

## **Ziinzibaakwadonaapinewin Migoshkaadendamowin Diabetes: A Struggle Within**

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### **Abstract**

*It is a silent killer, a killer that discriminates against no race, gender, sexuality, or creed. Diabetes afflicts one race more so than any other, this race is Native Americans. Although Native Americans have withstood removal, relocation, and assimilation, diabetes is the fight that Native Americans are losing. The population of Native Americans diagnosed with diabetes is growing by the day. The age of the diagnosed is getting younger and younger every year. The tribes are fighting, but without the proper education, prevention, and intervention it is a losing effort. The diabetic not only suffers from this disease, but other factors are also involved including physical, mental, and financial burdens. The tribe carries the burden of caring for these people. The financial impact can be felt throughout the tribe as funding is limited and quite often falls back in the lap of the diabetic. Until Native Americans can get the proper health care and funding to maintain that care diabetes will continue to grow.*

### **Introduction**

What is Diabetes Mellitus? There are two types of diabetes: Type 1 and Type 2. The most common type diagnosed is Type 2. It is a disease of insulin resistance. Insulin resistance is the inability of the body to use its own insulin to control blood glucose. Type 1 diabetes is where the pancreas does not produce any insulin. Diabetes is a major risk factor for the development of cardiovascular disease which is the leading cause of death in Native Americans. Some complications of diabetes are lower extremity amputations, diabetic retinopathy, and diabetic nephropathy (ADA, 2009).

This literature review will take a look at some of the effects that diabetes has on the person physically, mentally, and financially. It will also look into how the disease affects the tribe as the healthcare provider.

### **Literature Review**

#### *Effects on the People*

As Native Americans have survived throughout the years they have persevered and overcome much. Diabetes is one fight that is slowly taking the will, limbs and lives of Native Americans everywhere. The psychosocial impact sometimes results in the onset of depression. Once depression sets in there are many factors that inhibit the treatment and intervention. Alcohol, drugs, and smoking are three main factors that are many times pre-existing. These hinder the diabetic from overcoming the disease and from living a long life with the disease. Alcohol, drugs, and smoking can allow the person a quick release from the stress of the sickness however, may have a direct effect on blood pressure, and blood sugar. Stress from events in one's life include parents separating, interpersonal trauma (e.g., sexual abuse), and noninterpersonal trauma (e.g., life threatening accident). All these are stress variables and can adversely affect the diabetic. Being diabetic can also lead to higher levels of psychosocial stress (Jiang, Beals, Whitesell, Roubideaux, & Manson 2008).

<sup>1</sup>The tribe plays a role in funding received from the federal government. Indian Health Service (IHS) receives a budget from the federal government of approximately 3 billion to disburse to over 1.8 million Native Americans. The funding is unstable and unlike Medicaid and Medicare programs, the IHS is not an entitlement program. This means each year the funds are appropriated by the United States Congress. The recruitment and retention of professional staff is also an issue. Often times the tribe does not have the ability to pay the salary that these professionals are accustomed to earning at hospitals. I personally have fallen victim to the funding shortage. My situation involved a knee injury that was deemed pre-existing and my health insurance would not cover it. Indian Health Services got the bill and had no money to pay the surgery bill. I was left to pay the bill for the surgery. Many diabetics are also paying for their care out of their own pockets.

According to Helgeson and Francis (2006), Diabetes Mellitus (Type 2) is the most common diabetes diagnosed in Native Americans. The pancreas either does not produce enough insulin or it does not respond to the insulin properly. Often the pancreas initially makes insulin, but, over time, it loses the ability to produce this hormone. This can result in high blood glucose and may result in serious health problems such as heart disease, stroke, kidney failure, or blindness. American Indian and Alaskan Native communities are in the midst of a Type 2 diabetes epidemic. In fact 12.2% of American Indians in the United States over 19 years of age have diabetes (Association of American Indian Physicians, 2001). Native Americans are two to three times more likely to become diabetic than non Natives. While Native Americans were more likely to have below-the-knee amputations, in the United States Native Americans have the highest rate of amputation. Diabetes prevention programs have demonstrated that Indians at high risk for developing Type 2 diabetes could reduce their risk by 58 % through a lifestyle intervention of proper diet and exercise (Berry, Samos, Storti, & Grey, 2009).

Adult diabetes is spreading throughout Indian Country at break neck speeds. The biggest concerns when considering the impact diabetes has on Native Americans come from a lack of education, time management, healthy diet and cooking habits. One elder shared his vision for a diabetes prevention program:

We need to develop a holistic program for both adults and children that you can do comfortably within the confines of your daily work schedule or after school that includes some components of nutrition education, learning about time management, learning how to cook differently, learning about making lifestyle pattern changes on a daily basis, as well as exercise that is incorporated into your daily life (Berry, Samos, Storti, & Grey, 2009).

According to Edwards and Patchell 16.3 percent of American Indian and Alaska Native adults are diagnosed with diabetes compared with 8.7 percent of non-Hispanic whites. It is estimated that an additional 30 percent of American Indian and Alaska Natives have pre-diabetes (Edwards and Patchell, 2009).

As stated in Edwards & Patchell (2009), there has been a 68 percent increase in diabetes from 1994 to 2004 with a 95 percent of the diagnoses representing Type 2. There has been a 58 percent increase prevalence among American Indian and Alaska Native ages 20-29 from 1990-1998 compared with 9.1 percent of the general population

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<sup>1</sup> Authors personal knowledge

<sup>2</sup>Much of the concern for diabetics regards lifestyle change. Living a high energy consumption, low activity, sedentary lifestyle all point to a life of obesity and increased risk for diabetes among other diseases. Living in the traditional lifestyle before and during European contact was the opposite of this sedentary lifestyle. Many tribes harvested their own crops, hunted, and built shelters. These activities were physically challenging and kept all members in a high state of physical shape. Every activity required physical strength and endurance. Hunting parties would have to track the animal before and after the hunt then dress the carcass, butcher it and haul it back to camp. Gardening required digging, planting, picking or harvesting and the preparation or cooking. The consumption of organic vegetables, and the lean meats of the deer, bear, and buffalo allowed for a high energy level and low fat intake. This intake and the active lifestyle resulted in living a long and healthy life. Many tribes also moved with the seasons. The movement required the packing of all belongings and necessities for the upcoming season. This meant the tear down of any shelter, storage of food, and all personal possessions. Horses were not always available so this was all done by the individual members of the tribe or camp. Some of these moves were rather long and over terrain which made the move quite arduous especially on foot.

<sup>3</sup>As times progressed during post-European contact many things were introduced that made life a lot easier for the natives. The advent of horses, metals, guns, and easier gardening methods allowed for many to move away from doing things the traditional way. Not all of these things introduced had a positive impact. The introduction of disease, alcohol, and dependence on the federal government for aide stripped away the will and soul of the individual. One such example was the role of the male as a warrior, provider, and protector. Diabetes was not known at the time of European contact so other diseases such as small pox, measles, and pneumonia began to ravage the native population. Men, women, and children all perished. The sickness and disease that spread took away the males ability to hunt, work, and fight. The male grew weaker, and could not do the things he once could. The convenience of the tools and weapons made life easier but also brought a sedentary lifestyle which paved the way for failure. The warrior, hunter, and protector were positions of great pride, and these men were often seen as great leaders. Great leaders, warriors, and hunters were not sick, weak, or lazy. The effects of diabetes and the other diseases were debilitating and fatal. The population decreased, as did the land and resources natives depended on so heavily. The tribes were granted sovereignty, and self-determination. Sovereignty is the power to self-govern or rule, and self-determination is the power to choose your own path. It is clear that diabetes along with the other illnesses have a direct effect on these two powers. Taking away the leaders who represent the natives takes away their right to be a self-determinant, sovereign nation. The stripping of these basic rights is felt throughout Indian country from the youth to the elders.

### *Effects on the Tribe*

For America's Indigenous people of the last century the land has been taken, the food was limited, and the Native American family structure was gone. Native Americans were deprived of their religion, were uneducated and the poorest of the poor. This culminated in the mid-nineteen hundreds. After centuries of federal and state policies of termination, removal, and assimilation Native Americans were substantially worse off than white American society. Yet the fact that

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<sup>2</sup> Authors personal knowledge

<sup>3</sup> Gary Johnson First Nations Studies class lecture

tribal nations endured and survived, some even thriving is a testament to their resilience and strength (Edwards & Patchell, 2009).

The United States Commission on Civil Rights Report attributes the current health and illness to these policies and states the following:

This is the result of the nation's lengthy history of failing to keep its promises to Native Americans, including the failure of Congress to provide the resources necessary to create and maintain an effective healthcare system for Native Americans...and culture, social, and structural barriers continue to exist and limit Native American access to health care (Edwards & Patchell, 2009).

As the rates of diabetes diagnosis rise, the morale and will of the Native people sinks lower and lower. One thing that seems to be working slowly are community based programs. These programs require participation to succeed and require the commitment necessary to make these lifestyle changes to prevent and live with the disease. These programs require not only involvement, but also collaboration. This means that active involvement of community members is required in all phases of the project, from conceptualization to implementation, and revision. But here too we must be careful of hollow ideology. Increasingly, successful community-based projects are ones in which community members and outside advisers have equal roles in project planning, implementation, review, and revision (Smith-Morris, 2006).

It is important to not only deliver a program to prevent diabetes, but also to imbed the program into the community so that health, nutrition, and exercise become a part of everyday life. The development of a program that is participatory and community based, delivers nutrition, exercise, and behavioral interventions on an individual, family, and community level will be planned with continued input and feedback from the community (Berry, Samos, Storti & Grey, 2009).

Growing up on the reservation the author has seen firsthand the elders and young adults suffer from these diseases and eventually die. We as Native Americans believe we are all related and when you lose a relation it affects you, negatively. Coping with the loss often leads people to turn to “stress relievers” such as alcohol, drugs, and smoking.

#### *What are Tribes Doing in Response to These Issues?*

Tribes are starting to educate youth at a early age so as they grow they can make healthier choices. In 2002 the crisis concerned the Tribal Leaders Diabetes Committee which prompted the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) to begin funding a national initiative titled “Diabetes Education in Tribal Schools (DETS) K-12 Curriculum Project” to address the epidemic of Type 2 diabetes among American Indian/Alaska Native populations (Helgeson & Francis, 2006).

In the summer of 2005, the Keweenaw Bay Ojibwa Community College also began a pilot testing their DETS high school curriculum. The diabetes qualitative research lesson, “Diabetes as Seen by the Community” was pilot tested in a one-week summer institute. Fifteen high school students attended the program, ranging from grades 8-12, encompassing two local public school districts.

Initially most students were able to demonstrate only minimal knowledge concerning the disease. This assessment was based upon pre- and post-journaling assignments and classroom

discussions. Students were asked prior to any instruction and then again on the last day of class to write journal answers to the following questions:

1. What do you know about diabetes?
2. Do you think that diabetes is something you should be concerned about? Explain.
3. Do you think some types of diabetes are preventable? Explain.

By the end of the week the majority of students, through their journal narration, could describe a basic clinical definition and illustrate the consequences of Type 2 diabetes (Helgeson & Francis, 2006).

I look at the children on the reservation and, I am saddened. So many are already on the path to diabetes. Educating the children on the importance of nutrition, exercise, and an overall healthy lifestyle is a huge first step in prevention. Today on my reservation there are programs in place to address these issues. There is a program called Testing Reality and Indian Lifestyles (TRAILS). TRAILS emphasis on the issues of education, nutrition, and exercise teach the youth there is a better, healthier life to live.

The program is open to children in K-12th grade. Some parts of the reservation are isolated and the children that live here do not have the opportunity to interact with others. The TRAILS program transports every child that wants to join to and from the community center. The youth are fed snacks and juices and taught about the importance of eating healthy, exercising, and education. The social interaction, playing games, and sports builds bonds of friendship, teamwork, and sportsmanship. All this incorporates a positive attitude and outlook. For some families this is all that is needed. The parents see their children eating healthy and talking about what they have learned, which then rubs off on them.

Another program on the reservation is the Mashkizibi Boys and Girls Club. Like the TRAILS program the Boys and Girls Club emphasizes the same things. These programs are excellent avenues and provide a place for the kids to go and be active. The boys and girls club is also open for children in K-12th grade. The kids play games, eat healthy, go on trips, and create traditional arts and crafts. There are also traditional activities done. The kids are taught to sing, drum, and dance. Giving the kids positive, constructive activities to do keeps them active and off the streets. All of this is leading them down a positive pathway.

### *Personal Experience*

Growing up on the reservation I watched diabetes spread amongst tribal members, and soon into my family. I witnessed my grandfather's amputations starting with just the toes, then the feet, and a few months later below the knee. He did not exercise or stay fit, but he also did not take the diseases he was afflicted with seriously. I believe my grandfather feared the truth and let the symptoms lie in the weeds for far too long. When he finally did fall ill the diagnosis of heart disease and diabetes were beyond prevention and it became intervention. My grandfather always down played the doctors recommendations. Having to close his business and having little or no income also played a part in the stress variable adding to complications. Blockage of arteries created poor circulation especially to the lower limbs, thus resulting in nerve damage and amputation. I have another grandfather that suffers from diabetes, and watched the same cycle start with him. He too has lost his toes and if it were not for the intervention of his children I am not too sure he would be around today. He too let the symptoms go undetected for far too long,

and it has affected his health in many ways. The poor eating habits, a sedentary lifestyle, and depression all have contributed to the heart disease and diabetes he now lives with.

Overall, there are many programs on the reservation that are intended on improving the lives of the tribal members. However, the funding for these programs runs out or the program fails because of non participation, or mismanagement. I have seen the finances for healthcare fall far short of meeting an acceptable standard for tribal members. The clinic on my reservation continually has problems retaining the personnel and up to date equipment. The financial aspects of this disease and its impact on the diabetic contribute to other issues they have to deal with. The tribe having limited funding means the bill falls back on the patient. This creates stress, and adds to the depression of the diabetic. Transportation to and from appointments becomes a problem. Buying healthier foods and learning to cook healthier are also problems. The conveniences of eating out, eating fast food or just not eating at all have proven to be detrimental to the survival of the diabetic.

### *Where do we go from Here?*

Moving forward and ultimately winning the war on diabetes is not far from becoming a reality. With the education, prevention, and intervention of this disease taking on a full head of steam it is up to the individual whether he wants to die from diabetes or live with it. The programs that teach farming and gardening of natural organic foods are a step in the right direction. Cooking this food in a manner that is beneficial to people is the next step. Finally people need to make the commitment to keep living in a healthier way. Funding for wellness centers and gyms will promote exercise. Taking care of and respecting the center is essential. Gyms on most reservations are not nice, they could be, and with some accountability and care everyone can use these facilities. Once the change is made in their lifestyle, feeling better, looking better and living better is possible.

The following examples are five best practice programs focused on diabetes prevention. All five programs were selected by the Indian Health Services. The first program, The Trimdown Program, is sponsored by the Albuquerque Service Unit and is a six-week intervention aimed at assisting participants to incorporate healthy eating habits and physical activity with the support of others (Indian Health Service, 2006).

The second program, The Lifestyle Balance Program sponsored by Gallup Medical Center, is a 22 week comprehensive program that adheres to the Diabetes Prevention Program curriculum. Participants meet weekly and individually with a coach on a regular basis. This program includes problem identification and solving, positive thinking and tools for stress management (Indian Health Service, 2006).

In the third program, the Lionel R. John Health Center-The Seneca Health Trail Blazers-Trails of the Iroquois, the participants attend weekly sessions for support. The progress of each participant is tracked. Using a clan animal, the participant's progress is tracked by moving the animal across a map of the state of New York and along a trail from the tribal territory to other tribes across the state. Participants receive beads and leather to make a bracelet or necklace for weight loss (Indian Health Service, 2006)

The fourth program, the Red Lake Band of Chippewa Indians-Weight Management Program, is community-based and meets twice a week for six to eight weeks. The focus is on lifestyle change and group support. Lastly, the fifth program, Fresno Native American Health Centers- Greatest Loser Program, incorporates behavior modification, spiritual and mental health

approaches in this ten week wellness program for Native Americans who live in an urban area (Indian Health Service, 2006).

These programs are making a difference. The programs listed were primarily descriptions; therefore, more studies that will evaluate the effectiveness of culture-specific diabetes prevention interventions with Native American populations are still needed. These programs are incorporating a group dynamic. The group dynamic allows the participants to work together. No one person is alone in their fight with diabetes and that is important in the successful completion of the program.

### **Conclusion**

As Native Americans move into the next generation it is obvious that we as a people need to make changes. As Native Americans we need to change how we think, live, and work. Before the days of European contact Native Americans lived and worked together. It is that lifestyle we need to bring back. These changes cannot be made over night, they require time and effort. By educating our youth, and re-educating the adults and elders we are taking the necessary steps to make this happen. There is a traditional belief that each generation works for the next 7 generations. By educating our youth on this disease and how to prevent it we are ensuring that generation's survival, and the generations to follow. With this knowledge comes the power to overcome the struggle within, Diabetes.

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