

**Beyond Sweet Blood:  
Perceptions of Type 2 Diabetes in Kahnawake**

Shannon Audrey Dow

A Thesis

In

The Department

of

Sociology and Anthropology

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## **Abstract**

### **Beyond Sweet Blood: Perceptions of Type 2 Diabetes in Kahnawake**

Shannon Audrey Dow

This research explores perceptions of type 2 diabetes among Kahnawakero:non through insight provided by the subjective narratives of those living with the disease. Subjective narratives are considered within the theoretical framework of critical medical anthropology with regards to biomedicine, as well as in relation to biomedical diagnostic procedures for classifying diabetes and its treatment strategies. I extend existing anthropological research into diabetes by highlighting how subjective narratives reveal both a critique of and movement beyond the clinical and diagnostic encounter. I therefore suggest that subjective narratives of type 2 diabetes can be seen as a political discourse, in that they simultaneously provide insight into the place of individuals and populations within society, while revealing that - however real the physical complications associated with type 2 diabetes may be - not everyone agrees on the ways in which type 2 diabetes actually constitutes a “health problem.” In the case of Kahnawake, perceptions of type 2 diabetes reveal that the health problem of the disease is not limited to sweet blood per se, but rather lies outside of the clinic and the body, and within broader social and political relations, and specifically, a community history.

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You give but little when you give of your possessions.  
It is when you give of yourself that you truly give.

- Kahlil Gibran, *The Prophet*

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“You got sugar - you’re an Indian, you know!”

- Conversation partner, Kahnawake

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# 1. Introduction

Type 2 diabetes is characterized by the inability of the body to use insulin. Insulin is necessary for transferring glucose to the body's cells, and the inability to use insulin leads to high levels of sugar in the blood, or "sweet blood."<sup>1</sup> Chronic high levels of blood sugar or hyperglycemia characteristic of diabetes is associated with serious "complications" including damage, dysfunction and failure of various organs, most notably the kidneys, eyes, nerves, heart and blood vessels. Those living with type 2 diabetes are therefore at substantial risk of heart attack, heart failure, amputation, kidney dialysis and stroke (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003). Type 2 diabetes can affect anyone, however the disease has impacted some populations more than others. Specifically, statistics reveal what researchers have called an "epidemic" of diabetes among the aboriginal population in Canada, with prevalence rates three to five times higher than the general Canadian population (National Aboriginal Health Organization, 2005).<sup>2</sup>

A recent study in Kahnawake, a Mohawk reserve near Montreal, Quebec, revealed that prevalence rates of type 2 diabetes in the community are approximately two times higher than rates in the general Canadian population. Prevalence of type 2 diabetes is therefore lower in Kahnawake compared with prevalence rates among the indigenous

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<sup>1</sup> I use the term "sweet blood" at some points in this text in referring to and alternating with the term "type 2 diabetes." In addition, in some cases I use the term "diabetes" to talk about diabetes mellitus generally (i.e., not limited to type 2 diabetes).

<sup>2</sup> The term "prevalence" here refers to the number of existing instances of diabetes in a population at a given time.

population nationally.<sup>3</sup> Yet, despite a prevalence rate lower than the national aboriginal average, diabetes remains one of the main health issues in Kahnawake. As a result, a great deal of attention has been paid to community lead and controlled diabetes treatment, education and prevention. The question of how Kahnawakero:non experience type 2 diabetes, however, has not been dealt with sufficiently.<sup>4</sup> Physicians and researchers working in Kahnawake, in addition to Kahnawakero:non, have confirmed that such exploration is important because it could better inform and guide diabetes treatment, education and prevention approaches in the community. This research therefore explores perceptions of type 2 diabetes among Kahnawakero:non through insight provided by the subjective narratives of those living with the disease. Subjective narratives are considered within the theoretical framework of critical medical anthropological theory with regards to biomedicine, as well as in relation to biomedical diagnostic procedures for classifying diabetes and its treatment strategies.

I became interested in studying perceptions of type 2 diabetes in Kahnawake through my previous involvement in research which explored health service access in rural and remote indigenous reserve communities in British Columbia. Through discussions with health directors, community health representatives, and community members in eleven reserve communities, this research attempted to clarify how technology (i.e., “telehealth”) could be used to mitigate the existing gaps in access to health services in these communities (see Dow et al., 2004). The research revealed that

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<sup>3</sup> In this text I use the terms “aboriginal,” “indigenous,” “First Nations” and “native” to discuss indigenous nations in Canada and generally.

<sup>4</sup> Kahnawakero:non is pronounced, approximately, “Gah-nah-wa-gey-row-non” and is a term I use frequently in this text in speaking specifically about Kahnawake Mohawks. According to Phillips (2000), the term loosely translates as “those who reside on the rapids” (i.e., in Kahnawake) (p. 4).

issues such as geography and degree of isolation were part of a larger system that inhibits access to health services in rural and remote reserves. For example, people overwhelmingly pointed to the role that federal and provincial health policy plays in mediating and adversely affecting access to health services. People said that their access to health services was diminished and otherwise limited when provincial health regions were re-zoned or when reserve communities signed agreements such as the federal Health Transfer Policy.<sup>5</sup> Most importantly, people spoke about health in ways that had very little to do with actual health services. The research questions did not ask about peoples' perceptions of health, yet these perceptions became quite salient and clear as the study progressed, and almost always evoked social etiologies. For example, the fact that the land surrounding the reserves - perceived by community members not as Crown land but rather as traditional and often sacred territory – was being clear cut, damaged and destroyed by logging companies, was a main factor that people said adversely affected the health of communities. Thus I was lead to the current research through a desire to learn more about how subjective narratives of health and disease can bring insight to otherwise presumed, and often medically-based, etiologies of ill-health and disease, as well as related structuring of health services.

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<sup>5</sup> The federal Health Transfer Policy (1986) claims to alter the ways in which health services have historically been provided to aboriginal communities, by devolving control over community (i.e., on-reserve) health services from the federal government to aboriginal communities (see [http://www.hc-sc.gc.ca/fnih-spni/pubs/agree-accord/10\\_years\\_ans\\_trans/index\\_e.html](http://www.hc-sc.gc.ca/fnih-spni/pubs/agree-accord/10_years_ans_trans/index_e.html)). Communities that had undertaken Health Transfer did so with the understanding that Health Transfer would result in more control over the structuring of health services on-reserve, only to be left with less resources and flexibility than they had prior to Health Transfer. For example, in some communities that had undergone the Health Transfer Policy, nurse availability significantly decreased as a result of funding arrangements. In some communities this meant having enough funding to employ only one nurse for an entire community of up to 700 people. This affected people's access to health services because the resulting nurse availability post-Transfer was not considered sufficient for the needs of the community.

Lived experiences of health and disease do often speak of social etiologies and, by extension, of social interventions. It should be of no surprise, then, that the questions of how and why type 2 diabetes arises are often central to the lived experience of this condition. Biomedical diagnostics for type 2 diabetes, however, do not account for how and why the disease comes to be in particular individuals. The fact that how and why type 2 diabetes comes to affect certain individuals is reflective of an ideological commitment to seeing disease as objective entities that exist in individual bodies (Rock, 2003a). This approach, however, by neglecting how the social world affects the health of people, risks delegitimizing individuals' suffering while perpetuating the process of medicalization within which life problems become articulated and explicated *only* as health conditions (e.g., drug addictions, obesity, aging, violence) (Kleinman, 1995, p. 38). The ability to define and survey "health status" as a purely medical issue has moreover enabled biomedicine to construct certain groups, such as the Canadian aboriginal population, as pathological. Construction of the aboriginal population as such enables the perpetuation of patterns of paternalism and dependency (Waldram, 1995). Thus while biomedicine purports to be a neutral science, it is heavily inflected by power, and it both arises from and shapes the ways in which we interpret ourselves, our world, and the relationships between humans, nature, self, and society (Gordon, 1988).

Insight into subjective narratives is therefore meant to construct an alternative discourse that challenges the legitimacy of biomedical epidemiological discourse (O'Neil, Reading, & Leader, 1998), and many anthropologists have illustrated the necessity of exploring subjective health experiences. Good (1994) for example has reminded us that experience is fundamentally cultural, and that our primary access to experience is through

analysis of cultural forms. Narrative analysis, he says, can shed light on the relation between culture and experience, and narrative plots, or the underlying structure of the story, can shed light on how people perceive the onset of illness, its unfolding and the language of its expression (p. 146): in other words, how disease, which refers to organic pathologies and abnormalities, is brought to individual consciousness (A. Young, 1982). Lock (1993) has further illustrated that subjective narratives are important ways through which to expose and understand the context of otherwise broad generalizations and abstractions of biological and statistical information – subjective narratives, she argues, provide an important constraint to the ways in which this information can be interpreted.

Moreover, Rivers (2001 [1924]) noted the importance of considering how people talk about disease and disease causation, arguing that ideas about the causation of disease “are not empty beliefs devoid of practical consequences, but act as the motives for processes of treatment” (p. 10). Kleinman (1988) furthered this exploration into illness narratives, the human experience and communication of symptoms and suffering:

Illness narratives edify us about how life problems are created, controlled, made meaningful. They also tell us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in the particular context of our life situation; we express our distress through bodily idioms that are both peculiar to distinctive cultural worlds and constrained by our shared human condition (p. xiii).

Envisioned in this approach to illness and its therapy is an interconnectedness of social world and inner experience, a symbolic “bridge” connecting body, self, and society.

Narratives are moreover both event-centered, in that they concern human action and interaction, and experience-centered, in that they not only describe what someone does in the world, but what the world does to them (Mattingly, 1998). Examination of these interconnections can better explicate experiences of suffering, thereby contributing to the

provision of more effective care, including, in the case of type 2 diabetes, education and prevention.

Anthropologists who have explored subjective narratives of type 2 diabetes have amply illustrated the importance of paying close attention to reports of lived experience. However, the research tends to focus on the study of illness experience, neglecting insight into diabetes itself as a dynamic and even contested subject. The “illness experience” approach presumes that those living with type 2 diabetes agree not only on the biomedical diagnosis and classification of diabetes as a disease, but also on how they fall into diabetes classifications. Yet perceptions of type 2 diabetes in Kahnawake reveal that Kahnawakero:non living with the disease are not simply passive consumers of dominant biomedical ideologies; they actively question the disease categorization of type 2 diabetes. By neglecting to consider people as agents in the construction and critique of type 2 diabetes as a disease category, anthropological insight into type 2 diabetes has risked perpetuating the mind / body dualism at the heart of the biomedical model of diabetes diagnosis and treatment (cf. Adelson, 2000). I therefore extend existing anthropological research into diabetes by bringing to light how subjective narratives reveal both a critique of and movement beyond the clinical and diagnostic encounter. That is, this thesis takes as its point of departure biomedical understandings of type 2 diabetes, past research into perceptions of type 2 diabetes, and perceptions of type 2 diabetes among Kahnawakero:non living with sweet blood, in an attempt to illustrate that not everyone agrees with what exactly diabetes is, where it comes from, and at what point blood is sweet enough to be typed as diabetic. I therefore suggest that subjective narratives of type 2 diabetes can be seen as a political discourse, in that they

simultaneously provide insight into the place of individuals and populations within society, while revealing that - however real the physical complications associated with type 2 diabetes may be - not everyone agrees on the ways in which type 2 diabetes actually constitutes a “health problem.”

In order to frame my discussion, I have divided the remainder of this thesis into five chapters. Chapter 2 gives an overview of subjects and methods, including an overview of Kahnawake, research methodology, community advisory committee, data collection, data analysis procedures and ethics approval. Chapter 3 provides the foundation for the chapters that follow, and includes a review of anthropological theory on biomedicine, extending these to a review of anthropological exploration on perceptions of diabetes. In Chapter 4, I discuss diabetes mellitus, referring specifically to the Canadian Diabetes Association 2003 *Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada*, in order to outline diabetes diagnostic criteria, treatment, care and prevention. I also discuss how diabetes is diagnosed at Kahnawake’s Kateri Memorial Hospital Centre (KMHC), as well as the prevalence of type 2 diabetes in Canada, among the aboriginal population and among Kahnawakero:non. Chapter 5 includes results and discussion, where I draw from the previous three sections to discuss perceptions of type 2 diabetes among Kahnawakero:non living with type 2 diabetes. Finally, I conclude by discussing the implications of this study’s results for understandings of type 2 diabetes, and for treatment, prevention and education approaches in Kahnawake.

## 2. Situating the Research: Place, Methods and Ethics

### Introduction

This chapter gives an overview of subjects and methods, including a brief history of Kahnawake and insight into three specific aspects of its recent past: the St. Lawrence Seaway, Bill C-31 and Kahnawake membership, as well as the 1990 Oka crisis. These areas have been expanded upon here to give context to later discussion of the relationship between type 2 diabetes, land and identity. This chapter further provides an overview of research methodology, the community advisory committee, data collection and analytic procedures, in addition to ethics approval.

### Kahnawake

Kahnawake is part of the Iroquois Confederacy and one of eight communities comprising the Mohawk Nation.<sup>6</sup> Kahnawake's name, meaning "at the rapids," was given in 1676 when the community was established near the Lachine Rapids (known as the *Sault St. Louis* by the French) along the St. Lawrence River, in southern Quebec. The land base from which Kahnawake originated included 60, 000 acres of land from the *Seigneurie du Sault St. Louis*, and derived from two French Crown grants to the Society

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<sup>6</sup> The Iroquois Confederacy refers to the Mohawks, Oneidas, Onondagas, Cayugas, and Senecas. The Confederacy predates European contact and influence, and was based on a clan system and the principle of consensus decision-making. It was a network of relations that joined households to villages, villages to nations, and subsequently the five Confederacy nations together into a political alliance. The Mohawks are the "Keepers of the Eastern Door;" the name given for protecting the eastern flank of the Confederacy. The other four nations to the west are the "Keepers of the Western Door." Communities that make up the Mohawk nation include Akwesasne / St. Regis (located in Quebec, Ontario & New York State), Ganienke (located in New York State), Kanesatake (located in Quebec), Tyendinaga (located in Ontario), Wahta / Gibson (located in Ontario), Kanatsiohareke (located in New York State) and Ohsweken / Six nations / Grand River (located in Ontario).

of Jesus (Ghobashy, 1961). The land was granted on condition that it would revert to the Crown only if the Iroquois abandoned it, and the purpose of the grants was to mission and minister to the Rotinohshonni (the Iroquois or “people of the Longhouse”) (Reid, 2004, p. 21). Kahnawake was originally populated by Kanien’kehaka, practicing Catholics who had migrated to Kahnawake from the Mohawk Valley in upstate New York.<sup>7</sup> Thus the community always had and retains a definite Catholic character; however, the Kanien’kehaka neither replaced their religious beliefs with Catholic beliefs nor did the Jesuit teachings necessarily clash with Kanien’kehaka religious beliefs. Kanien’kehaka traditional spiritual practices have therefore persisted and even meshed with Catholicism over time.<sup>8</sup> Clans (extended family) continue to function, the matrilineal character of the community remains, and traditional practices of marriage and courtship have persisted (Alfred, 1995; Reid, 2004).

The community of Kahnawake arose out of a history of Kanien’kehaka relations with European powers. The first Kanien’kehaka contact with Europeans is reported as having occurred in 1609 (Devine, 1922; Reid, 2004). At this time a small group of Kanien’kehaka encountered and were defeated by a French-Algonquian force under Samuel de Champlain. The confrontation embittered and defined Kanien’kehaka-French relations for the next half-century, over which time the Kanien’kehaka established trade with the Dutch and later the English. Hostility towards the French continued throughout the 1640s, in part related to the Kanien’kehaka’s efforts to establish, secure, protect and

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<sup>7</sup> Kanien’kehaka is pronounced, approximately, “Gah-nia-geh-haga” and means “the People of the Flint.” It is the term I use throughout this thesis in discussing Mohawks generally, beyond Kahnawakero:non (Kahnawake Mohawks).

<sup>8</sup> Though some Kahnawakero:non say that Catholicism and Kanien’kehaka religious beliefs did clash, and as a result the Longhouse religion went underground for some time for survival reasons.

expand control over the European fur trade. Throughout the 1600's the Kanien'kehaka moved back and forth between the English and the Dutch as trading partners and military allies. In 1667 they found themselves at the heart of the struggle between the English and the French, who were battling for Kanien'kehaka loyalty and support, and eventually the Kanien'kehaka realigned with the French (Reid, 2004, pp. 4-6). They did however continue to maintain allies with both the French and the English, and later in the war of 1812 they supported the British defense of Canada against American aggression. Their loyalty, however, did not gain them respect by Canada as a sovereign nation separate from the rest of the country. Following the war, the Kanien'kehaka had no significant economic or military strength to give to Canada, and they were therefore considered politically irrelevant to European powers (Alfred, 1995).

General success in military and economic objectives provided the Kanien'kehaka with a large number of war captives, both white European and Indian, who were over time adopted into their clans. The Kanien'kehaka have a strong history of adoption into their communities, and outsiders could, regardless of race, be incorporated into families and therefore made Mohawk through acceptance into a clan (Simpson, 2003). Adoption helped to offset the devastating population losses resulting from epidemics, such as smallpox, which wiped out more than half the total population of Kanien'kehaka villages in 1634 (Reid, 2004, p. 2). Thus adoptions have had a significant cultural impact on the Kanien'kehaka, and early Kahnawake has as a result been described as a "multicultural" refugee community, constituted by different kinds of Iroquois people and other Christian Indians from Quebec (Simpson, 2003, p. 77). Today, Kahnawake remains a multicultural community inhabited by Mohawks of various backgrounds, religions and beliefs.

In the late seventeenth century, and throughout the eighteenth century Kahnawakero:non were engaged in traditional subsistence activities, such as raising crops of corn, fishing and hunting, as well as trading both within Kahnawake and with surrounding French communities (Devine, 1922). These activities changed when Kahnawake's land base began to diminish, particularly after reserve status was made permanent upon the acceptance of the Indian Act by the community in 1890 (Simpson, 2003, p. 63). By the late nineteenth century the expropriation of Kahnawake lands had greatly impacted traditional food gathering practices, and Kahnawake gradually moved towards an economy based on wage labour (Reid, 2004, p. 17). At this time, Kahnawakero:non men gradually became involved in the fur trade, and found work in logging, freighting and piloting on the St. Lawrence River. Farming was also an economic option at this time and practiced mainly by women, but few Kahnawakero:non continued to pursue it, possibly due to continued decrease in land base (Reid, 2004, p. 18).

Many men also began to work in steel and construction, and today Kahnawakero:non men, known as ironworkers, continue to work in steel and construction, commuting between Kahnawake and other cities such as Toronto, Boston and New York. Men and women also work in local white-collar careers in the community that have arisen through Kahnawake community development. In addition, over the past twenty years the cigarette industry in Kahnawake has been an economic boon to the community, and the financial impact has been so great as to be difficult to measure. Up to 1, 000 Kahnawakero:non are estimated to work in the retail area of cigarettes (Deer,

2005).<sup>9</sup> Today with an estimated population of 7,000 people, the community is characteristically “white-collar” by employment and income standards (Macaulay et al., 2002, p. 465); at approximately \$30, 000 per year, Kahnawakero:non have one of the highest annual incomes per family of any other indigenous community in Canada (Alfred, 1995, p. 2).

Changes in the lifestyles of Kahnawakero:non from Kahnawake’s establishment to today have in part resulted from alterations to the land. Land cessions have over time considerably diminished the original land base of Kahnawake and since the early 1900’s approximately 50,000 acres of Kahnawake territory have been lost, as a result of land sales by the Jesuits and later the Department of Indian Affairs.<sup>10</sup> Land expropriation is therefore quite central to the collective consciousness of Kahnawakero:non. As Alfred (1995) stated:

The presence of railways, highways, and electric towers cross-cutting the reserve is a source of anger for Mohawk people in Kahnawake, and the gradually accumulating frustration due to the piecemeal erosion of the Mohawk land base has tainted the Canada-Kahnawake relationship for over a century (p. 156).

Today, the Mohawk Council of Kahnawake has grant claims that include the original seigniorial grants, 3,000 acres of which now cover the local municipality of Chateaugay (Simpson, 2003, p. 63). The reserve area of Kahnawake now resides on approximately

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<sup>9</sup> The Province shut down the cigarette industry in Kahnawake in 1993. The collapse of the cigarette industry was an indication of the amount of revenue that flows through Kahnawake from the trade, and the town went into a recession with the loss of the cigarette trade at that time. Since then, the trade has been revitalized, and cigarettes are now actually manufactured in the community. Cigarette stands decorate many streets of Kahnawake. Not everyone in the community supports the cigarette industry because it invites many non-Kahnawakero:non into the community who cause traffic accidents by slowly prowling the streets looking for cigarette stands. Moreover, tobacco is a sacred plant for the Kanien’kehaka, and therefore some people consider the selling of it disrespectful to their culture and beliefs. Some Kahnawakero:non also recognize cigarette smoking as a health risk, and they are therefore concerned that promoting cigarettes on such a large scale may affect the health of the community.

<sup>10</sup> Through the Indian Act, the Minister for Indian Affairs retains authority over land management on Indian reserves. This means that the Minister for Indian Affairs has the authority to sell or lease reserve land for public purposes.

12,000 acres, and the community is 10 minutes away from Montreal by vehicle, located between the suburban municipalities of St Constant, Delson and Chateauguy.

Thus not only has Kahnawake's land base diminished over time, it has been drastically altered as a result of the development of surrounding suburbs and the related build up of Canada's nationhood (e.g., Kahnawake reserve land has been expropriated for a number of Canadian nation-building projects, including construction of the St. Louis Lake and Province Railway and the St. Lawrence Seaway) (Reid, 2004, p. 18). Yet the land that Kahnawakero:non live on today, in addition to Kahnawake's original land base that lies outside of the borders of present day Kahnawake, is perceived by them to be the territory of the Iroquois people. Therefore, as Simpson (2003) has stated, the concept of the territory is strongly maintained by Kahnawakero:non in asserting themselves and their Mohawk identity:

The construct of "territory," with self-imposed borders and the rights that flow from habitation in that region, carries with it an ideological power that Mohawks have maintained in their figuring of their distinctive selves and their figuring of outsiders since their move from the [Mohawk] Valley. Hence, the imposition of borders between Canada and the US, with the coercive power of the state behind them, is an affront to Mohawk identity – which draws from the notion of a preexisting and existent larger Mohawk territory with its own borders that predate the creation of Canadian and American borders (p. 81).

Horn-Miller (In Press) has further stated that for Kahnawakero:non, in the past both identity and sense of belonging were determined by familial and communal relationships and patterns of land use. Thus continued changes to the land have altered the relationship of Kahnawakero:non to the land and to each other, which is related to the alteration and even weakening of their culture and traditions (p. 27).

The lifestyles of Kahnawakero:non have also shifted alongside changes in community governance. While clan and familial ties still exist as important aspects of

Kahnawakero:non identity and sense of belonging, the importance of these ties has changed and in some ways diminished over time, particularly since the adoption in 1890 of an Indian Act-chartered Band Council. The Mohawk Council of Kahnawake (MCK) is composed of an elected Grand Chief and eleven Council members, and under federal purview is exclusively responsible for the administrative and financial dealings of the reserve. By accepting the Band Council into the community, Kahnawake also accepted the notion of Indian status and band membership as defined by patrilineal descent, which clashes with Rotinohshonni matrilineal tradition. For this and various other reasons, not all Kahnawakero:non perceive the MCK as a legitimate governing body. Three parallel governmental institutions therefore exist as an alternative to the MCK, modeled on the Longhouse, the traditional Iroquois model of governance. The Longhouses politically represent Kanien'kehaka who do not participate in governments that are not Iroquois - any government other than the Longhouse is perceived as a foreign political body that should not have any authority over Mohawk decision-making. The Longhouses are the focal point of social, cultural and political activity for a minority of Kahnawakero:non (Alfred, 1995; Simpson, 2003).

The adoption of the Indian Act and a Band Council form of governance does not mean that Kahnawakero:non agree upon or consent to the legitimacy of Canadian institutions. Kahnawake continues to affirm the nationhood of the Kanien'kehaka as distinct from the nation of Canada by taking authority over the dealings of the reserve (Alfred, 1995; Simpson, 2003). The community has since the late 1960s and early 1970s maintained control over health services, education, economic development and community services. Kahnawake also controls community police (Peacekeepers),

emergency services (Kahnawake Fire Brigade, ambulance), and justice (Court of Kahnawake) (Macaulay et al., 2002, p. 465). Kahnawake has also developed and / or accepted other institutions in the community such as services and business complexes, as well as a credit union, the Caisse Populaire Kahnawake. In addition, Kahnawake assumes control over a number of other services such as youth programs, social clubs, language retention and cultural development programs, sports programs, a local radio station and a newspaper. As I discuss below, Kahnawake also controls community membership.

### ***“Health” in Kahnawake***

Though an extensive discussion of “health” in Kahnawake is beyond the scope of this thesis, a brief overview of health concepts specific to Kahnawake and the Kanien’kehaka is necessary for understanding Kahnawakero:non perceptions of type 2 diabetes. Health for the Kanien’kehaka does not necessarily centre on health services. Nevertheless, one of Kahnawake’s most notable assertions of authority and control is through community health services. Kahnawake has a strong history of control over health services, and Kahnawakero:non can access health services at the Kateri Memorial Hospital Centre (KMHC), Kahnawake’s hospital – the only hospital to be both owned and operated by an Indian band in Canada.<sup>11</sup> Health services at KMHC are governed by a single Health and Social Services Commission, Onkwata’karitahtshera.<sup>12</sup> Onkwata’karitahtshera envisions health as connected to physical, emotional and spiritual realms. Thus according to Onkwata’karitahtshera, Kahnawake does not separate “health

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<sup>11</sup> KMHC is named after the blessed Kateri Tekakwitha. Born of a Christian Algonquin mother and a Mohawk father in 1656, she is a significant figure in that she, a native woman, was baptized a Christian and devoted her life to the faith.

<sup>12</sup> Onkwata’karitahtshera is pronounced, approximately, “Ong-wa-da-ga-rey-dad-sera” and loosely translates from Mohawk to mean “for all the people to be concerned in the area of good health.”

problems” from “social problems,” and improved health in Kahnawake is sought through attention to the “root causes” of health problems and through prevention and promotion activities (Interview, Health Administrator, August 18, 2005).<sup>13</sup>

Not separating health from social problems is moreover founded in the belief of wellness. While not all Kahnawakero:non view health in exactly the same way, the concept of wellness forms a major component of Kanien’kehaka society. Individual wellness is dependent upon the wellness of others, and when the individual has balance in all physical, emotional and spiritual realms both the clan and community are thought to prosper. This implies that when one person begins to heal, all Kahnawakero:non begin the healing process. Thus while each person has a responsibility for his or her own wellness, the community is also responsible to make sure that each person contributes to the collective wellness of Kahnawake. The individual and the collectivity are moreover ultimately responsible for caring for the Seventh Generation, which for Kanien’kehaka represents those as yet unborn.

Invoking the responsibility of individuals towards collective wellness further suggests that health is related to what is happening around each individual. Health and

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<sup>13</sup> That “health” is a cultural concept is evidenced by the ways in which the Quebec and Kahnawake situate their health priorities. Quebec currently identifies two separate categories in which priority areas are identified, including “health problems” and “social problems.” Under health problems, Quebec lists the following priority areas: avian influenza, clostridium difficile, influenza, SARS, STDs/HIV-AIDS/Hepatitis C, suicide and West Nile Virus. Under social problems, Quebec lists the following priority areas: alcoholism and drug addiction, domestic violence, gambling problems, sexual assault, teenage pregnancy, and troubled youth (see <http://www.msss.gouv.qc.ca/en/>). In 2005, Onkwata’karitahtshera identified seven top health priorities including, in order of priority: addictions, mental health, diabetes, violence, cardiovascular disease, parenting and cancer. The number one health priority, addictions, is said to impact the next four priority items. Violence and mental health are considered to directly link to addictions and surface through relationships among community members, while Onkwata’karitahtshera also recognizes the correlation between addictions and diabetes. The difference between Quebec’s priority areas and Kahnawake’s priority areas is exemplified less by the areas listed than by how health is envisioned. That is, Onkwata’karitahtshera does not differentiate “health problems” from “social problems,” while Quebec does.

leading a balanced life are linked to the principles outlined by the Great Law of Peace, an ancient narrative which describes Iroquois political and social structures. The Great Law of Peace affirms that one must be at peace with oneself and ones surroundings, have respect for oneself and others, act in a responsible manner and remain accountable for one's actions (Alfred, 1995). Thus health and balance derive from being of "one mind," with all of Mother Earth including people, the waters, fish, plants, animals, trees, the sun, the moon, etc. (Native Self-Sufficiency Center, 1993; Reid, 2004).<sup>14</sup> Not being of one mind suggests that a person is out of balance, and therefore not healthy.<sup>15</sup> Coming back into balance directly relates to the land and the well-being of all those inhabiting Mother Earth. According to the Great Law of Peace, expropriation of land and subsequent alteration of it would therefore affect the health of the people. Thus to speak about what constitutes a health priority in Kahnawake, addressing the issue of land is essential.

Ever since Kahnawake reserve status was made permanent in 1890, Canada's presence in the community has been alternatively perceived as an encroachment on the community, or as useful and tolerable. As Simpson (2003) has stated, Canada was positively or negatively received depending on whether Kahnawakero:non felt they were being encroached upon, something which was ultimately framed by Canada's appropriation of and / or threat of expropriating land (p. 83). Thus here I expand upon three specific events in recent history to give context to later discussion of the interrelationship of type 2 diabetes, land and identity. The building of the St. Lawrence

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<sup>14</sup> As evidenced in the Iroquois thanksgiving address, Ohen:ton Karihwaterhkwen ("words before all else"), which is spoken at the opening and close of ceremonial and governmental gatherings. The speaker gives the address on behalf of the people, and the address is based on the belief that "the world cannot be taken for granted, that a spiritual communication of thankfulness and acknowledgement of all living things must be given to align the minds and hearts of the people with Nature."

<sup>15</sup> Dreams are also central to Kanien'kahaka spiritual belief, and dreams are understood as an expression of the desire of a person's soul that if not acted on, could lead to sickness.

Seaway and the 1990 Oka crisis are two recent events involving land expropriation or the threat thereof. A further threat was Bill C-31, a federal bill passed in 1985 as a way to redress the patrilineal bias in the Indian Act.

### *The St. Lawrence Seaway*

Construction of the St. Lawrence Seaway was approved through the St. Lawrence Seaway Act and began in 1954 as a joint Canada-US venture. Kahnawake fought against the building of the Seaway, appealing in Canadian courts, and going so far as the United Nations, but without success (Ghobashy, 1961, pp. 113-120). The project was completed in 1959, extending along 69 miles of channel and 45 miles of dikes at a cost of over one billion dollars. The purpose of the Seaway was to improve shipping on the St Lawrence River, and to improve the exploitation of the river's potential for hydroelectric power. The canal is 27 feet deep and two hundred feet wide, a result of 100 square miles of condemned property, 1,262 acres of which belonged to Kahnawake (Phillips, 2000, p. 1).

The damage done to Kahnawake's landscape was irreparable. The Seaway literally cut off Kahnawake from the riverfront, which was considered the centre of economic and cultural activity and a rich source of food for Kahnawakero:non, including frog legs, berry bushes which grew along the water, and fish. The river was also a place for exercise for children and the elderly. Moreover, families were relocated from their houses at the riverside, resulting in houses in the community being packed closer together. The loss of space in the community resulted in disappearance of large gardens, livestock, and small vineyards and orchards (Phillips, 2000, p. 38). The Seaway thus became another confining element to Kahnawake's landscape, which was at that time surrounded by highways and railroad tracks, and threatened by the continuing

encroachment of suburbs such as Chateauguay from the west and Cote-Ste-Catherine from the east. The river, says Phillips (2000) “literally and symbolically represented movement of people, money, resources, whereas the Seaway brought stagnation” (p. 40).

The expropriation of land for the construction of the Seaway has been considered by some Kahnawakero:non anthropologists as the most wrenching of land expropriations for Kahnawake, so much so that it has served as the impetus of the modern nationalist consciousness in Kahnawake. As Simpson (2003) has stated, the Seaway “embodies the experience of intrusion of Canada into the territory and minds of Kahnawakero:non” (p. 83). Prior to the construction of the Seaway, Kahnawake incorporated elements from Canada while being able to persist as a nation; the construction of the Seaway was the first interaction perceived to jeopardize Mohawk identity, and it is a constant reminder of Canada’s intrusion into Kahnawake territory (Phillips, 2000, p. 15). Simpson (2003) and Phillips (2000) argue for further examination of the social and symbolic dimension of the land expropriation that led to the construction of the Seaway. As I will later discuss, there is also a need to examine the Seaway from the perspective of health and the health consequences perceived to arise, in part, from its construction.

### ***Bill C-31 and Kahnawake Membership***

Some thirty years following the construction of the Seaway another event threatened the nationhood of Kahnawakero:non, one that arose simultaneously from within Kahnawake and from outside. The legislation of Bill C-31 in 1985 reinstated on the federal registration of Indians in Canada, all Indian women who had previously lost

their status upon marriage to non-Indian men.<sup>16</sup> Within five years of its passing, the status Indian population in Canada rose by 19%, and by August 1995 the status Indian population had further risen from a 1985 level of 360,241 to 586,580 (a total of 226,339 people). Women represented the majority of those who gained (or regained) status.<sup>17</sup>

The original estimate of the growth in the number of registered Indians as a result of Bill C-31 was only 56,800; the actual increase therefore far exceeded that anticipated (Furi & Wherrett, 1996). However resources on reserves such as education, social services and health were not and have never been matched to account for this increase.

On this issue, Parliament has noted that,

[t]he issues associated with Bill C-31 and, more broadly, with Indian status and band membership raise fundamental social and political questions about what it means to belong to a community and who has the right to determine membership. Conflicts between reinstated women and communities have highlighted these questions. Linked to status and membership are also practical issues regarding the provision of programs and services, and the additional costs created since those who attain status become eligible for federal programs and services (Furi & Wherrett, 1996).

Following the passage of Bill C-31, each band was responsible for deciding how they would apply it to their own community, by either accepting or denying new Status Indians back on their local band list. Thus conflicts over community membership have entered into indigenous communities because of Bill C-31, and have in some cases

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<sup>16</sup> Legal definitions the term “Indian” have existed since 1850, with the introduction of federal legislation governing Indians. Definitions of the term included any person of Indian birth or blood, any person belonging to a particular group of Indians, and any person married to an Indian or adopted into an Indian family. Over time, the definition of Indian was narrowed. In 1869 Indian women who married non-Indian men lost their Indian Status and their children were no longer entitled to be registered under the federal register of Status Indians.

<sup>17</sup> In fact, a woman from Kahnawake undertook the equal rights campaign that led to the eventual passage of Bill C-31. Mary Two-Axe Earley was driven to campaign for equal rights for Indian woman after her non-Status friend from Kahnawake passed away and was denied burial in Kahnawake. Earley spent nearly two decades campaigning before Parliament passed Bill C-31 in 1985 (see [http://www.elections.ca/eca/eim/article\\_search/article.asp?id=29&lang=e&frmPageSize=&textonly=false](http://www.elections.ca/eca/eim/article_search/article.asp?id=29&lang=e&frmPageSize=&textonly=false)).

resulted in harsh regulations regarding who can and cannot enter into and retain membership on band lists.

Prior to 1985 Kahnawake had enforced Canadian rules regarding women who married non-Indians because the Indian Act had become part of the consciousness of many Kahnawakero:non after 1890 (Simpson, 2003, p. 96). The threat of Bill C-31 therefore came simultaneously from within and without the community. At 1, 253 individuals, Kahnawake had a high number of Bill C-31 registrants, and with already threatened resources and a smaller land base following the construction of the Seaway, the community had to find a way to control who was allowed to enter into community membership. Bill C-31 therefore informed the *Mohawk Law on Membership* which came into effect in 1984. The law is considered the Mohawk Council of Kahnawake's response to the Indian Act amendment, designed to undermine the authority of the federal government and its attempts to integrate those who regained status through the federal register (Alfred, 1995; Simpson, 2003). The *Mohawk Law on Membership* stated that people born to Mohawk parents after 1984 must possess a minimum of 50% native blood to be put on Kahnawake's band list. This conflicted with the provisions of Bill C-31, which reinstated children who had blood quanta below 50% if their mother was half Indian. The membership policy was moreover influenced by two recommendations that arose in 1981. First, the eviction of non-Indians on the reserve, and second a moratorium on mixed-marriages, which stated that any Mohawk who married a non-Indian lost their rights to residency, land ownership, voting and office holding on the reserve (Simpson, 2003, p. 98). Thus since 1981 Kahnawakero:non have been required to "marry-in" (i.e.,

marry another person who has at least 50 percent Indian blood) in order to keep their place in the list of members in the community (Alfred, 1995, p. 165).

Since this time, another law was written using as parameters for membership lineage, clan membership, Kanienkeha (Mohawk) language acquisition, respect for mother earth, and respect for established laws and customs of the community. While this law moves away from membership based on blood quantum, it does not resolve the issue of women disenfranchised by out-marriage. These women remain unrecognized as long as they are married to non-Indian men (Simpson, 2003, p. 23). The new *Kahnawake Law on Membership* was put into effect November 10, 2003. People wanting to gain membership in Kahnawake have to apply, and an elder's council has been put in place to adjudicate all applications. Regarding the *Kahnawake Law on Membership*, Horn-Miller (In Press) has expressed concern that,

... the effects and outcomes will have a detrimental impact on the genealogical stability of the community as increasing numbers of people choose to marry within the community to remain on the membership rolls instead of broadening the gene pool by marrying out. This may result in serious birth defects and increased health problems in the future (p. 33).

I will later return to the issue of membership, "marrying-in," and how perceptions of type 2 diabetes among Kahnawakero:non are linked to discussions of the "strength" and "weakness" of the community.

Where race and sex were previously not influential factors in determining membership in Kahnawake, they are said to have become meaningful categories for determining membership when resources became threatened (e.g., through land expropriation such as the Seaway) and when Mohawks became "Indians" (i.e., through the Indian Act) (Simpson, 2003, p. 94). Simpson (2003) has illustrated that such threats

pulled Kahnawakero:non away from what were flexible ideas of clan membership and openness to adoption and assimilation of outsiders into Mohawk society, to a discourse of race for determining membership. Horn-Miller (In Press) has further stated that membership in Kahnawake has over time become a right of the individual's access to resources, rather than an issue traditionally considered in the context of what is best for the community (p. 9). Given that individual health is linked to the health of the clan, departure from ideas of clan membership and movement towards race used to determine membership implies an erosion of the strength of the clan and therefore disruption to the health of the individual and community. Moreover, as much as Bill C-31 and Kahnawake's membership laws are linked to land and resources, they also illustrate the extent to which the bodies of Kahnawakero:non have been classified and managed over time, both by Canada and by Kahnawake.

### ***The 1990 Oka Crisis***

Fifteen years following the passage of Bill C-31 a third major threat to Mohawk land emerged. The Oka crisis was a 78 day armed stand-off between Mohawks and the *Sûreté du Québec* (SQ), Quebec's police force, and later the Canadian Armed Forces. The crisis began the summer of 1990 following the announcement by the Municipality of Oka that it was going to expand a local golf course onto Kanehsatake Mohawk land. In solidarity with Kanehsatake, Mohawks of Kahnawake erected barricades on the Mercier Bridge, the main commuter bridge that connects the island of Montreal to the suburbs that line the St. Lawrence River. A precedent for Oka was set in 1988, when Royal Canadian Mounted Police conducted a raid on illegal contraband cigarettes in Kahnawake. In response to the invasion, Kahnawakero:non blocked the Mercier bridge

for 29 hours (Goodleaf, 1995). Moreover, the events in Kanehsatake were not new to the Kanien'kehaka people, who had by this time been struggling for control over their land for centuries and who, as exemplified by the construction of the Seaway and Kahnawake's response to Bill C-31, would no longer allow Canada or Quebec to freely meddle in their affairs.

The Oka crisis brought out the worst in Kahnawake's suburban neighbors, as fury, hatred and racism were openly expressed; many staged nightly violent protests at police barricades surrounding the community. When in late August 1990 the Canadian army threatened to invade Kahnawake, 100 Kahnawakero:non families who chose to flee the community by car were stoned by a mob of white rioters from LaSalle, Lachine, and Chateaugay (Goodleaf, 1995, p. 63). Many elders had to be taken by boat across the St. Lawrence River for respite from the stress. The community was marked by stress, and Kahnawakero:non were restricted from entering and leaving Kahnawake. As one conversation partner stated, it was like being "held prisoner in your own community."<sup>18</sup> In addition, the SQ stopped all shipments of food and medical supplies from entering Kahnawake. In response, Kahnawakero:non organized food banks and community kitchen facilities where food was rationed and redistributed to families (Goodleaf, 1995, p. 119). In an interview with CBC ten years later, Kahnawake Chief Joe Norton spoke of the Oka crisis as something that can never be forgotten:

Use the army, use the police . . . [They] want to stone us. Want to attack us.  
Prevent us from moving goods back and forth during that time period for our

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<sup>18</sup> The term "conversation partner" is used throughout this text to refer to Kahnawakero:non living with type 2 diabetes who participated in an interview. Traditionally, anthropologists have referred to such participants as "informants," however as I later mention, I was told that the term "informant" is not appropriate in the context of indigenous research methodology. Out of respect for indigenous research principles, I therefore chose to use the term "conversation partner" in its place.

peoples' health and safety – [like] food and medicine. And people who needed to be taken out of the community for medical purposes and medical reasons were stopped and held for hours by those people [rioters from LaSalle, Lachine, and Chateauguay] while the police just stood around and didn't do a damn thing. You can *never* forget that - you can never forgive that (Leishman, 2000).

For some conversation partners, as I will later discuss, food rations, levels of stress during Oka and memories of Oka are perceived to have lead to rising levels of sugar in the blood of individuals and the community.

These events only barely delve into the history of Kahnawake and the Kanien'kehaka people – a history that began well before reported contact with Europeans in 1609 - however they are important and have been expanded upon here because they inform the ways in which Kahnawakero:non living with type 2 diabetes speak about the disease based on their understandings and experiences of community history. Moreover, by situating the history of Kahnawake within the history of Quebec and Canada, even if only partially, I attempt to frame an understanding of how and why blood tends to be sweeter among Kahnawakero:non than among Canada's non-aboriginal population.

## **Methodology**

Methodological approach included interviews and participant observation. Eleven semi-structured interviews were conducted. Conversation partners were Kahnawakero:non over the age of forty who are living with type 2 diabetes. Four of these interviews were with men, seven with women. Three follow-up interviews were conducted following the completion of the initial interviews. The purpose of follow-up interviews was to verify or confirm information and themes that had arisen during the interview process. The diabetes nurse educator at KMHC provided a list of people interested in participating in an interview, and made the initial contact with participants.

Kahnawakero:non interviewed resided in Kahnawake, however some were transient and resided for part of the year or on-and-off elsewhere. Some of those interviewed had in the past lived in other Canadian or American cities such as Toronto or New York, and some continue to transit between Kahnawake and another place they called home. By mentioning this I mean to affirm that while this research is based in Kahnawake, a reserve community, the research does not stop at Kahnawake. It is evident through subjective narratives of type 2 diabetes that perceptions and experiences of type 2 diabetes extend beyond the reserve.

At the time of interviews, individuals were using various treatment approaches (further discussed in Chapter 4) for their diabetes including changes in diet and exercise and prescribed medications. All who were interviewed were taking some form of prescribed medication the purpose of which was related to their diabetes (e.g., to help control blood sugar levels) and / or complications arising from diabetes (e.g., high blood pressure, poor circulation). Two people reported they were taking insulin at the time. All had experienced one or more diabetes-related complications, including heart attacks, strokes and circulatory disorders. Number of years of living with type 2 diabetes ranged from 1 to 20 years.

I also interviewed two non-native physicians who work in Kahnawake to gain insight into their perspectives on type 2 diabetes in the community, and to further understand how diabetes is diagnosed at KMHC.<sup>19</sup> Understandings of type 2 diabetes in Kahnawake were further enriched through discussions with staff at KMHC and the Kahnawake Shakotiiia'takehnhas Community Services (KSCS), Kahnawake's Health and

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<sup>19</sup> Currently there are no native physicians working at KMHC.

Social Services agency. Staff members at KMHC and KSCS are identified in this thesis as “Health Administrators.” Snowball sampling helped to locate key individuals from KMHC and KSCS, who could then refer to others who would be important participants for this study.

Fieldwork took place from June to September. I spent time in Kahnawake, attending the annual pow-wow, frequenting the Kanien'kehaka Raotitiohkwa Cultural Center,<sup>20</sup> listening to K103, Kahnawake's Radio Station,<sup>21</sup> and reading about the community and current events in the Eastern Door, the community newspaper.<sup>22</sup> I was also invited to a Kahnawake Schools Diabetes Prevention Project (KSDPP) Community Advisory Board (CAB) meeting at the outset of my fieldwork.<sup>23</sup> There I learned how research was presented back to the community and the ways in which people responded to research results. For example, in referring to recent research that explored obesity of students in two of Kahnawake's schools, one CAB member noted her concern about the potential harm that the publication of these research results could impose on the schools (i.e., the research might negatively affect the experiences of obese students in these schools). The CAB member noted that a differentiation must be made between research that is *useful* for the community and research that is simply interesting, and that future research implications must be considered. Her voice stays with me as I consider the

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<sup>20</sup> The cultural centre holds a small library with information on Mohawk and Iroquois studies, and Mohawk language courses also take place at the centre. The centre is currently also establishing a small gallery / museum.

<sup>21</sup> K103 is accessible at [www.k103radio.com](http://www.k103radio.com).

<sup>22</sup> The Eastern Door is accessible at [www.easterndoor.com](http://www.easterndoor.com).

<sup>23</sup> KSDPP was formally founded in 1994 as a partnership of the people of the community of Kahnawake, community based researchers of the Kateri Memorial Hospital Center and the Kahnawake Education System, and academic researchers of McGill University and the Université de Montréal. The key objectives of KSDPP are to promote active living, to promote eating in balance and to raise diabetes awareness through school- and community-based interventions “congruent with native culture and learning styles.” (see [www.ksdpp.org](http://www.ksdpp.org)).

extent to which the current research is useful to Kahnawake, and the future implications of my research.

In addition, I attended two diabetes support group sessions, one in September and one in October, which further informed my understandings of peoples' experiences living with type 2 diabetes. The support group sessions were made up entirely of women.<sup>24</sup> During these sessions I was encouraged to ask questions relating to my research. I did not however consider the support group sessions to be "focus group" sessions where I facilitated by asking questions to the group. Rather, I joined the support group sessions as a participant observer and at times, when I felt appropriate and / or when I was asked, posed questions to the group. I also attended the Perspectives on Wellness Gathering in Kahnawake from October 27-28, where traditional healers from the community discussed health and wellness in relation to Kanien'kehaka traditions.<sup>25</sup> The Wellness Gathering was organized by Native Thoughts, a local business that provides services in grief counseling and workshops in healing through cultural practices.<sup>26</sup> The Perspectives on Wellness Gathering enabled a better understanding of health and healing in the specific context of Kahnawake.

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<sup>24</sup> In fact, conversation partners associated talking about diabetes with women, but noted that men were not inclined to discuss diabetes because of a "macho" attitude. That women are more willing to admit that they are "going through a rough time" was further evident at the Perspectives on Wellness Gathering (see below) I attended, where most participants were women. One of the healers at the gathering noted that the reason for such a high turnout of women was because women are "willing to learn to heal." She explained that this is because women are the healers, which arises from their role in creating and caring for the future generations. Thus the healer affirmed that "when one woman starts her healing journey, we all begin to heal."

<sup>25</sup> I refer to "traditional healers" as those who presented their insights at the *Perspectives on Wellness Gathering*.

<sup>26</sup> According to Native Thoughts, "*Tonsaionkwaterihwate:ni* is the Kanienkeha (Mohawk) word or term for, 'We are changing our thinking,' as we learn through experience, we change our thoughts. When we change our mind thoughts to match our heart thoughts, we will achieve harmony within. And now our healing has begun and will continue for future generations" (see [www.nativethoughts.com](http://www.nativethoughts.com)).

While this study explores perceptions of type 2 diabetes among those living with the disease in Kahnawake, it is limited by the extent to which it can speak of broader understandings of type 2 diabetes among Kahnawakero:non not currently living in Kahnawake or who are in-between Kahnawake and another place or other places. The research is also limited in that it focuses on those living with type 2 diabetes, yet excludes a large population of Kahnawakero:non who are not living with type 2 diabetes. This study is further limited by the lack of identifying features accompanying narrative analysis. While I have indicated conversation partners' gender, I have not indicated age except for to say that all conversation partners were aged forty or older. A person's age influences the ways in which people speak about their life experiences, and therefore this study would have benefited from the inclusion of this information within the narrative accounts used. However, because I had assured all conversation partners that their identities would remain confidential, and given that the use of gender *and* age may have enabled identification of the narrators (especially since some narratives reveal other information about lifestyle, profession, family make-up, etc), I chose not to include this information.

### **Community Advisory Committee**

Soon after the beginning of my fieldwork I established a Community Advisory Committee with the help of a physician at KMHC and two other community members (an elder and a doctoral student from Kahnawake). The committee was developed to help inform my research from the perspective of the community, and to strengthen and balance the insight given from my academic committee. The Community Advisory Committee provided insight that helped re-frame questions and revise the consent form

that had earlier been approved by the University Human Research Ethics Committee (HREC) at Concordia (see below). For example, I was informed by my community advisory committee that the term “informant” is inappropriate for use in the context of research in Kahnawake. The term “conversation partner” was recommended in its place (Appendices III, IV). I am not claiming that by using the term “conversation partner” rather than the term “informant” I have eliminated power relations that exist between myself and those interviewed. The term does however reflect the shared process of research as exemplified in indigenous research methodologies (Smith, 1999). In addition, the Community Advisory Committee read the thesis draft, and provided feedback which clarified certain references and which helped strengthen the arguments made.

### **Data Collection and Analytic Procedures**

Interview format used an open-ended explanatory model framework (Kleinman, 1978). Conversation partners were asked when they were diagnosed with type 2 diabetes, their thoughts on the causes of type 2 diabetes, their thoughts on why they personally developed type 2 diabetes, the prevalence of type 2 diabetes in their family, what treatment approaches they use to manage and / or treat their diabetes, their thoughts on why type 2 diabetes was so prevalent in Kahnawake, among other related questions. Physicians were asked about the causes of type 2 diabetes, the preventability of type 2 diabetes and their opinions on why type 2 diabetes was a health issue in Kahnawake. All interviews were conducted in English. All interviews were tape recorded with the permission of each conversation partner, and later transcribed. Field notes were recorded following interviews to capture theoretical insights during the process of data collection.

All interviews (aside from those with physicians) took place in peoples' homes. Conducting interviews in peoples' homes enabled a perspective into their lives that would not have been revealed if interviews had been conducted in an alternative location. Oftentimes family members were present while interviews were taking place, and they openly made comments over the course of the discussion. These interactions helped to situate conversation partners' experiences of diabetes. My role as the interviewer moreover varied from interview to interview, with some extending into entire afternoons over coffee and lunch, and some lasting an hour. In addition, I was told by some people that the interviews were actually beneficial because it gave them a chance to express themselves, as one conversation partner stated, "you were my therapy session today."<sup>27</sup>

Data was analyzed using interpretive thematic analysis. Kleinman's (1988) explanatory accounts of illness through explanation and emotion served as a backdrop for interpretive thematic analysis (pp. 43-56). By identifying illness meanings evoked by explanation and emotion I could gain a better idea of how those living with type 2 diabetes fashion explanations of the various aspects of illness and treatment. I could then extend these narratives to illustrate how they speak to history, politics, culture, and ways in which the bodies of Kahnawakero:non have been "shaped" and governed over time,

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<sup>27</sup> The interview process was moreover inevitably linked with peoples' assumptions of what I expected them to say. As illustrated in the final comments of an interview with one conversation partner:

**Conversation partner:** Tell me something, did I help you out on this, at all?

**Shannon:** Yes, of course. You feel like you didn't?

**Conversation partner:** Ya . . . I hope you learned something from me, I felt like I didn't do a thing.

**Shannon:** I'm not looking for answers. I'm looking to talk to people about their experiences.

**Conversation partner:** Well, I don't know how well I did.

As the person asking questions it was impossible to know the extent to which people discussed their experiences according to what they truly believe versus what they wanted me to hear.

and also how Kahnawakero:non govern themselves. Through such analysis, the narratives reveal both a critique of and movement beyond the clinical and diagnostic encounter.

Narrative texts were transcribed during the process of fieldwork and were read repeatedly to identify patterns of recurring ideas and experiences that merged conversation partners' perspectives. Categories and themes were formulated through this process. I brought categories and themes that I was seeing over the course of thematic analysis to the Community Advisory Committee for further confirmation and understanding, and conceptual themes were refined and synthesized into an account of participants' perceptions of type 2 diabetes.

As Good (1994) reminds us, my understandings of the experiences of each conversation partner are shaped in some measure by the feelings provoked in me upon hearing their stories (p.140). My own response to these stories, in the form of this thesis, is culturally grounded. My position as a female anthropologist, that I am not from Kahnawake and that I am not indigenous, all influence how I have interpreted the stories presented and how I have chosen to structure this thesis. Perhaps of most important note: I am not living with type 2 diabetes. There is only so far, then, that I can delve into the experience of type 2 diabetes. My positioning in all of these areas situates, shapes, and to some extent limits the views represented in this thesis. These same factors would also have influenced the interview process – the ways in which people told me their stories and the information they were willing to confide in me.

### **Ethics Approval**

Foundational to shaping this research has been the process of obtaining ethics approval at the levels of the community and the academic institution. A brief look at

ethics approval procedures at both levels illustrates that ethics are rooted in culture. There are two ways to approach ethics approval for research in Kahnawake: 1. through KSDPP, and 2. through the Onkwata'karitahtshera Health and Social Services Research Council. KSDPP has developed a Code of Research Ethics that researchers working with KSDPP must abide by (Macaulay et al., 1998). The Onkwata'karitahtshera Health and Social Services Research Council is made up of two members from Onkwata'karitahtshera Health and Social Services Commission and three other community members. It is a sub-committee of Onkwata'karitahtshera Health and Social Services Commission, which is itself made up of all senior management in Onkwata'karitahtshera, two community elders, and three Chiefs from the MCK. For the purposes of my research I was required to enter into contract with the Onkwata'karitahtshera Health and Social Services Research Council.

The Research Council was founded in 1998 to address peoples' request to have more control over research that was being conducted in the community. The community had experienced negative consequences of research in the past, and people were also aware of what they considered to be unethical research that has taken place in indigenous communities across Canada.<sup>28</sup> Guided by the principles of ownership, control, access and possession of findings (OCAP), the Research Council is in place to act as a "gate keeper" to those wanting to conduct research in Kahnawake. The council therefore strives to protect the community from potentially harmful research practices by ensuring that the

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<sup>28</sup> For example, BC's Nuuchahnulth Tribe gave hundreds of blood samples in the early 80's for an arthritis study, and two decades later learned that the researcher had kept nearly 1,000 vials of their blood to use in future work. People who had given blood samples had not granted permission to the researcher for this work (this story is mentioned at the Canadian Institutes of Health Research site: [www.cihr-irsc.gc.ca/e/29083.html](http://www.cihr-irsc.gc.ca/e/29083.html)).

research process is relevant and respectful, that information collected is being validated by the community and that all research done in Kahnawake is presented back to the community (Interview, Health Administrator, August 24, 2005). Furthermore, the Research Council is in place to ensure that research benefits the community of Kahnawake. This is outlined in the Research Council's *Contract to Conduct Research within the Territory of Kahnawake*, which states that research must be beneficial not only to the individuals involved, but to the community as a whole. Research must ultimately empower the community "to support community goals of health and wellness, to promote healthy lifestyles, improve its self-esteem and to fulfill its traditional responsibility of caring for the Seventh Generation" (Onkwata'karitahtshera Health and Social Services Research Council, 2005).

I submitted my research proposal along with my research consent form and interview protocol to the Research Council in May, after which my proposal and accompanying information were reviewed and accepted by the Research Council (Appendix V). I did not officially sign my contract with the Research Council until August, after I had negotiated ownership of data and authorship of my thesis with the Council. The initial contract I was given would have required me to allow the Research Council to own all data that I collected, including tapes, transcripts, etc. It would have also required me to acknowledge the community of Kahnawake as an author on my thesis. After some negotiation and an amendment to the research contract, we agreed that I could own the data collected and that I would be the sole author of my thesis. Upon signing the research contract I also agreed to provide the Research Council with a copy of my thesis and to present my research results to the community. In addition, over the

course of my fieldwork in Kahnawake I was required to write monthly progress reports to the Research Council explaining where I was at in my research timeline, any problems I was having regarding my research, etc.

At Concordia I was required to submit my Ethics Review Summary Protocol Form (SPF) (i.e., my ethics review application) to the University Human Research Ethics Committee (HREC) at the departmental level. I therefore submitted my SPF to the department of Sociology and Anthropology in May, where an appointed professor within the department approved the application. The application requires a brief description of the research, how the research is funded, sample of persons to be studied, method of recruitment of participants, a description of the process of informed consent and examples of consent forms to be used in the research, an explanation of post-research debriefing, a description of how participants' information will remain confidential and the handling of data (i.e., how data such as tapes will be stored and eventually destroyed), etc. The application also required I submit sample questionnaires for approval (University Human Research Ethics Committee, 2005).

While both ethics guidelines are meant to protect informants and researchers (and universities), they diverge somewhat in the principles of OCAP. While I was required to negotiate with the Onkwata'karitahtshera Health and Social Services Research Council to ensure that I could retain ownership of the data I collected, including authorship of my thesis, the concepts of ownership, authorship and control of data seem otherwise to be presumptions made by the HREC (i.e., that the researcher automatically owns the data collected and therefore controls where it is stored and how and when it is destroyed). The presumption that data ought to be owned by the researcher is in contrast to decolonizing

methodologies involving ownership, control, access and possession of research by indigenous nations (Smith, 1999). These methodologies have been described as a political response to what indigenous nations see as colonial approaches to research and information management (Schnarch, 2004). Ownership of data, which includes its storage, accessibility and disposal, by a community research council rather than the researcher him or herself can however place researchers in an awkward position of having to guarantee confidentiality to their informants / conversation partners and then hand over data (whether de-identified or not) to a research council which will then own the information and control the storage and disposal of it.

The ethics guidelines further diverge in the principle of presenting research back to informants and / or communities. While the HREC requires information about how the researcher will provide post-research explanations and / or debriefing to informants, the HREC does not *require* that the researcher present the research results back to the community where research was conducted or to those who participated in the research. This is in contrast to the Onkwata'karitahtshera Health and Social Services Research Council contract, which requires that researchers present their research back to the community of Kahnawake. Presenting research back to the community is meant to instill a sense of responsibility on the part of the researcher to the community. Presenting research back to the community also upholds the principle of using research as a way to empower the community, as outlined in Research Council contract.

The principle of empowerment is also a contentious issue, however, and the responsibility of researchers to conduct research that will benefit the community implies that researchers must also be able to gauge what kind of research, exactly, will benefit an

entire community. Yet communities are always made up of various outlooks on what does and does not equal community benefit! In the case of Kahnawake, for example, while the Research Council accepted my research project based on the premise that the research will be beneficial for the community, the Research Council does not represent the opinions of the entire community of Kahnawake (given, for example, that the Research Council is supported by the Band Council, a governing body that is not seen as legitimate by some Kahnawakero:non). Therefore it is not certain that all Kahnawakero:non would agree with the Research Council that my research will actually benefit the entire community.

Working with both research ethics guidelines is obviously not impossible. However doing so required that I simultaneously respect, through my relationship with the Research Council, the sovereignty of Kahnawakero:non to make decisions about research in Kahnawake territory, while at the same time I had to abide by guidelines outlined by Concordia's HREC that are in many ways considered colonizing methodologies (cf. Smith, 1999). Moreover, my experience in negotiating my research within the limits of OCAP indicates that while such methodologies have potential to empower indigenous communities, the benefits of these methodologies must be explored further. The principles of OCAP are highly limiting for researchers, and they may even be harmful to communities and community members given that they may not adequately protect those participating in research studies (i.e., because through OCAP researchers are required to give up their data to a governing body that may or may not be considered legitimate by community members).

### **3. Biomedicine, Diabetes and Anthropology: Pursuing How and Why**

#### **Introduction**

I ground this thesis with a brief literature review of the critiques that anthropologists have raised regarding biomedicine. From this, I provide an overview of how anthropologists have approached the study of diabetes, and the reasons for why anthropologists' work remains limited.

#### **Anthropological Insight into Biomedicine**

Extensive literature now exists that considers biomedicine as a cultural and ideological construct. Gordon (1988) has noted that biomedicine, as a product of Western culture and society, arises from the ways in which we interpret ourselves, our world, and the relationships between humans, nature, self, and society:

The biological reductionism by which modern medicine is frequently characterized is more theoretical than actual; in its effects, biomedicine speaks beyond its explicit reductionist reference through the implicit ways it teaches us to interpret ourselves, our world, and the relationships between humans, nature, self, and society. It draws upon and projects cosmology (ways of ordering the world), ontology (assumptions about reality and being), epistemology (assumptions about knowledge and truth), understanding of personhood, society, morality, and religion (what is sacred and profane) (p. 19).

Though biomedicine both constitutes and is constituted by society, such interdependency is denied by biomedical theory and ideology which claim neutrality and universality.

Nettleton and Watson (1998) have further noted that the biomedical model is in fact open to differing interpretations over time, even among health care professionals (e.g., doctors may use one explanatory model when speaking to medical audiences, and another when

speaking to patients). The categorizing of biomedical disease is therefore actually influenced by social, historical and political contexts, and clinical information is open to a certain degree of interpretation (p. 94).

Kleinman (1995) has further illustrated that biomedicine is as plural as other areas of the social world:

Medicine . . . like religion, ethnicity, and other key social institutions, is a medium through which the pluralities of social life are expressed and recreated . . . biomedicine is as plural as primary care practitioners in public clinics, rehabilitation experts in a veterans medical center, heart surgeons in a for-profit hospital chain, nurse practitioners in a rural hospital, psychoanalysts in office practice, social workers on the streets with the homeless mentally ill, and military health planners (p. 24).

It is therefore suggested that biomedicine and its efficacy must be considered within the broader context of changing social and political relations, and as a culture that changes and adapts over time. In fact, Kleinman (1995) has stated that the purposes of biomedicine have altered over time, from an early emphasis on human grounds of illness and care which is shared with other healing traditions, to economic and political priorities. Thus Kleinman notes that biomedicine has been “remade” via the regulation of bureaucratic rationality, state control, and the market, and can be more commonly associated with other agencies of government than it can be with the biomedicine that existed at the beginning of the nineteenth century (p. 39).

Anthropologists have argued, however, that there are nevertheless core characteristics of biomedicine. Young (1979) has illustrated that biomedicine is part of an internalizing system, whereby “physiological explanations are indispensable for organizing medical strategies” (p. 74). Explanations and therapeutic strategies of biomedicine are organized around microlevel processes that recognize only the internal,

biomedical conception of sickness. The focus of biomedicine is the diagnosis and treating of disease, and diagnostic classification is “rationalized around abnormalities in the structure and function of particular body organs and systems, and bounded phenomenologically by each individual’s body” (p. 7).

More recently Young (1982) has affirmed the distinction between disease, the organic pathologies and abnormalities taking place within the body, and illness, how disease and sickness arise in individual consciousness. He further carved out a specific definition for sickness, which he says is “the processes through which worrisome behavioral and biological signs, particularly ones originating in disease, are given socially recognizable meanings, i.e., they are made into symptoms and socially significant outcomes.” All cultures have rules for translating signs into symptoms and for linking symptoms to etiologies and interventions, while evidence from interventions are used to confirm these translations and legitimize outcomes (p. 270). Thus Young distinguishes causes from mechanisms (i.e., what originates external to the body from what is happening within human bodies) (see Rock, 2003a, p. 138). Recognition of sickness is essential because biomedical diagnostics take the individual as object, and therefore do not require us to account for the ways in which social relations shape and distribute sickness.

Rock (2003a) has further extended Young’s (1982) analysis by arguing that much biomedical *research* actually gives rise to externalizing explanations. In contrast to externalizing explanations in other medical systems that rely on purposive agents, “[e]xternalizing explanations in biomedical research encompass socially-structured environments, unintended consequences, and bodily states deemed to have developed at

random . . . ” (p. 138). Thus, for example, much of contemporary genetic knowledge about type 2 diabetes actually attributes sweet blood to the environment surrounding human bodies. This means that biomedical knowledge is not limited to what is internal to the human body, and “biomedicine itself exhibits pluralism: biomedical research and clinical praxis rely on different epistemologies to reckon the origins of sickness” (p. 166).

Thus while biomedical research gives rise to externalizing explanations (etiology), biomedical diagnosis and treatment frames understandings of disease as internal to the sick body (physiology), controlled independently of the circumstances in which individuals are situated (Rock, 2003a, p. 166). Biomedical diagnostics are therefore related to naturalism, as Gordon (1988) has argued, and represent the assertion of “autonomy of ‘nature’ from ‘supernatural,’ from human consciousness, from ‘culture,’ ‘society,’ ‘morality,’ ‘psychology,’ and particular time and space” (p. 23). Thus sickness is approached as a natural phenomenon, and knowledge about sickness is developed through scientific rationality and practiced on the human body, nature’s “human representative” (Gordon, 1988, p. 23). This has been further addressed by Scheper-Hughes and Lock (1987) as the singular premise guiding biomedicine - the opposition between spirit and matter, mind and body, and real and unreal.

Kirmayer (1988) has addressed the notion of the Cartesian division characteristic of biomedical diagnostics, arguing that the dominant metaphor in biomedicine is the “body as biochemical machine” whereby,

[t]he patient is the owner of the body-machine which is brought to the physician for repairs. A rational patient adheres to the rules of the sick-role: seeking out medical expertise, giving the body over to be examined and complying with the treatment regimen. When patients deviate at any step in this process they may be judged irrational or responsible for their illness. Even when the norms of illness behaviour are strictly followed, if medicine cannot explain or alleviate illness, the

patient may be blamed for its failure. These maneuvers act to maintain the rationality and coherence of the biomedical world view even while they disqualify the patient's suffering or moral agency (pp. 57-58).

Anthropologists have therefore argued that the world view of biomedicine is founded in values of rational control and distance from bodily-felt meaning, thus biomedical diagnostics serve as a powerful reinforcer of duality. This is entirely separate from more holistic views of medicine, where external forces are said to structure and influence individual experiences of health and well-being, and are therefore considered a part of the healing process.

Kleinman (1995) has moreover written the most pertinent analysis of biomedical power for this discussion. He noted that biomedical analysis does not consider broader aspects of the social world that can affect the health of individuals, and this is central to the perpetuation of the process of medicalization:

Biomedicine is not just any bureaucracy and profession, it is a leading institution of industrialized society's management of social reality. Biomedical constructions of the various forms of human misery as health problems are reinforced by societal regulations that can influence all sectors of experience, from the courts to the workplace to the household. This process of medicalization is responsible for certain of biomedicine's most controversial attributes. Biomedicine's sector of influence continues to grow as more and more life problems are brought under its aegis. Alcoholism, other forms of drug abuse, obesity, aging, child abuse, violence – all are presently articulated as health (or mental health) conditions . . . No other therapeutic system can exercise this degree of power, because no other has become so powerful a part of the state's mechanisms of social control (p. 38).

Nettleton and Watson (1998) have further suggested that biomedicine has privileged status in comparison with other authoritative institutions because it is considered to be informed by "objective and rigorous scientific knowledge" (p. 89). Moreover, it was with the development of the biomedical model of illness and disease that the importance of the

patients' interpretation of illness diminished (i.e., subjective narratives or illness narratives), and objective science became paramount.

Waldram (1995) among others (e.g., O'Neil et al., 1998), have further noted the power of biomedicine in the context of state-aboriginal relations in Canada:

Regardless of whether infectious diseases or social pathologies predominate in epidemiological profiles, we must not lose sight of the fact that biomedical definitions of health and disease are inextricably linked to larger structures of authority and power. The ability to define and then survey such parameters as "health status" carries with it the power to construct institutions of healing that prescribe, proscribe, and regulate behaviour. The creation of the image of aboriginal communities as socially pathological . . . in turn provides a rationale for policies of paternalism and dependency (p. 260).

Rock (2003a) has even gone so far as to assert that recent medical students in Canada have been taught that the epidemic of diabetes among indigenous peoples is a result of genetic destiny. Thus, "the use of genetic differences to explain the distribution of sweet blood can lead to 'naturalizing' social inequality" (p. 171). O'Neil, Reading and Leader (1998) have further argued that epidemiological portraits of aboriginal sickness act as "powerful social instruments for the construction of aboriginal identity." Epidemiological knowledge actually constructs understandings of aboriginal society that serves to reinforce unequal power relationships, thus, "an image of sick, disorganized communities can be used to justify paternalism and dependency" (p. 230). The authors therefore discuss the need to construct an alternative discourse that challenges the legitimacy of the dominant (i.e., biomedical) epidemiological discourse. An alternative discourse would contribute to the production of knowledge about aboriginal communities that could shift relations of surveillance and by extension relations of power between the state and aboriginal peoples.

Moreover, explanations for health and ill-health have been noted as important because such explanations are directly related to the provision of health services for aboriginal communities. Waldram (1995) has argued that emphasis on cultural or biological explanations for aboriginal health have served to reinforce existing stereotypes of aboriginal people, “particularly by concentrating on perceived deficiencies, vulnerabilities, and weaknesses.” Such emphasis has “contributed little either to the understanding of aboriginal health or to effective solutions to actual health issues” (p. 269). The implication is that recognition of aboriginal perceptions of health could give insight into how community health services can be better structured to meet specific community health needs. Tait (2003) has extended this analysis by noting that aboriginal communities have continuously lobbied for control over health, education and social services, not only to be able to structure community services, but to control the definition of problems and solutions occurring in their communities (p. 183). Control has taken the form of community governed research projects (e.g., KSDPP) and programs on health and social issues, and control over research and community services has revealed more holistic approaches to understandings of community health. That is, while research integrates standard biomedical interests, it also tends to include social, emotional and spiritual concerns as integral to health, as well as a focus on health generally rather than sickness profiles used in mainstream epidemiology (O’Neil, 1993, pp. 34-36).

### **Reconsidering Type 2 Diabetes through Anthropology**

Adelson (2000) has argued that while medical anthropologists have focused on the critical study of illness experience and the clinical encounter, they have neglected the study of health, perpetuating the mind / body dualism at the heart of the biomedical

model of disease and treatment. Thus “the disease / illness distinction does not address or acknowledge the social relations inherent in illness or *health* problems – how, in other words, those experiences are shaped and distributed in society” (p. 118). I would extend this critique specifically to anthropological insight into diabetes which - up until Rock’s (2003a) study which challenges received wisdom about diabetes - had not been subject to anthropological analysis. Up until this time, studies exploring perceptions of type 2 diabetes (e.g., Ferzacca, 2000; Schoenberg, Drew, Stoller, & Kart, 2005) and specifically studies focused on aboriginal perceptions of type 2 diabetes (e.g., Abonyi, 2001; Garro, 1995; 1996; Hagey, 1984; Lang, 1985; Sunday, Eyles, & Upshur, 2001) while insightful tend to presume that those living with type 2 diabetes understand and agree with diabetes diagnostic procedures. That is, the research focuses on the study of illness experience, neglecting insight into diabetes itself as a dynamic and even contested subject.

A great deal of attention has therefore been paid to perceptions of type 2 diabetes which evoke social etiologies, including, in the specific case of aboriginal perceptions, negative sociocultural changes occurring in aboriginal communities and rapid cultural change leading to the replacement of traditional foods with refined and processed foods. For example, Garro’s (1996) study of causal accounts of diabetes among three Anishinaabe (Ojibway) communities revealed that Anishinaabe speak about diabetes in the context of food, weight and inheritance, relating the situation of today (i.e., the consequences of changes occurring after the arrival of Europeans) to that of yesterday (i.e., before colonization). Lang (1985) in her study of diabetes and health care in a Sioux community, further suggested that “[t]he Sioux view the underlying cause of diabetes as

another development in the major lifestyle changes that they have undergone, especially during the past century of reservation life” (p. 251).

Focus on perceptions of type 2 diabetes which assert that social forces are at work is essential because such insight highlights how the social world plays out in individuals, revealing the limitations of a biomedical view that situates diabetes within individuals’ bodies. Yet while anthropologists have asserted that social forces are at work in the development of type 2 diabetes among indigenous people, their conclusions are narrow in that they often situate *solutions* to the high prevalence of diabetes among indigenous populations in relation to medicine. For example, while Lang (1985) confirmed that the Sioux link prevalence of type 2 diabetes in their communities to colonization and “reservation life,” she ultimately concluded that diabetes prevention and management is possible through community involvement:

Progress will be made if ideas of lower body weights and weight control, shifts in dietary emphasis, and increased physical activity take hold . . . The Dakota [Sioux] . . . have valuable resources in their concept of physical / spiritual well-being as a unity and in their traditional “way back” dietary patterns of a wide variety of natural foods. These complex traditions, with focused community and tribal action, can be used to complement and reinforce the medical resources that are currently available in dealing with a number of health-related problems, diabetes in particular (p. 257-258).

Community action would likely help to address the issue of type 2 diabetes among the Sioux (as community action has done in Kahnawake, i.e., KSDPP), but what about the fact that the Sioux perceive “reservation life” itself as causal factor in the development of type 2 diabetes in their communities? What about the fact that reservation life for many indigenous communities does not allow these communities to practice “traditional dietary patterns,” and even prevents them from being able to access “natural foods”?

Moreover, the “illness experience” approach presumes that those living with type 2 diabetes agree not only on the biomedical diagnosis and classification of diabetes as a disease, but also how they fall into diabetes classifications. Thus narratives of subjectivity have to some extent supported biomedical insight into diabetes because they have been used by anthropologists without critique of diabetes as a disease category. But what if those living with type 2 diabetes actually question the point at which diabetes begins? What if those living with sweet blood question how they fall into categories of people considered “high risk” for type 2 diabetes? While Abonyi (2001) begins to extend analysis of diabetes by arguing that diabetes must be viewed as both symptom and sickness (following A. Young, 1982), she gives only brief insight into diabetes as a disease, leaving little room for examination of diabetes as itself a dynamic subject. Thus while recognition of diabetes as symptom gives room to consider how social, cultural and political relations, as well as the impact of historical processes interact to sweeten blood, the study is limited in that it presumes that those narrating their experiences with diabetes agree with how diabetes is diagnosed, and how they are situated within this diagnosis. It moreover does not consider how individuals’ bodies are categorized, quantified and governed through the process of biomedical diagnosis.

Rock (2003a) has since deconstructed diabetes, exploring sweet blood and how it has become recognized as a social problem in Canada and other countries. She used anthropological theory to challenge received wisdom about diabetes, arguing that statistically-fashioned populations “undergird the very definition of diabetes as a disease,” and that biomedical knowledge about diabetes situates how we understand diabetes as a social problem (Rock, 2003a, p. 103). Rock has therefore argued for a

progressive stance on diabetes, one that invokes social interventions and acknowledges the reality of diabetes, “a politics that is sensitive to how people’s bodies are produced and governed” (Rock, 2005a, p. 483). Rock’s study is limited, however, in that it only briefly explores perceptions of diabetes among those living with sweet blood.

Perceptions of type 2 diabetes in Kahnawake reveal that Kahnawakero:non living with the disease are not simply passive consumers of dominant biomedical ideologies; they actively question the disease categorization of type 2 diabetes. We must therefore acknowledge that not everyone agrees with what exactly diabetes is, where it comes from, and at what point blood is sweet enough to be typed as diabetic. It should be as relevant, then, to consider that – however real the physical complications associated with type 2 diabetes may be – not everyone agrees upon the ways in which diabetes constitutes a “health problem.” This implies that not everyone agrees upon how to address the issue of sweet blood. Abonyi (2001) and others have argued well that insight into narratives of subjectivity moves beyond a biomedical model of type 2 diabetes. Yet this argument must be pushed further to consider that those living with type 2 diabetes also critique the point at which type 2 diabetes begins.<sup>29</sup> In other words, while biomedical understandings of type 2 diabetes have a vital role in the theory and practice of medicine, it is clear they must be further supplemented with insight into lived experiences of type 2 diabetes so as to provide a more comprehensive understanding of the disease (cf. Farmer, 1999).

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<sup>29</sup> In the specific context of this thesis, that narratives of subjectivity support anthropological theory that challenges received wisdom of diabetes as a disease may be related to the information locally available to Kahnawakero:non. Kahnawake has for ten years hosted a reputable community diabetes prevention program (KDSPP) and Kahnawakero:non also have access to a Mohawk Diabetes Nurse Educator and a nutritionist at KMHC. This means that people in Kahnawake likely have much better access to diabetes education than in some indigenous reserve communities where anthropologists have conducted research. Nevertheless, that anthropologists have not incorporated discussion of how people critique or question diabetes diagnosis but rather have focused on the experience of illness is surprising.

Subjective narratives reveal that we need to continue to broaden how we understand the complex ways in which certain forces – including social, cultural, political and historical factors, disease classification itself, and how individuals and populations enter into these classifications – can lead to type 2 diabetes. I begin the process of going “beyond sweet blood” with an overview of diabetes mellitus.

## 4. Diabetes Mellitus

We don't always need to talk about diabetes, we *are* diabetes.

- Woman at diabetes support group session.

### **Introduction**

In this chapter, I discuss diabetes mellitus, referring specifically to the Canadian Diabetes Association 2003 *Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada*, in order to outline diabetes diagnostic criteria, treatment, care and prevention. I also discuss how diabetes is diagnosed at Kahnawake's Kateri Memorial Hospital Centre (KMHC), as well as the prevalence of type 2 diabetes in Canada, among the aboriginal population and among Kahnawakero:non.

### **Types of Diabetes**

The Canadian Diabetes Association (CDA) (2003) currently defines diabetes mellitus as "a metabolic disorder characterized by the presence of hyperglycemia (high blood sugar levels) due to defective insulin secretion, insulin action or both."<sup>30</sup> Symptoms of high levels of blood sugar or hyperglycemia include extreme thirst, frequent urination, dry skin, hunger, blurred vision, fatigue and nausea. The CDA, the American Diabetes Association, and the World Health Organization recognize four main etiological types of

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<sup>30</sup> The diagnosis and classification of diabetes goes back to ancient Greece, with the first known diagnosis of diabetes dating back to 1552 B.C. The term "diabetes" actually comes from the Greek word meaning "to run through" and for the Ancient Greeks, diabetes was associated with food running through the body instead of fueling it. Early descriptions of diabetes therefore included "the melting down of flesh and limbs into urine." Diabetes was diagnosed by "water tasters" who would drink the urine of people suspected to have diabetes, and the urine of diabetics was thought to be sweet tasting. The Latin word for honey, "mellitus," was used to describe this sweet tasting urine, hence the still used term "diabetes mellitus" (see [http://www.diabetes.ca/Section\\_About/timeline.asp](http://www.diabetes.ca/Section_About/timeline.asp)).

diabetes. In all cases, the chronic hyperglycemia characteristic of diabetes is associated with serious “complications.” Complications include damage, dysfunction and failure of various organs, most notably the kidneys, eyes, nerves, heart and blood vessels. Those living with diabetes are therefore at substantial risk of heart attack, heart failure, blindness, amputations, kidney failure and stroke (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003).

Type 1 diabetes (formerly known as juvenile diabetes mellitus or insulin-dependent diabetes mellitus) is characterized by a failure of the pancreas to produce insulin and develops most frequently in children and adolescents. Insulin is essential for survival because it enables the transfer of energy (glucose) into the cells that make up the body. Those living with type 1 diabetes suffer from a build up of glucose due to lack or deprivation of insulin (i.e., glucose cannot be transferred to and utilized by the body’s cells). Type 1 diabetes was fatal prior to the discovery of insulin and its commercialization in the 1920s, and therapies for preventing the onset of type 1 diabetes have not yet been identified. The failure of the pancreas to produce insulin is said to be primarily a result of pancreatic beta cell (insulin producing cells) destruction. The cause of beta cell destruction is unknown, however most cases involve an autoimmune response (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003). Immune-mediated destruction of pancreatic beta cells has been noted as a process likely incited by environmental factors in genetically predisposed persons. Rock (2003a) however has pointed out that while certain combinations of genes have been shown to increase the likelihood of developing type 1 diabetes, studies have shown that even

identical twins show concordance for type 1 diabetes only one-third of the time (see Barzilai & Shamoon, 1997).

Type 2 diabetes (formerly known as maturity-onset diabetes mellitus or non-insulin-dependent diabetes mellitus) accounts for 90 percent of all diabetes cases. Type 2 diabetes generally occurs in adults after age 45, however increasingly type 2 diabetes is being diagnosed in children, teenagers, and younger adults (especially among aboriginal populations). That such younger diagnoses are occurring is cause for alarm since early onset of type 2 diabetes increases the likelihood of complications and of death at a younger than average age (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003). Type 2 diabetes is characterized by the inability of the body to use the insulin produced. While the bodies of people living with type 2 diabetes produce insulin to varying degrees, this insulin is not always effective in enabling the transfer of glucose into cells. Unlike type 1 diabetes, type 2 diabetes often goes undiagnosed for many years because hyperglycemia develops gradually and at early stages it is not evident enough for the individual to notice the symptoms of diabetes and therefore seek treatment (The Expert Committee on the Diagnosis and Classification of Diabetes Mellitus, 2002, p. S9). An individual can therefore have varying degrees of sweet blood before the physiological processes associated with diabetes become apparent. It is possible, therefore, for people to live with type 2 diabetes, and die as a result of complications associated with type 2 diabetes (e.g., stroke, heart attack) without being diagnosed with the disease (Rock, 2003b, p. 141).

High body mass and infrequent physical activity are considered two main factors leading to the onset of type 2 diabetes. In addition, the Canadian Diabetes Association

(2003) lists risk factors for type 2 diabetes to include being 40 years of age or older, having a first-degree relative with diabetes, being a member of a high-risk population (e.g., people of aboriginal, Hispanic, South Asian, Asian or African descent), among others (see Table 1). As with type 1 diabetes, genetic etiological explanations for type 2 diabetes have been put forth but are disputed, and recent research hypothesizes that type 2 diabetes may be caused in part by fetal malnutrition (see Benyshek, Martin, & Johnston, 2001). Rock (2003b) has stated that consideration of risk factors is at the heart of the criteria used to define cases of type 2 diabetes, and primary (i.e., averting the onset of disease) and secondary (i.e., averting the progression of complications) prevention strategies center on the measurement of risk factors as noted above (p. 145).

Gestational diabetes mellitus refers to glucose intolerance with first onset or recognition during pregnancy. Over 50 “other specific types” of diabetes are listed under a fourth category (see Figure 1), which are all uncommon and consist mainly of “specific genetically defined forms of diabetes or diabetes associated with other diseases or drug use” (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003).

**Table 1: CDA Endorsed Risk Factors for Type 2 Diabetes**

Age $\geq 40$ years
First-degree relative with diabetes
Member of high-risk population (e.g. people of aboriginal, Hispanic, South Asian, Asian or African descent)
History of IGT or IFG*
Presence of complications associated with diabetes
Vascular disease*
History of GDM
History of delivery of a macrosomic infant
Hypertension*
Dyslipidemia*
Overweight*
Abdominal obesity*
Polycystic ovary syndrome*
Acanthosis nigricans*
Schizophrenia†
Other (see Figure 1)

\*Associated with the metabolic syndrome

†The incidence of type 2 diabetes is at least 3 times higher in people with schizophrenia than in the general population. Using data collected in 1991, the prevalence of diabetes was assessed in >20 000 individuals diagnosed with schizophrenia. The rate of diagnosed diabetes was 9 to 14%, exceeding rates for the general population prior to the widespread use of new antipsychotic drugs.

GDM = gestational diabetes mellitus

IFG = impaired fasting glucose

IGT = impaired glucose tolerance

Table 1 and Figure 1 (below) are adapted from: Canadian Diabetes Association Clinical Practice Guidelines Expert Committee (2003). Canadian Diabetes Association 2003 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada. *Can J Diabetes*, 27(suppl 2).

## **Figure 1. Etiologic Classification of Diabetes Mellitus**

- I. Type 1 diabetes mellitus. Beta cell destruction, usually leading to absolute insulin deficiency
  - A. Immune mediated, B. Idiopathic
- II. Type 2 diabetes mellitus. Insulin resistance with relative insulin deficiency to secretory defect with insulin resistance
- III. Gestational diabetes mellitus. Onset or recognition of glucose intolerance in pregnancy
- IV. Other specific types.
  - A. Genetic defects of beta cell function
    - 1. Chromosome 20, HNF-4alpha (formerly MODY1)
    - 2. Chromosome 7, glucokinase (formerly MODY2)
    - 3. Chromosome 12, HNF-1alpha (formerly MODY3)
    - 4. Mitochondrial DNA
    - 5. Others
  - B. Genetic defects in insulin action
    - 1. Alstrom syndrome
    - 2. Leprechaunism
    - 3. Lipotrophic diabetes
    - 4. Rabson-Mendenhall syndrome
    - 5. Type A insulin resistance
    - 6. Others
  - C. Diseases of the pancreas
    - 1. Cystic fibrosis
    - 2. Fibrocalculous pancreatopathy
    - 3. Hemochromatosis
    - 4. Neoplasia
    - 5. Pancreatitis
    - 6. Trauma/pancreatectomy
    - 7. Others
  - D. Endocrinopathies
    - 1. Acromegaly
    - 2. Aldosteronoma
    - 3. Cushing syndrome
    - 4. Glucagonoma
    - 5. Hyperthyroidism
    - 6. Pheochromocytoma
    - 7. Somatostatinoma
    - 8. Others
  - E. Infections
    - 1. Congenital rubella
    - 2. Cytomegalovirus
    - 3. Others
  - F. Uncommon forms of immune-mediated diabetes
    - 1. Anti-insulin receptor antibodies
    - 2. 'Stiff-man' syndrome
    - 3. Others
  - G. Drug or chemical induced
    - 1. Atypical antipsychotics
    - 2. Beta-adrenergic agonists
    - 3. Diazoxide
    - 4. Glucocorticoids
    - 5. Interferon alfa
    - 6. Nicotinic acid
    - 7. Pentamidine
    - 8. Phenytoin
    - 9. Protease inhibitors
    - 10. Thiazide diuretics
    - 11. Others
  - H. Other genetic syndromes sometimes associated with diabetes
    - 1. Down syndrome
    - 2. Friedreich's ataxia
    - 3. Huntington's chorea
    - 4. Klinefelter syndrome
    - 5. Laurence-Moon-Bardet-Biedl syndrome
    - 6. Myotonic dystrophy
    - 7. Porphyria
    - 8. Prader-Willi syndrome
    - 9. Turner syndrome
    - 10. Wolfram syndrome
    - 11. Others

## **Diagnostic Criteria**

How are your sugars?

- Woman at diabetes support group session

Rock (2003a) has pointed out that one of the most notable features of current diagnostic criteria for diabetes is the lack of attribution to cause. That is, “knowledge about *how* or *why* a given body developed sweet blood is not required to make the diagnosis of diabetes” (p. 119). Diagnosis is based strictly on levels of sugar in the blood, and a laboratory measurement of blood glucose must be obtained in order to make a diagnosis of diabetes. This measurement is obtained through a fasting plasma glucose (FPG) test and / or an oral glucose tolerance test (OGTT). The FPG test involves measuring the sweetness of blood many hours after the last intake of calories (up to eight hours or more) (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003). An OGTT involves a drink of sugar (75 grams of glucose in liquid form) given on an empty stomach after which blood glucose levels are tested every half hour for two hours (MacManus, 2001). While the FPG test is currently the clinical standard (according to CDA recommendations), the OGTT is still performed and is often considered to be the “gold standard” diagnostic test for both type 1 and type 2 diabetes (Rock, 2003a, p. 80).

It is worth noting that not all agree on standards of testing. While the CDA suggests the use of an FPG test as the clinical standard, and the American Diabetes Association recommends the use of the FPG test alone for the diagnosis of diabetes, studies from both Japan and Europe indicate that solely using the FPG test would result in many individuals with diabetes to be classified as non-diabetic (Kuzuya, 2000). Further studies have noted that the use of an FPG test as the only diagnostic criteria in

screening for diabetes would result in approximately one third of diabetic individuals left undiagnosed (Borch-Johnsen, 2001). Rock (2003a) has further argued that the promulgation of the FPG test by the CDA in fact sacrifices a certain degree of accuracy and precision for “commensurability, universality, and especially convenience” (p. 90).

A FPG of  $<6.1$  millimols of glucose per litre of blood (mmol/L) is considered normal, while the current diagnostic criteria endorsed by the CDA states that a person is considered to have diabetes mellitus if their FPG level equals 7.0 mmol/L of blood or higher. This value is said to correlate with a 2-hour plasma glucose (2hPG) value of  $>11.1$  mmol/L in a 75 gram OGTT. The Canadian Diabetes Association (2003) has further recognized that elevated blood glucose levels, even if below the stated threshold for diabetes, also have clinical consequences. Such elevated blood glucose levels, in the absence of an actual diagnosis for diabetes, have been labeled “prediabetes,” the term for describing impaired fasting glucose (IFG) and impaired glucose tolerance (IGT) (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003).

IFG and IGT refer to an intermediate metabolic stage between normal glucose homeostasis and diabetes (Meltzer et al., 1998, p. S11). Prediabetes, also commonly referred to as “borderline diabetes,” is said to place individuals at risk of developing diabetes, including the complications associated with diabetes. A person is considered to have IFG if their fasting plasma glucose levels are within the range of 6.1-6.9 mmol/L and an OGTT reveals 2hPG of  $<7.8$ . A person is considered to have IGT if their fasting plasma glucose levels are  $<6.1$  mmol/L and an OGTT reveals 2hPG of between 7.8-11.0 mmol/L. A person is considered to have both IFG and IGT if their FPG is within 6.1-6.9 mmol/L and an OGTT reveals 2hPG of between 7.8-11.0 mmol/L (Canadian Diabetes

Association Clinical Practice Guidelines Expert Committee, 2003). Not all individuals with prediabetes progress to diabetes, and many diagnosed with IGT can, through modified lifestyle and / or weight loss revert back to normoglycemia (normal blood sugar levels). Up to five percent of people with IGT can progress to diabetes (most often type 2) each year. Lifestyle interventions have shown to be effective in delaying or preventing the onset of diabetes in people with IGT (MacManus, 2001).

While the current diagnosis for diabetes occurs at a FPG of 7.0 mmol/L (and / or >11.1mmol/L in a 75 gram OGTT), this has not always been the case. The current diagnostic level came into place in 1998 when the clinical practice guidelines for the management of diabetes in Canada were adjusted (see Meltzer et al., 1998). At this time, the FPG diagnostic level dropped from 7.8 mmol/L to 7.0 mmol/L. The current FPG diagnostic level is said to be the result of population studies that observed the correlation between high blood glucose levels with serious microvascular pathologies, most notably eye disease, kidney disease, and circulatory disorders (The Expert Committee on the Diagnosis and Classification of Diabetes Mellitus, 2002, p. S5). CDA has stated that the reason for this change was to increase the sensitivity of FPG and increase the number of people to undergo testing:

A recent re-evaluation of population studies suggests that an FPG level of 7.0 mmol/L correlates most closely with a 2hPG level of 11.1 mmol/L and best predicts the development of microvascular disease. The lowering of the FPG diagnostic level from 7.8 to 7.0 mmol/L ensures that both the FPG and 2hPG define a similar degree of hyperglycemia and risk for microvascular disease. It also permits the diagnosis of diabetes to be made on the basis of a commonly available test — the FPG (Meltzer et al., 1998, p. S6).

Increasing the number of people tested is meant to decrease the number of undiagnosed cases of type 2 diabetes. Alteration in the guidelines also reveals the ways in which ideas

of biomedical disease diagnosis and thresholds of normalcy and pathology change over time. In Young's (1982) terms, the way diabetes is socially recognized has changed over time, and thus so has the point at which people enter into diabetes diagnoses - the point at which people "become" sick with sweet blood.

### **Treatment, Care and Prevention**

Treatment for diabetes mellitus varies by type. It is generally recommended that type 1 diabetics self-monitor their blood glucose levels three or more times daily, in addition to three to five daily insulin injections.<sup>31</sup> Type 2 diabetics have been shown to have improved outcomes if their blood sugars are kept within recommended limits, and this is facilitated through regular monitoring of blood glucose levels. In addition, it is recommended that type 2 diabetics uptake lifestyle modifications, such as increased physical activity and changes in diet with a goal of achieving a healthy weight for their height. In both cases, nutrition therapy is recommended as integral to treatment of diabetes and patient self-management (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003). Nutrition therapy includes following a healthy diet based in *Canada's Guidelines for Healthy Eating*, namely consuming a variety of foods from the four food groups (grain products, vegetables and fruits, milk products, meat and alternatives) and ensuring adequate intake of carbohydrate, protein, essential fatty acids,

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<sup>31</sup> Blood sugar testing is done by using a glucose meter which generally requires that the individual prick his or her finger, and allow a drop of blood to be placed on a test strip which is then inserted into the glucose meter. The meter reads the blood sugar level and then provides a corresponding number that is then, ideally, recorded so that the individual can monitor what affects their blood sugar levels (e.g., types of food, activity level, etc.).

vitamins and minerals.<sup>32</sup> Nutritional therapy has been shown to improve glycemic control and when used in combination with other components of diabetes care (e.g., increased physical activity, decreased levels of stress) and can improve clinical and metabolic outcomes, thereby preventing future diabetes related complications. For type 2 diabetes, oral antihyperglycemic agents are recommended if modification of food intake and lifestyle does not bring blood glucose levels under control (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003).

Ultimately, diabetes primary and secondary prevention methods focus on self care, self-management and changing individuals' diet and lifestyle, and should be ongoing:

Within a model of chronic disease, diabetes care should be patient centred and focused on self-management. It is most effective when delivered in a manner that provides ongoing education and comprehensive care together as essential components. It can be enhanced through the use of a variety of educational and behavioural approaches as well as community supports. The timeliness of referral for self-management education should be based on the severity of presenting symptoms, the degree of metabolic control and the person's understanding of immediate survival and safety skills and long-term management practices (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003).

Indeed, the medical language of diabetes centers on the terms "management," "control," and "responsibility" (Feudtner, 2003, p. 65). Yet patients' own language of diabetes often differs, and Rock (2003b) has pointed out that the self-management approach to diabetes prevention and management presumes stable mental health, which does not always coincide with lived experiences of diabetes.

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<sup>32</sup> For *Canada's Guidelines for Healthy Eating* see [http://www.hc-sc.gc.ca/fn-an/nutrition/diet-guide-nutri/fg-ga-guide\\_e.html](http://www.hc-sc.gc.ca/fn-an/nutrition/diet-guide-nutri/fg-ga-guide_e.html).

By presuming stable mental health, prevention interventions based in self-management presumes that individuals have the *capacity* for secondary prevention (i.e., to avert or delay physical complications). By adopting these diagnostic criteria “physicians and diabetes organizations imply that people need to be equipped – personally, socially, and materially – to exert influence over their own futures” (Rock, 2003b, p. 151). Yet the complications of diabetes may still be viewed by health professionals as “physical” rather than “mental” problems. Rock (2003b) therefore argues for greater recognition of the links between diabetes and distress, most notably that lived experiences of diabetes may include features associated with mental health problems such as depression and anxiety (pp. 149-153). That people need to be equipped to exert influence over their own futures so as to “manage” diabetes also suggests that land, community governance and assertion of nationhood are quite central to understanding type 2 diabetes in Kahnawake, a point I come back to later.

To date there is no safe and effective way to prevent type 1 diabetes completely, although secondary prevention through intervention has been shown to be possible in cases of both type 1 and type 2 diabetes. For example, the Diabetes Control and Complications Trial (DCCT) demonstrated that intensive insulin treatment and treatment of hypertension of type 1 diabetes significantly delays the onset and slows the progression of microvascular complications (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003). Tests for hyperglycemia can identify individuals with type 2 diabetes, and testing in individuals with risk factors for type 2 diabetes or with diabetes-associated conditions is therefore recommended by the CDA as

an early diagnostic measure to prevent later complications. Specifically, current recommendations state that:

1. All individuals should be evaluated annually for type 2 diabetes risk on the basis of demographic and clinical criteria.
2. Screening for diabetes using an FPG should be performed every 3 years in individuals > 40 years of age. More frequent and/or earlier testing with either an FPG or 2hPG in a 75-g OGTT should be considered in people with additional risk factors for diabetes.
3. Testing with a 2hPG in a 75-g OGTT should be considered in individuals with an FPG of 5.7 to 6.9 mmol/L in order to identify individuals with IGT or diabetes.
4. In individuals with IGT, a structured program of lifestyle modification that includes moderate weight loss and regular physical activity should be implemented to reduce the risk of type 2 diabetes.
5. In individuals with IGT, pharmacologic therapy with metformin (biguanide) or acarbose (alpha-glucosidase inhibitor) should be considered to reduce the risk of type 2 diabetes (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003).

Early diagnosis and intervention forms the basis for screening for type 2 diabetes, and catching diabetes early is driven by the potential to avert microvascular and macrovascular complications, and by extension to decrease costs to the health care system (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003). Physicians have conflicting views on routine screening, however, with some suggesting that diagnosis defines otherwise healthy people as sick, with implications that may follow for the individual and for treatment. Others say that people with undiagnosed type 2 diabetes are in fact not healthy because they do have a higher chance of developing health problems which would affect (i.e., decrease) their life expectancy (Rock, 2003b, p. 141).

## **Diabetes Diagnosis and Education at KMHC**

In diagnosing type 2 diabetes, physicians at KMHC follow the national standards outlined by the Canadian Diabetes Association (Interview, Physician, November 1, 2005). Patients are screened through an “index of suspicion,” based on insight into risk factors for diabetes such as being 40 years of age or older, obesity, having a family history of diabetes and being a member of a “high risk” group. Physicians working at KMHC screen high intuitively because aboriginal ancestry is an additional risk factor for diabetes. In addition, people are screened for symptoms of diabetes, such as fatigue, extreme thirst and frequent urge to urinate, and young women who have had gestational diabetes during pregnancy are re-screened post-partum (Interview, Physician, October 18, 2005).

Not all doctors necessarily follow exactly the same strategy for screening for diabetes, and while national standards are followed there may be variation in how frequently physicians screen their patients and / or the point at which physicians recall patients for follow-up tests (i.e., FPG and / or OGTT) (Interview, Physician, October 18, 2005). This implies that a patient who moves from one physician to the next - due, for example, to recent physician turnover at KMHC - may experience variation in screening approaches.<sup>33</sup> Diagnostic tests are usually confirmed a second time at a check-up six

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<sup>33</sup> Provincial government regulations have resulted in recent physician shortage at KMHC. Quebec's health Ministry controls how many physicians are transferred to each health service delivery region per year, and while KMHC can recruit within a pool of physicians working in the region, each hospital has a designated number of physicians it can hire and hospitals must seek prior approval from the health ministry to bring on new physicians. Physician turnover is also related to current billing rates, and while physicians are paid by the Regie de l'Assurance Maladie Quebec (RAMQ), currently in Quebec the discrepancy between clinic billing rates and private practice billing rates for doctors is increasing with clinic billing rates remaining the lower of the two. KMHC must respect RAMQ clinic billing rates, and this has had the affect of enticing doctors to leave the province (or the country) or switch to private practice, which contributes to KMHC recruitment difficulties. To deal with the physician shortage, evening clinics at KMHC were recently

months or a year following an initial test, or earlier if levels of sugar in the blood reveal impaired fasting glucose (IFG). If blood sugar levels are in the diabetes range then a FPG and / or OGTT would be performed sooner, within a few weeks to rule-in or rule-out diabetes. The point at which one *becomes* diabetic, however, was less easily defined, as one physician pointed out, because it is difficult to know, from an initial abnormal result to a second abnormal result, the point at which someone actually receives a label of IFG or “diabetic” by their physician (Interview, Physician, October 18, 2005).

After being diagnosed, people are referred by their doctor to the KMHC Diabetes Nurse Educator, a Mohawk from Kahnawake. In some cases, often among those where diabetes runs in their family, patients refer themselves to the Diabetes Nurse Educator for preventative education or if they are seeing in themselves the symptoms of diabetes. Generally people prefer individual counseling rather than group counseling because they want to remain private about their health situation. Those desiring group counseling can attend the diabetes support group sessions at Kahnawake Shakotiiia'takehnhas Community Services (KSCS) or alternatively they can go to counseling at a clinic in Montreal or Chateauguay (Interview, Health Administrator, June 27, 2005). Through diabetes education, information is relayed to patients about their diabetes and related complications. Diabetes education focuses on general health and wellness, and patients are also taught about medications and healthy living, such as eating habits, maintaining healthy weights, physical activity, and lowering stress levels. Diabetes education is ongoing for patients at KMHC, and through ongoing education patients are counseled

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decreased to one per week and one morning clinic per week was cancelled, and patients of certain physicians were told they had to go elsewhere for medical care (Personal Communication, December 11, 2005).

through a self evaluation, a process by which patients reflect on their eating habits, level of physical activity and lifestyle factors such as levels of personal stress. Ultimately diabetes education at KMHC teaches self management of diabetes, and strategies for prevention are the same as strategies for management and control (Interview, Health Administrator, June 27, 2005).

## **Prevalence and Incidence of Type 2 Diabetes**

### ***Diabetes in Canada***

Data from the National Diabetes Surveillance Strategy (NDSS) indicate that in 1998/1999, the physician-diagnosed prevalence of diabetes in adult Canadians (i.e., people over 20 years of age) was about five percent (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003). A study by Ohinmaa et. al. (2004) further predicts that the number of prevalent cases of diabetes in Canada will increase from 1.4 million persons in 2000 to approximately 2.0 million persons in 2010 and 2.4 million persons by 2016. The study therefore predicts that the number of cases of diabetes in Canada will increase by approximately 72 percent between 2000 and 2016 (p. 4).

Prevalence and incidence rates for type 2 diabetes are rising the fastest in developing countries. They are also rising in ethnic minority groups and disadvantaged communities in developed nations, and studies have revealed that in Canada and the United States, type 2 diabetes is more common in those with low education levels and income (Benyshek et al., 2001). In 1999, for Canadians between 35 and 64 years of age, 48 percent of people with diabetes compared with 38 percent without diabetes were in the

lower two quartiles of income adequacy (calculated as a relation between house hold size and total income before deductions) (Health Canada, 1999). Chaufan (2004) has further illustrated that in the United States, type 2 diabetes has been increasing over the past 20 years among the working poor (p. 35). Poverty has therefore been noted as an important factor in the prevention and control of diabetes. These numbers also reveal that cases of type 2 diabetes are not randomly distributed.

### ***Diabetes among the Aboriginal Population***

We have diabetes like the coloured people have AIDS.

- Woman at diabetes support group session

Type 2 diabetes is documented as having rapidly increased among indigenous peoples in North America since the mid-twentieth century, from virtually none to a situation described as “epidemic” following the end of the Second World War (Garro, 1995, p. 37). According to the *First Nations Regional Longitudinal Health Survey* (RHS) (2005), which surveyed 22, 602 First Nations people, including 238 First Nations communities, the prevalence of diabetes in First Nations adults is 14.5 percent, much higher than the general Canadian population. Among First Nations adults with diabetes, 78.2 percent have type 2 diabetes, nearly ten percent have type 1 diabetes, and nearly ten percent are “pre-diabetic.” In addition, First Nations are being diagnosed with type 2 diabetes at a younger age than the general population, where diagnosis usually occurs after the age of 30 (p. 19).

High rates of type 2 diabetes among the aboriginal population have been associated with increased rates of cardiovascular risk factors and cardiovascular disease, hypertension, peripheral vascular disease and renal disease and premature death. 88.7

percent of First Nations adults surveyed reported one or more adverse consequences related to diabetes. For example, problems with feeling in hands or feet, vision problems, circulation problems, problems with legs and feet, kidney function, infections, and heart problems. The prevalence of heart disease and hypertension in First Nations adults with diabetes is four times higher than the prevalence found in First Nations adults without diabetes. Moreover, only about seven percent of First Nations adults with diabetes reported having a healthy weight, compared with 29.7 percent without diabetes (National Aboriginal Health Organization, 2005, p. 21).

Chronic conditions arising from diabetes are considered a major health burden to Canada. The CDA (2003) reports that a person with diabetes incurs medical expenditures that are 2.4 times higher than that of a person without diabetes. The total healthcare costs for individuals with diabetes are estimated to increase by approximately 75 percent from \$4.66 billion in 2000 to over \$8.14 billion in 2016 (Ohinmaa et al., 2004, p. 4). Because the duration of illness is a predictor of the rate of complications, the rate of complications and therefore cost to the health system is predicted to increase as age at onset decreases (K. T. Young, Reading, Elias, & O'Neil, 2000, p. 562). Research has therefore predicted that the diabetes-related costs of aboriginal people will increase at a higher rate than in the non-aboriginal population due to the early age of onset in First Nations (Blanchard, Wajda, & Green, 2000).

At the same time, not all First Nations access health services, and according to the RHS reasons for not accessing health services included cost and culturally inappropriate or inadequate services. Moreover, 27 percent of adults with diabetes compared with 18.7 percent of those without diabetes indicated a lack of access to non-insured health benefits

(NIHB) which made it difficult to access diabetes-related medication and other medical supplies.<sup>34</sup> Relatedly, 21.2 percent of those living with diabetes compared with 15.2 percent of those not diagnosed with diabetes reported that lack of access to and denial of approval for services under NIHB limited their access to health care. Nevertheless, most First Nations adults with diabetes (89.8 percent) reported to be undergoing treatment in the form of pills and insulin. People also reported to treat their diabetes by watching their diet, exercise, taking traditional medicines and visiting a traditional healer or participating in traditional ceremonies (National Aboriginal Health Organization, 2005, p. 21).

That surveys reveal such a high rate of diabetes in the aboriginal population has concerned researchers who note that before the 1950s, type 2 diabetes was rare in aboriginal populations (K. T. Young et al., 2000). This reference must be considered in light of the fact that prior to the 1950s statistical data are lacking, and since then few indigenous nations have been continuously monitored longitudinally for any length of time (Health Canada, 1999, p. 39). Moreover, demographic and statistical numbers do not provide a comprehensive picture of the aboriginal population in Canada, nor do they reflect the diversity of experiences among individuals and communities (Adelson, 2005, S47). The statistics are however noteworthy; that type 2 diabetes has reached epidemic proportions among the aboriginal population only within the last fifty years speaks volumes to the changes that have occurred in Canada during this time. Current and projected distribution of type 2 diabetes in the aboriginal population (and other

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<sup>34</sup> Non-Insured Health Benefits are provided by Health Canada as a “national, needs-based health benefit program that funds benefit claims for a specified range of drugs, dental care, vision care, medical supplies and equipment, short-term crisis intervention mental health counselling, and medical transportation for eligible First Nations people and Inuit” (see [http://www.hc-sc.gc.ca/fnih-spni/nihb-ssna/index\\_e.html](http://www.hc-sc.gc.ca/fnih-spni/nihb-ssna/index_e.html)).

populations as noted above) also reveals that it is imperative to question why differing prevalence and incidence of type 2 diabetes exists *between* populations (Rock, 2003b, p. 147).

### ***Causes of Type 2 Diabetes in the Aboriginal Population***

Why is it that First Nations people have higher incidences as opposed to some other cultural groups?

- Conversation partner

The onset of type 2 diabetes has been attributed to both genetic and lifestyle factors, and much attention has been given to the role of genetics in type 2 diabetes given the variation in rates between ethnic groups. Neel's (1962) "thrifty genotype" hypothesis attributed high rates of diabetes in aboriginal populations to genetically determined adaptation to changes in lifestyle. By allowing the body to accumulate fat, the thrifty gene is said to provide protection against starvation during seasonal fluctuation in food supply. This would not be possible in those not carrying the thrifty gene (i.e., those of European ancestry). Neel proposed that the thrifty gene is now maladaptive due to changing environment and food consumption patterns and a general decrease in physical activity, which leads to diabetes. Studies in aboriginal populations have more recently revealed genetic "markers" suggestive of association with diabetes, and associated plasma insulin levels among aboriginal populations at "low risk" for diabetes to be comparable to that of European ancestry (K. T. Young et al., 2000, p. 563).

Rock (2005) has however pointed out that type 2 diabetes has never been linked to a specific stretch of DNA and that genes are not portrayed as the ultimate cause. She has argued that genetic research into type 2 diabetes moreover invokes external phenomena to account for the onset of diabetes, including genetic inheritance from one's

parents, evolutionary changes over time and interactions between the external environment and the individual body. In this sense, the origins of sickness are actually located *outside* of sick bodies (Rock, 2005b, pp. 122-124). Research supports this assertion by suggesting that the combination of genetic and environmental factors may result in increased rates of type 2 diabetes among the aboriginal population in Canada. Environmental factors include negative sociocultural changes occurring in aboriginal communities, rapid cultural change and alterations in the geographic landscape leading to the replacement of traditional foods with refined and processed foods. These factors, in part, have led to decreased rates of physical activity, and they all contribute to high rates of obesity in aboriginal communities (both risk factors for type 2 diabetes) (Health Canada, 2000).

Studies have also specifically emphasized that social inequality plays a role in the prevalence of diabetes among indigenous people, and Rock (2005a) has recognized diabetes as symptom and symbol of poverty and social inequalities. In this sense, Rock argues that high rates of type 2 diabetes in aboriginal people in Canada reveals how contemporary forms of inequality are embodied (p. 474). If poverty and type 2 diabetes are linked, for example, through the types of foods that people have the capacity to purchase or the lifestyles people with lower income levels might lead (e.g., type of work, stress, etc.), then it is of important note that the RHS revealed nearly 76 percent of First Nations adults surveyed across Canada reported a total household income of \$50, 000 or less (National Aboriginal Health Organization, 2005, p. 51).

### *Type 2 Diabetes among Kahnawakero:non*

About 50 years ago... maybe there was a lot of diabetes at that time but nobody knew!

- Conversation partner

Diabetes is said to be relatively unheard of in Kahnawake prior to 1950, however the first diabetic in Kahnawake was recorded as early as 1926 (Jacobs, 2005, p. 78), and oral history speaks to the existence of diabetes in the community since the early 1930's (Interview, Physician, November 1, 2005). Since this time, prevalence of type 2 diabetes in Kahnawake has increased, and cases continue to be recorded through client lists and research into diabetes in the community.

In 1981 a chart review was conducted of 544 people in Kahnawake, equaling 92 percent of the registered Mohawk Indians aged 45-64 years. 12 percent of those reviewed were found to be diabetic, a prevalence rate more than double that reported in a white American population of the same age group, and with similar income and education level (Montour & Macaulay, 1985, p. 1221). This study was later extended to survey adults with diabetes for clinical characteristics related to vascular disease. They found that 63 percent of people surveyed had macrovascular disease (any of ischemic heart disease, cerebrovascular disease, or peripheral vascular disease). This was over six times the rate of macrovascular disease than among a sample of Kahnawakero:non without diabetes and matched for age and gender (Macaulay, Montour, & Adelson, 1988). Other findings from this study revealed that half of the total study population smoked or had smoked, and both groups had a high mean body mass.<sup>35</sup> 82 percent of the diabetic men, 90 percent of

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<sup>35</sup> The *Canadian Guidelines for Body Weight Classification in Adults* defines body mass index (BMI) as an index of weight-to-height (kg/m<sup>2</sup>). The BMI is considered the most widely investigated and most useful

the diabetic women, 70 percent of the nondiabetic men and 78 percent of the nondiabetic women were clinically obese (Macaulay et al., 1988).

A later study revealed that there were differences between Kahnawakero:non and diabetics in other native communities. The mean age at onset of diabetes among Kahnawakero:non at 59 years was ten years higher than that observed in Oneida Iroquois of Ontario, and the rates of macrovascular disease among diabetic subjects in Kahnawake were higher than those found among Cree / Ojibwa in Ontario and Manitoba (Montour, Macaulay, & Adelson, 1989). Further to this, in the late eighties a study by an anthropologist revealed that, while nearly all participants in the study fell above the standards of obesity, diabetic Kahnawakero:non did not show a propensity to truncal obesity (Adelson, 1987). This was in contrast to the view that associated type 2 diabetes (NIDDM at the time) with centripetal patterning of subcutaneous fat. Thus the commonly understood association of higher risk for diabetes with centripetal patterning of subcutaneous fat was not found in Kahnawake. This would have furthered the understanding that diabetes is not experienced in the same way across aboriginal populations in Canada.

Information from these studies was presented back to the community by two family physicians. The number of people who went for diabetes screening at KMHC subsequently increased, and dissemination of findings also led to pressure for change in the community. Ultimately, after returning the research results to the community the physicians were requested by community elders to develop a diabetes prevention program that would specifically focus on young children (Montour & Macaulay, 1988). The

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indicator of health problems that are associated with being under and overweight (see [http://www.hc-sc.gc.ca/fn-an/nutrition/weights-poids/guide-ld-adult/index\\_e.html](http://www.hc-sc.gc.ca/fn-an/nutrition/weights-poids/guide-ld-adult/index_e.html)).

Kahnawake Schools Diabetes Prevention Program (KSDPP) was the result of this request and has since been recognized as a successful diabetes prevention program with a primary mode of governance based in Kanien'kehaka cultural values of participatory democracy and shared decision-making (Cargo et al., 2003).<sup>36</sup>

A recent community study reveals that Kahnawake incidence rates now parallel national rates. The study further reveals that Kahnawake prevalence rates are approximately two times higher than rates in the general Canadian population, which is much lower compared with most other aboriginal communities in Canada (many of which have rates three to five times that of the general population). One can postulate that improved education, increased employment, programs for diabetes education and prevention and other health promotion efforts all may have influenced lower rates of type 2 diabetes in Kahnawake. I also suggest that lower rates of type 2 diabetes in Kahnawake may be related to the community's assertion of governance over the reserve, and a reflection of the extent to which self governance and cultural continuity positively affect health (cf. Chandler, 2003).

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<sup>36</sup> The key objectives of KSDPP are to promote active living, to promote eating in balance and to raise diabetes awareness through school- and community-based interventions "congruent with native culture and learning styles." The KSDPP intervention program uses a holistic approach based on living in balance (i.e., being well in mind, body, emotion and spirit) and caring for future generations. This is reflected in KSDPP's vision statement (see [www.ksdpp.org](http://www.ksdpp.org)):

All Kahnawakero:non are in excellent health. Diabetes no longer exists. All the children and adults eat healthily at all meals and are physically active daily. The children are actively supported by their parents and family who provide nutritious foods obtainable from family gardens, local food distributors and the natural environment. The schools as well as community organizations, maintain programs and policy that reflect and reinforce healthy eating habits and daily physical activity. There are a variety of physical activities for all people offered at a wide range of recreational facilities in the community. All people accept the responsibility to cooperatively maintain a well community for the future Seven Generations.

## 5. Perceptions of Type 2 Diabetes in Kahnawake

### Introduction

I have divided this chapter into four main sections.<sup>37</sup> The first section explores Kahnawakero:nons' perceptions of the diagnostic process. That is, how conversation partners narrate the experience of being diagnosed with type 2 diabetes. The second section discusses Kahnawakero:nons' perceptions of the implications of being on the "borderline." Here I discuss the ways in which people situate themselves between the normal and the pathological. The third section discusses fear as arising from being "surrounded by diabetics," and the ways in which people link having diabetes to broader understandings of diabetes among Kahnawakero:non and indigenous populations. The fourth section discusses "being surrounded" or encroached upon as a community, as linked to collective levels of community stress and "bitterness." This section travels "beyond sweet blood" in that it seeks to illustrate how people perceive type 2 diabetes to be related to factors largely outside of their control.

Nearly all conversation partners referred to the experience of having type 2 diabetes as "having sugar," which may be related to the way in which the term "diabetes" translates from Kanienkeha. While conversation partners offered a few variations in the

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<sup>37</sup> While these sections are used conceptually, a single narrative often overlaps across more than one section and people's experiences of type 2 diabetes are likely more complex than what I have presented here. Moreover, each experience of diabetes is unique, and while insightful, these narratives represent only a partial view among Kahnawakero:non living with type 2 diabetes of what it means to live with type 2 diabetes. Nevertheless, thematic analysis provides a context in which to illustrate subjective perceptions of type 2 diabetes and, moreover, the implications for biomedical understandings of the disease. I have in some cases quoted at length to avoid editing out important meaning from the narratives. In order to keep the narratives as intact as possible, I have also, at times, included myself as the person asking questions.

translation, the Kanienkeha term *teiionekwenhsatsikhe:tare*<sup>38</sup> was repeated as the most accurate way of describing diabetes. *Teiionekwenhsatsikhe:tare* translates as the “sugar is on top of the blood.”<sup>39</sup> When people referred to diabetes as “having sugar,” then, given that some conversation partners were Kanienkeha speakers, they may have been directly translating from the Kanienkeha word *teiionekwenhsatsikhe:tare*. One conversation partner explained to me that *teiionekwenhsatsikhe:tare* is when “sugar has been added to the blood, like a layer of cake has been added onto another layer of cake.” This implies that in order to get rid of diabetes, one must remove the sugar that is *on* the blood. This understanding is in contrast to biomedical perceptions of diabetes which affirm that diabetes results from high levels of sugar *in* the blood. In the context of conversation partners’ perceptions of type 2 diabetes, *teiionekwenhsatsikhe:tare* is also symbolic in that the word suggests that because sugar has been added to the blood and not mixed with it, diabetes can be treated and prevented upon removal of the sugar that is on top of the blood. Conversation partners’ perceptions of type 2 diabetes suggest that to remove sugar from the surface of the blood, it is first necessary to know where the sugar came from, and how and why sugar settled *on top of* the blood of Kahnawakero:non specifically.

### **“Every Indian’s a Diabetic that Walks into that Clinic”**

They just told me one day that I am diabetic now. So now I have a new doctor. On my last visit she asked me, “Who told you you have diabetes?” So I told her. She says, “I don’t see it.”

- Conversation partner

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<sup>38</sup> Pronounced, approximately, “dey-oh-ney-gwen-sad-si-gah-da-re.”

<sup>39</sup> Although some say that *teiionekwenhsatsikhe:tare* means “our blood is too sweet.” I was told however that the translation “our blood is too sweet” is idiomatically representative of the intent, but linguistically away from the Mohawk thinking. “Sugar is on top of the blood” was therefore explained to me as a translation closer to the Mohawk thinking.

People started getting diagnosed as diabetic a little at a time.

- Conversation partner

Anthropologists have not yet encouraged discussion of how people living with type 2 diabetes negotiate the identity of “being diabetic” – how people both identify with and challenge this label. Anthropologists have instead focused on how individuals negotiate their identity in the context of diabetes (e.g., Abonyi, 2001), neglecting to consider how people actually contest the ways in which diabetes itself is defined. Yet given that conversation partners repeatedly questioned the extent to which blood is “sweet enough” before it is typed as diabetic, it would be misleading to discuss diabetes among Kahnawakero:non living with the disease without considering how people interpret its diagnosis – how people interpret the ways in which sugar is on top of the blood.

Conversation partners identified physicians as those who define the cut-off point for diabetes diagnoses. Their discussions of the point at which blood is “sweet enough” indicated how physicians at KMHC diagnose diabetes among natives and among Kahnawakero:non specifically. Conversation partners therefore associated the high rates of diabetes among Kahnawakero:non with being native (i.e., that those of aboriginal ancestry are considered to be at high risk for diabetes). The perception was that because natives are considered at high risk for diabetes, doctors were inclined to medically “make” diabetes among Kahnawakero:non. In this sense, four conversation partners proposed that the reason so many people in Kahnawake have diabetes was, in part, a result of the way diabetes is being diagnosed in the community. In the words of one woman:

**Conversation partner:** They say nowadays every Indian's a diabetic that walks into that clinic. And some of them [Kahnawakero:non] don't even like going to the clinic because of that. They know they should go. They're not going for diabetes. They say, "Oh I'm going to walk in and they're going to tell me I'm a diabetic." So that's another thing, in the last five to seven years you keep hearing them call natives diabetics . . . What are they doing about it? Like my aunts, they say "We're not going there [KMHC] even if we're sick. They're going to tell us we're diabetic even if we're not going for that." That's what they say, a lot of the elders, they say "I don't want to go there." They eventually go, but they say "If we go, right away they're going to tell us [that we're diabetic] even if we're not!" This is what the elders' attitude is – everybody's diabetic they say now. They say, "If you go in for your foot, you're diabetic. If you go in for a cough, you're diabetic." Some of them say, "I only have to go there if I think I have to die, I'm not going there until I have to go there." Maybe somebody should be looking at these doctors and saying – are people really diabetic? Is there a big history? What are the results that they're given? If somebody is 6.9 are they being treated as diabetic? If they're 7.2 are they really high range? Is there anyone doing that, looking at those things? You're giving everybody that's 6.9, you're putting them all on medicine, but maybe somebody else is only putting them on when they're in the sevens. Is there a difference? I even ask my doctor, "if you keep telling me I'm in the high range, how come you keep putting me on it [medication]?" He said, "well sometimes you're above the high range." I said "how many times?" [He said] "Enough times to be worried about." I question that.

**Shannon:** Do you think it has anything to do with doctors' ideas about natives being diabetic?

**Conversation partner:** Ya, that's what I think . . . Maybe they come in with that mentality . . . Maybe some come in with the philosophy that, "Ya, they [natives] are [diabetic]. It's going up. Look for it." Some are coming in with that philosophy and hopefully it will help control it [diabetes] but some just say, "Well you're going on it [medication], [you're] a little high, you're diabetic." I wonder, I question it.

Conversation partners suggested that while current diagnostic criteria may help to "control" levels of diabetes in Kahnawake, understandings of high rates of diabetes in the aboriginal population have led physicians to believe that "every Indian's a diabetic," and so, conversation partners said, they are "looking" for diabetes among natives.

Moreover, conversation partners questioned the point at which one *becomes* diabetic; the point at which blood is too sweet. Conversation partners went back and

forth, recognizing the seriousness of high blood sugar yet questioning how blood, as something so fluid, can be strictly numerically defined as normal or pathological. They used the language of biomedicine to question at what point blood is “sweet enough.” It is worth remembering that those who tested at 6.9 mmol/L (as noted by the woman above) would not have been clinically diagnosed with diabetes according to the 1998 CDA diagnostic criteria, when the FPG diagnostic level was 7.8 mmol/L. They would, however, be close to, or clinically diagnosed with diabetes according to current criteria. Not one conversation partner talked about the 1998 change in diabetes diagnostic criteria, yet their narratives exemplify the ways in which they attempt to grapple with a diagnosis said to be based strictly on levels of sugar in the blood, but that as a biomedical category has changed over time.

The process of becoming diabetic became even more complex when conversation partners discussed how diagnostic procedures may vary from one doctor to another. They felt that not all doctors strictly follow the CDA diagnostic criteria, and that some “treat people as diabetic” if their FPG is, for example, 6.9 rather than 7.0 mmol/L. This point was further expanded when I asked whether they thought that accessing health services outside Kahnawake would result in different outcomes or fewer diagnoses of diabetes among Kahnawakero:non, to which one woman responded:

I wonder if we [Kahnawakero:non] were going to the outside to white doctors if it would be different. Like not the reserve doctors. A lot of us say that we wonder why, when we go outside to see someone else [e.g., a doctor in Montreal], they say, “Well how come you’re on medicine?”

Would doctors in a Montreal clinic likewise diagnose Kahnawakero:non as diabetic the same way as doctors working in Kahnawake? They might not, because not every doctor screens for type 2 diabetes in the exact same way. Thus conversation partners’ skepticism

about diagnosis relates back to their perception that those who go for testing at KMHC are being diagnosed as diabetic even if they are not really diabetic, because “every Indian’s a diabetic that walks into that clinic.” This belief could actually arise out of conversation partners’ experience of variation in the ways in which physicians come to screen for and address type 2 diabetes.

Moreover, knowledge about at risk populations directly influences diabetes testing procedures for individual patients. Frequent testing for diabetes may therefore be a reason for why some conversation partners perceived doctors to be willing to put Kahnawakero:non on medication, if testing does reveal high levels of sugar in the blood. According to the CDA, many Kahnawakero:non have “additional risk factors” for type 2 diabetes. For example, Kahnawakero:non over the age of 40 would be considered to have more than one risk factor (i.e., being over 40 and aboriginal equals two risk factors), and thus for Kahnawakero:non over the age of 40 there is reason for more frequent testing. That is, more frequently than every three years otherwise recommended for non-aboriginals over the age of 40 and with no additional risk factors. This suggests that KMHC doctors *are* “looking” for diabetes among Kahnawakero:non, based on guidelines outlined by the CDA.

Conversation partners’ perceptions of the diagnostic process reveal that they do not simply accept the diabetes diagnostic classification. That they questioned the point at which one is typed as diabetic, and moreover how they fall into the category of an “at risk” population, indicates how ideas of normalcy and pathology are embodied and believed (or distrusted). Such questioning may reveal peoples’ resistance to biomedical definitions of disease (Garro, 1995). These narratives also challenge received wisdom

about diabetes as a disease, and the ways in which diabetes is brought to exist in the bodies of Kahnawakero:non. In this sense, conversation partners offered a critical examination of the “social conditions of knowledge production” (A. Young, 1982); they questioned how medical facts are predetermined and produced through clinics, clinical practice guidelines, research, etc., and how these facts apply to them. Their reference to “having sugar” further puts to question received wisdom about diabetes – how can sugar can be *in* the blood, when, according to *teiionekwenhsatsikhe:tare*, it is *on top* of it?

### **Being on the “Borderline”**

They put you on [medication] when you’re on that borderline. How many of us are on the borderline?

- Conversation partner

Conversation partners situated themselves between the normal and the pathological through discussion of being on the “borderline.” The term “borderline diabetes” was used by conversation partners to refer to having been in the “high range” prior to being diagnosed with diabetes, that is, the extent to which their blood sugar levels were pushing 7.0 mmol/L. Understandings of being on the borderline therefore related to how people spoke about the onset of diabetes and subsequent embodiment of the diagnosis, and almost all conversation partners referred to having at one point been “borderline.” Some conversation partners reported that they were told they had been on the border for many years prior to actual diagnosis, but that they had done nothing to prevent against progressing to diabetes. For example, they did not make lifestyle modifications as suggested by their doctor, which resulted in their blood sugar levels rising and their eventually having to be put on medication. That some conversation partners did not make lifestyle changes upon first being told they were “on the border”

could be related to how people interpret what it means to be borderline diabetic. These understandings may actually clash with reasoning behind why physicians use this term to relate the condition of impaired fasting glucose (IFG) or impaired glucose tolerance (IGT) to their patients.

I was told by one physician that being borderline diabetic is like being borderline pregnant – it does not exist. However, some physicians at KMHC were reported to use this term conceptually when speaking with their patients because patients are thought to be able to better understand what is meant by “borderline” rather than “impaired fasting glucose.” Telling patients that they are borderline diabetic is meant to portray to them a serious condition for which they need to take great caution, so as not to progress to diabetes (Interview, Physician, October 18, 2005). Few conversation partners, however, described being “borderline” in this manner. Rather, some interpreted it as an inevitable rite of passage towards type 2 diabetes, while others saw it as a place that they could revert back to. One conversation partner suggested that she may have already reverted back to the borderline.

Having at one point been borderline diabetic was discussed in relation to current experiences of diabetes, and what it meant to be diabetic, yet still often have sugars that were “normal.” Having normal blood sugar levels over the course of daily testing provoked questioning of whether or not one may have reverted back to being on the borderline. Moreover, that some days you could have normal blood sugars and the next day have high blood sugars also somewhat discredited the diagnosis of diabetes, which is based strictly on a specific level of sugar in the blood. The occurrence of normal blood sugars directly influenced the extent to which people consistently tested their blood, and,

in four instances, people had chosen to cease daily blood glucose testing because every time they tested, their sugars were “normal” (i.e.,  $<6.1$  mmol/L). As one man stated: “It’s [blood sugar] pretty much stabilized, so I don’t need to check it everyday because it’s always around the same number.” Testing was therefore seen as an invasive procedure and a waste of time when the results every time revealed blood sugar levels that were either “borderline” or “normal.”

What it meant to be on the borderline of having diabetes moreover presented some confusion when conversation partners reflected on when they were first diagnosed with diabetes. Reflecting back sometimes one year and sometimes twenty years, conversation partners faltered on the point at which they were diagnosed with diabetes based on understandings of having at one point been on the borderline. Moreover, medication played a powerful role in influencing the ways in which people identified themselves with diabetes, and being put on medication seemed to be the point at which conversation partners identified with the title of “being diabetic.” As one man stated, “I never had no problem with anything, just when I retired. [At age] 67 to 68, they noticed that I was startin’ to get sugar - borderline, they call it. So it kept [going] up until about 70 and then I started taking pills.” In speaking about the point at which one was diagnosed with diabetes, it was sometimes difficult to determine if a conversation partner was speaking about borderline diabetes (i.e., IFG or IGT) or clinically diagnosed diabetes.

Often through medication prescribed by physicians at KMHC, individuals attached themselves to the specific identity of “being diabetic.” Moreover, understandings of being in the “high range” and being put on medication further linked

back to understandings of the medical “making” of diabetes in Kahnawake. In reference to being prescribed medication by her doctor at KMHC, one woman stated:

I just told him, “I know what kind of doctor you are, you keep telling me I’m in the high range and now you’re putting me on medicine.” And he said “Oh, I don’t get anything out of this,” and I said, “Sure you do, that’s more statistics that how many people are diabetic in Kahnawake.” He just said, “Well sometimes you’re over.” So I said, “If you’re over once or twice then you’re considered diabetic?” He just said, “Well with your weight gain and that, but I’d rather put you on medicine.” And I said, “Well what if I don’t take it?” “It’s up to you,” he said. So I took it. What can I do? I guess it can’t harm me if I take it. Hope not . . . I guess they do that here if you’re in the high-normal range – they put you on medicine just so you don’t develop it. I guess which is good in the long run. But what if you’re in the high range all the time and you don’t go over?

While recognizing that medicine acts as a preventative measure for the progression of diabetes-related complications, conversation partners asked: If my blood sugar is for the most part in the normal range and only sometimes high, then at what point did I *become* diabetic? Moreover, what if your blood sugar levels are in the high range all the time but don’t “go over?” In some cases, as described above, conversation partners related doctors’ willingness to put people on diabetes-related medication to having more statistics about how many people in Kahnawake are diabetic. One woman associated being put on medication with being a “number”:

**Shannon:** Why do you think so many people in Kahnawake have diabetes?

**Conversation partner:** I think the number is exaggerated. I think if you look at the numbers on the borderline that are being diagnosed, if you look at that number, if they’re different. If you exclude the group that’s on that borderline I wonder what the number would actually be. Are we just all given that medicine to prevent, or to just be a number?

The prevalence of type 2 diabetes in Kahnawake was questioned through perceptions of what it means to be on the borderline.

These insights illustrate the ways in which the experience of diabetes raises the question of exactly the point at which diabetes comes to be in – or on top of – the blood of individuals. People asked - At what point is my blood “sweet enough?” Borderline diabetes, as an in-between stage, creates a grey area between what is normal and what is pathological. Those living on the borderline therefore occupy a liminal state, and being in this state implies that while people are not yet diabetic, they are also not “healthy,” because their blood sugars are considered impaired or abnormal. High levels of sugar in the blood demarcate peoples’ bodies as abnormal, yet being able to still have normal blood sugar levels, even if “on the border,” also implies that there remains a certain normalcy within the pathological. For some conversation partners, the perception was that as much as the body’s sugars rise and fall, diabetes itself may weave its way in and out of the body, moving back and forth across the “borderline.”

That conversation partners identified with being diabetic at the point of taking medicine also tells an interesting story of how biomedicine interacts with the experience of diabetes. While testing was in some cases forfeited, medication was reportedly taken regularly even if conversation partners thought they may have reverted back to the borderline. While conversation partners tell a story of diabetes that challenges the point at which we can begin to understand diabetes as a disease entity, taking prescribed medication, even if they doubted their diagnosis, suggests the power of biomedicine. That biomedical definitions of health and disease are linked to larger structures of authority and power is evident in the ways in which people regulate their behaviour according to treatment strategies involving pharmaceutical intervention. It is even more evident when people report giving up on strategies based on monitoring blood sugars, a balanced diet

and regular exercise in exchange for medication. That individuals continue to take medication even if they question their doctor's advice and / or diagnosis is further evidence of the extent to which they learn to govern themselves and their bodies. It also suggests that the relationship between patient and physician is more than just a technical interaction, but is in part a reinforcement of authority of the physician's advice over the patient's beliefs about the illness experience (Taussig, 1980). By questioning the point at which they become diabetic, conversation partners to some extent invalidated doctors' diagnoses. However, they tended to re-validate this diagnosis by taking prescribed medication.

### **A Pervasive Fear of Diabetes**

I'm surrounded by diabetics.

- Conversation partner

It's [diabetes] so common now, every second person or every third person you talk to and they're diabetic.

- Conversation partner

Being aware of the prevalence of type 2 diabetes in Kahnawake – through education at KMHC and KSDPP and through interactions with family and friends – was reported by conversation partners to create a pervasive fear at individual and collective levels. They suggested that fear arose from feelings of being “surrounded by diabetics,” because everywhere around them, Kahnawakero:non were constantly reminded of what is to come. Moreover, conversation partners were aware that they were part of a population at high risk for type 2 diabetes, and their narratives therefore often situated people as both aboriginal *and* diabetic.

While difficult to witness the suffering of others, the fear evoked in people as a result of being “surrounded by diabetics” and having seen others suffer, was on the one hand considered by conversation partners an important factor for controlling diabetes and for preventing future diabetes-related complications. One woman described her experience of witnessing family members suffer from diabetes-related complications:

I have a brother and sister that died from diabetes, one went blind and his kidney went and he had to go on dialysis . . . . My brother died from a heart attack, and then my sister had to have her legs amputated. She died from it. So it was kind of a scary thing when that happened. So when you look at that, you say, “Well geez, I don’t want to go through the same thing.” So it’s all these things that you have to bear in mind when you’re a diabetic so that you don’t abuse yourself and end up getting amputated. At my age now, I’d still like to be around for a while.

Through witnessing the suffering of others, often close family members, conversation partners gained motivation towards secondary prevention of type 2 diabetes.

Conversation partners also said that the harsher affects of diabetes were always in the back of their mind. People were afraid of progressing to physical complications, and fear served as motivation for secondary prevention. As one man stated:

I know the hard-hitting stuff about . . . the harsher realities of diabetes. Like eventually it will affect your eyes, your extremities, you might end up getting gangrene. That stuff was part of the initial awareness that I was put through [at KMHC], and it’s there – it’s in the back of my mind. I mean I know full well that if I do go out of control, that’s probably where I’m headed. So that’s sort of a big turn for me in the sense that I have to make a choice. I can choose to take the advice, eat healthy, exercise, or fall back into the old habits and I’ll be okay for how long? Something in my body goes wrong. I have another heart attack or one of the other complications with diabetes. That’s always in the back of my mind.

Conversation partners said they learned about the reality of diabetes through education at KMHC and KSDPP, and through seeing others suffer from diabetes-related complications. Knowledge about what diabetes can do to the body was repeatedly

reported by conversation partners as a “deterrent,” influencing how people decided to take control of their own health.

Moreover, while all conversation partners were taking some form of diabetes-related medication, many expressed fear at the thought of having to take insulin (except for those already taking insulin) because it was associated with the end stages of the disease. Most importantly, conversation partners associated insulin with loss of personal freedom which was in many cases already considered limited as a result of diabetes. Insulin was perceived as ruling people and staying off insulin was symbolic of the control conversation partners still had over their bodies and their lives. Thus they noted, for example, that they “have to work harder to stay away from insulin.” They considered the loss of freedom associated with having to go on insulin a motivating factor to control sugar levels and prevent future diabetes-related complications.

Conversation partners also fused their fear of diabetes with perceptions of genetic and hereditary susceptibility to the disease, perceptions which in many cases related back to “being Indian.” Genetic explanations of the disease were incorporated into views of diabetes that were at once biological, social and cultural in nature (cf. Weiner, 2001), and the terms “hereditary” and “genetic” were used simultaneously to describe why type 2 diabetes has affected individuals and Kahnawakero:non collectively. For example, for some conversation partners, the fact of being aboriginal provoked fear because this automatically meant that they, their families and the community were at risk of developing type 2 diabetes and / or physical complications. In some cases conversation partners thought that getting type 2 diabetes was inevitable, precisely because they were aboriginal and because diabetes ran in their family. While they expressed fear and

concern for their children and for the future of the community, type 2 diabetes was also considered a “fact of life,” and “just another thing you gotta live with.” One woman even suggested that there was “no place to hide” from the disease:

Diabetes is just like an everyday thing for me because it runs throughout my whole family. I lost my mother, I lost my father, I lost my sister, and I lost my husband, all to diabetes, or complications thereof . . . . There was nothing that I could have done to stop it . . . . What are you gonna do? If it runs in your family, it runs in your family.

Conversation partners who thought that genetics and / or heredity were the main cause of type 2 diabetes were more likely to think that they could not have prevented the onset of type 2 diabetes. The onset of type 2 diabetes may therefore actually represent a lack of control – for some conversation partners, they could not have prevented the onset of type 2 diabetes in the first place.

While clearly recognizing that being aboriginal was a risk factor for type 2 diabetes, conversation partners also alternatively tied the cause of their diabetes to lifestyle factors such as exercise or “being lazy,” food intake and poor eating habits, being overweight and personal stress levels – all things thought to be within one’s control. They therefore attributed their diabetes to being a member of a high risk group *and* to their own responsibility for their personal health. In this sense, fear of acquiring type 2 diabetes and progressing to physical complications was related to fear of losing control of the self, of one’s lifestyle and therefore on one’s blood sugars:

**Shannon:** What do you think are the causes of type 2 diabetes?

**Conversation partner:** First of all I guess as Mohawk people we have this propensity towards it [type 2 diabetes]. In the first place, because, I guess its historical background where we had that efficiency gene, where we would bulk up in the summer . . . over the winter months it would be lean times so it was accepted then that you would bulk up, and in the winter months your body would use up the storage of fat. But, my younger days I did construction, I did iron work,

and I used to burn off the calories. As was the case with a lot of men, when I left iron work . . . I didn't abandon my eating habits. Sometimes I wouldn't eat breakfast at all, pick up a fast food lunch, and then a big meal for supper, plus a few beers . . . . So that all led to why [the onset of diabetes]. I'd say . . . 80 percent of it is lifestyle, 20 percent of it is probably heredity - the genes that I was given. That's the way I see a lot of it. I know that it's preventable. Type 2 is probably preventable in 90 percent of the cases.

Type 2 diabetes was considered preventable when associated for the most part with lifestyle choices and responsibility for personal health, and only partially to "the genes that were given."

Feelings of being "surrounded by diabetics" – through seeing people suffer from diabetes-related complications and through interpretations of genetics and heredity – implies that while doctors may be "looking" for diabetes among Kahnawakero:non, based on clinical practice guidelines, so too might Kahnawakero:non themselves. At least, it was evident through the stories of those living with diabetes that fear of acquiring type 2 diabetes has threaded its way into the daily lives of many Kahnawakero:non. This was suggested through discussion with some conversation partners who mentioned that their children were "paranoid about getting diabetes" and therefore they were "always testing themselves." Knowledge about the high prevalence of type 2 diabetes in Kahnawake therefore seems to have contributed to an expectation of diabetes – some Kahnawakero:non may be expecting, or even constructing their futures to include type 2 diabetes.

Nevertheless, the process by which diabetes has become recognized as a community health issue in Kahnawake has resulted in people speaking openly about diabetes in the community, even if – or perhaps because – diabetes is associated with fear. Conversation partners noted, for example, that, "since the diabetes prevention

[KSDPP] has been around, people are more aware of what is happening in this community. When you hear about statistics, it kind of makes you think.” Many times over, conversation partners noted that diabetes was something that people never used to talk about. As one man stated, people used to “feel very threatened to speak about diabetes” and therefore it was “hidden in the closet” for many years. Though awareness of diabetes as a community health issue seems to provoke fear in people, that diabetes has come out of “the closet” for people to discuss was considered by all conversation partners as positive because it has stimulated an active response to the disease at a collective level. Diabetes-related complications were discussed as reason to be afraid of what is to come for oneself, but also for the Seventh Generation. That younger people in Kahnawake are being diagnosed with type 2 diabetes was deplored because it represented the extent to which type 2 diabetes is affecting everyone, most importantly, the future of the community. Conversation partners therefore affirmed that it is the responsibility of everyone living with diabetes to educate others about the disease, with the intention to prevent its onset in future generations. As one man stated, “We all have a role to play. We all have a responsibility for the whole community – how do we, as the ones living with diabetes today, leave a stronger message behind?”

### **“We’ve Been Surrounded”**

[We] don’t like the idea that we know darn well that a thing like that [Oka crisis] can happen again tomorrow. We don’t like the idea, but we know it can. So you gotta get the mindset that the possibility is there. I don’t want to see it again, nobody wants to see it again, but the possibility is there. It all depends on the attitude of the governments and stuff like that.

- Conversation partner

[W]e don’t do the things that our ancestors do anymore cuz we’ve been surrounded.

- Conversation partner

It's a constant battle to keep it [blood sugar] at that [normal] level. Sometimes it's not just the food that you eat – it's everything around you.

- Conversation partner

While conversation partners attributed lifestyle factors such as poor diet, being overweight and lack of exercise to the onset of type 2 diabetes, they also suggested that high rates of diabetes exist among Kahnawakero:non collectively because Kahnawake has been “surrounded.” Being surrounded meant that Kahnawakero:non have been encroached upon by Canada, for example in the form of land expropriation. Being surrounded was also associated with community and federal policies and laws. Conversation partners proposed that being surrounded leads to collective stress in Kahnawake, and seven conversation partners suggested that prevalence of type 2 diabetes in Kahnawake is therefore the result of stress resulting from being surrounded.

Some conversation partners also related the prevalence of type 2 diabetes in Kahnawake to “bitterness.” They suggested that some Kahnawakero:non were bitter or resentful about being encroached upon or “surrounded.” Bitterness was therefore related to spiritual imbalance, and one conversation partner suggested that in Kahnawake peoples' spirits are embittered, and that their bodies are overcompensating for spiritual bitterness by making sugar. Another conversation partner further stated that in order to prevent against type 2 diabetes, you have to “get the bitterness out of you!” Getting rid of bitterness was a matter of “letting go” of things that had happened to Kahnawakero:non in the past. People therefore have to “let go” of the stress caused by being surrounded. Not everyone felt this way, however, and reference by one conversation partner to the

sight of the Seaway as “making my blood boil” is a reminder that for some letting go of the past is not easy, and possibly not even a desirable process.

The extent to which type 2 diabetes was perceived to be related to collective stress or “bitterness” varied from individual to individual, and stress is obviously not at the root of every case of diabetes. Nonetheless, the issues raised by conversation partners are supported by studies which illustrate that stress can actually affect blood glucose concentration (e.g., Peyrot, McMurry, & Kruger, 1999). Thus while biomedical diagnosis frames an understanding of diabetes as controlled independently of the circumstances in which individuals are situated, for Kahnawakero:n perceptions of diabetes were often directly linked to community history and the position of Kahnawake within Canadian society.

Conversation partners suggested that stress, fear, suspicion, cautiousness and the need to “hang onto culture” characterized a collective consciousness in Kahnawake. They attributed these factors to the collective sweetening of blood. One man described why he thought type 2 diabetes is so prevalent in Kahnawake:

**Shannon:** Why do you think so many people in Kahnawake have type 2 diabetes?

**Conversation partner:** I think there’s no doubt that it’s been a struggle for the community to survive as a distinct Mohawk community in spite of all of the attempts by the dominant society to assimilate us into their mainstream. You just have to look back at some of the policies by the federal and provincial governments and the way that they treated us and you can see that it’s caused us to become not only stressed but also suspicious, somewhat fearful, cautious. I mean when someone lives under those conditions always it’s bound to produce those kinds of reactions. I guess [it is] the internal body chemicals that would lead to what the researchers are saying causes stress. We don’t know what the next move of the government is going to be in terms of our financing, our resources. They’re always talking about cutting back, and for a lot of people that’s a worrisome thing. The fact that we’re living – there always seems to be a constant need for the dominant society to take as much as they can from us in terms of land. Or even worse, not allow us the opportunities to become self-sufficient . . . .

People live here. We're trying to survive. Hang on to our culture . . . . Trying to maintain a decent lifestyle when we don't know when the other shoe is gonna drop. When another crisis is gonna happen. Like in '90 [Oka crisis]. When the government is gonna announce that it's gonna try to chop off another hunk of land for whatever development project, or some other big major change in policy. I know an example. The government initially through the Indian Act at one point disallowed that if any Indian woman married a non-Indian man, she lost her rights. Now all of a sudden they realized, they're the leaders in human rights, they realized that policy was a big mistake, so they reversed it. Now they're saying that all Indian women and their children, under Bill C-31, should be able to come back and benefit on the reserve. However, they didn't give any resources back to the communities to be able to provide services for the influx of people coming back. So that's creating stress and internally it creates stress where people are saying we got all these people that we don't even know that are coming back into the community, and all of a sudden when we ask for something there's no money for that.

Conversation partners referred to always "bracing" for what the government was going to do next. They reported that Kahnawakero:non were therefore constantly under stress, as one man stated:

**Conversation partner:** It's a very stressful reserve whether we agree to it or not, because so many things are happening. Everybody's under stress. Stress is one of the worst components to develop diabetes.

**Shannon:** Why is there so much stress?

**Conversation partner:** It's just cuz everything that's going around. Even with the government and everything. We're constantly under stress cuz we don't know what the governments are gonna do to us. We don't know what's gonna happen next. So we're always on alert. Your mind never gets a chance to relax.

That people could not "relax" their minds was related to knowing that, for example, another Oka crisis could happen any day or that the self-sufficiency of Kahnawake could be eroded.

Conversation partners specifically recalled the Oka crisis as a source of collective stress for Kahnawakero:non. The Oka crisis was considered yet another way in which Kahnawake was being or had been surrounded. Conversation partners suggested that the

Oka crisis increased peoples' levels of stress, and increased stress caused sugars to "go up." They also recalled that food and medicine were hard to come by in Kahnawake during the Oka crisis. Many relied on food rations during Oka, and while people living with diabetes were given priority for fresh fruits and vegetables, three conversation partners said that they remember feeling guilty going first for the food. They therefore did not prioritize themselves at the time. Crossing over the "borderline" into being diagnosed with type 2 diabetes, and going from no medication to being put on diabetes-related medication was in one case attributed specifically to pre-and post Oka. Moreover, the memory of Oka was associated with present day individual and collective levels of stress in Kahnawake. Conversation partners associated the continued broadcasting of media footage of the Oka crisis each year with bringing emotions back for people, and even for children who did not actually experience the event. Conversation partners said that stories and media coverage brought young people back to the event, and that introducing them to the memory of Oka affects their current health. Thus memories of the Oka crisis were considered by conversation partners to lead to high prevalence of type 2 diabetes among Kahnawakero:non, even among young people.

While conversation partners thought that federal policy and "bracing" for what is going to happen next was related to collective stress in Kahnawake, collective stress was also perceived to arise from Kahnawake's own laws and policies. Conversation partners suggested, for example, that the *Kahnawake Law on Membership* is to some extent linked to high rates of type 2 diabetes in the community. That people were concerned about losing their place in the community's membership was considered stressful – a constant stress that could lead to type 2 diabetes. In addition, membership issues intertwined with

conversation partners' perceptions of genetic and family inheritance of type 2 diabetes. Marrying-in and segregation of Kahnawakero:non from the "outside" were therefore perceived to progressively genetically "weaken" the community. One woman described how the *Kahnawake Law on Membership* is related to diabetes in the community:

**Shannon:** How do you think diabetes is related to the membership law?

**Conversation partner:** It's part of the problem, it is. I think that's part of the problem. If people marry from the same – what's the result? Say they, if they went out [of Kahnawake]. If they didn't want to marry non-native, if they went out and married a native maybe from another community, there could be getting away from marrying within your own [family] here. But then if their [health] problem is the same thing out in the other [community] – because diabetes, the statistics say it's in all the native communities!

Conversation partners suggested that the *Kahnawake Law on Membership* was linked to "weakening" the health of Kahnawakero:non because it governs people's decision to "marry-in." Conversation partners therefore suggested that blood was becoming increasingly sweet in Kahnawake as a result of how Kahnawakero:non are situated in, and to a large extent governed by both community and federal policy. Yet even marrying and having children with someone from another native community was not considered to prevent against passing diabetes to future generations because, statistically speaking, diabetes runs through – or sugar is *on top of* - the blood of *all* natives.

Being "surrounded" was also associated with the extent to which food is "pure" or not. "Pure" food was directly related to community gardens, and conversation partners said that people do not plant gardens anymore because there is not enough space leftover for gardens in Kahnawake. In some cases, people attributed the lack of space to the construction of the Seaway (cf. Phillips, 2000). Some conversation partners therefore thought that type 2 diabetes was the body's reaction to store-bought food, or food that is

no longer pure. “Pure food from the garden,” or food grown without chemicals and fertilizers, was associated with the years before diabetes became prevalent in Kahnawake, as one man stated:

**Conversation partner:** It [type 2 diabetes] could be prevented, sure. Today, the way I look at it, they got so much stuff in the fertilizers in the plants that they grow today. Long time ago they didn’t have fertilizers. We had our own garden in the yard, big gardens back when they had big land. [We would] plant potatoes and keep it for the winter. We had a root cellar, put all the food in there. Turnips and carrots, potatoes, put them away for the winter. That’s what we ate. Boil them, everything was boiled. Today they got these fertilizers. You see the big tractors with the big tanks, so they grow fast and big, that’s killing everybody.

**Shannon:** The chemicals?

**Conversation partner:** Ya. Too many chemicals in the food. That’s the whole problem. It’s not like only here [in Kahnawake], it’s all over the place . . . . We’re lucky, we got a little garden, we get what we can from there and we don’t use no chemicals. That’s what causes the diabetes. Go to the grocery shop and look at all the foods, look at all the kinds of stuff that’s in there, the preservatives.

“Impure” or store bought food was associated with the current high prevalence of type 2 diabetes in the community and everywhere. That diabetes was perceived to result from chemicals on food that people eat meant that diabetes is, in the absence of chemicals, preventable. Food was therefore associated not only with personal dietary choices, but moreover with changes occurring as a result of social and environmental factors affecting Kahnawake (cf. Garro, 1996).

While conversation partners associated the construction of the Seaway with being “surrounded” and as a result with loss of land and gardens in the community, the Seaway was also associated with decreased physical activity. The river was described as a place where Kahnawakero:non used to swim, wash clothes and collect water. Conversation partners suggested that not being able to pursue these activities anymore has contributed

to lack of physical activity in the community, which was considered a causal factor for type 2 diabetes:

**Shannon:** Do you think that the construction of the Seaway is related at all to diabetes in Kahnawake?

**Conversation partner:** It could be, because we had the river, we used to go swimming. I grew up at the riverside, at the wharf. That was right near the hospital there. So everyday we swam. We swam either on this side of the river or where the wharf used to be. People used to come in the summertime, people from outside the community would come and we'd all be in the water and say 'Hey mister throw a dime, throw a quarter,' and we'd all dive. Ya, that probably has something to do with it. People used to picnic by the river. Kids were always by the river when we were growing up.

Yet conversation partners also attributed lack of physical activity among some Kahnawakero:non to people's choice to take advantage of modern technology such as television. That people could no longer go swimming in the river, wash clothes in the river, collect water from the river, and socialize at the river was coupled with the reality that they now watch television, use washing machines and sit in front of computers. As one man stated: "Out of your whole body, which one [part] has the muscle that you most use on a daily basis? The thumb!"

Conversation partners related "being surrounded" to a constant collective stress and "bitterness" which leads to type 2 diabetes. They also affirmed that many Kahnawakero:non have chosen lifestyles which put them at risk for developing type 2 diabetes. Thus while they recognized the individual responsibility for health, they also perceived type 2 diabetes to result from social and environment factors. They suggested that such factors arise from both within Kahnawake (e.g., the *Kahnawake Law on Membership*) and from outside (e.g., federal policy, land expropriation). Conversation partners' recognition of specific aspects of history, in addition to current social issues, as

contributing to high rates of diabetes in Kahnawake is therefore evidence of the profound limitations of a biomedical view that informs diabetes diagnostics and treatment through insight into bodily processes. Their perceptions can therefore be viewed as expressions of resistance to biomedically oriented practitioners who tend to highlight individual responsibility for diabetes by making recommendations that patients go on medication, lose weight, change their diet, and get more exercise (Garro, 1995). Moreover, and perhaps most importantly, subjective narratives question the extent to which sweet blood is actually the health problem, when its etiology seems to be at least partially grounded in factors outside of individual bodies. Treatment for type 2 diabetes that is based in self-management and control brings with it a powerful metaphor of moral condemnation directed at the individual, yet if being surrounded is at least partially responsible for high rates of type 2 diabetes among Kahnawakero:non, then what does this say about who is responsible for type 2 diabetes? What does this say about the capacity for Kahnawakero:non to prevent and control type 2 diabetes? It may perhaps be more accurate to suggest that in some cases (though not necessarily all) the health problem is not sweet blood per se, but rather colonization and “being surrounded.”

The association of type 2 diabetes with a particular level of sugar in the blood situates diabetes in the “neutral” language of science. In so doing, type 2 diabetes is depoliticized. Moreover, because diabetes has been medicalized, it is that much more likely to be transformed from the social to the biological. Narratives of subjectivity among Kahnawakero:non living with type 2 diabetes reclaim the disease from science, and situate sweet blood within social, historical and political frameworks. In so doing, narratives that go “beyond sweet blood” exemplify the link between the social body and

the bodies of Kahnawakero:non (cf. Scheper-Hughes & Lock, 1987). According to Kahnawakero:non, type 2 diabetes is as much a social issue as it is a medical issue, and type 2 diabetes therefore at least partially results from being “surrounded.”

## 6. Conclusion: “How Do We Plant the Garden?”

When I was growing up, everybody planted . . .

- Conversation partner

One conversation partner brought me to her backyard garden. She showed me how the beans grew up the corn stalks, and piled dozens of tiny red tomatoes into my hands. She explained to me that her granddaughter was learning how to plant a garden, and that they planted this garden together. “How do we plant the garden?” she asked as she considered how to transfer knowledge about type 2 diabetes to future generations. How can Kahnawakero:non “plant the garden?” How can they proceed with living a healthy life when they are “surrounded?” How can they grow “pure” vegetables when their land keeps getting smaller and smaller? How can they reinforce that Kahnawakero:non *are* healthy, and that it is not all about sickness and sweet blood?

Biomedical definitions of diabetes are limited in that they do not consider how and why diabetes comes to be in individual bodies. While anthropologists have done well to say that subjective experiences of diabetes go “beyond sweet blood” and even implicate environmental factors that shape individual bodies, they have not pushed the research further to consider that those living with type 2 diabetes may actually challenge the point at which we begin to understand the disease. Framing our studies as such implies that both anthropologists and those living with type 2 diabetes agree with the biomedical diagnosis and classification of diabetes as a disease. Yet Kahnawakero:non repeatedly questioned the point at which blood is “sweet enough” to be typed as diabetic. Moreover, *teiionekwenhsatsikhe:tare* – the notion that sugar is on top of the blood rather than in it – suggests that understandings of type 2 diabetes in Kahnawake must include

insight into where sugar comes from, and how and why it settled on the blood of Kahnawakero:non specifically. Thus perceptions of type 2 diabetes among Kahnawakero:non living with the disease must be considered through insight into the ways in which people talk about both the diagnostic process and how type 2 diabetes goes “beyond sweet blood.”

By seeing those living with diabetes challenging the biomedical definition of diabetes as a disease, we gain deeper insight into what it means to live with type 2 diabetes. Conversation partners discussed the ways in which they perceived KMHC physicians to diagnose or “make” diabetes among Kahnawakero:non. That Kahnawakero:non are part of a high risk group for diabetes was considered to influence physicians’ diagnostic practices, making them more “willing” to diagnose diabetes in aboriginals. Moreover, narratives illustrated that being “borderline” had implications for what it meant to “be diabetic” and have high sugar, and people asked: at what point is blood “sweet enough?” Thus while anthropologists have considered how culture contributes to the ways in which illness is presented, how care is evaluated by the patient, and how one cares for oneself, narratives of subjectivity among Kahnawakero:non suggest that it is also imperative to ask how culture influences biomedical disease classification and related diagnostic criteria, how these criteria change over time, and how such changes affect certain populations, in this case Kahnawakero:non (cf. Rock, 2003a).

In addition, conversation partners suggested that being aware of the prevalence of type 2 diabetes in Kahnawake causes a pervasive fear in people, because it creates a sense of seeing what is to come. Nonetheless, fear was associated by all conversation partners

with “leaving a stronger message behind” so as to prevent future cases of diabetes in Kahnawake. Moreover, the efforts of KSDPP and KMHC to raise awareness about diabetes in the community were considered essential for addressing the issue of diabetes at the collective level. Diabetes was further situated in collective stress and “bitterness,” which conversation partners said arose from feelings of being encroached upon. Conversation partners therefore related the Seaway, Bill C-31 and Kahnawake’s membership laws, and the 1990 Oka crisis to the prevalence of type 2 diabetes collectively. This knowledge serves as a resource for assigning meaning and responding to illness (cf. Garro, 2000), but, more importantly, it forces us to question the extent to which Kahnawakero:non can be considered personally responsible for acquiring type 2 diabetes when it is clear that they perceive, and it is quite possibly true, that type 2 diabetes has arisen from their being surrounded. By what mechanisms, as Farmer (1999) has asked, do social forces become embodied as personal risk? What role does being surrounded play in the development of type 2 diabetes in Kahnawake? Conversation partners have suggested that being surrounded has in fact played a central role in the development of type 2 diabetes in the community.

Yet type 2 diabetes has not affected Kahnawake as drastically as it has other aboriginal communities in Canada. Kahnawake diabetes prevalence rates in 1985 were twice the rates in the general Canadian population (Montour & Macaulay, 1985) and current community data indicates that these rates remain about the same. This is much less than the rates of type 2 diabetes in the aboriginal population nationally. These rates of type 2 diabetes in Kahnawake can be seen as a reflection of good education, increased employment, programs for diabetes education and prevention and other community

health promotion efforts. Given that conversation partners linked diabetes to issues of land, resources, cultural continuity and governance, I would propose that current rates of type 2 diabetes in Kahnawake, as compared with other aboriginal communities, may also indicate the extent to which community control over health and other community services have positively impacted the health of the community over time (cf. Chandler, 2003).

In addition, I suggested at the outset of this thesis that narratives of subjectivity about diabetes are a political discourse in that they simultaneously provide insight into the place of individuals and populations within society, while revealing that not everyone agrees upon the ways in which type 2 diabetes constitutes the health problem.

Kahnawake:non are daily being diagnosed with type 2 diabetes and learning how to take control of their diabetes through treatment and education at KMHC. Each person diagnosed with type 2 diabetes learns through the Mohawk Diabetes Nurse Educator about realistic long-term modifications in diet and activity patterns with the idea that people will then be able to take control of the disease. Because conversation partners considered the etiology of type 2 diabetes as linked to a history of land expropriation or the threat thereof, in addition to poor eating, laziness and being overweight, they implied that the health problem originates at least in part in social issues. Diagnostic procedures and education at KMHC should therefore consider incorporating how historical events such the Seaway, the Oka crisis and Bill C-31 and collective stress play a role in the development of type 2 diabetes in Kahnawake. This would support a view of health that is integral to social issues, and may provide more appropriate and effective care for Kahnawake.

Focus on self-management and clinical intervention moreover neglects the role of disease classification itself, how disease classification situates individuals as “at risk,” and the related implications of so doing. Thus diagnostic procedures and education at KMHC, and prevention education at KSDPP could also incorporate discussion of diabetes as a disease category that has changed over time, including the ways in which certain populations, namely the aboriginal population, come to be categorized as “at risk.” In so doing, while invoking standard biomedical interests, diagnosis and education would further recognize and support the cultural dimension of health and disease. It is also worthwhile, and perhaps even ethically imperative, to inform Kahnawakero:nnon patients about how the CDA clinical practice guidelines have come to be, and who has been involved in drawing them up (see Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2003). This would further enable Kahnawakero:nons’ understanding of how they, as aboriginal people, are perceived within national clinical practice guidelines.

Ultimately, however I would strongly assert that the health problem of type 2 diabetes is not limited to sweet blood per se, but rather it lies outside of the clinic and the body, and within broader social and political relations, and a specific community history. In the specific context of Kahnawake this implies that type 2 diabetes has at least partial origins in land expropriation and a collective stress and “bitterness” resulting from colonization and feelings of being encroached upon. The community – perhaps through but definitely not limited to diabetes prevention and education – therefore must find a way to address the collective issue of “being surrounded.” By extension, Canada must too address (or continue to address) how we have surrounded Kahnawake. In other words,

endeavors focused on the management and prevention of type 2 diabetes must be linked to efforts to enable Kahnawakero:non to gain control over their lives, which is directly related to regaining back, and taking control over, their land.

### **Future Research**

Recommendations for future research include a deeper historical analysis of “health” in Kahnawake. Such analysis could reveal further insight into how diabetes, in addition to other community health issues, has come to be. Moreover, analysis by a speaker of the Mohawk language could relate important ideas on how health is passed to future generations through language, and the disruption that colonization may have played in this process (see Adelson 2000). While I chose to interview those over the age of 40, future studies could explore perceptions of type 2 diabetes among younger people. This may give further insight into the varied views on diabetes in Kahnawake. An important research study would also include or focus on perceptions of type 2 diabetes among those not living with the disease. Finally, it was suggested at the outset of this research to examine how the Depression era may have entered into peoples’ narratives. No one that I spoke with related the Depression to diabetes in Kahnawake, but it may be worthwhile to examine how this period, and later federal relief and family allowances corresponded with the beginnings of type 2 diabetes in Kahnawake.

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## Appendices

## **Appendix I: Interview Protocol (conversation partners / patients)**

### **A. Perceptions of diabetes**

1. How would you describe your experience of living with type 2 diabetes?
2. Do you remember when you were first diagnosed?
  - a. What was it like when you were first diagnosed?
  - b. When were you first diagnosed with type 2 diabetes?
  - c. Where were you diagnosed?
  - d. Who diagnosed you?
  - e. How did you feel when you were first diagnosed?
3. What do you think are the causes of type 2 diabetes?
4. What do you feel are the reasons that you got type 2 diabetes?

### **B. Control over diabetes**

1. Do you test yourself on a regular basis? Why / why not?
2. What was your sugar the last time you checked?
3. Do you consider your diabetes well-controlled? Why / why not?

### **C. Education / prevention**

1. Who gives you information about diabetes?
  - a. Why do you use this / these sources for diabetes education?
2. In your opinion, what kind of information is useful for controlling your diabetes?
  - a. Why is this information useful to you?

### **D. Treatment / support**

1. How do you manage / treat your diabetes?
2. What are your sources for support?
  - a. Why do you use these sources for support?
3. Do you use the health services (e.g., at the hospital, the healing lodge) in the community to treat / manage your diabetes?

#### **If yes:**

- a. What specific services do you use?
- b. How often do you use these services?
- c. Why do you use these services?
- d. Do you feel that the health services available in the community are adequate for addressing your health needs? Why / why not?

#### **If no:**

- a. What services do you use?
- b. How often do you use these services?
- c. Why do you use these services?
- d. Do you feel that the services you use are adequate for addressing your health needs? Why / why not?

### **E. Closing questions / Individual perspectives on the collective**

1. How has your life changed since you were first diagnosed with diabetes?
2. How do you feel now?
  - a. How have you been affected physically by diabetes?
  - b. How have you been affected emotionally by diabetes?
3. Has your family been affected by your diabetes?
  - a. How has your family been affected by your diabetes?
4. Why do you think so many people in Kahnawake have diabetes?
5. Do you feel type 2 diabetes can be prevented? Why / why not?

## **Appendix II: Interview Protocol (physicians)**

1. How long have you been working in Kahnawake?
2. How many patients, approximately, do you work with who have type 2 diabetes?
3. Do you feel that type 2 diabetes is one of the most serious health issues in Kahnawake?
  - a. Why / why not?
4. When do you think type 2 diabetes started becoming a health issue in Kahnawake?
5. Why do you think type 2 diabetes has become so prevalent in Kahnawake?
  - a. What do you think are the reasons for why people in Kahnawake are getting type 2 diabetes?
6. How is type 2 diabetes diagnosed? / What method of diagnosis do you use in Kahnawake?
  - a. What is the process by which people are diagnosed as diabetic?
7. How is type 2 diabetes treated?
  - a. What are the most common medications that you prescribe for your patients in Kahnawake?
8. Do you feel that the diabetic patients you work with are satisfied with the health services available at the Kateri hospital?
  - a. Do you ever get feedback from your diabetic patients?
9. Do you feel that type 2 diabetes in Kahnawake can be prevented?
  - a. Why / why not?

### **Appendix III: Research Consent Form (patients)**

This research has been approved by the Kahnawake Research Council (please see approval letter attached). This program of research is being conducted by Shannon Dow as part of her master's degree in the department of Sociology and Anthropology at Concordia University, 1400 de Maisonneuve Blvd. W. LB-681; Ph: (514) 848-2424 ext. 2141; Email: [socanth@vax2.concordia.ca](mailto:socanth@vax2.concordia.ca). The Concordia supervisory committee for this research consists of Professors David Howes, Shelley Reuter and Nadia Ferrara.

#### **Purpose**

I have been informed that the purpose of the research is as follows: The current research will explore the relationship of my understandings of diabetes to how community health services meet my health needs.

#### **Procedures**

The research will be conducted in the community of Kahnawake. As a conversation partner, you are invited to participate in an interview that will last approximately 60 minutes. Shannon Dow will conduct all interviews, and she would like to tape record the interviews so that nothing is missed.

#### **Benefits and Risks**

There are no risks known to be associated with your participation in this study. Research findings will be written up in the form of a master's thesis and presented to the community of Kahnawake and to the research community at Concordia. In the future, research findings may also be published. Your participation may inform ongoing community diabetes treatment and prevention in Kahnawake.

#### **Confidentiality**

All collected information will be kept strictly confidential and only Shannon Dow will have access to the data. No individual will be identified from the collected information. The interviews will be transcribed and any information that could identify you will be removed from the document. Your name and any identifying information will not be reproduced in the production of any final research results.

Tape recordings of the interview will be stored with Shannon Dow in a locked filing cabinet and destroyed at the end of the study. Only Shannon Dow will have access to the tapes and transcripts.

#### **Contact**

If you have any questions, concerns or require additional information, please contact Shannon Dow at (514) XXX XXXX or by email at [XXX@XXXX.XXXX](mailto:XXX@XXXX.XXXX). If at any time you have questions about your rights as a participant in this study, please contact the Research Ethics and Compliance Officer, Concordia University, at (514) XXX-XXXX.

#### **Statement of Consent**

I understand that this conversation will be recorded and written notes will be taken so that nothing is missed from the conversation. I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences. I understand that my participation in this study is confidential (i.e., the researcher will know, but will not disclose my identity). I understand that the data from this study will be used for Shannon's master's thesis and may be published. I understand that Shannon is seeking written consent to participate in this study but that if written consent is not possible then verbal consent will be taken.

I have read the above description of the study. I have had the opportunity to ask questions about it, and I consider that I have been fully informed. I freely consent to participate in this study.

NAME (please print)

---

SIGNATURE

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## **Appendix IV: Research Consent Form (physicians)**

This research has been approved by the Kahnawake Research Council (please see approval letter attached). This program of research is being conducted by Shannon Dow as part of her master's degree in the department of Sociology and Anthropology at Concordia University, 1400 de Maisonneuve Blvd. W. LB-681; Ph: (514) 848-2424 ext. 2141; Email: [socanth@vax2.concordia.ca](mailto:socanth@vax2.concordia.ca). The Concordia supervisory committee for this research consists of Professors David Howes, Shelley Reuter and Nadia Ferrara.

### **Purpose**

I have been informed that the purpose of the research is as follows: The current research explores the relationship of people's understandings of diabetes to how community health services meet people's health needs. This interview will explore my understandings of diabetes in Kahnawake from my perspective as a physician working in the community.

### **Procedures**

The research will be conducted in the community of Kahnawake. As a conversation partner, you are invited to participate in an interview that will last approximately 30 minutes. Shannon Dow will conduct all interviews, and she would like to tape record the interviews so that nothing is missed.

### **Benefits and Risks**

There are no risks known to be associated with your participation in this study. Research findings will be written up in the form of a master's thesis and presented to the community of Kahnawake and to the research community at Concordia. In the future, research findings may also be published. Your participation may inform ongoing community diabetes treatment and prevention in Kahnawake.

### **Confidentiality**

All collected information will be kept strictly confidential and only Shannon Dow will have access to the data. No individual will be identified from the collected information. The interviews will be transcribed and any information that could identify you will be removed from the document. Your name and any identifying information will not be reproduced in the production of any final research results.

Tape recordings of the interview will be stored with Shannon Dow in a locked filing cabinet and destroyed at the end of the study. Only Shannon Dow will have access to the tapes and transcripts.

### **Contact**

If you have any questions, concerns or require additional information, please contact Shannon Dow at (514) XXX XXXX or by email at [XXX@XXXX.XXXX](mailto:XXX@XXXX.XXXX). If at any time you have questions about your rights as a participant in this study, please contact the Research Ethics and Compliance Officer, Concordia University, at (514) XXX-XXXX.

**Statement of Consent**

I understand that this conversation will be recorded and written notes will be taken so that nothing is missed from the conversation. I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences. I understand that my participation in this study is confidential (i.e., the researcher will know, but will not disclose my identity). I understand that the data from this study will be used for Shannon's master's thesis and may be published. I understand that Shannon is seeking written consent to participate in this study but that if written consent is not possible then verbal consent will be taken.

I have read the above description of the study. I have had the opportunity to ask questions about it, and I consider that I have been fully informed. I freely consent to participate in this study.

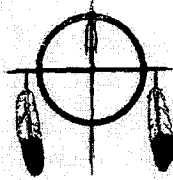
NAME (please print)

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SIGNATURE

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## Appendix V: Onkwata'karitáhtshera Approval



### **ONKWATA'KARITÁHTSHERA**

*Kahnawake's One Health & Social Services Agency*

P.O. Box 1440

Kahnawake, Quebec J0L 1B0

Tel: (450) 632-6880

Fax: (450) 632-5116

May 30, 2005

Shannon Audrey Dow  
[REDACTED]

Kwe Shannon,

We acknowledge receipt of your request on May 5, 2005, to conduct research about Community Health Services in Kahnawake. The Onkwata'karitáhtshera Health and Social Services Research Council has approved your research request.

As noted in my e-mail to you on May 27, 2005, the Research Council requires that you submit a monthly update (OHSSRC Report) on the progress of or any setbacks of your research project. The Research Council also requires that you submit a final report within 30 days of completion of your research project. I will forward you a copy of the Research Council's contract when it has been approved.

On behalf of the Research Council we wish you much success with your "Community Health Services in Kahnawake" project and your future endeavors. Please do not hesitate to contact me for any further information.

Skennen kowa,

[REDACTED]  
Onkwata'karitáhtshera Coordinator  
[REDACTED]