboriginal Peoples in Urban Centres* (Ottawa: Minister of Supply and Services, 1993). In the US, the 2000 Census reported that 45 percent of those identifying as American Indian and Alaska Native reside in urbanized areas, while two-thirds live outside Indian lands. Heather Howard and Susan Lobo, "Indigenous Peoples, Rural to Urban Migration, United States and Canada," *The Encyclopedia of Global Human Migration*, ed. Immanuel Ness (New York: Blackwell Publishing Ltd., 2013), DOI: 10.1002/9781444351071. wbeghm297.
- 3. The oft-cited Kahnawake Schools Diabetes Prevention Project in Canada, a reservation-based program, is a notable exception. In this program, detailed ongoing critical reflection of research and programming processes have been integrated with community-based knowledge, design, participation, and evaluation mechanisms since program implementation in the mid-1980s (Louise Potvin, Margaret Cargo, Alex M. McComber, Treena Delormier, and Ann C. Macaulay, "Implementing Participatory Intervention and Research in Communities: Lessons from the Kahnawake Schools Diabetes Prevention Project in Canada," Social Science and Medicine 56 (2003): 1295–305.
- 4. Rebecca Hagey, "The Phenomenon, the Explanations and the Responses: Metaphors Surrounding Diabetes in Urban Canadian Indians," Social Science and Medicine 18, no. 3 (1984):

- 265–72; Rebecca Hagey, "The Native Diabetes Program: Rhetorical Process and Praxis," Medical Anthropology: Cross-Cultural Studies in Health and Illness 12 (1989): 7–33; Linda Brazeau, "History," National Aboriginal Diabetes Association, http://www.nada.ca/about/history/lindas-story/; Fran Lowry, "New Native Healing Centre in Toronto Opens Eyes of Non-Native MDs Who Work There," Journal of the Canadian Medical Association 148, no. 2 (1993): 270; Lavallee and Howard, Urban Aboriginal Diabetes, 10.
- 5. Thomas Abel, "Cultural Capital in Health Promotion," in *Health and Modernity: The Role of Theory in Health Promotion*, ed. David McQueen, Ilona Kickbusch, Jurgen M. Pelikan, Laura Balbo, and Thomas Abel (New York: Springer, 2007), 41–72; Thomas Abel, "Cultural Capital and Social Inequality in Health," *Journal of Epidemiological Community Health* 62, no. 13 (2008): 1–5; Pierre Bourdieu, "The Forms of Capital," in *Handbook of Theory of Research for the Sociology of Education*, ed. J. E. Richardson (New York: Greenwood Press, 1986), 241–58.
- 6. Heather Howard, "Dreamcatchers in the City: An Ethnohistory of Social Action, Gender and Class in Native Community Production in Toronto," (PhD diss., University of Toronto, 2004); Heather Howard, "The Friendship Centre: Native People and the Organization of Community in Cities," in Aboriginal peoples in Canadian Cities: Transformations and Continuities, ed. Heather Howard and Craig Proulx (Waterloo, ON: Wilfrid Laurier University Press, 2011), 87–108.
 - 7. Bourdieu, "The Forms of Capital," 247.
 - 8. Howard, "Dreamcatchers in the City"; Howard, "The Friendship Centre," 87-108.
 - 9. Bourdieu, "The Forms of Capital," 247.
- 10. James Waldram, Revenge of the Windigo: The Construction of the Mind and Mental Health of North American Aboriginal Peoples (Toronto: University of Toronto Press, 2004), 292.
- 11. Victoria Freeman, "Toronto Has No History!' Indigeneity, Settler Colonialism and Historical Memory in Canada's Largest City," (Ph.D diss., University of Toronto, 2010); Heidi Bohaker, "Nindoodemag': The Significance of Algonquian Kinship Networks in the Eastern Great Lakes Region, 1600–1701," The William and Mary Quarterly 63, no. 1 (2006): 23–52; Donald Smith, Mississauga Portraits: Ojibwe Voices from Nineteenth Century Canada (Toronto: University of Toronto Press, 2013).
- 12. Rodney Bobiwash, "The History of Native People in the Toronto Area," in *The Meeting Place: Aboriginal Life in Toronto*, ed. Frances Sanderson and Heather Howard-Bobiwash (Toronto: Native Canadian Centre of Toronto, 1997), 5–24; Howard, "The Friendship Centre," 87–108.
- 13. Howard, "Dreamcatchers in the City"; Howard, "The Friendship Centre," 87–108; Howard and Lobo, "Indigenous Peoples."
- 14. Details about the establishment of the contemporary Toronto indigenous community can be found in Howard, "Dreamcatchers in the City"; Howard, "The Friendship Centre," 87–108; Sanderson and Howard-Bobiwash, The Meeting Place; Don McCaskell, Kevin FitzMaurice, and Jamie Cidro, TARP: Toronto Aboriginal Research Project Final Report (Toronto: Toronto Aboriginal Support Services Council, 2011). For broader discussions and other studies of urban indigenous community development throughout North America, see Howard and Lobo, "Indigenous Peoples"; Howard and Proulx, Aboriginal Peoples in Canadian Cities: Keeping the Campfires Going: Native Women's Activism in Urban Areas, ed. Susan Applegate Krouse and Heather Howard (Lincoln: University of Nebraska Press, 2009); American Indians and the Urban Experience, ed. Susan Lobo and Kurt Peters (Walnut Creek, CA: AltaMira Press, 2001). For a range of detailed ethnographic and historical studies in cities other than Toronto, see Coll Thrush, Native Seattle: Histories from the Crossing-Over Place (Seattle: University of Washington Press, 2007); Renya Ramirez, Native Hubs: Culture, Community and Belonging in Silicon Valley and Beyond (Durham: Duke University Press, 2007); Joan Weibel-Orlando, Indian Country, L.A.: Maintaining Ethnic Community in Complex Society (Urbana and

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- 18. Sanderson and Howard-Bobiwash, *The Meeting Place*; Howard, "The Friendship Centre," 87–108; Howard and Lobo, "Indigenous Peoples."
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 - 23. Lavallee and Howard, Urban Aboriginal Diabetes, 37-44; Howard, "Healing Processes."
 - 24. Brazeau, "History"; Lowry, "New Native Healing Centre," 270.
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- 66. MC Sage, "Artists/M.C. Sage/Lyrics/the plague," www.reztorepride.com. Spelling and grammar are given as in the original source. Challenges to the conventions of English spelling and grammar are used in hip-hop lyrics sometimes to accommodate the rhyme but also to purposefully write against the boundaries of mainstream cultural acceptability and, according to Marianne Ignace, an aspect of "marginalized ghetto culture among indigenous youth" (personal communication, June 21, 2011). For a broader discussion, see Marianne Ignace, "Why Is My People Sleeping? First Nations Hip-Hop Between the Rez and the City," in Aboriginal Peoples in Canadian Cities: Transformations and Continuities, ed. Heather Howard and Craig Proulx (Waterloo: Wilfrid Laurier University Press, 2011), 203–26; Marcyliena Morgan, "Nuthin' but a G thang': Grammar and Language Ideology in Hip Hop Identity," in Sociocultural and Historical Contexts of African American English, ed. Sonja Lanehart (Amsterdam: John Benjamins Publishing Co., 2001), 187–209.
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