



So That the People May Live (Hecel Lena Oyate Ki Nipi Kte): Lakota and Dakota Elder Women as Reservoirs of Life and Keepers of Knowledge about Health Protection and Diabetes Prevention

## Journal of Health Disparities Research and Practice

Volume 1 | Issue 2

Article 2

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2007

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### Recommended Citation

Satterfield, Dawn W.; Shield, John E.; Buckley, John; and Alive, Sally T. (2007) "So That the People May Live (Hecel Lena Oyate Ki Nipi Kte): Lakota and Dakota Elder Women as Reservoirs of Life and Keepers of Knowledge about Health Protection and Diabetes Prevention," *Journal of Health Disparities Research and Practice*: Vol. 1: Iss. 2, Article 2.

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## Abstract

Around the world, Type 2 diabetes is on the rise, affecting adults and youth from societies in the throes of industrialization. Over time, uncontrolled diabetes can leave in its wake people facing renal failure, blindness, and heart disease, and communities daunted by new, chaotic phenomena. Westernized lifestyles are a recognized explanation for the escalating prevalence. The web of causation, however, may be broader and thicker, woven by complex interactions with environmental, sociological, and historical roots. The purpose of this participatory ethnographic study was to document, understand, and support Lakota and Dakota elder women's beliefs and knowledge about health protection and diabetes prevention. In-depth interviews were conducted with nine elder women to learn: (1) about the factors attributable to diabetes, (2) about related narratives addressing health protection and diabetes prevention, and (3) how knowledge about health protection is shared. The elders saw diabetes as an outside, unnatural disorder, the contributing influences of which are external as well as internal. They offered narratives about chaos, restitution, testimony, and quests for cures and meaning. The elders connected health to traditional values and ways, the land, and memory. Reservoirs of wisdom reside in the knowledge systems of tribal elders who remember when diabetes was unknown. Health leaders at local and national levels would be wise to respect and draw upon this knowledge for guidance in program planning and policy development.

## Keywords

Dakota Indians; Diabetes; Health education; Health promotion; Health protection; Indians of North America; Native Americans; Non-insulin-dependent diabetes – Prevention; Older women; Teton Indians

## Cover Page Footnote

The authors wish to express their deepest respect and gratitude to the elders and co-workers of the Community Health Representative and Diabetes Programs who so generously shared their wisdom, insight, guidance, and time, in hopes that they might help their people. We would like to thank the Tribal Council Health, Education, and Welfare Committee of the Standing Rock Nation for their review and approval of this participatory project. Special thanks are offered to Randy Bear Ribs, Bernadine Broken Leg, George Brave Bull, Larry Brown, Chris Burd, Jolene Cadotte, Melda Crow Feather, Randy Dog Skin, Rosalyn Fast Horse, Daryl Iron Shield, Gerald Iron Shield, Elaine Keeps Eagle, Virginia Leaf, Aubrey Skye, and Waylon Yellow Earrings for their assistance.

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### **Abstract**

Around the world, Type 2 diabetes is on the rise, affecting adults and youth from societies in the throes of industrialization. Over time, uncontrolled diabetes can leave in its wake people facing renal failure, blindness, and heart disease, and communities daunted by new, chaotic phenomena. Westernized lifestyles are a recognized explanation for the escalating prevalence. The web of causation, however, may be broader and thicker, woven by complex interactions with environmental, sociological, and historical roots. The purpose of this participatory ethnographic study was to document, understand, and support Lakota and Dakota elder women's beliefs and knowledge about health protection and diabetes prevention. In-depth interviews were conducted with nine elder women to learn: (1) about the factors attributable to diabetes, (2) about related narratives addressing health protection and diabetes prevention, and (3) how knowledge about health protection is shared. The elders saw diabetes as an outside, unnatural disorder, the contributing influences of which are external as well as internal. They offered narratives about chaos, restitution, testimony, and quests for cures and meaning. The elders connected health to traditional values and ways, the land, and memory. Reservoirs of wisdom reside in the knowledge systems of tribal elders who remember when diabetes was unknown. Health leaders at local and national levels would be wise to respect and draw upon this knowledge for guidance in program planning and policy development.

**Key Words:** diabetes, native Americans, prevention, health protection

## Introduction

Many Oceti Sakowin communities recite a prayer and rallying cry that reminds them of a common purpose: “Hecel lena oyate ki nipi kte” (“So that the people may live”). In the 1970s, Mrs. Josephine Hollow of the Standing Rock Nation stitched these words onto a star-quilt banner to mark the finish line of the Nation’s annual sobriety run. The mother of six adult children, two of whom are community health representatives (CHRs), Mrs. Hollow was concerned about the health of her family and the tribe’s future generations. Today, the phrase continues to hold deep meaning for tribal people dedicated to protecting their community’s health. Tribal leaders in many communities are committed to promoting the health of their people, especially their youth, in the face of new threats like Type 2 diabetes.

## Methods

### Diabetes: A “New” Disease Among Native People

Described as a disease of “acculturation”<sup>1</sup> and “civilization,”<sup>2</sup> diabetes increased eight-fold in the United States over the past 50 years.<sup>3</sup> However, diabetes was rare among American Indians until the 1950s,<sup>4</sup>—so uncommon that some believed indigenous people might be immune.<sup>5</sup> In the past 50 years, however, diabetes has become one of the most common and serious illnesses among American Indians and Alaska Natives (AI/AN).<sup>6</sup> The toll from diabetes is devastating, compounding a long legacy of loss of lands, culture, and language.

While disease rates differ by area, American Indians and Alaska Natives overall are 2.2 times as likely to have diabetes as non-Hispanic whites.<sup>7</sup> Until 1943,<sup>8</sup> diabetes was undocumented among people native to the Plains; however, in 1996, diabetes affected Plains people at a rate four times higher than non-Hispanic whites.<sup>9</sup>

Type 2 diabetes in youth,<sup>10</sup> once considered a “medical oddity,”<sup>11</sup> has become a disturbing phenomenon emerging in all US populations. It reminds some observers of the rarity of Type 2 diabetes in AI/AN people just 50 years ago. From 1994 to 2004, the prevalence of diabetes doubled among young (under 35 years) American Indians and Alaska Natives served by the Indian Health Service (from 8.5 to 17.1 per 1,000 population).<sup>12</sup>

If not controlled over time, diabetes can damage every organ in the body, diminishing the quality and length of life. One of the disease’s most disabling complications is end-stage renal disease (ESRD-DM), requiring dialysis two to three times per week or a kidney transplant. In

1999, American Indians and Alaska Natives had a national prevalence rate of treated ESRD 3.5 times greater than white Americans.<sup>13</sup>

### **Type 2 Diabetes Etiology and Prevention**

Obesity<sup>14</sup> and sedentary living<sup>15</sup> are powerful risk factors for Type 2 diabetes. The rise in obesity in the US (a 74% increase from 1991 to 2001) has set the stage for escalating rates of diabetes, evidenced by a 61% increase in diagnosed diabetes from 1991 to 2001.<sup>16</sup> Mounting evidence suggests that other physiological factors play important roles, including the intrauterine environment which may predispose some offspring to Type 2 diabetes.<sup>17, 18</sup>

Scientific evidence confirming the feasibility of preventing or delaying the onset of Type 2 diabetes was released in 2002 from the National Institutes of Health, which led a randomized clinical trial in a Diabetes Prevention Program (DPP). The DPP, with 3,234 adult participants including 171 American Indians, found that intensive lifestyle interventions that achieve and maintain a seven percent loss in body weight and 150 minutes of physical activity a week reduced the risk by 58%.<sup>19</sup> The DPP offers new hope to families and communities at risk for diabetes.<sup>20</sup>

There is a continuing need to document the descriptive experience of diabetes from the perspectives of indigenous people.<sup>1</sup> Without historical and sociological contexts, etiological explanations for chronic illness have been said to be “impoverished,”<sup>21</sup> focusing on the behavior of individuals rather than the risk-laden conditions that contributed to their development in the first place.<sup>22</sup> More attention must be paid to chronic illnesses rooted in historical legacies of dispossession of the lands, culture, and language of American Indians.<sup>23</sup>

### **Perceptions about Diabetes**

Illness explanations as either (1) natural or disharmonizing internal forces and personal choices, or (2) unnatural, external forces imposed from the outside, are sometimes offered by indigenous peoples.<sup>24, 25</sup> Diabetes has been viewed as not only “new,”<sup>26, 27</sup> but as an “outside”<sup>28</sup> or “unnatural” disorder,<sup>2</sup> and “a white man’s sickness”<sup>26, 29</sup> that requires “white man’s medicine.”<sup>30</sup> Diabetes has also been called “the new smallpox.”<sup>31</sup> In interviews with 33 Navajo people with diabetes, Huttlinger noted the difficulty of integrating the disease concept of diabetes, as an outside disorder, into lives which maintain an integral belief in the importance of harmony and balance.<sup>28</sup>

Older people remember a time when there was no word for diabetes in indigenous North American languages because it was unknown.

In more recent times, words for “diabetes” have been created in some indigenous languages. The Dakota word for “diabetes,” pronounced “SKOO-yah-wah-zon-kah,” links “sweet” and “sickness.”<sup>32</sup>

Diabetes is a common enemy in many indigenous communities, viewed as a trickster.<sup>33,34</sup> Linwood Tall Bull (Northern Cheyenne) notes that diabetes is also a teacher,<sup>35</sup> instructive about the interconnectedness of the health and welfare of people and the natural environment and the need to make decisions with a “long view” toward their impact on the future. Sayings such as “look to the mountain” by the Tewa Pueblo<sup>36</sup> and “for the next seven generations” in the warrior tradition<sup>37</sup> illustrate this view.

### **Traditional Knowledge Needed in these Times**

Traditional knowledge—traditional ecological knowledge and local knowledge—has been defined as a natural science grounded in lifetimes of intimate daily observation, habitation, and experience.<sup>38</sup> Traditional native knowledge is “knowing the country” (i.e., the environment and its interrelationships); it is holistic, rooted in the spiritual health, culture, and language of the people, notes the Alaska Native Science Commission.<sup>39</sup> “A blueprint for a way of life that has survived,” this local knowledge has been undervalued by conventional science.<sup>40</sup>

In many Western circles, local knowledge is assumed to have been made obsolete by the rapid developments of biomedical science, beginning with germ theory in the 19th century.<sup>21</sup> Restricting science to that of biomedical knowledge, however, not only blocks investigation into the root causes of illnesses, but can further demarcate lines between “experts” and local people.<sup>41</sup> Exclusive attitudes violate one of science’s most fundamental principles: to reject the uncritical acceptance of theories and the foreclosure of certain questions, even if they are uncomfortable.<sup>42</sup> Indeed, the word “research,” derived from the Old French “recherchier,” means “to look at again.”<sup>43</sup>

Diabetes is a complex chronic illness that deserves to be looked at again, with a broader perspective. It clearly “fails to yield to the fine, precise, dissecting lens of modern medical science,” note Joe & Young, citing Urdaneta and Krehbiel.<sup>2</sup> Exploring the web of interacting pathways of illness causation and respecting traditional knowledge about health may help to identify more relevant models to address the escalating diabetes pandemic.<sup>44</sup>

## Purpose of this Project

Western scientists have a great deal to learn from indigenous people about health protection, disease prevention and recognition of the inter-relatedness of health with all aspects of living. Avery wrote, "The entire Navajo belief system is based on maintaining harmony, and thus, preserving health in a kind of master preventive plan."<sup>45</sup>

Diabetes is a relatively new illness for American Indian and Alaska Native people. The knowledge of elders who have observed times when diabetes was rare as well as the present epidemic is precious. The purpose of this project was to understand, document, and support Lakota and Dakota elders' beliefs and knowledge about causal influences of diabetes and observations about prevention and health promotion. Because the people, the place and the history are important to this understanding, some background is provided.

## Standing Rock Nation: People and Place

Often the name by which an indigenous tribe or group refers to itself can be translated as "people" or "human beings."<sup>46</sup> The Oceti Sakowin people, reflecting the seven council fires, or tribal divisions, spoke three distinct languages: Lakota, Dakota, and Nakota.

Although the Treaty of Fort Laramie of 1868 had guaranteed the security of the Great Sioux Reservation, the US government annexed the Black Hills, sacred to the Oceti Sakowin people, from them in 1876 in pursuit of gold. In 1980, over 100 years later, the case was brought to the US Supreme Court which ruled for the people, stating that, "a more ripe and rank case of dishonorable dealing will never, in all probability, be found in our history."<sup>47</sup> The court awarded \$106 million to the tribes, who have never accepted the settlement based on principles. In 1887, the Dawes Allotment Act divided Indian lands to break up the land base on reservations. Individual allotments, "most of very poor quality," were made to the indigenous people, with the remainder opened to non-Indians for homesteading.<sup>46</sup> In the face of starvation, a new religion called the Ghost Dance emerged, offering hopes for survival and a return of the buffalo. More than 300 Lakota people who had gathered to practice the dance were massacred at Wounded Knee, South Dakota, in December 1890, by the US Seventh Cavalry, the unit led by General George Custer into defeat by the Sioux and Cheyennes at the Battle of Little Big Horn in 1876.<sup>46</sup>

The Standing Rock Reservation is home to the Hunkapapa Lakota people. It straddles the central border of North and South Dakota for more than 2.3 million acres. About 980,000 acres are trust land owned

by the tribe while the balance is fee land of non-Indian-owned school and township lands. About 50,000 acres is reservoir-taking area created by the Oahe Reservoir as part of a plan to control the Missouri River and provide water for electricity and irrigation by building dams north of the river. In 1948, the Army Corps of Engineers began constructing a dam in the face of some opposition from the tribe. One-quarter of the population had to evacuate their homes prior to the flooding of 160,889 acres of “prime agricultural lands.”<sup>48</sup>

In 1995, the reservation documented about 11,672 enrolled members. The average life expectancy for American Indians in the Aberdeen area (e.g., North Dakota, South Dakota, Nebraska, and Iowa) in 1994–96 was 64.8 years, compared to the US, all races, at 75.8 years. Almost 50% lived below the poverty level, compared to 13.1% for all populations.<sup>49</sup>

### Education

Boarding schools and mission schools, established to “civilize” Indian children, provided much of the education for adults over age 40. The first boarding school, Carlisle Indian School, opened in Pennsylvania in 1879 with the motto, “To kill the Indian and save the man.”<sup>50</sup> Current generations of youth attend schools governed by the tribe.

### Values

Everything is interwoven, interconnected, and related, and this principle is integral to the values of the Lakota and Dakota peoples. People brought up in strong extended families (“*tiyospaye*” in Lakota), with stalwart Lakota beliefs, are able to function in two worlds because they have a good sense of who they are.<sup>51</sup> Biological and sociological parents are embedded in the *tiyospaye*, through which all are related—hence, the prayer “*mitakuye oyasi’in*” (“relatives all”)—noted the late Beatrice Medicine, a tribal member.<sup>51</sup>

Four cardinal Lakota virtues are (1) sharing and generosity, (2) wisdom, (3) fortitude, and (4) bravery. The *tiyospaye* and the people’s intrinsic values and beliefs are tied to the native language and to key ceremonies like the Sun Dance, a three or four day dance in which the tribe gathers to ensure renewal of individuals, the tribe, and the larger world. The Sun Dance, banned by the US government until 1978, had reemerged in the 1950s and, about 1963, began to function as a revitalization movement for the people.<sup>51</sup>

Generosity and sharing (“*wawokiye*” in Lakota) are cardinal values among Lakota and Dakota people.<sup>46,51</sup> People brought up in these ways are instructed never to be stingy.<sup>51</sup> A tribal member, and occasionally



an outsider, is said to have “heart” if he or she shares in Indian beliefs and attitudes which emphasize generosity.<sup>46</sup> Another important virtue is “wowahwala,” which refers to peace, calmness, and the will to be unaggressive.<sup>52</sup> The tribe’s elders demonstrate the value of generosity by sharing knowledge and conveying it in a patient, unimposing manner that shows respect for others’ experiences and encourages people to seek their own understanding. Perceptions of the mysterious, sacred, and universal creative force, or the “wakan,” are intimately connected to all aspects of the culture and to respect. The term “Great Spirit” is translated from “Wakan Tanka,” “the great incomprehensibility.”<sup>53</sup> The name for children, “wakanyeja,” “the sacred ones,” emphasizes their “wakan” aspect.<sup>51</sup>

## Health

Health is a primary virtue of the Lakota people.<sup>52</sup> The word for health is “wicozanni,” referring to “life” and “humans,” and includes “mni,” for “water.”<sup>54</sup> Health for indigenous people is “located within a text of historical accountings, land, and the production and interpretation of traditional activities,” notes Adelson.<sup>55</sup> The land (“makeoce,” pronounced “makeoche” in Lakota) molds the people<sup>56</sup> and is central to health. “American Indians hold their lands—places—as having the highest possible meaning, and all their statements are made with this reference point in mind,” said Vine Deloria, Jr., a late member of the tribe.<sup>57</sup>

People native to the Northern Plains were described by the European explorers who met them, including Lewis and Clark, as vigorous and strong. Because there was little immunity to contagious diseases, exposure to diseases of the Europeans (e.g., whooping cough, influenza, diphtheria, measles, chickenpox, and cholera) had devastating effects. The scourge of smallpox killed thousands of people, reducing several tribes to 25% or less of their original number.<sup>46</sup> Destruction of traditional sources of food, especially the buffalo, by the US Government, created famine and starvation. In 1889, deaths exceeded births.<sup>46</sup>

The changes in diet that occurred with reservation life have continued to influence health. Rations, later called commodities, provided by the government since the 1880s, usually consisted of low-grade meat or salted pork, flour, salt, sugar, coffee, candles, and soap. These were distributed meagerly because they were considered to be supplemental until the people were sustained by agriculture. To stay hunger, rations were used by the people to create foods such as “fry bread,” flour deep-fried with lard.<sup>31</sup> Today, commodities of surplus agricultural products are selected and managed by the tribe.

## Methods

### Interview Participants

The community's elders are respected as "the teachers"<sup>54</sup> who carry a "burden of goodness" of the hope and of the prophecies that good things will be returned to Indian people.<sup>58</sup> The tribe's CHR program identified elders from the eight districts, respected in their communities for their wisdom and moral standing. Many more elders were identified, both men and women, who would have made important contributions to understanding about health protection and diabetes prevention. However, the small size of the study (limited to 9 participants) curtailed opportunities to interview more elders. At the beginning of the interviews, participants were offered a gift of ceremonial pouch tobacco and asked to share their insights about health and diabetes prevention. Participants signed an informed consent. Their contributions were to remain anonymous unless they chose to disclose their identities. Each elder was provided a copy of her transcript and audiotape.

The participants were nine Lakota and Dakota tribal women elders ranging in age from 67 to 84 years old; their mean age was 72.5 years, and their median age was 69 years. All of the participants had grown up "in the country" in log homes or, in a few cases, tipis on the Missouri River or its tributaries. Several of the elders and most of their mothers and aunts had attended off-reservation boarding schools. Each participant had family members with diabetes and four had diabetes themselves. All of the women were or had been married; five of their husbands had had diabetes, four of whom had died.

### Interview Questions

In-depth interviewing allows for questions needing "deep" information about matters such as lived experience, values and decisions, cultural knowledge and perspectives.<sup>59</sup> The questions were identified and refined by the authors and staff members of the CHR and Diabetes programs. The primary questions and prompts for the semi-structured interviews are shown in Table 1. The interviewer was the lead author who had been first connected to the tribes' CHR and Diabetes programs through ongoing diabetes education collaborations since 1997.<sup>60</sup>

### Narrative Analysis

Stories can help people and communities to organize their experiences and connect them to a healing and meaningful purpose.<sup>61</sup> People often use storytelling to explain illness because it provides a way to give meaning to the experience and to place it in context. Illness narratives—

**Table 1. Interview Questions and Prompts**

Main Questions	Questions or Prompts for Participants
To what factors do Lakota and Dakota elders attribute diabetes?	Could you please talk about the changes in health and in diabetes you have seen in your lifetime?  What things do you think have contributed to the rise of diabetes among your people? Among the world's people?
What narratives do these elders offer related to health protection and diabetes prevention?	What do you think helped to protect people from illnesses like diabetes in earlier times?  What foods do you think helped people to stay healthy? Are there special things we should understand about food that we may be overlooking?  Could you talk about feeding of children?  How important is physical activity in terms of staying healthy?  What about the land should we understand related to health?  How could people be strong and healthy again? And prevent diabetes? What should the community do to protect children?
How do these elders express their concern and share their wisdom?	How important is it to share memories and knowledge about health with your people? With outsiders?  Are there stories you think your people should hear to help protect their health?  What would you most like to communicate to your people about health and prevention of illnesses?

the stories that always surround episodes of illness and healing for those who live through them—are not limited to an individual's story, but also can include the experience and healing of a collective social body, or community, that has been oppressed.<sup>62</sup> Explanatory models provide a way to organize illness narratives to gain understanding of the ways in which an illness episode is interpreted and understood by those affected. Explanatory models have been used by many researchers in work to understand personal models of diabetes.<sup>63, 64, 65</sup>

The elders' responses to the interview questions were embedded within their narratives. For analysis of responses to the first question about attributions for diabetes, narrative stories were classified according to the tendency to attribute illness to either externalizing, outside forces or to internalizing influences aligned with personal choices. The integrated, holistic nature of thought and speech shared by these elders was continuous throughout the dialogues. While integrated themes were not readily distinguished into categories, careful analysis of transcripts allowed the four genres identified in Frank's work on explanatory models<sup>62</sup> to help organize the narratives:

1. Restitution narratives emphasize positive responses and outcomes and consist of stories of coping with illness, rebuilding and re-moralization.
2. Chaos narratives are stories of disorder, distortion, and fragmentation and are characterized by anguish, threat, and uncontrollability.
3. Quest narratives emphasize a search for either cure or meaning and transcendence within and through illness.
4. Testimony narratives are explicitly moralized forms of stories that seek to bear witness or to give voice to those who suffer.

## Findings

The holistic orientation to health, illness, and prevention for these elders was evidenced in the stories they told, always interwoven with their indigenous language. As one elder said when referring to various categorical tribal programs, "It all should be interrelated, just like the spoke of a wagon wheel. If you have one thing broke in it, it can't go around." Diabetes was not consistently distinguished from other threatening conditions, with many responses being inclusive of other conditions. Another elder clarified, "I'm not only talking about sugar. I'm talking about what's going on. It causes heartache, you know?"

The experience of illness also was not bound by personal experience but included the network of tribal members. All of the elders used the words, "we" and "our" often, and one spoke of "my Indian people." The compassion of the elders for their people and the desire to help to prevent problems like diabetes, if they could, was evident throughout the interviews.

Respect underpinned all of the discussions about health, including respect for the gifts of the Creator, including food, water, and land. The related value of spirituality was considered to be essential to health by the majority of the elders.

## Attributions for High Rates of Diabetes

The elders spoke of diabetes as an "outside" disorder. Although many of the "internal" attributions for diabetes, such as being overweight and sedentary, are in agreement with biomedical explanations for diabetes, the participants' explanations plumbed deeper "root" causes of rising diabetes rates. When respect is absent, "manmade problems" abound, affecting the people's health. A lack of respect contributes to sicknesses and other problems because individuals stray from the ways

that are “true.” Failing to respect food is tied to the lingering external influence of boarding schools as well as to modern societal trends that commercialize high-calorie convenience foods. Respect and foresight are also essential to environmental decisions that have an impact on the people’s health.

Related to respect were frequent expressions of gratitude to the Creator for life and gifts given. Having gratitude is “giving back thanks,” according to one elder. Relying on God for help and guidance was a prominent theme; words such as “the great power,” “the Great Spirit,” “Creator,” “Lord,” “Jesus,” “Wakan Tanka,” and “Tunkashila” were used interchangeably. “There’s only one God,” one elder stated. Another said, “God Creator is the One that created us all to help each other.”

### **Diabetes from the Outside: Chaos Stories of Loss**

References to diabetes as an unnatural, external disorder that played no part in the history or culture of the people were threaded throughout all of the interviews; elders commonly referred to it as “this diabetes,” “that diabetes,” and “this manmade diabetes.” The observation that diabetes is “new” voiced a perception that its appearance had been unexpected. “It just came all of a sudden, and it was like it went to everybody,” one elder said.

#### **Loss of Land**

“Water is life,” noted several elders. Through chaos stories, the elders told of the “washing away” of their homes in the 1950s, their longing for the clear water of the Missouri, and their fears about the safety of the water supply today. The elders noted that drinking a lot of water as a traditional healthful practice has been displaced in modern times by drinking sugar-laden products such as “pop” and other sweetened drinks. The elders were concerned by the recent “outside” influence of advertising for these products and trends that encourage people to eat indiscriminately and stay inside and watch television. These external trends influence people to make choices that put them onto “messy roads,” said one elder.

The loss of fertile lands that contained wild beans and turnips growing along the river, as well as many medicines that “went under,” accompanied the loss of ways that were remembered fondly for fostering hard work and family togetherness. One elder spoke of lingering grief and stress and another spoke of “sadness and hurt” in relation to the loss of foods, activities, and cultural ways after “they moved us here, all together.” Another elder described returning with her aunt to her homeland

after the water rose over it, saying, "We just cried." The elders related youthful memories of the log homes they shared with their parents and grandparents and how, when these homes were covered with water and people had to move to higher ground, the free electricity promised for the newly built government homes never materialized. Several elders questioned the fairness of the decisions to allow controlled flooding and subsequent decisions about compensation. One elder described confronting the US government officials in the late 1940s about the damage she had observed:

"We lived in a log house, but we didn't have to worry about paying electricity. We had wood to burn for the winter, to cook with, and to keep warm... Certain dirt we'd haul and we'd daub it up the log house, and it will be warm in the winter time.... And the lights, we used kerosene or a gas lamp if we were rich. And we had the rich, fertile land where we put our gardens in and we ate from the garden. We helped ourselves. Corn and beans, potatoes, onions ... not the wild onions on the prairies, but these were along the river, and their blades were three-cornered. They grew about this tall, and on top they had yellow seeds, flowers. And we used them for cooking. But grandpa would take that and use that for cold medicine, like a poultice under lungs if they're sick in the winter time, coughing.... We lost that. There's nothing now. There's many medicines that we lost, that grew along the river. We could use it [now]. They robbed us of everything. They all died out. The seeds can't grow, you know...and we didn't realize to go and collect them and start them. See, we're so in a hurry to get out of that bottom land to move...so they robbed us of that. And even, I told the Army Corps of Engineers, I said, "You guys, you're listening to that President or whoever is giving you the orders to make dams on our Indian reservation." We depended upon everything that grew along the river. The big trees so that we can make log houses for ourselves, the trees that bared fruit, even the little tiny mice, deer mice, that collected our beans.... And they built these dams to annihilate us.... They're slowly doing that because we solely depend upon this ground."

Several elders talked about the loss of the buffalo, confinement to reservations, and the resulting helplessness imposed by the government and how these had continuing effects on the health of the people. Although reservation life brings ongoing problems, including isolation and joblessness, one of the elders stated that she disliked the "brainwashing" that conveyed the message that reservation land was the worst land.

She felt that this despairing attitude contributed to health problems and that it is important to understand that the land is good and can “always sustain life.” This belief was echoed by several elders, one of whom said, “The land is good and will be healthy to us if we use it in the right way, the way we’re supposed to use it.”

### **Boarding Schools**

Boarding school experiences were “mixed,” as one elder said, leaving legacies that were both negative and positive. Several mentioned that the goal of the schools was to “civilize” the children when they were, in fact, “already civilized.” They described the grief of students forced to be away from home and how habits learned in boarding schools were at odds with their cultural values. Several elders maintained that these discordant ways, the isolation from families, and the scarcity of food had contributed to intergenerational problems that continue to affect the health, including obesity. One elder described her husband’s experience:

“He said, ‘When I went to boarding school, they’d put us all at the table—so many of us little boys and then the big boys. The food was all put out on the table, like family style. And the big boys would take all the meat, and leave all the other food they didn’t want to us little boys. So if you could grab something, you would grab it and would try to eat it as fast as you could.’ And I always thought that that was the way he ate. He ate very, very rapidly. I come from a family where my mother never went to boarding school, and I never went to boarding school. So food had always been kind of a part of us. But not in a way where we had to worry that there wouldn’t be enough, or that someone would take it away from us. And I think that many of our people who were forced to go to boarding school went through some kind of experience like that with food. Some people kind of deny that it happened that way, but I think it happened with probably many of our people, which is why when there is food, they all just hurry to eat it.”

Other elders associated boarding school habits regarding food and possessions with adoption of the unfamiliar trait of “stinginess.” They contrasted this new trait with their traditional ways of generosity, suggesting that the new ways influence current choices, including food intake. One elder said:

“When I grew up, my grandma used to make me go stop wagons that were coming down the hill, and bring them home so that we could feed them and tend to their horses, and then

they'd be on their way. 'Cause there was a road that passed our house by the river, the riverbed, along there.... So she said, 'There's a wagon coming; go stop them and go over there and bring them back.' So that's the way we were [when] we grew up. But in boarding school, everything of yours was labeled. Even your comb, it was labeled, and you weren't supposed to touch other people's things. You had lockers that you locked and you had your key around your neck. And so we were taught not to touch, and not to lend other things. And so I thought, 'They taught us to be selfish.' We were taught not to share.... We had to march to school, we had to march to dinner, and sometimes our meals weren't exactly what we were used to, but we had to learn how to eat because our matron sat there and said, 'You have to eat everything that's on your plate before you can get up.' So some things that we didn't like, we learned to like, like lots of butter."

Another elder recounted:

"My mother went to boarding school, but she was already a young woman; she was soon to be 17 years old when she went to Bismarck. I remember she talked about how they never had enough meat to eat at the boarding school.... I'll never forget what she [an older friend of her mother] told us, she said, 'I got a sore eye. Oh, my eye was sore. So, finally this nun took me, and she rolled up this bread in milk, and put that on my eye, and covered it with a bandage. As soon as I got out of her sight, I just took that bread with milk, and ate it. That's how hungry I was.' Another one of my mother's friends said when she went to boarding school, 'I worked in the bakery. In those days, we used to wear bloomers and I would stuff all of these biscuits inside that elastic around my knees and passed them out to my friends. Who cared that they came from my bloomers? We just ate them.' We would laugh, too. But think about the seriousness of that happening to them. With something that is so essential—food."

### **Other Outside Influences**

Several elders mentioned the influence of alcohol in relation to health. Viewed as an "outside" context introduced by the dominant culture, one elder vehemently questioned, "Why did United States Uncle Sam make this liquor?" Another elder noted that alcohol and tobacco use, adopted by soldiers during the Korean and World Wars, became popular among their people when the soldiers returned home with these



new habits. On the other hand, drinking alcohol was also included on the list of “natural” or “internal” attributions by several elders who implied that abusing alcohol is also a personal choice that can be associated with not having a “strong mind.”

Words are powerful in this culture, and a number of the elders suggested that being told that one had a history of diabetes or was likely to get it could invite its eventual development. The risk factor of genetic inheritance or family history, commonly listed in diabetes literature, was “not believable,” said one elder, because many people had no earlier relatives with diabetes. Another declared:

“People say, ‘You’re at an age where you’re going to get diabetes.’ They say it’s genetic that we get diabetes. My husband said, ‘My grandma and grandpa weren’t diabetics,’ so it’s not inherited. I think if they never say that again it would be good.”

### **Internal, Natural Attributions for Diabetes**

Although diabetes was viewed as an outside disorder, early in the interviews participants acknowledged the physiological contributions of obesity, poor nutrition, and physical inactivity to the development of diabetes. One of the elders used metaphors for physical inactivity—“couch potato,” “being loggy,” and living in a “push-button generation.” Each of the elders talked about the value of physical activity, describing it in words including “being active,” “work,” “hard work,” and “manual work.” Several elders used the term “junk food” to describe less healthy food choices. Drinking “pop,” or soda drinks, a practice the participants abhorred, was seen as a personal, disharmonizing choice that is mediated by societal trends from the outside. A number of elders noted that “it takes a strong mind” to recognize and resist temptations offered by clever and enticing advertising. One elder expressed her hopes that her grandchildren would steer away from “that messy road of eating junk food.”

The elders who had diabetes themselves offered personal responsibility explanations for its onset. Their attributions were internal, relating to disharmony in their lives at the time of its onset. Several said they were overweight when they were diagnosed. Although she considered herself physically active in caring for many young children with few resources, one elder said she had gained a lot of weight when her children were young. She tied her weight gain to being sad and overwhelmed with the responsibilities of raising children after the early death of her husband. This elder ended a narrative about her diagnosis by saying that she was “ashamed” that she had developed diabetes, adding, “I

thank God for my long life. The sickness I have is all my fault, too much eating the wrong food. That's a sin against my body."

An elder who had a serious complication of diabetes blamed herself for not taking diabetes seriously when she was diagnosed more than 20 years ago. She spoke of "forgetting, in the rush of life," the values and teachings from her own elders and not realizing until too late the extent to which she had compromised her health. All of the elders with diabetes spoke of their present-day high level of physical activity and how they prepare and eat good foods, especially traditional foods, like soups, which several had cooking on their stoves during our visits. They attributed their present good health to these lifestyle habits and to having followed medical advice.

Most of the elders mentioned lack of food preparation as a major contributor to poor health, including diabetes. "We don't cook our food anymore. We depend on the can opener," said one. The elders recalled that protective foods were "simple foods." Narratives included ways of gathering, preparing, and storing foods, including gathering wild turnips and using these, squash, onions, and lean meats like venison and pheasant, in soups.

Finally, most of the elders felt that overlooking traditional early infant foods contributed to the development of health problems later in life. Several elders noted the importance of teaching children about good foods. One elder recalled the practice of mothers and grandmothers carefully holding a piece of squash or bean in the mouths of older infants so they could suck on them while the woman said "waste" (pronounced "washteh"), a Lakota word meaning "good." The elder contrasted this early childhood guidance in healthy nutrition to unwise practices in present times, in which some children are given fried snacks and sweetened drinks early on.

The elders also expressed their beliefs in the value of breast-feeding, not only for its physical benefits, but for the strong and enduring emotional bonding it fosters between mother and child. One elder described her efforts to encourage breast feeding among new mothers in her family.

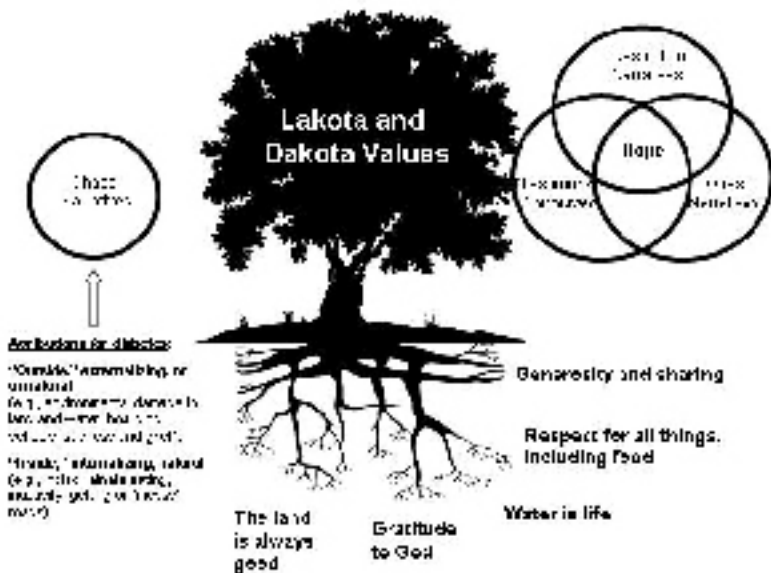
## **Ways that Protect Health**

Storytelling serves as an indirect, non-threatening strategy to communicate messages through a teller who allows the listener to interpret the material in his or her own way.<sup>61</sup> The elders folded advice within stories as they offered external and internal attributions for the increasing prevalence of diabetes. By sharing sad stories (chaos) balanced with

stories of restoration and hope (restitution), the search and appeal for solutions, healing, and meaning (quest), as well as moral and cultural teachings (testimony), these elders identified ways that protect health and prevent diabetes and associated problems. Figure 1 provides a conceptual illustration that includes the 'root' attributions for diabetes, along with the chaos narratives, balanced by the restitution, quest, and testimony narratives that offer instruction and hope for the future.

Protection from diabetes in the past was attributed to "hard work," eating traditionally prepared foods; respect for all things, including food; being generous rather than stingy; gratitude to God; and prayer. The elders largely agreed on these factors and on the attributions for their own improved health. Most of the elders appeared to have adapted their traditional ways to certain modern conveniences. For example, some elders use electric crock pots to make soups and artificial sweeteners to flavor some foods. The suggestions offered by the elders are consistent with conventional medical advice. The depth and context of what these elders deemed to be related to health, however, are much richer and dimensional. For example, Western professionals tend to instruct about eating "the right" or "proper" foods whereas the elders' discussions of food centered on respect and gratitude for it.

**Figure 1. Display of the Balance of Attributions for Diabetes and Stories of Loss (Chaos) with those of Healing and Hope (Restitution, Testimony, Quests), Grounded by Cultural Values**



## Restitution Narratives

The elders offered restitution narratives that typically pertained to healing through traditional medicines and prayer, in addition to modern medicines. One elder said, "We're very different. We know who we are, and our spirituality is so meaningful. Prayer is very powerful." Another elder reflected, "Praying helps a lot. It puts peace in your mind because you know, sooner or later, we're going to die, but we hurry it along by not taking care of ourselves. You know, that's a true fact. We hurry along our death by ignoring advice."

In explaining how their people stayed healthy until the past half-century, all of the elders described how "we helped each other" and found ways to "heal ourselves." One elder recounted, "Seems like we took care of each other. When somebody was sick, all these neighbors, they'd come and take turns helping. Somebody would hang a lantern outside to show that someone's sick in that household. That was really nice. Everyone helped each other. When somebody butchered, they gave everybody a share of their meat."

The elders were encouraged by the tribe's support for traditional ways, including the efforts of the tribe's Diabetes and CHR programs. One said:

"The wake-up call [of] our way of life is coming back. All these programs, they never used to start with a prayer. Now they begin with a prayer. And then the ways of life have been instilled in the minds of the Indian people...like "don't drink a lot of pop, don't eat a lot of junk food, eat the right kinds of food, and drink a lot of water."...They're teaching the children now, mostly in schools and in programs. So these things are coming back. And then the elders have been utilized. They've been asked to speak here and there... So these are some of the things that I call the waking call of all Lakota people. It's going to benefit our young generation."

## Quest Narratives

Narratives categorized as quest narratives were some of the most spiritually grounded; several elders sought spiritual intervention for the sake of curing diabetes. One of the elders wished that spiritual leaders would, "put their whole hearts into it and find a cure," or that they would go on a vision quest so they could help their people. Quest narratives also included seeking spiritual guidance to help people keep their minds "strong." Several of the quest narratives emphasized survival and the importance of tribal sovereignty. One elder stated, "I always remem-

ber what my husband said: ‘We’re survivors; no matter what the United States government will do to us, remember we are survivors.’” Another said:

“The treaties are here for life because they were signed; they smoked the pipe, the chiefs or our relatives, and we stand on our treaties. Because of treaties, the government promised to provide the ... free health ... and we were supposed to get free electricity. That never happened. So all these promises that were made are all called broken promises. And then one of the senators or somebody said that they don’t believe in the treaties, saying, ‘They’re too old.’ So [our leaders] said, ‘Well, we don’t believe in your Constitution either; that’s too old.’”

### **Testimony Narratives**

The stories classified as testimonies usually provided a teaching point, sometimes a moral one. A number of the elders mentioned that they tend their own gardens. Several talked about gathering plants like sage tea to prevent and treat diabetes. One elder said:

“My mother used to tell me, ‘Your children come first. They are your valuable gift so you should raise them right.’ So I always say, ‘Those are your crops.... If it’s getting weedy, kind of fix it, get the weeds out, the bad weeds out. And let it grow by itself. If your crops grow, you’re going to get a good crop....’”

Three elders told a story of learning to gather “earth beans” from a cache created by mice near the riverbank. Grandmothers and aunts taught younger women to find the mice trails leading to the mounds. The women took corn and fat to trade with the mother mice, along with a traditional song asking for the exchange, and with such respect and reciprocity, they were not bitten as they gathered the special beans for their own families, leaving some for the mice families, as well.

### **Sharing Wisdom**

Humility is a hallmark of the type of teaching an elder gives. As one said, “I’m not trying to be somebody.” Most of the elders have been called on to participate in educational venues about health and diabetes prevention and control in their communities, including tribal education videos and local radio programs. Several of the elders with diabetes share poignant stories to help others avoid the sadness they have known because of diabetes. One of the elders said, “If you don’t share it, it will spoil. Like water that stays, it will become stale. But a stream is always giving life.”

## **Grounded in Values and Meaning: The Place of Place**

Respect, the most fundamental of values for American Indian and Alaska Native peoples,<sup>66</sup> grounded the stories offered by these elders as they talked about health promotion and diabetes prevention. Respect for food, water, the land, and the work they entail, as well as for each other, were recurring themes. The emphasis on the goodness of these gifts, despite all that has happened, was revealing. "The land is always good," one elder declared as she closed a narrative about the move to the reservation in her grandmother's time and the more recent flooding of the bottomlands. Another affirmed, "The land is the provider." On the other hand, lack of respect was seen as a key attribution for diabetes and illness, both on the part of individuals making personal choices and on the part of more powerful forces that, without foresight, have "not used the land as it should be used."

"Place," defined as "where groups of people have invested themselves—their thoughts, their values, their collective sensibilities and to which they feel they belong,"<sup>67</sup> was illuminated in the stories shared by the elders. The "place of place" in health and well-being may be uniquely understood by people who have lost land, language, or culture.<sup>23</sup> Michael Bird noted, "Dispossession is at the root of health disparities."<sup>23</sup> Like other people for whom their "places," "the commons," and "the land" are invested with meaning and memories of their ancestors, these elders emphasized group survival over self-interest, and long-term sustainability over short-term gain.<sup>68</sup> One of the elders' primary concerns was for the health of future generations and, to that end, they generously shared their wisdom, in hopes that their experiences might be of benefit.

## **Implications: The Place of Story**

The onset of the escalating Type 2 diabetes epidemic some 50 years ago represents an ongoing post-traumatic stress response for many indigenous communities.<sup>28</sup> Unbounded by the experiences of those who are actually ill with diabetes, the experience of tribal communities living with this relatively recent phenomenon reminds us that the social course of illness, the personal and collective experiences of illness, and awareness of the disease's potential impact on future generations are all connected.<sup>21</sup> Reducing the illness experience to one of individuals, with a focus on cognitive processes that affect individual behavior change, contributes to a regime of knowledge in which the actual social, historical, and environmental roots and distribution of disease have been "misrecognized"<sup>62</sup> and solutions overlooked. Similarly, the disruption of people's relationships with their homelands in terms of health and

diabetes rates has not received much attention.<sup>69,70,71</sup> Yet the eroding of land bases reduces gathering and growing traditional foods and physical activity associated with acquiring these foods.<sup>72</sup> The importance of land on which children can explore, discover, and play for the mental, physical, emotional, and spiritual health of future generations must also be considered, for all people.<sup>73</sup>

Through stories, the elders identified the root causes of illnesses like diabetes—balancing the sad, chaotic stories with humor and stories of healing and restitution, quests for cures and meaning, and testimonies with moral instruction. Traditional stories, such as the one about “earth beans” shared by several elders, gently remind listeners about reciprocity and generosity (the story can also be found in a recording).<sup>74</sup> Also voiced in the stories were memories of resourcefulness and admiration for their ancestors’ resilience and wisdom in sustaining their culture despite persistent survival challenges. The humorous story shared by an elder contrasting the age of the treaties to the age of the Constitution, for example, was part of a longer narrative about cultural survival. Community efforts based in the culture have begun to include reviving language and culture instruction, reinstating traditions that will benefit young people, and culturally-based messages and programs of the tribal health and diabetes programs.

At the heart of the oral tradition shared by many American Indian and Alaska Natives is a deep belief in the power of words to affect people and to empower visions for the future.<sup>61,67</sup> A powerful story can engender a shift from hopelessness to a new, empowering vision for the future.<sup>61</sup> A positive, meaningful story allows the listener to recreate his or her own “story” for meeting new challenges, allowing internalization of knowledge and recall of messages that are internally consistent with a person’s existing values.<sup>75</sup>

The elders of the Standing Rock Nation provided insightful stories that lend a broader view of some of the root contributions to diabetes and to the importance of cultural values in program efforts, grounded in respect for the land; the gifts of food, water, and work; and mutual support. Their appreciation for their communities’ traditional ways is reflected in diabetes programs across the country, described by the I.H.S. Division of Diabetes Treatment and Prevention<sup>76</sup> as well as local and regional publications. Elders across the country have contributed not only to the success of these programs, but also to new communication resources espousing traditional values, such as honoring the gift of water for health.<sup>77</sup> The wisdom of elders in health and diabetes prevention is the theme of the “Eagle Books,” stories by Georgia Perez, illustrated by

Patrick Rolo and Lisa A. Fifield, with the Centers for Disease Control and Prevention, I.H.S., and the Tribal Leaders Diabetes Committee (available at [www.ihs.gov/diabetes/resources](http://www.ihs.gov/diabetes/resources)).<sup>78</sup> Elders are involved in reading and elaborating on these stories in many communities.<sup>79, 80, 81</sup>

“Don’t be fooled—stories aren’t just entertainment,” wrote Leslie Silko in her book, *Ceremony*. “They are all we have, you see, all we have to fight off illness and death. You don’t have anything if you don’t have the stories.”<sup>82</sup> Communities have powerful stories to fight off illness and death because elders, who knew a time when diabetes was rare, are sharing knowledge that can represent a blueprint for survival.<sup>40</sup> Many elders are reservoirs of knowledge and hope who share the vision: “so that the people may live.”

## Acknowledgments

The authors wish to express their deepest respect and gratitude to the elders and co-workers of the Community Health Representative and Diabetes Programs who so generously shared their wisdom, insight, guidance, and time, in hopes that they might help their people. We would like to thank the Tribal Council Health, Education, and Welfare Committee of the Standing Rock Nation for their review and approval of this participatory project. Special thanks are offered to Randy Bear Ribs, Bernadine Broken Leg, George Brave Bull, Larry Brown, Chris Burd, Jolene Cadotte, Melda Crow Feather, Randy Dog Skin, Rosalyn Fast Horse, Daryl Iron Shield, Gerald Iron Shield, Elaine Keeps Eagle, Virginia Leaf, Aubrey Skye, and Waylon Yellow Earrings for their assistance.

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