DAWN WANNAMAKER SATTERFIELD
"So that the people may live -- Hecel lena oyate kin nipi kte:" Lakota and Dakota Elder Women as Reservoirs of Knowledge about Health Protection and Diabetes Prevention
(Under the direction of LAURA K. MCCORMICK)

Type 2 diabetes is spiraling upward around the world, ensnaring adults and youth from societies in the throes of industrialization. Over time, uncontrolled diabetes leaves in its wake people facing renal failure, blindness, or heart disease, and communities with little hope for preventing this "new," chaotic phenomena. Westernized lifestyles (e.g., physical inactivity, processed foods), in concert with human genomes yet being mapped, are recognized explanations for the escalating prevalence. The web of causation, however, is woven by complex interactions with environmental, sociological, and historical roots.

Reservoirs of adaptive capability reside in the knowledge systems of indigenous elders who have, in their lifetimes, known the rarity of diabetes and the epidemic's impact on their people. The purpose of this 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 among 9 elders served as the primary method to answer these research questions: 1) To what connected factors do Lakota and Dakota elders attribute diabetes? 2) What narratives do they offer that reveal health protection and diabetes prevention as culturally constituted practices, both in the past and the present? and 3) How do these elders express their concern and share their wisdom? Secondary methods included exploratory fieldwork, observation, and documentary photography.

This study revealed diabetes as an "outside," or externalizing, disorder for which attributions were both externalizing (e.g., environmental damage, sadness, boarding school eating habits) and internalizing, involving personal imbalance (e.g., inactivity, indiscriminate eating). Chaos narratives were balanced with narratives of restitution,

testimony, quests for cures and meaning, and health wisdom. Emergent themes included: the “place” of place, local knowledge, storytelling, and memory in emotional, mental, spiritual, and physical health; the goodness of the land; water as a gift of life; respect for all things, including food; gratitude to God; generosity and sharing. Health messages need to be rooted in understanding and cultural values, including hope.

INDEX WORDS: Diabetes, Indigenous knowledge, Local knowledge, Indigenous elders, Ethnoecology, Biomedicine, Conventional science, Story, Narrative, Health, Health protection, Health promotion, Diabetes prevention, Culturally constituted practices, Cultural values, Illness.

“SO THAT THE PEOPLE MAY LIVE -- Hecel lena oyate kin nipi kte:” LAKOTA AND DAKOTA ELDER WOMEN AS RESERVOIRS OF KNOWLEDGE ABOUT HEALTH PROTECTION AND DIABETES PREVENTION

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Stories of the life they live,
The pain they felt,
The tears they cried,
The cards they were dealt.
The dreams that died.

Laughter of the sweeter times,
The dreams they hoped,
The gifts they gave,
The words they spoke
The prayers they prayed.

Tradition perseveres,
After all these years
The strong ties hold
As the stories are told,
A part of their good hearts.

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neighbors can draw strength, knowledge and support. John Eagle Shield, Director of the Program, helped me realize early on that we shared "the same heart and many values" (Smith et al, 1997). I thank him for his open mind and heart and wise instruction, the subtleties of which I often catch only later as I drive on down the road. John's family made me a relative, creating treasured connections that now include my own family.

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CHAPTER 1

INTRODUCTION

Advocates for public health apply population-based approaches to help promote health and prevent illness in communities. To communicate our vision and objectives to stakeholders we often employ the literary device of metaphor with words such as "foundation, support, construct, build, strengthen" and light-based metaphors like "to enlighten" and “to spotlight”- so entrenched in our discourses that we overlook the philosophical and value commitments within them (Lakeoff & Johnson, 1980). Metaphors organize sociological work to help "make sense" and privilege one order of "facts" over another because they so clearly enable communication. A matter of central concern can hinge on a well-chosen metaphor that holds the key to illustration and understanding about what is meaningful in people's lives, add Lakeoff and Johnson. Using a metaphor to describe metaphor, Richardson calls it the "backbone of social science," which, like a spine, link parts together into a coherent whole (1999, p. 519).

Among the Lakota and Dakota people there is a prayer and rallying cry that links people together to promote health. “Hecel lena oyate kin nipi kte” is translated to English as “so that the people may live.” In the 1970s an elder of the Standing Rock Sioux Nation, Mrs. Josephine Hollow, created a banner with this vision to mark the finish line of the nation’s annual sobriety run. Today this phrase holds significant meaning and memories for many tribal people dedicated to protecting and restoring the health of their people.

To do the work of this dissertation I kept this phrase in my heart. For the conceptual framework of this dissertation, I, less gracefully, used metaphors and figurations, some of which mirror more complexity than coherence (St. Pierre, 1997) though they were intended to help create shared understandings. These include the spider's web, story, cultural "worlds" of similarities and contrasts negotiated with the help

of "dragonfly" mediators, and “consilience,” or the unity of knowledge which can occur when inductive facts and theory are linked across disciplines and sources of knowledge (Wilson, 1998). These represent just the “tip of the iceberg” of the metaphors heard in the narratives revealed by this ethnographic field experience and all the rich, deep meanings that could be drawn from it. Following the presentation of my conceptual framework, I have provided a summary and a brief description of the organization of the remaining chapters in which metaphors, figurations, and stories continued to unfold.

Need for the Study

In 1995, the world's people with diagnosed diabetes numbered 135 million (4%), a dramatic increase from 30 million in 1985. By the year 2025, it is projected that 300 million people will have diabetes (5.4%), with a 170% increase expected to occur in industrializing countries (Narayan, Gregg, Fagot-Campagna, Engelgau, & Vinicor, 2000). The United States (U.S.) as a whole experienced a six-fold increase in diabetes over the past 40 years. A recent national analysis revealed a 49% increase in known diabetes, including gestational diabetes, in the U.S. in the past decade (Mokdad et al., 2001), and a 76% increase among people in their 30s (Mokdad et al., 2000). Rates of diabetes among American Indians and Alaska Natives (AI/AN) are at least three times that for U.S. residents at large, according to the Centers for Disease Control and Prevention (CDC, 1998).

The actual numbers of people with diabetes are even higher because another 30 to 50% of cases are undiagnosed (Narayan et al., 2000). Almost all of the rates represent type 2 diabetes, long considered a “middle-aged” disease (Mazur, Joe, & Young, 1998). In a surprising turn of events in the history of diabetes science, epidemics of type 2 diabetes have been reported among children and adolescents in the U.S. and around the world (e.g., Japan, Libya, Bangladesh, Hong Kong, Australia). This alarming phenomenon is emerging in all U.S. populations and in countries adopting increasingly Westernized lifestyle patterns (FagotCampagna et al., 2000).

The history of diabetes can be viewed as an unfolding story with ancient origins dating back to documentation of a rare condition, which tended to occur among the well-fed rich, according to the Egyptian Papers of the Dead about 1500 B.C. (von Egelhardt, 1989). In the past century, the burden of type 2 diabetes has paradoxically settled on socioeconomically disadvantaged people (CDC, 1992). It is recognized by a growing number of observers as a disease of acculturation (Olson, 1999), prompting some to question the "price" of civilization (Joe & Young, 1993).

Type 2 diabetes meets the criteria for a postmodern view of complexity theory, with its etiology and sequelea lying in large or sufficiently complex systems that interact richly, openly, and non-linearly including with the environment (Cillilers, 1999) in the broadest sense (e.g., physical, sociocultural, political). The shocking phenomena among youth approaches a state of chaos, defined by Stewart (1989) as stochastic behavior, still governed by laws but not by linear methods (Masterpasqua & Perna, 1999). It might be argued that earlier onset of type 2 diabetes is still linear, but this new phenomena is lawless, challenging agencies and organizations to quickly rewrite literature and scramble to develop policies to help schools recognize and care for diabetes. The interactions with the environment are little understood, and often assumed to center on the immediate, familial and social environment, not the physical environment.

In the face of rising challenges to health for the world's people as a whole, and for Native North American peoples, in particular, posed by this complex, chaotically changing phenomenon, it is important to acknowledge and gain understanding of local knowledge and practices that helped to protect people from diabetes until relatively recent times. At the 1995 Third International Conference on Diabetes and Indigenous Peoples in Winnipeg, Canada, a consensus emerged that there was a dearth of descriptive research on the experiences of Native people around diabetes (Olson, 1999). Additionally, there is a “missing tradition” of descriptive research among women

(Reinharz & Chase, 2002). These gaps in the literature have contributed to the lack of existing models or frameworks for integrating knowledge from various domains in ways that respect local, indigenous knowledge in the ways of health protection and illness prevention. Without recognizing this knowledge, the "story" of diabetes cannot be understood or new paths for action embarked upon.

Purpose of the Study

The purpose of this ethnographic study was to document, understand, and support Lakota and Dakota elders' beliefs and knowledge about health protection and diabetes prevention. In-depth interviews were conducted among nine Lakota and Dakota women elders from the Standing Rock Nation. Naturalistic depth was added by the researcher's field experience over the previous four years in learning from community health representatives and other tribal members, and elders in this Plains Indian nation. In many ways, this experience and working at the CDC in Atlanta, Georgia, provided multiple sites for reflection and holistic theorizing about the information gleaned and insight granted. The hopes for documenting and understanding ways of knowing about diabetes causation and prevention in local communities include those that conventional practitioners will become more sensitive to the strengths of local knowledge, understand better the root causes of and solutions for diabetes, and communities will be supported to use their reservoirs of knowledge about survival to take social action for diabetes prevention among their people (Travers, 1995).

An *a priori* theory upon which this study was built is the value of indigenous cultural knowledge and representations for understanding interacting factors contributing to diabetes causation prevention - viewing the whole of these as part of a story with teachings for the future as this chaotic condition rises around the world. In this theoretical stance, conventional medicine's focus on the human body, disease identification, and objectivity was suspended in favor of efforts to gain a more comprehensive picture of this global challenge to human health.

Research questions

The research questions for this study were: 1) To what connected factors do Lakota and Dakota elders attribute diabetes? 2) What narratives do these elders offer that reveal health protection and diabetes prevention as culturally constituted practices, both in the past and the present? and 3) How do these elders express their concern and share their wisdom?

Conceptual Framework

For this dissertation, the conceptual framework is built on a view of diabetes as a story, rapidly unfolding with new twists, turns, and characters. The broadest theme in the story of diabetes is the question, "is diabetes trying to speak to us?" In this view of people and phenomena, like diabetes, as stories, all of the information and data become context for the story, making it more fully and accurately understandable for others (Nagai-Jacobson & Burkhardt, 1996). At the heart of context-centered knowledge is action, or action research, which aims to solve real-life problems in context (Greenwood & Levin, 2000).

Stories can help people and communities to organize their experiences and connect them to healing and meaningful purpose (Carter, Perez, & Gilliland, 1999) focused on Lakota and Dakota elder women's narratives around diabetes, both personal and collective, to help make sense of this phenomenon, understand its meanings to people and to communities, and to suggest collaborative actions which are faithful to the context of the stories.

The value of listening to peoples' stories for understanding the global story of diabetes

Language is a centerpiece (Richardson, 1999) of this work, linking participants and researcher into story as it connects meaning, social reality, and issues of power and representation. Simon Ortiz, in introducing his book of short stories, Men on the Moon, (1999) said:

> Story speaks for you. Story speaks for me. Simply put, story speaks for us. There is no other way to say it. That's a basic and primary and essential concept. Story has its own power, and the language of story is that power. We are within it, and we are empowered by it. We exist because of it. We don't exist without that power. As human beings, we as personal and social cultural entities, are conscious beings because of story, no other reason. (p. iix).

Stories are always and in every way, partial, notes Steedly (1993). They are on one hand explicitly partisan and on the other, incomplete and fragmentary. They speak for themselves, make no claims to narrative authority over another and accept no other's claims over them. The memorableness of a story, as opposed to the transience of information, is rooted in its lack of explanation.

Knowledge about how to interact with the land is passed from generation to generation through stories (Austin, 1998). Nabhan (1997) cites Leslie Silko's words that land-based cultures see "the world and themselves within that world as part of a continuous story composed of innumerable bundles of stories…" (p. 63). Carter and colleagues (1999) applied Silko's words from her book, Ceremony (1977), about the way stories bringing people together in loss or grief, "Don't be fooled - stories aren't just entertainment. 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" (p. 181).

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 empower visions for the future (Carter et al., 1999; Basso, 1997). Because of respect for the power of words, and of silence, language is considered sacred and to be used in ways that count for good. Words are to be taken seriously and to be remembered. An economical, lean and often tentative narrative manner is common to many Native North American speakers, notes N. Scott Momaday (1997), perhaps because the risk of loss is constant and language is never to be taken for granted. "A song, or a prayer, or a story, is always but one generation

removed from extinction. By the same token the storyteller...who takes it upon himself to speak assumes the responsibility of speaking well, of making his words count. The spoken word is the means by which he must keep alive his way of life. There is no other possibility of cultural survival" (p. 28, 29). The oral tradition narrative, adds Ortiz (1999), is still the main way in which human cultural knowledge is conveyed today.

One of the most basic courtesies speakers display is to show respect for their hearers by refraining from "speaking too much" so that they may build freely and creatively on the speaker's depictions, using their own picturing abilities (Momaday, 1997). Chief Joseph (quoted in Nerburn, 1999) of the Nez Perce, Wal-lam-wat-kin band, in Washington, D.C., pleading for his people a year after submitting to the U.S. military during their unsuccessful flight to Canada, said, "...it does not take many words to tell the truth" (p.153).

Tribal narratives, or stories, are remembered as survival, where "archshadows of tribal consciousness and the shadows of names and natural reason are overheard," notes Vizenor (1994, p. 157). Within tricksters like coyote and raven, he finds "the wild ironies of survivance, transformation, natural reason, and liberation" (p. 146).

There is, in general, great complexity, and seeming chaos, involved in the causality and care of type 2 diabetes. Within, however, lies the context of individual and collective stories to speak for us of what has happened and to us what we should know for the future. These stories are also ones of survival, and sometimes transformation.

The culture and stories of conventional medicine and public health

The culture, or shared meanings, of conventional medicine, too, is based in stories, beginning in ancient Greece (USDHHS, 2001). And public health, a field concerned with the health of an entire population, is rooted in the 19th century story of a doctor, John Snow, who identified the source of cholera in a community through geographically referenced data and used maps rhetorically to convince others (Goodman & Wennberg, 1999) Yet the integrated stories of cultures, meanings, and history are often forgotten

when scientists focus on the pressing challenges posed by disease epidemics. Holistic health, which maintains a "salutogenic view (which) considers health a dynamic search for existential equilibrium" (McKinlay & Marcau, 2000, p. 26), scientists tend to rely on the more dominant, mechanistic concept of medical science focusing on disease states and on factors that predispose people to, are associated with, or increase the chances of entering a disease state. This more pathogenic view has become a cornerstone of health worldwide, grounded in evidence acquired through scientific and empirical methods that hold objectivity to be the highest standard (USDHHS).

Public health is broader than conventional medicine's focus on diagnosis, treatment, and etiology of cause of an illness to include disease surveillance, health promotion, disease prevention, and access to and evaluation of services. This approach is based on the conviction that it is inherently better to promote health and to prevent illness before it begins (USDHHS, 2001, p.12), ideally an "upstream" versus a "downstream" view of prevention (McKinlay & Marceau, 2000, p. 26). Because public health approaches focus on the promotion of protective factors, it should also train research lens onto key protective factors such as resilience, including strong communities, spirituality, and other factors reflecting social capital.

A view of cognitive systems and interacting factors using the spider's web metaphor

A core belief of indigenous peoples around the world is grounded in the intimate, moral link between humankind and the earth (Momaday, 1997; Naranjo & Swentzell, 1989; Csordas, 1989; Morgan & Weedon, 1990; Morse et al., 1991; Adelson, 1998; Bird, 2001). The intricately constructed spider's web has often been used to illustrate the interconnectedness and reciprocity, or interdependence, of all life (Gutierrez & Kendall, 2000; Kreiger, 1999; Nazarea, 1999; Cajete, 1999). Perhaps most recognizable are the words attributed to Chief Seattle (quoted in Bird, 2001) as he addressed the United States government in the 1850s during treaty negotiations involving the Duwamish, Suquamish

and other Puget Sound tribes, "Man does not weave the web of life; he is merely a strand in it. Whatever he does to the web, he does to himself" (p. 3).

The intricacy of the web "reflects overlapping from behind" from the influence of generations of elders," notes Turner (1989). Healing, which for indigenous peoples transcends curing to embrace balance in physical, spiritual, emotional, and mental dimensions, "gathers webbed strength from all its sources," continually providing reinforcing evidence for interconnectedness (p. 20).

Instructors in the field of epidemiology, the study of patterns of disease among populations, use the "web of causation" as a tool to reinforce to students the complexity of chronic diseases, including diabetes, which entail diverse causal and contributory pathways intersected by specific risk factors and outcomes. Yet while the metaphor enlivens guidance to look for multiple causes and effects among the implications of host, agent, and environment, some critics are dismayed by epidemiology's focus on "risk factorology" (McKinlay & Morreau, 2000, p. 26) and individual risk factors, perpetuating the idea that risk is individually rather than socially determined and limiting the examination of causality (Jack, Liburd, Vinicor, Brody, & Murry, 1999).

Kreiger (1994, 1999), herself an advocate for stronger theory development in epidemiology, notes the web metaphor's limitations in illustrating the varying strength, or thickness, of the various "risk" factors that contribute more causality than others, or that gain strength as they dynamically interact with others. She recently suggested the metaphor be expanded beyond the sticky web and its unlucky catches to embrace the sum of environmental or "ecosocial" factors that influence the location of the webs in the first place -- the number of webs, the density of trees, and the ratio of flies to webs.

Prior to these applications of the web metaphor in the social sciences, Clifford Geertz (1973) had noted humankind's "own role in constructing webs of significance," adding, "I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning" (p.5).

Such mentorship, emerging in the 1960s, led many social scientists, including anthropologists, outside the unquestioned acceptance of grand theories of culture to the study of symbols, meanings, and cognition (Marcus & Fisher, 1996), how power is generated and diffused (Weiner, 1995), and today, permits "blurred genres" of blended disciplines (Geertz) involved in the study of human events to engage in postmodern thinking that rejects simplistic, or reductionist, accounting and opens doors to contextual, interpretive study. Additionally, because diabetes is a complex condition dynamically interacting with social, cultural, historical, and physical environments in both its causation and care, tracing relevant links may help individuals, families, and communities to find meaning and purpose in the cultural strengths, resilience, and local knowledge.

Threats to broader, more interpretive, culturally-based thinking in terms of health and illness, illustrated by the web in this writing, are very real in this new millennium, however. Local, state, and national health programs must try to respond to increasing demands from stakeholders for immediate outcomes, within a short time period, that prove the value of economic investments. Sought-after answers meet the criteria for proven associations of the scientific method, introduced in 1965 by Hill -- magnitude, consistency, specificity, dose-response, and biological plausibility (McKinlay & Marceau, 2000).

In just the past decade, a paradoxical twist of the web metaphor has been frenetically spun as "the web" has come to refer, most often, to computer technology that makes a wide range of information more readily available than imagined even five years ago. The electronic "web" is just one example of society's escalating expectations for instant knowledge. Demands for instant gratification, convenience, "supersizing," and economic growth of certain industries are reflected in larger societal trends greatly influencing the lives and health of the world's people (Sclosser, 2001). Ritzer (1998) coined "the McDonaldization thesis," to refer to the Americanized emphasis on an

"increase in efficiency, predictability, calculability, and control through the substitution of non-human or human technology" (p. vii). While modeled and spearheaded by the fast food chain, the term is inclusive of many modern phenomena that reflect the trend.

Even more recently, scientific technology, advancing at a frenetic pace, is generating exciting promises for the future, including gene therapy to treat diseases almost as quickly as the human genome is completely mapped. Some see in this initiative, however, a type of biophysiologic reductionism that could prompt a return to the germ-theory approach still dominating Western medicine (McKinlay & Marceau, 2000; Kunitz, 1994). Such solutions hold potential to "misrecognize" the social roots and distribution of disease, as well as overlook or exacerbate the disruptive and morally ramified effects of illness on the life-worlds of those affected (Kleinman & Seeman, 2000, p. 232). In the course, scientists may forget that "what is medically relevant is culturally determined" (Adair, Deuschle, & Barnett, 1988, p. 4).

On the other hand, there are encouraging signs that bioscience, or conventional science, is coming to value an emerging body of evidence that health outcomes are influenced by social factors (e.g., unemployment, social support, racism, community cohesion), collectively known as "social determinants of health" (Marmot & Wilkinson, 1999; CDC, 2001). The literature on contextual issues such as these is scant, however, and a national conversation on such issues has yet to be started (Jones, 2000). Until the causal pathways between social determinants and health outcomes are better understood, conventional science will likely continue to legitimize only specialized forms of knowledge considered more objective with high evidence quality than experiential knowledge archived by people over centuries (Gitlin & Russell, 1994). Monopoly of the definition of knowledge reflects a prevailing worldview among scientists, policymakers, and others, who, certain of successful scientific and technological achievements, tend to devalue the ideas, experiences and collected wisdom of others (Smith et al., 1997).

In maintaining the hegemony of conventional science, proponents fail to realize that the health sciences, too, are socially constructed, and reflexively related to society and culture. There are strong cultural, economic and political reasons that health research takes the position that it does. The core of postmodernism introduces doubt that any method, discourse, or theory can be claimed as "the truth" (Richardson, 1999, p. 517). Postmodernist thought and careful analysis of our values and approaches, as scientists, could challenge the position that science is the objective accumulation of value-free knowledge with the moral authority to discount other contributions because they are nonlinear or outside the accepted realm (Cunningham-Burley & Boulton, 2000).

Virginia Nazarea (1999) wrote:

> "The reduction of dynamic, situated systems of understanding embedded in history, politics, and environment to homogenous, pan-human categories and systems of classification bereft of any meaningful context has distracted us from the implications and the repercussions of different latitudes and points of view on the local capacity for self-determination, on the nurturance of diversity, and even more fundamental, on creative choices balancing persistence and change (p. vii.).

We need enlightenment to change the direction of the story of diabetes. For this to happen we must not be distracted from valuable sources of adaptive knowledge because these do not fit into the hegemony of modern science.

Local, traditional knowledge is needed for understanding the contextual story of diabetes

The value and importance of local knowledge is assumed, in many circles, to have been made obsolete by the rapid developments of biomedical science, beginning with the germ theory in the 19th century (Kunitz, 1994) and continuing to modern times as genetic codes are being unmasked and technology spirals forward. Such attitudes violate one of science's own fundamental principles to reject the uncritical acceptance of theories and models (Martin-Baro', 1994). These assumptions not only block investigation into root causes, including social determinants of health, and knowledge that has served for

centuries, but also further demarcates lines between experts and local people (LeCompte & McLaughlin, 1994), breaking threads that might have led to collaboration.

The word "research," derived from the old French, "recerchier" means "to look at again" (Smith et al., 1997, p. 7). Joe and Young (1993) cite the observations of medical anthropologists, Urdaneta and Krehbiel (1989), that an obstruction to understanding diabetes has been the narrow focus of many researchers, although the disease clearly fails to "yield to the fine, precise, dissecting lens of modern medical science" (p.7). Inquiry into certain concrete questions tends be foreclosed because of scientists' discomfort with the answers, noted Martin-Baro' (1994). Looking at things again, with a wider lens, could help bring into clearer focus the multifactoral, interacting pathways to causation, knowledge, and collaboration needed to address the escalating epidemics of type 2 diabetes in youth and adults. Qualitative research, "open to new ways of seeing the world" (Krueger, 1998), provides a path for such inquiry.

Local ways of knowing, sometimes called traditional ecological knowledge (T.E.K.), or ethnoecology, is a natural science grounded in lifetimes of intimate daily observation, habitation, and (Nazarea, 1999; Wolfley, 1999). Revealing the inextricable link between the land and the people and the interconnectedness of all things (Nazarea, 1998), it bears "more than a fanciful resemblance to the genome of a species - that genome is a blueprint for a way of life that has survived" (Hunn, 1999, p. 26). Both culture and genes, according to Nazarea (1999), “are repositories of coded information essential to adaptation and survival” (p. 73). Cultural memories are according to Nazarea (1997):

> … our priceless legacy precisely because it took so long to shape them. Their value extends well into the future, especially in these changing times. There is another …coincidence that we need to bear in mind…. like many priceless treasures, (culture and memories) are fragile. They do not persist for long without care. They wither with neglect. (We refer to them) as slippery germs (p. vii).

Harold Conklin introduced ethnoecology as a science in 1954, in part hoping to instruct Western scientists about traditional knowledge's internal coherence and environmental and sociocultural adaptiveness, since they had dismissed it as inferior. A tool of Western science, ethnoecology emphasizes the role of cognition in framing human behavior, along with respect for an irreplaceable repository of cultural diversity. The field strives to systematically and ethically preserve cognitive systems including categories of knowledge in ecosystem conservation, classificatory systems, cultural heritage, and use of plant and animal species (Nazarea, 1999). Preserving local knowledge is critical notonly for its value to present and future human life and because it is situated in local, rather than global knowledge, making it very fragile (Hunn, 1999)

The most significant reservoirs of adaptive ability for the survival of the world's peoples depend on the preservation of indigenous knowledge and cultural diversity, notes Nazarea, stating, "in the long term, maintaining diversity is the only guarantee of stabilizing the intricate web of life..." (1998, p. 3). Women in particular, she adds, have paid attention to diversity because they have struggled to find ways to help their families to survive and adapt over centuries.

Informed partnerships at the service of communities must be the basis for all ethnoecological fieldwork, observed Nazarea, who developed a system for cultural memory banking, a systematic documentation of knowledge associated with traditional crops and plants (1998). The ethical stance of all who document local knowledge must be built on close examination of ethical principles. The issues and the ethics are particularly weighty when it might involve identification of indigenous medicines or foods. Because of increased awareness of scale of past and present misappropriation of knowledge and biogenetic resources by science and industry, safeguarding intellectual property rights, or traditional resource rights, as they may be called, has become a central issue in expression of indigenous self-determination, and a basis for greater political autonomy and economic self-sufficiency (Posey, 1999).

To help promote human health and ensure survival in the face of global epidemics of diabetes, all cognitive resources are needed. Bioscience, or conventional science, is obviously rooted in traditional ecological knowledge, although these connections are not always acknowledged. The challenge now is to avoid creating further divides between bioscience and local knowledge, or traditional ecological knowledge, replacing the tendency to separate with methods for respecting and cooperatively analyzing local knowledge.

The foundation of this dissertation holds a panoramic view of spiders' webs and their environment as a metaphor acknowledging the complexity of the causation, cure and prevention of diabetes epidemics. The image will also reflect the interconnecting and overlapping construction of local knowledge steeped in thousands of years of observation and imbued with the shared experiences of humans invested in endurance (Strauss & Quinn, 1997). At the conceptual travel, the movement across the web is from the margins, crossing to the center, rather than from the center outward -- based on the assumption that the viewpoint of modern science has been most privileged and centrist. A view from the outside margins, rather than the conventional, centrist location, positions us, notes Gitlin (1994), to better examine complexities of situations and of doing activist research. Attending to perspectives and stories will be the primary means of gathering, connecting, and communicating the interacting links of observation and meaning offered by participants.

The image of the web's interacting links could shift the spheres of influence, conventional science and local knowledge, not toward assimilation, but toward "consilience," defined by Edward O. Wilson (1999) as the linking together of inductive facts and theory across disciplines to create a common groundwork of explanation. He illustrates four domains, which are intuitively closely connected but in reality stand apart in the contemporary academic mind. (Figure 1.1), resulting in confusion. Concentric circles toward the central meeting point illustrate our placements in an increasingly

unstable and disorienting region for it is closest to the intersection where most real-world problems exist and fundamental analysis is needed. We must make this clockwise tour, Wilson contends, to unite knowledge for wise decision-making.

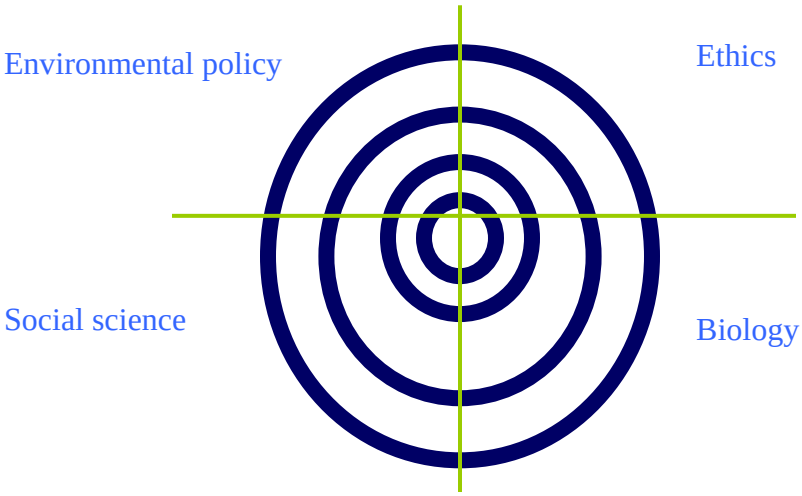


Figure 1.1: E.O. Wilson's example of the needed linking of science and learning for consilience of knowledge (1999, adapted from p. 9).

Another term that provides a metaphorical description of the processes involved in seeking unity of thought, or consilience, is that of "bricolage," used by qualitative researchers to describe the methodology of emergent construction across disciplines that is strategic, reflexive, and aimed at seeking solutions (Denzin & Lincoln, 1994). With these images before me, the sought-after clarity of a framework of consilience and the methodological foundation of a bricolage, as well as the work of being in the field, the purposes of and multiple methods for this work continue to unfold, reflected in more detail in Chapters 3 and 4.

Navigating borders of both worlds of knowledge - conventional and indigenous science

The spider's web provides an apt metaphor for the complexity of the multifactoral factors involved in causation and the multi-level, multi-system approaches needed to improve outcomes for chronic diseases including diabetes (Ellis,

1998). Similarly needed is "consilience" in linking domains of learning, with the goal of moving closer and respectfully to the center of real world problems.

Early in my work in Indian Country, I began to hear the expression, she, or he, “walks in both worlds," usually spoken with a measure of respect to describe a person who negotiates their native culture and Western society in a balanced way. Garrett described, "walking in two worlds" as the literal or symbolic process of being able to move between worlds (1998). References to Native people who "walk" or "live... in two worlds" are common (Cohen, 1994; Viola, 1998; Irvine, 1998; Adair et al., 1988; Johns, 1999) and the meaning has become shared so sufficiently that this shorthand expression no longer requires clarification, notes Peshkin (1997).

School educators involved in developing cross-cultural science curriculums have developed a conceptual basis for their work based on observation of the efforts of young students from indigenous cultures to study modern science, noting that students must navigate "cultural borders" when their worldview varies significantly from a Western-based scientific worldview (Phelan, Davidson, & Cao, 1991; Phelan, Davidson, & Yu, 1999). The perspectives of indigenous North American peoples are often at odds with the sphere of conventional science education, which tends to reflect Western cultural icons of prestige, power, and progress (Aikenhead, 1997).

The adoption of incongruent information does not replace a student's core beliefs, but rather represents "collateral learning" (Tippins, 1999). The transitions indigenous students make to secure collateral learning vary on a continuum from "smooth," "manageable," "hazardous," and "impossible" to negotiate, depending in large part on the degree of acculturation they bring to their classrooms (Phelan et al., 1991).

Similarly, conventional health science represents a subculture, replete with academic knowledge and technological advances but often characterized by fragmented specialization and failure to consider holistic approaches. Although the World Health Organization (W.H.O.) defines health as a "state of complete physical, mental, and social

well-being," not confined to the absence of disease (1948), public health continues to be defined by biomedicine (University of Edinburgh, 1989), is still influenced by the germ theory (Adair et al., 1988; Kunitz, 1994; McGrath, 1998; Anderson & Funnell, 1999; Geronimus, 2000), positioning disease intervention strategies in a "downstream" as opposed to an "upstream" location (McKinlay & Morreau, 2000).

Despite the contrasts between the worlds of conventional and indigenous, or local, knowledge, the spheres share parallels. Wisdom, states Basso (1997), "consists of a heightened mental capacity that facilitates the avoidance of harmful events by detecting threatening circumstances when none are apparent" (p.130), embodying prevention. Avery (1991), a Navajo physician noting the parallel values of prevention in both worlds, added, "the entire Navajo belief system is based on maintaining harmony and thus preserving health in a kind of master preventive plan" (p. 2271). Practicing prevention, occasionally referred to as "little medicine," can help avoid the need for "big medicine," or remedies and drugs required to treat acute or serious illnesses (Meuninck, 1995).

Another parallel between local knowledge and currently advocated diabetes care is an acknowledgement of the role of personal accountability in preventing and treating illness, which relates to the interest of some conventional scientists in therapeutic readiness (Adelson, 1996) and Prochascha and DiClemente's transtheoretical model, or stages of change (1992). A Northern Cheyenne tribal leader explained to me that readiness is part of the healing process, "the person needing help must go to the healer and meet him halfway" (Satterfield, 1999). Dialogue about health and illness often includes underlying themes of harmony and balance (Avery, 1991; Huttlinger, 1995; Wing, 1998). Wing's research comparing modern and folk healing concepts revealed parallels in each of these domains: origins of illness; harmony and balance; motion; symbols; and family and community. Only modern medicine's separation between the mind and body had no relation to folk healing concepts.

The interface of the two spheres, or "worlds," in navigating ways to share information and resources is visually illustrated in Figure 1.2. Affective skills may enable practitioners from either sphere to help others navigate borders (Murphy, Satterfield, Anderson, & Lyons, 1993). The dragonfly, a creature who lives in two worlds - born in the water and travels in the air - serves as the figuration or symbol for these mediators in my illustration. In part because of the tendency of Western health science to privilege itself, the history of colonization, and the perception that conventional research has been exploitive in its studies of Indian people (VanDevelder, 1998; Sevilla, 1999), Western practitioners must be particularly mindful and respectful of the integrity of the borders from the world of local knowledge, with the terms of navigation for permeability from outsiders to be determined by the community.

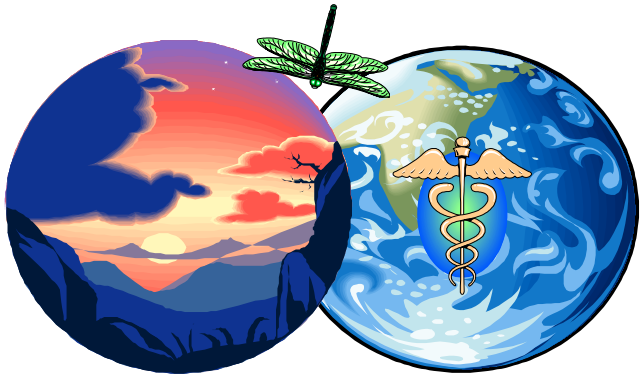


Figure 1.2: Borders of “Two Worlds” of knowledge – local and conventional, or bioscience. Mediators can facilitate navigation of knowledge between worlds.

Interfacing the worlds by respecting both

My conceptual framework highlights the need for a wider lens and more contextual focus for viewing the causality of diabetes, respectful negotiation of borders to acknowledge contributions of all knowledge in the baffling identification of contributors to current diabetes epidemics, and consilience in uniting the fields of knowledge for eventual action. Integrating sources of knowledge that share commonalities as well as

distinctions can strengthen the weaknesses of each, benefits which are similarly described for combining qualitative and quantitative research (Steckler, McLeroy, Goodman, Bird, & McCormick, 1992). The factual, reliable outcome data of quantitative methods are enriched by the depth that lends understanding to the issues, provided through qualitative research.

The larger goal is for conventional practitioners and researchers to begin a more inclusive process of investigation into human health problems, reducing the divide between scientists and community people's ways of knowing about health. The interdependence of diverse environmental, human, and spiritual relationships in health and disease causation and the role of health protection knowledge through generations of adaptation and survival, almost always described in relation to health by indigenous peoples, provides an example of knowledge conventional science has tended to overlook. Strong national leadership reminding professional colleagues of the value of such cognitive knowledge is needed. An orientation to co-learning and respect for local and bioscientific ways of knowing could have implications for development of more relevant, collaborative interventions at many levels.

In the meantime, collaborative examination of causation of diabetes in the context of historical and intergenerational grief, injustice, posttraumatic stress, and rapid changes in the physical environment (Bullock, 2001; Huttlinger, 1995; Lang, 1989) must occur. "Seldom do we understand the dynamics of traditional systems sufficiently well to predict what results of changes may be," observes Johns (1999, p.158). Now that we are facing health outcomes that are consequences of rapid environmental changes on a global basis, we need to learn more about the effectiveness of traditional systems as we garner the wisdom of multiple cognitive systems, merging these to find present-day solutions.

Diverse disciplines, sufficiently blended, can guide conventional scientists to interact more inclusively and respectfully with other systems. The fields of anthropology

and qualitative educational research provide participatory methods for the study of the cultures of science, with examination of issues of power and representation.

The still emerging field of health promotion also provides groundwork for embarking on new routes. Larry Green (1999), a pioneer in health promotion program planning, points out that science cannot be claimed as the primary guide for workers in multicultural health promotion. To achieve the reciprocity and balance that multiculturalism and equity demand, a combination of philosophical commitment, cultural knowledge, human sensitivity, and open communication must be brought to bear.

The field of public health in general lends support to a broader, interactive interpretation of causation and collaboration, illustrated by the occasional use of the web metaphor in epidemiology. A number of studies and consensus-building efforts in public health and health promotion fields have results in identification of core values for practitioners and dimensions of community capacity and sustainability (Freudenberg et al., 1995; Goodman et al., 1998; Lee, Fucillo, & Wolf, 2000; Fawcett, Franciso, Paine-Andrews, & Schultz, 2000). Public health's core principle of social justice can fortify us with the courage to use science for the benefit of people, but not wait on its final answers to engage people in the solidarity of a common struggle (Smith et al., 1997). This philosophy also supports efforts to engage with people in a common struggle to transform ethnocentric social structures, honor community knowledge about health protection, and eliminate societal and economic barriers of access to health maintenance and quality care (Duran & Duran, 1999).

Finally, the effect of local knowledge across cultures is additive, serving as a monument to our common humanity (Hunn, 1999). Local knowledge has provided the roots for growth of the relative newcomer, conventional or bioscience. Uniting the sciences and mobilizing their advocates to fight for a common goal of social justice (Stringer, 1996) could fortify the monument, helping to curtail epidemics of type 2 diabetes by acknowledging intricate pathways of causation, respecting ways of knowing

about health protection, and collaborating for action on all fronts -- local, national, global, economic, and political. As social scientists, stated Martin-Baro' (1994) our concern should "not be so much to explain the world as to transform it" (p. 19).

Summary

In this first chapter, I attempted to describe the need for this study, followed by a description of the purpose of the study and the research questions. The conceptual framework features a view of the history of diabetes as an unfolding story using a metaphor of webs in which many factors are seen to be reciprocally interacting in causation and responses to diabetes. A concept of interfacing worlds of conventional and indigenous knowledge is presented. The borders of these worlds can be negotiated with the assistance of cultural brokers who help to foster understanding. Consilience between the domains of knowledge for understanding and action can be promoted when knowledge from each domain is heard and respected.

Organization of the Remainder of the Dissertation

The next chapter, Chapter 2, provides a review of the published literature in diabetes, including epidemiology, pathophysiology of types 1 and 2 diabetes, complications of diabetes, known physiological risk factors, and the science available on primary prevention of diabetes. This review will be followed by a review of evolving knowledge of social and ecological determinants of health among American Indian people and a review of the literature on qualitative inquiry about diabetes among Native peoples.

Chapter 3 provides an overview of the methods employed in the study, including a description of qualitative research and the research design and process. Details of the primary and secondary methods of data collection and data analysis are provided. Chapter 4 includes a description of the research setting in a broad sense of the meaning of “reservation” so that discussions about land base, people, history, and values are included.

A description of the participants is provided, including some background information on their native language.

Chapter 5 highlights the findings of the grounded theory analysis of the discourse of the elders about attributions for diabetes and for health protection and their concern for communicating preventive messages to their people. Discussion of the findings and implications for practice for both health care advocates and for the tribe will be presented in Chapter 6.

CHAPTER 2

REVIEW OF THE PUBLISHED LITERATURE

This chapter presents a review of the literature on conventional, bioscientific knowledge about the rates of diabetes and its complications, particularly in American Indian and Alaska Native populations, the pathophysiology of diabetes, and the recognized risk factors. Less information is available about the social and ecological determinants of health and diabetes among indigenous North American people and published qualitative studies about perceptions of diabetes, its root causes, and recommendations for action are relatively few in number. This body of knowledge has been largely and regrettably ignored. This chapter, reflecting a review of published literature, cannot, therefore, present a balanced report of conventional and indigenous scientific knowledge, although an attempt to represent the latter in as much detail as possible has been made.

Rising Rates of Diabetes in the United States

In the last decade type 2 diabetes has become newsworthy as awareness grows that it follows on the heels, by only a few years, rising trends in overweight populations. This condition is emerging among children and young people, and the incidence is spiraling upward around the globe in industrializing countries. The past four decades have seen a sixfold increase in the prevalence of known diabetes in the United States (Figure 2.1). A recent analysis of data from the Behavioral Risk Factor Surveillance System (BRFSS) of the Centers for Disease Control and Prevention (CDC) found that the percentage of people in the U.S. who have diabetes, including gestational diabetes, increased from 4.9 to 7.3 percent from 1991 to 2000 (Mokdad et al, 2001). Figure 2.2 illustrates the increasing rates in states over the past decade. Among people 30 to 39 years, there was a startling 76% increase in the past decade (Modkad et al., 2000.). Type

2 diabetes accounts for about 95% of all cases of diabetes, the burden of which is disproportionately borne by AI/AN people, African Americans, Hispanic/Latino Americans, and Asian and Pacific Islanders. More than 18% of U.S. adults over age 65 have diabetes (CDC, 1998).

Diabetes was rare among American Indians and Alaska Natives prior to the mid-point of the previous century (West, 1973). However, in the past 50 years diabetes has become one of the most common and serious illnesses among people of many AI/AN nations (Narayan, 1997). The age-adjusted prevalence of diagnosed diabetes among AI/ANs over age 20 years is almost three times (10.9%) – and up to four times (15.9%) in the Plains tribes – that for non-Hispanic whites (3.9%) (CDC, 1998). These rates are based on available Indian Health Services (IHS) data; only about 60% of AI/ANs seek IHS services so these rates are probably underestimated.

We are indebted for much or our understanding of the natural history of diabetes to the Akimel O'odham (Pima) people in southern Arizona who participated in longitudinal epidemiologic studies since the 1960s (Gohdes, 1995). More than 50% of these adults over age 35 have type 2 diabetes, the highest reported rates of diabetes in the world (Knowler, Saad, Pettitt, Nelson, & Bennett, 1993). The rates are highest in offspring of parents who themselves developed diabetes at an early age.

Figure 2.3 shows a map prepared for I.H.S. using the Geographic Information System (GIS) with each black dot representing an I.H.S. patient known to have diabetes; it should be noted that the higher concentrations in the Southwest may be in part related to the aggressive screening programs conducted there.

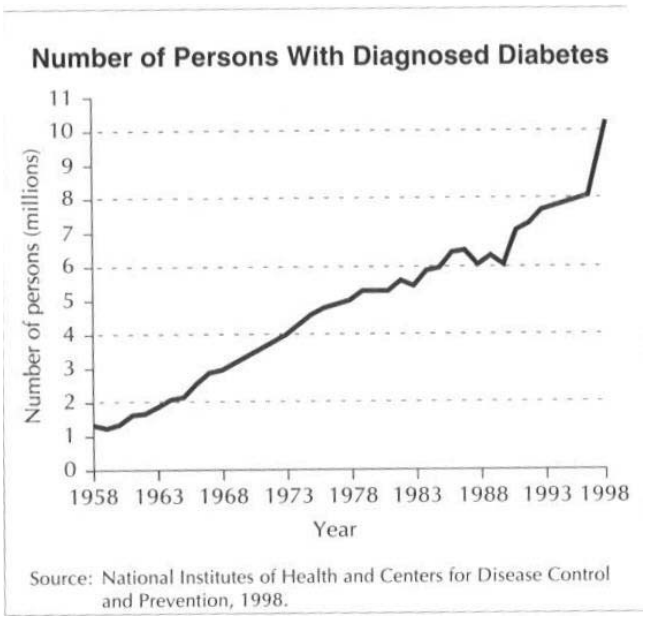


Figure 2.1 Numbers of Americans (in millions) from 1958 to 1998.

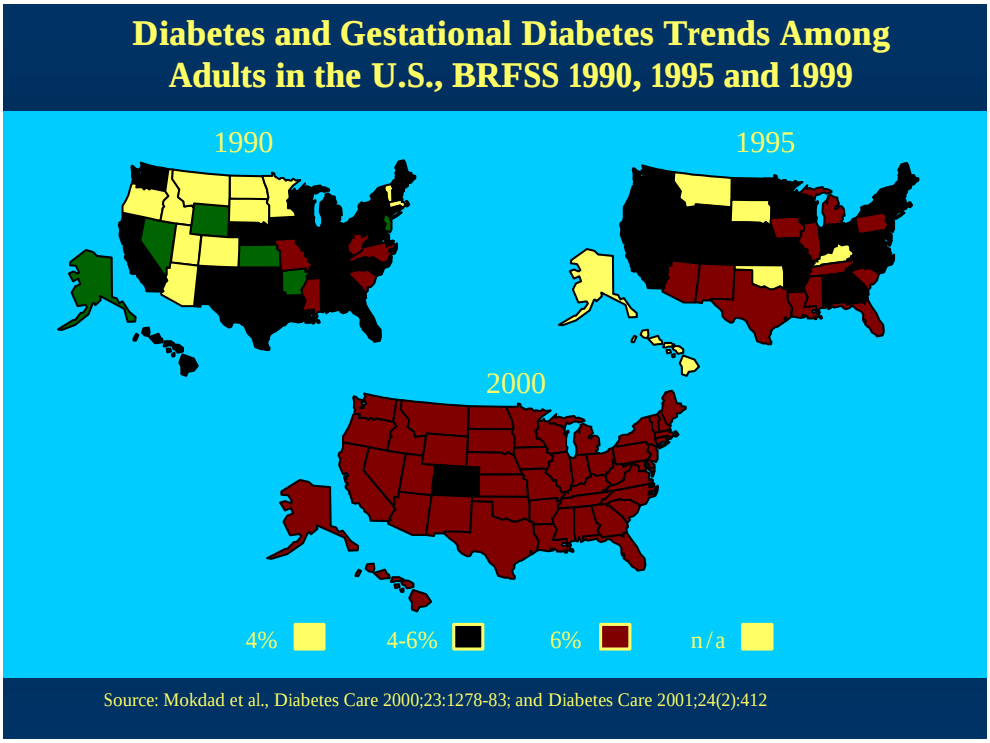


Figure 2.2: Rates of people with diagnosed diabetes or gestational diabetes shown by states in 1990, 1995, and 1999.

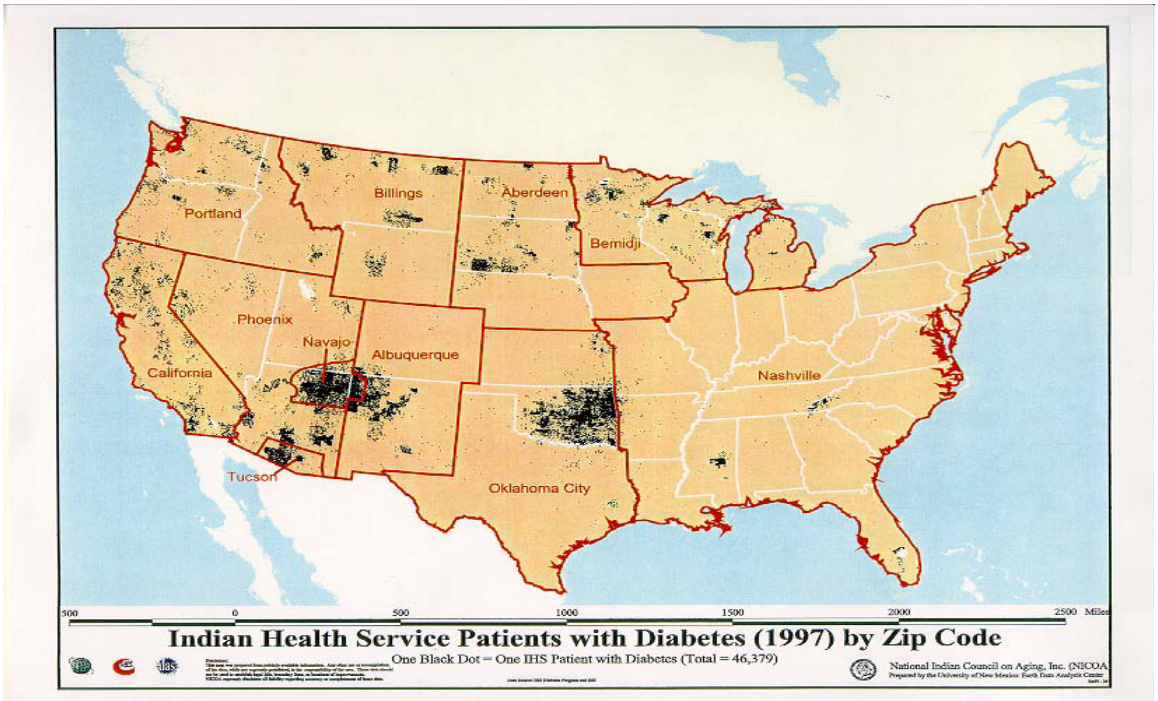


Figure 2.3: GIS map of I.H.S. clients known to have diabetes

Global Prevalence of Diabetes

In 1995 the prevalence of diabetes in adults worldwide was estimated to be 4%, or 135 million, expected to rise to 5.4%, 300 million people, by the year 2025. The W.H.O. projects industrialized countries will experience a 170% increase, from 84 to 228 million, whereas industrializing countries will see a 42% increase, from 51 to 72 million. Countries with the largest number of people with diabetes are, and will be in the year 2025, India, China, and the U.S (King, Aubert, & Herman, 1998). By 2025, over 75% of people with diabetes will live in industrializing countries and the majority will be 45 to 64 years old, rather than over 65 years, as it is industrialized countries, note Narayan and colleagues (2000), citing King and colleagues' work.

Differentiation Between Types of Diabetes

Awareness of the alarming rise in diabetes in this country and in the world must be accompanied by an understanding that these increases reflect the most common type of diabetes, type 2, formerly called non-insulin-dependent diabetes mellitus, or maturity-onset named for its propensity to occur after 45 years of age. The two main types of diabetes, type 1 and type 2, together affecting 6.5% of the adult U.S. population in 1998 (Modkad et al., 2000), share the phenomenon of high blood sugar, or hyperglycemia.

Metaphors offered by Olson (1999) are helpful for differentiating between the two types of diabetes. Picture a logging camp on a river, with the logs representing glucose molecules and the river a person's bloodstream. As the logs float down the river they should be taken out by workers at certain points on the banks, representing insulin as it transports glucose into body cells, particularly after meals. With type 1 diabetes, there are no workers (insulin) able to remove the logs. In the case of type 2 diabetes, the workers are ineffective or too far behind in removal to do a good job. The end result is the same – glucose builds up in the bloodstream causing damage to organs including the kidneys, the eyes, and the cardiovascular system over time, and in the case of type 1 diabetes, more acute problems with accumulation of ketone bodies and lipids, since in that case there are no workers (insulin) on the job at all until treatment with injected insulin is given. The types will be further described below, with attention to their greatly differing etiologies.

Both type 1 and type 2 diabetes are diagnosed by laboratory values confirming fasting plasma glucose values over 126 mg/dL. or a random plasma glucose over 200 mg/dL. Impaired glucose tolerance (I.G.T.), a preclinical stage for type 2 diabetes characterized by a 2-hour plasma glucose between 140 and 199 mg/dL., affects 15.6% of people 40 to 74 years. Impaired fasting glucose, affecting 10% of the U.S. population, is determined by a fasting glucose of 110 to 125 mg/dL. (Monaghan, 1999). Gestational diabetes refers to glucose intolerance recognized for the first time during pregnancy, typically at a screening test conducted during the 26^{th} to 28^{th} gestational week. After

delivery, maternal glucose levels usually return to normal but both the mother and her offspring, as already stated, are at greater risk for later development of type 2 diabetes (Pettit & Knowler, 1998).

Type 1 diabetes

Type 1 diabetes, formerly called insulin-dependent diabetes or juvenile-onset diabetes, accounts for less than 10% of the total cases of diabetes in this country. The etiology of type 1 diabetes involves an autoimmune attack on the insulin-secreting beta cells of the pancreas after exposure to yet-to-be identified environmental triggers (e.g., virus, toxin, stress). The condition occurs in genetically predisposed individuals, usually under 30 years of age. Its presentation is characterized by an acute onset of symptoms including weight loss, increased thirst and hunger, frequent urination, fatigue, and in 30 to 40% of cases, ketosis, which occur when 80 to 90% of the pancreas' beta cells are destroyed. Children and adults presenting with type 1 diabetes are not typically overweight, however, as the U.S. population in general becomes increasingly overweight, children with type 1 diabetes may happen to be overweight at the time of diagnosis (ADA consensus statement, 2000). Type 1 diabetes is more common in white children (Harris, Perkins, & Whalen-Brough, 1996) and relatively rare in Asians (Rosenbloom, Joe, Young, & Winter, 1999). The rate of type 1 diabetes in the U.S. is 1.7/1000 in the birth to 15-year age group, which has remained relatively stable in recent decades (LaPorte, Matsishima, & Chang, 1995). The dramatic onset of symptoms in youth have historically served to clearly distinguish type 1 diabetes from type 2 diabetes but this clarity is disappearing in some populations now seeing type 2 diabetes among youth (Dean, 1998).

Type 2 diabetes

Type 2 diabetes is far more common than type 1, accounting for at least 90 to 95% of all cases and people of African, American Indian, Hispanic, and Asian and Pacific Islander descent are more prone to it than their peers of European origin. While the symptoms of increased thirst and hunger, frequent urination, fatigue, and blurred

vision are likely to be present, the onset is much more insidious than type 1 and in fact, undetected diabetes in adults typically exists for an estimated seven years prior to diagnosis (Harris, Klein, Welborn, & Knuiman, 1995).

An Emerging Problem of Diabetes in Children and Adolescents

In a disturbing phenomenon that recalls the rarity and unnamed experience of diabetes among AI/AN adults prior to the 1950s, type 2 diabetes has emerged as an epidemic among youth of some indigenous North American populations. This phenomenon particularly burdens those populations with disproportionate rates among adults; however, it is now increasing in all U.S. pediatric populations, accounting for 8 to 45% of all cases of diabetes in childhood, compared to 1% in the 1980s (Fagot-Campagna et al., 2000). Currently type 2 diabetes is being reported among youth in many countries around the world, including Japan, Libya, Hong Kong, Bangladesh, Australia, and New Zealand.

The appearance of this phenomena among youth was first reported as a case series in 1979 among AI/AN teenagers (Mazur, Joe, & Young, 1998) and First Nations youth beginning in 1984 (Dean & Moffatt, 1988). From 1990 to 1998, the age-adjusted prevalence of diagnosed diabetes in the 12 IHS service areas increased 68% among those aged 15 to 19 years, from 3.2 to 5.4 per 1,000 (Acton et al., 2002). Among Akimel O'odham youth in this age group, 50.9 per 1000 have type 2 diabetes, identified by active population screening (Fagot-Campagna et al., 2000); this represents a two to threefold increase over the last 30 years (Dabalea, Pettit, Jones, & Arslanian, 1999).

The younger age of onset of type 2 diabetes portends serious consequences for the quality and the length of life for those affected, including families and communities. Because of the longer duration of disease as well as the challenge of achieving glucose control during youth, complications including renal failure, eye disease, and lower extremity lesions could occur by the 30s or even earlier for adults diagnosed as children

(Fagot-Campagna et al., 1999). Due to the clustering of risk factors at a young age, cardiovascular diseases may also occur in young adults.

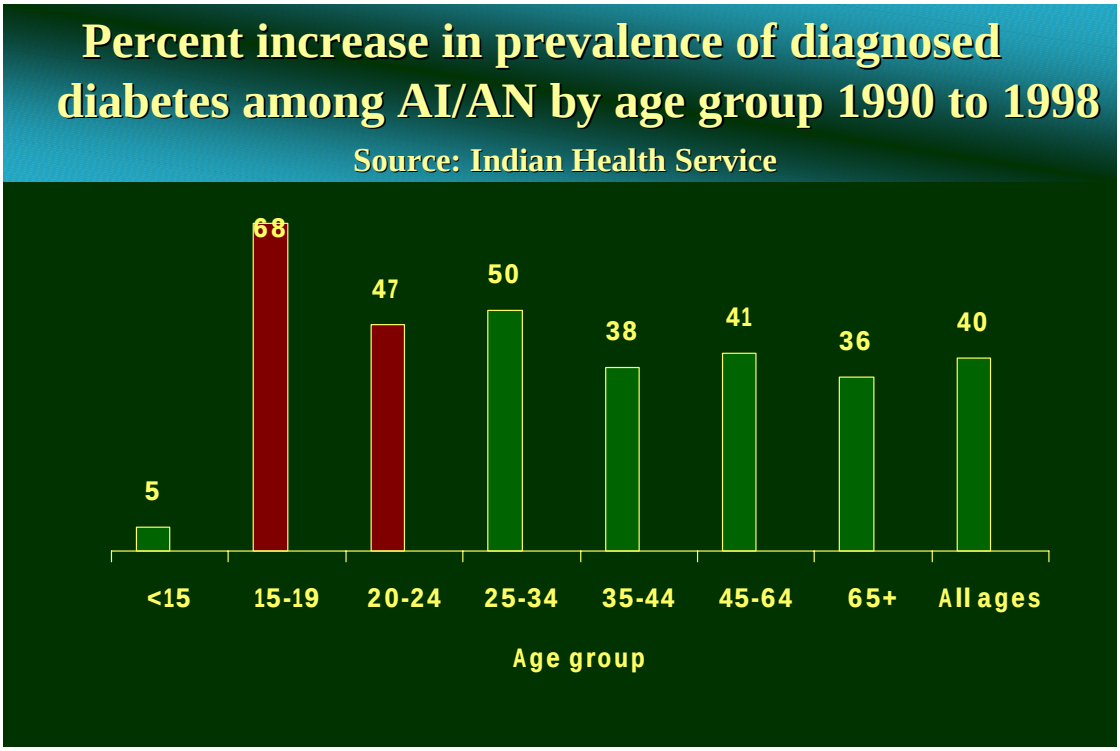


Figure 2.4. Percent increase in prevalence of diagnosed diabetes among American Indians and Alaska Natives by age group, 1990 to 1997.

And the emerging problem of diabetes in children may foreshadow higher prevalence rates in the future. Fagot-Campagna and colleagues (2000) observe that type 2 diabetes may be the "first consequence" of the obesity epidemic reported in North American youth from all populations and in all age groups (p. 671). Rising juvenile rates are, like those of adults, associated with rapid industrialization and related societal trends. Fourteen percent of children and 12 percent of adolescents are overweight (Must et al., 1998) and only one third engage in regular physical activity (CDC, 2000). The use of television and other electronic media has been strongly associated with physical inactivity and childhood obesity. Citing work by the Kaiser Family Foundation conducted

in 1999, Ponder (2000) noted that every week a typical child spends 38 hours a week using electronic media and their household views approximately 10,000 television food commercials.

Complications of Diabetes

Hyperglycemia, common to both type 1 and type 2 diabetes, unless rigorously controlled, contributes significantly to development of long-term macrovascular and microvascular diseases and injury to a variety of organ systems. Heart disease and strokes are two to four times higher among people with diabetes (CDC fact sheet, 1998). Ischemic heart disease accounts for the majority of diabetes-related deaths (ADA Expert Committee on the Diagnosis and Classification of Diabetes Mellitus, 2000). Peripheral vascular disease and another microvascular complication, peripheral neuropathy, contribute significantly to development of foot ulcers leading to amputations among people with diabetes, which numbered about 67,000 a year from 1993 to 1995 (CDC fact sheet, 1998). Diabetic retinopathy is the leading cause of blindness for persons aged 20 to 74 years, causing from 12,000 to 24,000 new cases each year.

Diabetes is the most common cause of end-stage renal disease (ESRD) in the U.S., and the incidence among people with diabetes has steadily increased over the past decades from an incidence of 5000 in 1982 to 27,851 in 1995 (CDC, 1997). Diabetes-related ESRD, which requires hemodialysis two to three times per week or a kidney transplant is six times more common among AI/AN people than that for the population overall (Narva, 1999). From 1990 to 1996, the rate of Native Americans with diabetes who began treatment for ESRD-DM increased 24% to about 580 per 100,000 compared to about 380 per 100,000 people in the overall population with diabetes (CDC, 2000).

Lower extremity amputations (LEA) are generally higher in Native populations. A rate of 24.1 LEAs per 1000 person-years among people living on the Gila River Indian Reservation, compared with 6.5 per 1000 person-years for the general U.S. diabetic population, was reported in 1988 (Nelson et al., 1988).

Scientific evidence for secondary and tertiary prevention of complications through rigid glucose control (e.g., near-normal blood glucose values) has conclusively been confirmed through several large clinical trials (D.C.C.T. Research Group, 1993; Ohkubo, 1995; Turnier, 1998). Prior to this, a number of multidisciplinary diabetes programs had documented reductions by fifty percent of lower extremity amputations and blindness (Diabetic Retinopathy Study Group, 1981; Reiber, Boyko, & Smith, 1995; Litzelman et al., 1993) through early detection and treatment of complications.

Physiological Risk Factors for Type 2 Diabetes

Insulin resistance

In stark contrast to the immune-mediated etiology of type 1, insulin resistance syndrome is the hallmark of type 2 diabetes. This metabolic state exists for some time before signs of diabetes appears, and it is characterized by fasting and/or postprandial hyperinsulemia plus one or more of the following: hypertension, dyslipidemias, obesity, and in women, menstrual disturbances, and hirsutism secondary to ovarian hyperandrogenism (Ponder, 2000). Hyperinsulemia, and related diabetes, obesity, hypertension and coronary artery disease constitute "Syndrome X," a concept popularized by Reaven and others (2000). Acanthosis nigricans, an easily identifiable skin lesion appearing as dark, velvety skin on the back of the neck and axilla, is a cutaneous marker for hyperinsulemia that has been observed in many insulin-resistant AI/AN, African American, and Latino youth and adults. It has been found among Winnebago and Omaha tribal children as young as three years old (Stuart et al., 1998).

Hyperinsulemia, in the form of increased pancreatic insulin secretion, may compensate for reduced hepatic and skeletal muscle insulin sensitivity for years in people with insulin resistance. In youth, however, puberty marks a steady, normal increase in insulin resistance secondary to increased secretion of growth hormone. It appears that in overweight, genetically predisposed youth, the insulin resistance of puberty prompts

quick erosion of insulin secretion due to excess production of glucose by the liver (e.g., glucose toxicity), followed by progression to type 2 diabetes (Ponder, 2000).

Obesity

Obesity (120% > ideal body weight), commonly associated with insulin resistance, has been established for several decades as a powerful risk factor for the development of Type 2 diabetes. Abdominal obesity has been associated most often with cardiovascular risk factors, including diabetes (Kahn, Dunbar, Ziemer, & Phillips, 1998). Obesity exposes a person to a higher risk for type 2 diabetes by a factor of three to four times (Knowler et al., 1981). For every kilogram of increased body weight in adults over age 25, the risk for diabetes increases by 4.5 % (Ford, Williamson, & Liu, 1997). Recent analysis of NHANES III data has found the development of type 2 diabetes is the most common comorbidity related to obesity (Must et al., 1999).

Must and colleagues (1999) recently reported, based on NHANES data (1988-1994), that over half of U.S. adults are overweight. Sixty three percent men and 55% of women (N = 5,884 adults, 25 years and older), had a body mass index of 26 kg/M^2 or greater (normal is 25 kg/M^2). Approximately 14% of children ages 6 to11 years and 12% of youth ages 12 to17 years are overweight, according to this data, more than doubling the percentages of affected children in the 1960s.

Obesity and the development of diabetes are strongly related in the Pima Indians (Knowler, Pettitt, Saad, & Bennett, 1990), noted previously to have the highest rates of diabetes in the world. Recent screening of three and four year old Pima children enrolled in Headstart (N=200) found that the body mass index (BMI) was greater than 18 in 43% of the children, significantly higher than the mean BMI of 15.3 for 5 year old children across U.S. populations, according to NHANES II data (Cook & Hurley, 1998).

A 1991 study found that self-reported rates of obesity among AI/AN people were 13.7 % of men and 16.5% of women, compared to 9.1% of men and 8.2% of women for

the U.S. population at large, and Arizona youth aged seven to 17 reported extremely high rates of obesity (44.1% for boys and 51.8% for girls) (Broussard et al., 1991).

Diet

While diet has been linked with diabetes for over 2,500 years (von Engelhardt, 1989), the exact role of dietary factors has eluded researchers (Narayan, 1997). Nutrition recommendations for people with diabetes are continually evolving based on new science as well as secular cycles (Wheeler, 2000), including recent controversies about the value of high-protein diets in weight loss and maintenance. Several recent, large studies have produced findings suggesting a certain foods play a protective role in primary prevention of diabetes. In a large population of women (Nurse's Health Study, 1984 to 1994), and independent of known risk factors, a higher intake of whole-grain foods was associated with lower risk for developing type 2 diabetes, whereas a higher intake of refined grain was related to increased risks for diabetes (Liu et al., 2000). Findings of Iowan women (N = 39, 988) showed strong inverse associations with incidence of diabetes and total grain, whole-grain, total dietary fiber, cereal fiber, and dietary magnesium intakes, after adjustment for other factors (Meyer et al., 2000).

Hunter-gatherer diets have been of some interest among scientists considering the lack of “diseases of civilization” among people living in these societies. Instead of the reliance on meat often assumed to constitute a large portion of such diets, however, Milton (2000) cites the research of Lee in 1968, and others finding that vegetable foods were actually the primary source of subsistence for most of the hunter-gatherer societies studied, with opportunistic consumption of animal matter.

It has been suggested that the complex carbohydrates found in desert foods and other traditional Native American plant sources slowed digestion and absorption of starches, helping protect people from diabetes, whereas their replacement with refined, high caloric single carbohydrate foods has had the opposite effect (Bennett et al., 1984). The glycemic index (i.e., an indicator of carbohydrate’s ability to raise blood glucose

levels) of staple foods (e.g., corn, lima beans, white and yellow tepary beans, mesquite, and acorns) traditionally consumed by Pima Indians has been found to be low, contrasted to those found in potatoes, bread, and processed cereals (Brand et al., 1990). Notably, the incidence of diabetes is significantly lower among people who consume foods with low glycemic indices (Salmeron, Manson et al., 1997; Salmeron, Ascherio et al., 1997). Such foods have also been shown to promote modest improvements in glycemic control among people with diabetes (Brand et al., 1991).

Other than the work described by the scientists examining the content and effect of these Southwest desert food staples, modern scientists know little about the glycemic effect of other traditional foods used for centuries by Native peoples (e.g., turnips and chokecherries in the Northwest), many of which are now hard to find because of past subjugation and continuing encroachment of tribal-owned lands. Meanwhile, media and other industrializing influences, as well as diminishing access to traditional foods have helped to set new norms for a "Big Gulp Culture" (Cajete, 1999, p. x). Frequent consumption of a "mini-market" diet (Nabhan, 1997, p. 204) consisting of highly processed foods that are generally incongruent with health (Johns, 1999).

Physical inactivity

Physical inactivity is another well-established link to the development of type 2 diabetes. Considerable evidence suggests physical activity helps to protect against development of type 2 diabetes in longitudinal studies of healthy women and men (Helmrich, 1995; Manson et al., 1991; Manson, Willett, Stampfer, & Colditz, 1995; Kriska, Blair, & Periera, 1994). Physical activity was inversely related to glucose intolerance, obesity, and central distribution of fat, particularly in Pima males, reported by Kriska and colleagues (1993).

More than 60% of American adults do not engage in levels of physical activity necessary to provide health benefits (at least 150 minutes per week). Insufficient physical activity is a growing problem among youth, as well. Analysis of CDC BRFSS

data found that more than a third of young people aged 12-21 years do not regularly engage in vigorous physical activity. Only 27% of high school students participated in high school physical education classes on a daily basis in 1997 (CDC, 2000).

Adler, Boyko, Shrayer, and Murphy (2000) found in a study of 666 Native Alaskans living in the Upi Delta that those with moderate and high levels of physical activity related to traditional activities were associated with a lower prevalence of glucose intolerance adjusted for age, ethnicity, BMI, and sex, than a reference group with low-level physical activity. Interventions designed to prevent weight gain and to promote physical activity have been implemented in many programs including the QUEST program among Akimel O'odham (Pima) school children (Cook & Hurley, 1998) and the Zuni Wellness Program for all community members (Leonard, Leonard, & Wilson, 1986).

Genetic predisposition

A genetic predisposition for insulin resistance and or type 2 diabetes has been established. The concordance for type 2 diabetes among identical twins is virtually 100% and 20% to 40% for fraternal twins. The search for genes responsible for type 2 diabetes is being conducted by genome scans and some genes have been identified implicated genes in particular populations, but the picture is in no way complete. Segregation analyses of sibling pairs suggest that type 2 diabetes is likely to be polygenic, although one or more major genes could also be involved (She, 2000).

Genetic susceptibility to diabetes is also believed to play a part in the high rates of diabetes shouldered by Native Americans and other indigenous people. A "thrifty gene," which theoretically promoted survival of all people by heightened storage of fat during times of plentiful food in preparation for periods of famine was proposed by Neel in 1962. Indeed, a genetic pattern, adaptive in earlier times, may be making AI/AN and other indigenous peoples especially vulnerable to the condition (Joe & Young, 1993). The fact that diabetes was rare among Native people prior to War World II, however,

suggests that genetic predisposition can only be a contributing factor to the diabetes epidemic. This is borne out by rising rates of diabetes across the U.S. in just the past decade, a period during which the gene pool of Americans has obviously not changed that rapidly (Mokdad et al., 2000).

Intrauterine environment

Mounting evidence suggests that the intrauterine environment of diabetes during pregnancy predisposes offspring to type 2 diabetes. Pettitt and Knowler (1998) identified diabetes during pregnancy, both gestational and diagnosed type 2 diabetes, as a major risk factor for later development of diabetes and hyperglycemia in their offspring, many of which are large at birth, over 9 pounds In fact, a secular increase in prevalence of diabetes among women of childbearing age might be partly responsible for the increasing prevalence of pediatric type 2 diabetes (Fagot-Campagna et al., 2000). Mothers with gestational diabetes are also more likely to develop type 2 diabetes themselves in subsequent years (Kjos, Henry, Lee, Buchanan, & Mishell, 1993).

Both high and low birth infant weights have been associated with later development of insulin resistance and diabetes. High birth weights, generally, are linearly associated with higher body mass indices (BMI) in adulthood, but inversely related to cardiovascular risk factors, suggesting to Kahn, Narayan, Williamson, and Valdez (2000) a gestational effect on muscle mass yet to be made clear. Barker (1999) examined 70,000 medical histories and found that low birthweight infant girls (< 5 pounds) were 1.83 times more likely to develop type 2 diabetes in later life than those weighing 7.1 to 8.5 pounds. The association of low birth weights with Syndrome X and later development of type 2 diabetes (Barker et al., 1993) raises critical questions about our understanding of the etiology of not only of diabetes, but other chronic disease burdens, including heart disease and cancer (Begley, 1999).

Early feedings

Early and inconclusive associations between first feedings (breast, bottle, or combination) and development of obesity in children and type 2 diabetes in adults have been made (Knowler & Pettitt, 1998). Among 720 Akimel O'odham (Pima) people, breastfeeding for the first 2 months of life was found to be associated with significantly lower rates of type 2 diabetes (6.9% and 30.1% among offspring of nondiabetic and diabetic women, respectively) compared to bottle-fed children (11.9 and 43.6% respectively) (Pettitt, Forman, Hanson, Knowler, & Bennett, 1997). Those who were exclusively breastfed had lower rates than those who were exclusively bottlefed in all age-groups. Among the 325 people exclusively bottle -fed, age-and sex-adjusted mean relative weights (146%) were significantly higher than 144 people exclusively breastfed (140%) or 251 people who had some breastfeeding (139%).

A recent study in Germany found the prevalence of obesity in children who had never been breast-fed (N = 4022) was 4.5% compared with 2.8% in ever breast-fed children (N = 5184). Further, investigators found a clear dose-dependent effect for the duration of breast feeding with a 30% reduction in risk of excess weight and a 40% risk reduction for obesity in children exclusively breast-fed for at least 6 months (N = 984) (von Kries et al., 1999). Similar results were found in a small study in Arizona with 21% of children exclusively breastfed for the first six months (N = 19) becoming overweight or obese compared to 52% of formula fed children (N = 82) (Begley, 1999).

Breastfeeding may also provide some benefit to mothers for the prevention of type 2 diabetes extending beyond the advantage of helping to reduce postpartum weight. A study of lactating women for a duration of 4-12 weeks (N = 404) showed improved glucose metabolism as indicated by a significantly lower area under the glucose curve, with lower fasting and 2-hour glucose levels compared to nonlactating women (N = 405), as well as higher fasting HDL cholesterol levels (Kjos et al., 1993).

The introduction of commercial infant formula in the 1950s, along with women's participation in the workplace, contributed to a decline in breastfeeding maintained throughout for most of the century until an upturn, particularly among college-educated women, was observed recently (1988 baseline for breastfeeding in early postpartum period: 52% and maintenance through 5 to 6 months: 21%; the 1998 baseline is 64% and 29%, respectively). Until the 1980s, mothers and infants were separated for much of their hospital stay, while mothers received educational information and formula supplies from infant formula companies (Wright, Naylor, Webster, Baure, & Sutcliffe, 1997).

There are significant health and cultural meanings attached to breastfeeding in traditional societies represented by the ethnic groups now most affected by type 2 diabetes (i.e., AI/AN, Hispanic, Pacific Islanders, and African descendents). Navajo women felt that it marked the child as being human and valued it for not only its nutritional qualities, but also for the psychological security it promoted. Women were encouraged to eat the traditional "strong" foods to maintain health for themselves and their child (Wright et al., 1997). Inupait Eskimo women were encouraged to breast feed for three to four years and to give special care to the selection of first foods (e.g., premasticated fish, fish liver, and fish soup), citing Lantis' 1958 work (Joe & Young, 1993).

However, socialization processes significantly influence attitudes towards breastfeeding, notes Higginbottom (2000), citing Dykes and Griffiths' work. Indigenous people, along with European descendents, were strongly influenced by the secular trend in the mid-twentieth century to abandon breastfeeding in favor of infant formulas. Although policies supporting breastfeeding in hospital and health care agencies were established in the 1980s, the rates of breastfeeding during the early postpartum period among AI/AN women was 47% in 1988 (national baseline, 54%). However, AI/AN mothers were more likely to still be nursing five to six month old infants according to 1988 data, 28 % vs. the national baseline of 21% (Healthy People 2000). The national

Healthy People 2010 objective is that 75% of all mothers will initiate breastfeeding in the early postpartum period and at least 50% will continue through the first six months.

Primary Prevention of Type 2 Diabetes

Many scientists and public health leaders have until recently been reluctant to support efforts directed at primary prevention of diabetes, citing an inadequate science base. Recent documentation of the escalating national and global incidence of type 2 diabetes and the emergence of type 2 diabetes in youth has helped to focus attention on the potential for prevention and positive, recently released, scientific findings about success in preventing or delaying diabetes has promised new hope for curtailing the epidemic at an earlier point of intervention.

A diabetes prevention study in Finland involving overweight participants with impaired glucose tolerance, or I.G.T. (N = 152) randomized into an intervention group with intensive support for lifestyle changes including weight loss, reduced dietary intake of saturated fats and increased intake of fiber, and physical activity had a 58% reduction in incident cases compared to the control group (N =143) over a 2 year intervention period (Tuomilehto et al., 2001) Adults with I.G.T. in Da-Qing, China (N = 577) participating in a diet and physical activity intervention had significantly lower 6-year incidence of diabetes than those assigned to control groups (X Pan et al., 1997).

The outcomes of a national randomized clinical trial, The Diabetes Prevention Program (DPP) revealed that an intensive lifestyle intervention reduced the risk of getting type 2 diabetes by 58% in participants that maintained physical activity at 30 minutes a day (150 minutes/week) and lost five to seven percent of their body weight. Involving 27 centers and 3,200 participants who were 25 years or older and who had impaired glucose tolerance (I.G.T.) but did not meet the criteria for diagnosis of diabetes upon entry into the study. All were overweight and 71 percent had a family history of type 2 diabetes (CDC, 2001).

Social and Ecological Determinants of Health and Diabetes Among AI/AN People

The reasons type 2 diabetes burdens some populations so heavily, including many American Indian communities, are not completely understood. Validly and valuably identified risk factors that have become universal knowledge (Kunitz, 1994) include powerful predictors for development of diabetes – obesity, physical inactivity, and genetic predisposition. Biomedical scientists are on the thresholds of new discoveries in the etiology of diabetes in not only genotyping, but a better greater understanding of the physiological role of the intrauterine environment when the mother has diabetes.

However, while such generalizable factors may be parsimonious, they may also be impoverished, observes Kunitz (1994). For some diseases, learning the social history is as important as learning the natural history, he adds, stating that the importance of diversity and local knowledge in our understanding of diseases in populations is little understood. Proponents of public health, according to DeBruyn, Chino, Serna, and Fullerton-Gleason (2001), have not often considered culture or history as contexts for developing prevention or intervention programs or looked to them as potential sources of variables for identification and measurement of risk and protective factor.

The literature on social determinants of health (e.g., unemployment, social support, racism, community cohesion) is limited but expected to grow in coming years (CDC, 2001; Marmot & Wilkinson, 1999). These factors are not only difficult to measure but also discomfiting, notes Jones (2000). "In a perfect world, the sociopolitical roots of power imbalance should be addressed," states Weiner (1999, p. 178). The world is far from this, but inclusion of social determinants of health and protective factors as variables is a start that can help to open the lens from a restricted focus on individual risk factors and the blame implicit in this to a wider, more panoramic view.

Recent history and socioeconomic status as social determinants of diabetes

Until the 1940s and 1950s, most Native Americans farmed, hunted, or fished on their land. A low-fat, high-fiber, high-carbohydrate diet based on traditional foods was

combined with a physically demanding life (Joos, 1984; Brand et al., 1990; Broussard, 1994). After World War II, the country's technology grew and Americans in general became less physically active and began eating foods higher in fat and low in fiber, including increasingly convenient, factory-produced, processed foods.

While much of the country benefited from the economic prosperity that began in the mid-century, Native Americans living on allotted reservation lands continued to face high unemployment and poverty. Commodity distributions and foodstamp programs were introduced to help combat the disparities in the 1950s and these programs continue, though greatly improved in their emphasis on nutritional content and their selection and administration by tribal, rather than U.S. government, officials. Unemployment and poverty remain high, averaging 16.2% of Indian males age 16 and older compared to 6.4% for the U.S. male population in general in 1990 and median household income for Indians residing in the Reservation States was $19,897 compared to $30, 056 for the general population, respectively (I.H.S., 1997).

Intergenerational grief and stress as social determinants of diabetes

Intergenerational grief and stress are determinants of health that have received little attention in the study of diabetes. Bullock suggests that the current model for diabetes needs to be expanded to encompass both the underlying reasons for certain unhealthy behavioral choices (e.g., overeating, less activity) and the health effects of stress, poverty, low self-esteem, social isolation, and personal and community trauma, all of which cluster in AI/AN people (2000). She adds that scientists should study resilience as much as disease and acknowledge the pain of personal and cultural traumas in the context of diabetes, which can be healing.

Similarly, Huttlinger's (1995) qualitative work among Navajo people identified diabetes as a posttraumatic stress disorder, "over time and generations, the psychological and physical trauma experienced by Native Americans as a result of colonization manifested themselves in disorders such as alcoholism and diabetes. Present-day Navajo

people are experiencing the effects of an intergenerational or secondary post traumatic stress disorder as a result of previous intergenerational trauma" (p. 12).

Brave Heart and DeBruyn (1995) have described the concept of historical unresolved grief, a phenomenon related to American Indians' experiences of massive losses of lives, land, and culture from European contact and colonization resulting in a long legacy of chronic trauma and grief across generations. Drawing on the literature from Jewish Holocaust survivors and other oppressed peoples, they suggest interventions be based on traditional ceremonies as well as conventional treatment modalities to help people begin journeys toward healing.

Land losses as a social determinant of diabetes

A related determinant of health and of influence in diabetes causation that has received little attention is that of the disruption of Native people's relationships with their homelands (Knowler, Pettitt, Savage, & Bennett, 1981; Brand et al., 1990; Nabhan, 1997; Johns, 1999). The loss of land bases, even in relatively recent times, could be an important determinant in diabetes causation, rarely mentioned in the literature. For many tribal nations, the amount of relatively fertile land for growing and hunting traditional foods has continued to shrink as industrial developments resumed or escalated after World War II, including drainage and development projects in Florida, (Joos, 1984) and dam constructions in eastern Washington, (Buchanan, 1997), New Mexico (Hunn, 1999) and North Dakota, (Van Develder, 1998). Loss of land bases reduces gathering and growing traditional foods and reduction in physical activity associated with acquiring these foods (Broussard, 1994).

During the 19th century and at least since 1600, the Mandan, Hidatsa, and Arikara tribes lived in agricultural communities living on the banks of the Missouri near what is now Bismarck, North Dakota, on the Fort Berthold Reservation and north of the Standing Rock Reservation. After small pox scourges devastated their populations, these tribes affiliated to ensure their survival. In the Pick-Sloan agreement of 1948, their land was

taken by the Corps of Engineers to make way for the building of Garrison Dam in an action that was ruled in 1984 by the Supreme Court to be illegal. The result was flooding of much of the productive bottomland on the reservation (VanDevelder, 1998). The homes of 349 families, as well as the ancient settlements, were covered with deep water and "New Town" was created as a replaced residential area. Like the three affiliated tribes, other Plains nations have also been affected, including Standing Rock where one quarter of the population left their homes in the flood areas which covered 160,889 acres of "prime agricultural lands" (N.D. Dept. of Public Instruction, p. 39) (see Chapter 4). The impact on health outcomes is unknown.

Much has been written about the Akimel O'odham (Pima) people living in the Sonoran Desert in the Gila River Indian community in Arizona, for whom diabetes affects half of adults over age 35 and is now affecting over 5% of youth aged 15 to 19 years (Dabalea et al., 1998). Their story, too, may have more to do with their land than has been acknowledged. Especially compelling is comparison of these rates to the Pima people living in their homelands in the Sierra Madres in Northwest Mexico, for whom rates of diabetes among adults are about 6% (Ravussin, Valencia, Esparza, Bennett, & Schultz, 1994). Researchers have shown that high-energy expenditure through physical activity, as well as traditional diets, help explain the contrasts in diabetes among people with the same genetic makeup (Esparza et al., 2000). Less tangible factors are likely also at play in the influence of high rates of diabetes among the Gila River Pima people. The Arizona Republic interviewed a number of people about the "Pima Plague" of diabetes. A 68- year old elder said of the bisecting of the Gila River for industrialization in the early half of the past century, "Life changed after the river stopped," (Sevilla, 1999, p.1). And 8-year old girl said:

> My people are the River People. We have lived by this river for 8,000 years. I have never seen it. Nothing. Just dirt and wind. I think it is so strange that I have

> never seen a river or ducks or deer. I am an Akimel O'odham and I have never seen a river (p.3).

When land bases are lost, also lost is the symbolic and cultural pride involved in the recognition of land as identity symbols (Halmo, Stoffle, & Evans, 1993). Land is inextricably linked to culture, society, the human body and spirit as a pervasive expression of continuity for all indigenous people around the world (McLuhan, 1994). "Our rootedness to the Earth is like tying a string to yourself and the other end to your mother," explains Navajo elder Roberta Blackgoat, cited by McLuhan (1994, p.27). The connections to the land are perceived to be spiritual and physical, embracing belongingness, gratitude and reciprocity, and generativity. Ron LaFrance, an Iroquois traditionalist, was quoted in McLulan's book (1994), "As Native American peoples, we come from land-based cultures. Our identities and well-being are intricately linked to our lands. As we think about the future of our communities, many of us worry that the proper, productive use of lands has diminished as a priority. In our culture, even today, to work with the land, with our Mother Earth, is among the most honorable of activities" (p. 383).

The investment of people in their places is profound, notes Basso (1997) who stated, "senses of place also partake off cultures, of shared bodies of "local knowledge" with which persons and whole communities render their places meaningful and endow them with social importance" (p. xiv). Guided by Rone Lupe, chairman of White Mountain Apache Tribe, to learn about how Apache people know their country and to make Apache maps, not "whitemen's maps" of which there were plenty, Basso reflected, "Apache constructions of place reach deeply into other cultural spheres, including conceptions of wisdom, notions of morality, politeness and fact in forms of spoken discourse and certain conventional ways of imagining and interpreting the Apache tribal past" (p. xv).

The experience of learning about place among anthropologists is “lightly charted territory,” (Basso, 1997, p. xvi) and for scientists addressing factors related to health and diabetes. However, it may be a critically important determinant of diabetes and of health for indigenous peoples. For the Whapmagoostui Cree of northern Quebec (Adelson, 1998) health is “located within a text of historical accountings, land, and the production and interpretation of traditional activities” (p.5). Health, and some contributing causes of diabetes, as well as its solutions, may rest in such accountings.

Perspectives about Health and Diabetes among AI/AN People

Holistic concepts of health are powerful statements of cultural ideals and represent a form for articulating identity in response to challenges to a tribe’s national identity and to its peoples’ health (Adelson, 1998; Lang, 1989). A worldview of interconnectedness embraces continuous acknowledgement of the integration of spiritual, psychological, and physical dimensions of health and well being (Csordas, 1989; Morse, Young, & Swartz, 1991; Huttlinger, 1995; Wing, 1998, Weiner, 1999), as well as a cooperative, rather than individualistic, orientation to life (Davis, 1999). Traditional healing represents a spiritual journey (Mehl-Madronna, 1997) involving a search for balance among the integrated dimensions and this search is enhanced by therapeutic readiness in seeking the help of a healer (Turner, 1989) and the intimacy of the relationship between the two.

Reflecting on the insight provided to her qualitative study on diabetes by the Dakota Sioux, Gretchen Lang (1989), cited Herzlick’s (1979) observations, "when an individual talks about health and illness, he also talks about something else, the nature of his links with his environment, physical and social, as well as aspects of social organization” (p. 319) As most people intuitively grasp, writes Mehl-Madrona (1997), “what happens to the body reflects what is happening in the mind and the spirit” (p. 17) and treating all of these dimensions as a whole is central to traditional medicine are often recognized as integral values to many Native peoples.

Conventional practitioners, in contrast, are not perceived to as understanding a holistic integration of health (Adelson, 1998). Modern health care delivery systems may appear to be fragmented because of the different set of beliefs, practices, and practitioners for each specialty practice as well as the dissociation of the body and mind (Morse et al., 1991). Garro and Lang (1993) stated,

> It is not the case that lay accounts of illness are simply impoverished biomedical accounts. Professional and lay models of illness develop to meet different objectives. Biomedical explanations of disease are geared to constructing a causal etiological model. Although lay accounts also address causal issues, they are perhaps more appropriately characterized as ways in which individuals attempt to make sense of the disorder that they are experiencing (p. 294).

In listening to Dakota people attempting to "make sense" of diabetes, Lang (1989, p. 305), said she came to understand that the narratives involved not only the individuals speaking, but their community identity and concern for other members, as part of a much larger, self-reflective narrative. Weiner (1999), who has analyzed ethnographic reports on perceptions of inheritance of diabetes among Indian people, noted that these perceptions, too, are embedded in individual and collective geneaologies and culture. Not limited to biological interpretation, as Western scientists view inheritance of the medicalized diabetes, interpretations include susceptibility, or "running in families," including Indian identity and inheriting cultural norms such as respecting those who offer food. She added that people gain a form of ownership as those who know diabetes personally and who create, shape, and comprehend local and shared views of etiologies. For some people, this may resolve frustration with their inability to control their diabetes, and raises the question, "If biomedical experts cannot cure diabetes, why should they have intellectual ownership over this condition?" (p. 175).

Diabetes is viewed by many Native people as a "new" disease, another in a string of diseases introduced by the dominant culture and analogous to "the new smallpox,

harking to the theory that the smallpox contagion was intentionally transmitted to Indians in the first part of this century (Hill, 1997, p. 27). Diabetes is also referred to by some as a “white man’s disease” (Morgan & Weedon, 1990, p. 19) or “white man’s sickness” (Garro & Lang, 1993, p. 299) which requires “white man’s medicine” Acton & Fiore, 1996). These perceptions are consistent with the universal indigenous healing concept of the dichotomous origins of illness as either natural or unnatural -- with diabetes being “unnatural” because its etiology and continued burden are associated with the hegemony of colonization (Wing, 1998, p. 145; Joe & Young, 1993, p. 6). In a qualitative study involving interviews with 33 Navajo people with diabetes, Huttlinger (1995) noted the difficulty people had in integrating the disease concept of diabetes, an “outside” disorder, into their lives which maintained an integral belief in the importance of harmony and balance. It is interesting that the findings of a metanalysis of qualitative studies on living with diabetes, primarily involving Euro-Americans, also found that achieving and maintaining balance is the most important goal (Paterson, Thorne, & Dewis, 1998).

In a study of four focus groups comprised of Indian people with diabetes conducted in Montana in 1996 (Acton & Fiore), major psychosocial and behavioral themes were identified through content analysis, coded by a team of 14 raters. The psychosocial themes included: 1) relevance of, and lack of outsider appreciation for, cultural traditions; 2) a historically-based sense of powerlessness over one’s ability to control diabetes, given its prevalence in Indian communities and a fatalistic belief that one will get diabetes regardless of anything one does to avoid or prevent it; 3) a historical mistrust of greater society, both in terms of services provided and treatments dispensed (e.g.,`white man’s medicine’); and 4) stigmatism and shame that one is “weak and out of balance.” The major behavioral issues were: 1) behavior of non-Indian health care providers who do not understand patient needs or constraints and who fail to communicate meaningfully; 2) cultural and community-specific expectations regarding food selection, preparation, portions and consumption within the social context; and 3)

avoidance of the health care system because of perceived lack of confidentiality in the system.

In two other focus groups conducted in 1996 on another reservation in Montana, participants stated that “this diabetes is adversely affecting their people, like a plague” in the words of one participant. Dismay about the causes of diabetes was voiced along with speculation about the role of food commodities and other interventions from the government. Words spoken by conventional health care providers were said to be very powerful which can become a curse when spoken in terms of possible events, such as “you could lose your leg.” (Satterfield, 1999).

Summary

This chapter attempted to provide an overview of diabetes as documented largely in the literature of conventional science. Emerging knowledge about social and ecological determinants of health including issues of great depth and complexity such as intergenerational grief and land losses has been introduced. The next chapter lays out the tradition, design, and methods for this study, focusing on participants’ collective experience in health observations and protection and concern about diabetes in a Plains Indian community.

CHAPTER 3

METHODOLOGY

American Indian elders have seen, in their lifetimes, the previously unknown illness of diabetes become a part of life and death for almost every Indian family they know. Women, who are typically “the cultivators of subsistence because they have the responsibility for seeing that everyone in the household is fed and cared for” (Nazarea, 1998, p. 81), have unique perspectives about this previously rare phenomenon. The pandemic of type 2 diabetes and its recent emergence among youth were detailed in Chapter 2.

The purpose of this ethnographic study was to document, understand, and support Lakota and Dakota elders' ways of knowing and teaching about health protection and diabetes prevention. It was made possible by an ongoing relationship between the researcher and health leaders of the represented tribe. Selected by community health representatives, 9 information-rich female elders were engaged in-depth interviewing in their natural setting, allowing the researcher to gain an understanding of the meaning of this phenomema and of health within their lives, with an eye to generalizing to “discovery” and to larger structures (Denzin & Lincoln, 2000). Because this study was designed to construct new integrations of knowledge, rather than test hypotheses, I focused on qualitative research using ethnography as the primary methodology. Observation in the field and through a sustained relationship with the Standing Rock Sioux Nation’s CHR program over four years added naturalistic depth to the interview data.

This chapter provides an overview of qualitative research design, the process of obtaining permission to conduct the study, and data collection methods of in-depth interviewing, participant observation, and optional methods of a participatory action

photographic technique including “photovoice.” This section is followed by descriptions of the research questions and the data collection strategies. Lastly, I explain the process of data analysis based on grounded theory using constant comparative analysis and examination of the elders’ narratives for understanding of their attributions for the epidemic, identification of the genres of illness narratives they offered, and links with beliefs and practices to their cultural knowledge and values.

Qualitative Research

Qualitative research is an empirical, socially located tradition, defined by its historical roots in anthropology and sociology, and, most critically, involving sustained interaction with the study participants in their own “natural” territory and in their own language (Kirk & Miller, 1986). “Qualitative research,” a more encompassing term than “ethnographic research” (Wolcott, 1994, p. 3), is more likely than the hypothetico-deductive method of quantitative research to lead to serendipitous findings and open new ways of seeing things, helping researchers to get beyond initial concepts and generate or revise conceptual frameworks (Krueger, 1998). The qualitative researcher, as the main instrument of measurement, respects the knowledge of local people and attempts to capture data on their perceptions from an emic, or “inside” perspective through a process of deep attentiveness, of empathetic understanding (for which the German word, *verstehen* is often used), and of suspending or “bracketing” preconceptions about the topics under discussion (Miles & Huberman, 1994, p. 6).

To illuminate the processes of qualitative research, with its inherent paradoxes of structure and freedom, Oldfather and West (1994) applied a metaphor of jazz music – characterized by an inclusiveness of the audience as the music unfolds that makes the findings rich and relevant to understanding. The improvisatory nature of jazz music is composed and adapted depending “on each musician’s hearing, responding to, and appreciating the performances of the other players.” Jazz music is “guided by a deep structure of chord progressions and themes,” and, qualitative inquiry, similarly, is guided

by “epistemological principles, socially constructed values, inquiry focuses, and findings emerging through analytic methodologies such as constant comparison”(p. 24). Like the participation of jazz musicians in shared, local cultures and artistic composition of collaborative, interdependent music, qualitative researchers are philosophers and interpretive bricoleurs, employing a variety of strategies and methods. In terms of a common thread linking all of these, qualitative data analysis deals with meaningful talk and action, state Coffey and Atkinson (1996).

The researcher’s paradigm, or basic set of guiding beliefs, according to Denzin and Lincoln (2000), encompasses these concepts: 1) ethics, which ask, “How will I be as a moral person in the world?” 2) epistemology, which poses the question, "How do I know the world? What is the relationship between the inquirer and the known?” 3) ontology, which raises basic questions about the nature of reality and the nature of the human being in the world, and 4) methodology, which focuses on the best means for gaining knowledge about the world (p. 157). Qualitative researchers need to identify their guiding paradigm, or “net that contains the researcher’s epistemological, ontological, and methodological premises” (p. 19).

Although all qualitative research is interpretive (Charmaz, 2000), my epistemology is that of social constructionism, which places priority on the phenomena of study and views data and analysis as constructing meaning and actions through the shared experiences of both researcher and participants. Constructivists do not find or discover knowledge so much as construct it as they invent concepts and models to make sense of experience (Schwandt, 2000).

My theoretical perspective is feminism, which can involve research for, rather than merely about, women (Olesen, 2000) and emphasizes engagement in the social struggles *with* those who have been exploited and subjugated. “The strength of feminist activist research lies in its ability to open contradiction and conflicts within collaborative practices” (Fine, 1994, p. 23). The self-reflective, reflexive thinking inherent in feminist

perspectives focuses on both the global and the local and takes into account multiple discourses including historical, political, economic, cultural, and everyday dialogue to prompt action and promote social justice.

"You have to be the person someone can talk to, and you have to be able to create a context where the person can speak and you can listen," notes Fine (1994, p. 20) in describing the relational skills of the feminist researcher. Relational accountability, which is an indigenous worldview that holds an individual responsible for respectful actions in relation to all living organisms (Wilson & Wilson, 1998), is consistent with feminist research. The words of Alice Walker, an Australian Aboriginal woman, quoted by Anderson and Wisdom (1998) illustrate the relational aspect and action-oriented focus of this approach, "If you are here to help me, then you are wasting your time. But if you come because your liberation is tied up in mine, then let us begin" (p. 699).

Ethnographic research, my primary methodology, focuses on the question, "what is the culture of this group of people?" Participant observation in the tradition of anthropology is an important ingredient, including intensive fieldwork in which the investigator is immersed in the culture under study (Patton, 1990, p. 67). While it may be complemented by epidemiological, biomedical and quantitative sociological data, it is ethnography that primarily lends itself to exploration of the ways in which illness intersects with a particular culturally constructed life-world and a particular life trajectory to produce a unique and irreducible constellation of experience (Kleinman & Seeman, 2000).

My ethnographic experience in the field included the time spent for data collection, described below, as well as exploratory field visits that have occurred since 1997 and which are described in greater detail in Chapter 4. Fieldwork may also be considered to include the continuous exchange of information and ideas in person, phone, and mail over the previous four years, with tribal health leaders, elders, and community health representatives. In some ways, the experience might be construed to reflect a

"multi-site" field experience which includes not only the contacts in the research setting and observations in other field settings and in the literature, but also reflecting and contrasting these with observations made in the experience of working in a federal agency whose mission is dedicated to disease prevention and health promotion with a focus on reducing the disproportionate burden of illness and premature mortality borne by racial and ethnic populations.

Research Design

The design for this ethnographic study, described above, featured in-depth interviewing among nine elders of the Standing Rock Sioux Nation. Major steps in the process are illustrated in Figure 3.1. The next subsections feature descriptions of the study conception, methods, and approvals, decision to interview female elders, and timeline.

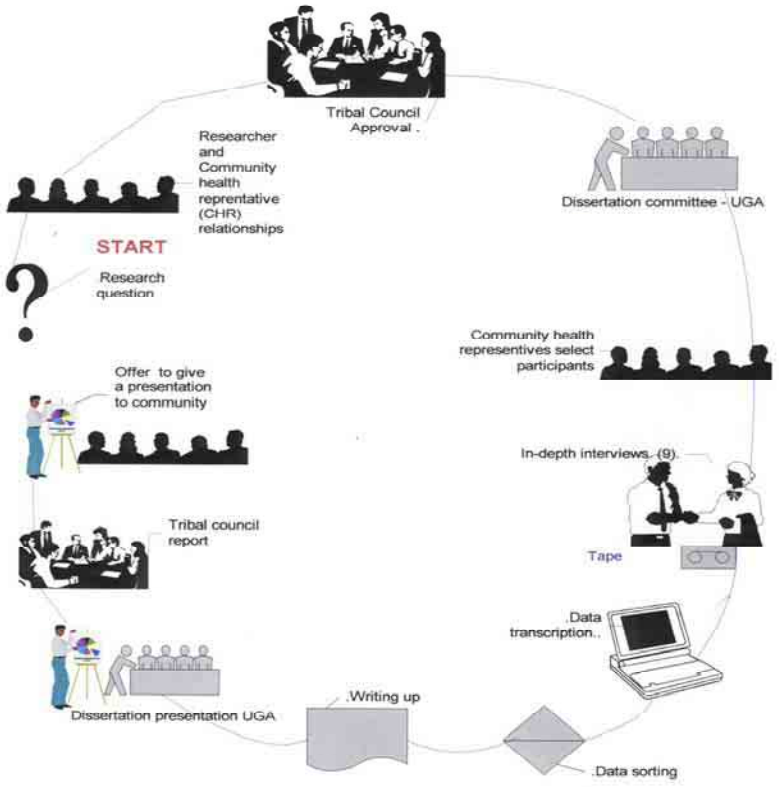


Figure 3.1. Process of research design and implementation.

Conception of the research questions and study methodology

The conception of the study and the research questions were born in dialogue with tribal people in the Standing Rock Sioux Nation about the epidemic of diabetes over the last four years. In addition to the interest of the Community Health Representative (CHR) program, I understood that support, guidance, and approval from the tribal council were required before I could apply for other institutional approvals (see the next subsection).

Believing that knowledge of human action can best be understood from the accounts and perspectives of the people involved (Schwandt, 1997), and because of the limited scope of this study, which precluded gathering life histories, I selected in-depth interviewing as the primary method for data collection. The naturalistic challenges of cross-cultural interviewing, Ryen notes (2000), include limited and slowly gained access to participants' perspectives. Valid data collection is facilitated by the interviewer's ability to develop trust and rapport and establish relationships with interviewees and the importance of trust and rapport cannot be overestimated. My sustained relationship with the tribe's CHR program opened doors of access to elders who were trusting and allowed rapport to develop, because of, first, trust in the judgment of their CHRs.

I chose to interview nine participants because this number is fairly representative in that the population of people over 65 years of both genders on the reservation is less than 300 (see Chapter 4). Those who are considered "elders" is smaller still, "only about a dozen," according to one gatekeeper. Also, more than nine participants would have required additional, lengthy clearances from my work at the CDC.

Permission to conduct this study

While working as a project officer for CDC in 1997, I was introduced to the tribal CHR Program director and staff by the North Dakota Diabetes Control Program coordinator. Thereafter, I maintained relationships with the program through phone calls and providing technical assistance when requested. I presented to the Tribal Health Director a proposal to conduct this research and he reviewed the purpose, research

design, consent form, and proposed interview questions and invited me, with Tribal Council approval from the Chair, to conduct the research through a letter dated June 5, 2000 (See Appendix A). The Tribal Council serves, basically, as an Institutional Review Board for all studies involving enrolled tribal members and issues affecting the tribe.

After receiving the invitational letter from the Tribal Health Director I sought Human Subjects Approval from both the CDC and the University of Georgia because I am an employee of the former and a student of the latter. Although I funded my own research, I wanted CDC to review and approve the research proposal so that they would be fully aware of my activities and I would be able to publish my findings in the future. After getting clearance from CDC's Division of Diabetes Translation, where I work as a health educator, I submitted a human subjects application to CDC in November 2000 and received approval in January 2001. Then I submitted a human subjects application to the University of Georgia in March 2001 and received approval in April 2001. A copy of the consent form, approved by all institutions, is shown in Appendix B.

The decision to limit participants to women elders

Originally I had planned to interview elders of both genders, assuring that at least half were women, believing that it was particularly important to attend to the voices of highly respected women who at advanced ages were likely to have learned from their own maternal forebears about the subsistence and health protection of families, including ideas about adaptation as environmental and other changes have occurred.

The emic experience of my fieldwork on the reservation, which included participating in community activities prior to and during the data collection period, however, gave me a greater understanding of the cultural knowledge of women, as well as of the protocol and propriety defining relationships with women and men, particularly among elders. Remembering that qualitative research is dynamic and the design, as well as analysis, must be "situationally responsive," (Krueger, 1998), I decided on June 7 to limit my study to inclusion of women elders only. When I spoke with the Community

Health Representative (CHR) Director, John Eagle Shield, about my observations he agreed and said, “Women are the carriers of the culture.” Dr. Beatrice Medicine, herself an elder and scholar from the Standing Rock Reservation, has documented that this phrase is often heard at Indian gatherings of women (1987).

The decision to focus on women elders’ perspectives provided more focus, comfort, and congruence with my epistemology about the importance of women’s words and insights. Steedly (1993) notes that if we fail to record the stories of women we may lose an irreplaceable source of indigenous knowledge about health, and in doing so, we would be repeating the exclusion of women’s voices that has occurred in the Western culture of the past. Medicine maintains that women's activities and orientation to Lakota life-styles have been slighted in the ethnographic literature and in contemporary studies (1987, p. 160). Elucidating women’s lives, she added, can help to appreciate the sense of harmony reflected in the way Lakota society functioned in the past and the present. “The fact that women are the primary socializers of children underlies their duties as teachers of values, language, culture, world view, rituals, and practices, and underlies the beliefs and behaviors of the Lakotas” (p. 170).

Methods for selecting participants and member checks

The CHR program was instrumental in helping me gain access to the community and also helped to identify information-rich elders respected in the community for their wisdom and moral standing. The CHR Director, in collaboration with the staff, prepared a list of women elders resourceful on the subject of health and diabetes and interviews were scheduled by telephone at a convenient time for the participant by the CHR in whose district the elder lived and who would introduce me to the elder (see “Description of Participants”).

The research design included transcription of the audiotaped interviews by the researcher. On the consent form, I promised to send each participant a copy of her tape and transcript with requests to make revisions or add comments and return the transcript

in a postage paid envelope I supplied. The transcripts and any additional conversations I could have with the elders were to serve as member checks while I simultaneously was to sort and analyze the data. I will present the study to the Health Education and Welfare Committee of the Tribal Council and, with their invitation, to a community audience.

Time line for data collection and analysis

Naturalistic depth was added to this study by the field experience on the reservation and sustained relationships with the CHR program, initiated in August, 1997. The specific timeline for data collection using the primary method of in-depth interviews and the related data analysis and member checks is illustrated in Figure 3.2. The participant observation, or data collection, period was from May 20 through June 17, with the first interview taking place June 9, 2001. Data analysis began with the first interview and continued throughout the writing of this dissertation. Member checks were conducted by postal correspondence, including two returned transcripts and a telephone conversation with one participant on October 21, 2001.

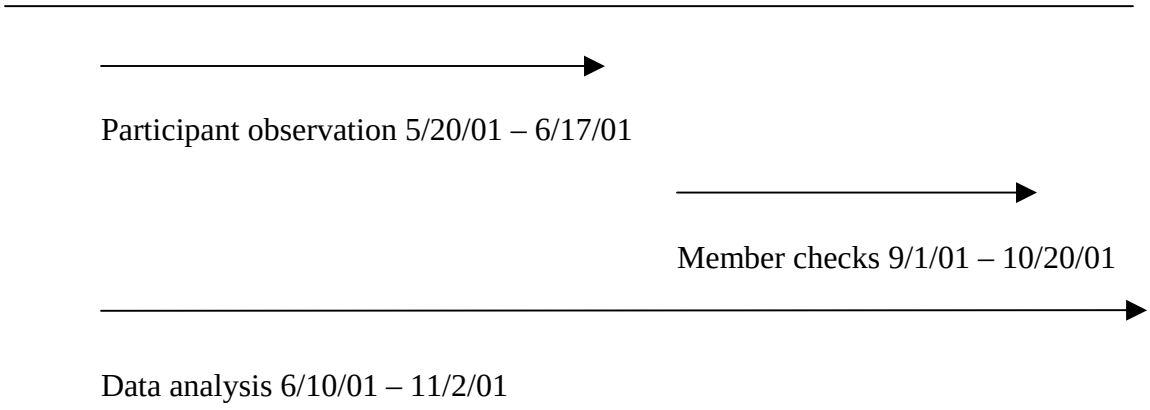


Figure 3.2. The specific plan for data collection

Research Questions

The research questions and related questions and prompts, which were to be used as indicated during the interview, are shown in Table 3.1. The primary questions were:

1) To what connected factors do Lakota and Dakota elders attribute diabetes?
2) What narratives do these elders offer that reveal health protection and diabetes prevention as culturally constituted practices, both in the past and the present?
3) How do these elders express their concern and share their wisdom?

Table 3.1. Research questions and related prompts

Research questions	Questions or prompts for participants
To what connecting factors do Lakota and Dakota elders attribute diabetes?	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 that reveal health protection and diabetes prevention as culturally constituted practices, both in the past and the present?	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? How important was/is physical activity in terms of staying healthy? Could you talk about feeding of babies? 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 like myself? 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 art of interviewing, state Dunbar, Rodriguez, and Parks (2002) "entails framing questions in a way that allows interviewees to maintain their dignity while they tell the stories that are important to them" (p. 294). The interviewer's charge, they add, is not only to ask carefully worded, culturally sensitive questions, framed to set the tone for the interview, but realize that the researcher's manner and introductions are very important. Self-disclosure of the interviewer in sharing ideas, attitudes, or experiences that may related to the interview topic is honest and may encourage respondents to be more forthcoming. For people of color and other marginalized people who may be skeptical or distrustful, based on years of misrepresentation and misinterpretation, these internal questions must be satisfactorily answered, "Who are you?" and "Why should I talk to you?" (Dunbar et al., p. 291).

The general statement of self-disclosure and purpose made at the introduction of the interviews is found in the next section. On the advice of the CHR Director, I offered a pouch of tobacco to the elder at the beginning of the interview because this is a cultural symbol of a humble request made with appreciation for the wisdom the elder has to offer. The acceptance of the pouch indicates the elder is willing to share their wisdom with the petitioner. I did not provide an incentive to the participants, but after the interviews I gave each participants a thank-you gift of a blanket and a small stuffed buffalo.

Data Collection Methods

I conducted participant observation throughout my experience in residence (May 20-June 17, 2001). The primary method of data collection used was in-depth interviewing. Additional, optional methods were offered to participants to supplement their words with photographs or maps, depending on their interest or usefulness. Participant observation, in-depth interviewing, "photovoice," and cognitive mapping are described in the following sections.

Participant observation

At the base of research methods in the social and behavioral sciences is participant observation of cues that lend meaning to the words of the person being interviewed. Observation can be considered to be broad and include documentation of relational correspondence and insights, as well (Angrosino & Mays de Perez, 2002).

My field notes were helpful in documenting observations, as noted. Listening over and over to the full audiotapes for meaning and for the dialogues of the interviews allowed me to hear voice inflections, silences, delivery and the passion or reticence with which some subjects were discussed. This recalled for me the within-case dynamics that had taken place during the interviews and allowed me to reflect on cross-case responses that I would have missed from reading the typed transcripts alone. This recall, which I did throughout the data collection and analysis periods, along with member checks and constant theorizing has allowed me to "make sense" of the findings.

In-depth interviewing

The method of data collection that I used for this study was in-depth interviewing, a tool researchers seeking "deep" information and knowledge concerning matters such an individual's self, lived experience, values and decisions, and cultural knowledge or perspective (Johnson, 2002, p. 104).

> It is recommended, according to Johnson, when "questions are of greater depth, where the knowledge sought is often taken for granted and not readily articulated by most members, where the research question involves highly conflicted emotions, and where different individuals or groups involved in the same line of activity have complicated, multiple perspectives on some phenomenon" (p. 105). I knew from my growing understanding of politeness and protocol that my initial disclosure and introduction about this study would be very important. I crafted this introductory statement in my field notes: I am very grateful for this opportunity to listen to you talk about health and about an illness affecting many

> people, diabetes. I understand it is the right thing to do to offer an elder tobacco as I ask for your words of wisdom on an important subject. Will you accept this? I hope I don't make too many mistakes and that you'll instruct me and forgive me when I do. I've worked in diabetes as a nurse for 20 years – first in downtown Atlanta in a diabetes clinic and the last 10 years at a federal agency, the Centers for Disease Control and Prevention, based in Atlanta, Georgia. I'm a student at the University of Georgia trying to learn more about ways to help people be healthy and prevent diabetes. I've seen a lot of problems caused by diabetes, when it's out of control, and I'm shocked that it now occurring in some children and this is happening around the world. It's sad to me because it means they could have kidney problems and things like that even by the time they're forty or so. I think we need to learn more about preventing this from people who hold wisdom about health and illness. And I'm trying to understand what people know here about how to prevent things like diabetes, because it was so rare till about forty years ago. I appreciate what women elders like yourself believe helped protect people then and now – what you think is good for health. And I would like to ask you to share your wisdom on this.

After explaining my purpose in a variation of this introduction, depending on the dynamics of the introduction, I offered the tobacco pouch and asked participants to sign the consent form after reading it or having me read it to them. As soon as this was done, and sometimes even before I had gotten the audiocassette recorder turned on, the elders began responding to the general question. I used two small audiocassette recorders with small microphone extensions to record the dialogues. The interviews lasted approximately 90 minutes each.

I listened to all of the tapes a number of times, in entirety, in June of 2001 and transcribed the interviews in July and August of 2001. I had some help in transcribing a few of the interviews from my 14-year old daughter and a friend who did some work at

home. The help was valuable in helping me to move the analysis along, but I found that the transcripts typed by my helpers had to be "filled in" by myself, listening again to each of the tapes, because I had the memory recall of the dynamics and emphasis of the conversations, as well as some cultural knowledge about the rhetorical choices and the application of Lakota or Dakota words in certain instances.

After transcribing the interviews, I sent participants one copy of the audiotaped interview, two copies of their transcripts, a self-addressed stamped envelope, and a letter inviting them to return in the enclosed envelope one of the transcript copies with any marks they wanted to correct or add to their words. The purpose of this was to serve as a member check and an additional transcript copy was provided so participants could retain a personal copy of their words for their families, if they chose to do so.

Photovoice

"Photovoice," a participatory process of photodocumentation recently introduced to the field of public health (Wang& Burris, 1997), is "a process by which people can testify, represent, and enhance their community,"(p. 369), helping to affirm the ingenuity and perspective of vulnerable populations by helping people to record and reflect on their community's strengths and concerns and promote critical dialogue and social action. The tool also provides powerful visual images that may help policy makers to visualize the need to reconsider policies (Wang, Yi, Tao, & Caravano, 1998). At the beginning of the interview, I gave participants instant cameras (Polaroid One step ^{tm}) with film, along with instructions about how to use the camera and the option of providing pictures as illustrations of concepts or items we discussed. Photos could include events or sites believed to have some enduring cultural meaning, as well as more mundane images, such as tools like garden hoes.

While I did not receive current photographs from the elders, there was a great deal of interest expressed in taking photographs to help me to illustrate the issues they thought were relevant to health and diabetes prevention. To help my understanding, and also

realizing that pictures might help support their interest in having others visualize the nature of health and diabetes prevention, from their perspectives, various elders said they planned to obtain pictures of powwows, healthful plants found on the plains, and homegardens and send these to me. One elder said she wanted to get a grandchild to take a picture of her as she tanned a deer hide. To date I have not received any photographs but in a member check one of the elders reiterated her interest in me including these and gave me suggestions for obtaining pictures that would, in particular, document environmental changes caused by flooding of lands near the river.

Cognitive mapping

A second optional visual strategy I offered participants was that of cognitive mapping. A cognitive map provides a picture of how people perceive space, giving attention to wayfinding and the structure and design of physical space; such maps can include not only physical attributes of a place, but stories about it, and information on how to behave in it (Austin, 1998). I made clean paper and a pencil available, mentioning this to each participant prior to the interview, in case they deemed a drawing or a map helpful for explanation. None of the elders offered to draw or write anything on the paper, probably because oral communication was most natural and sufficiently answered the questions. This option was not pursued further since it was not utilized.

Member checks

Because of the oral nature of communication that is best known among the tribal people on the reservation and the inadequacy of mail or telephones for communication, once I had to leave the field, I had not counted on being able to conduct member checks about the accuracy of my transcriptions or to conduct follow-up discussions. However, I wanted to give participants an opportunity to correct statements if they wished, so I sent all participants two copies of their transcripts, their audiotape, an addressed stamped envelope, and a letter thanking them and explaining the option to return a transcript with corrections. I received two transcripts in return by mail and although neither included

corrections, the elders wrote personal notes asking me to “take out the `you knows’” in their dialogue and one elder asked me to “fix” her grammar so these could be retained for their families, presumably so the elders would not be embarrassed and their humility would not be in question, in the case of the “you knows.” Copies with these corrections will be returned to them. I conducted a very instructive member check by telephone with one of the participants October 21, 2001.

Data Analysis

Constructive theorizing emerges from a perceived problem, an unsatisfactory condition in the world – in this case, type 2 diabetes affecting more and younger populations that until relatively recent times was rare. Theorizing is engaging in the art of explanation for the purpose of problem solving – through collecting ideas, analyzing content, judging the credibility and worth of the reasons and ideas and marshalling conclusions in the most cogent reasoning possible (Mithaug, 2000). Qualitative data analysis is theorizing -- a pervasive, inductive reasoning activity that takes place throughout the life of a research study.

All data, we must recognize, are incomplete and partial versions, and through our data collection and analysis, “we produce only versions of the social world,” note Coffey and Atkinson (1996, p. 15). Even triangulation cannot be summed or aggregated to form a complete picture. In fact, coding and categorization, the usual tools of qualitative data analysis, have been associated with a “culture of fragmentation” that, while necessary to handle large volumes of data, imply a mechanistic process that does not adequately reflect the holistic, contextual nature of the data. This can be distressing to qualitative researchers, who tend to recognize the complexity of social worlds rather than reflecting “mentalities that cannot cope with the uncertainties and ambiguities of social research” (p. 15). The more data is examined from different viewpoints, the more it can reveal the data, Coffey and Atkinson claim, in answer to these concerns. Applying additional methodological frameworks, which serve to affirm, rather than deny, the diversity of

social phenomena and exploration can help researchers avoid the limitations of reductive approaches and reflect the complexity of the data.

As data are segmented and divided into meaningful units as part of analysis, connection to the whole must be maintained, requiring methodological knowledge and intellectual competence on the part of the researcher, note Coffey and Atkinson (1996). Analysis as a term refers mainly to the tasks of coding, indexing, sorting, retrieving, or otherwise manipulating data, or data handling, for many researchers. For others, analysis refers primarily to the imaginative work of interpretation and the more procedural, categorizing tasks related to the preliminary work of ordering and sorting the data.

Transforming data is accomplished through the researcher's process for expanding and extending data beyond a descriptive account, according to Wolcott (1994), using three primary ingredients - description, analysis, and interpretation. Description includes singling out things worthy of note and relegating others to the background. Analysis encompasses tasks such as identifying patterned regularities in the data, comparing with other cases, and displaying findings. Interpretation transcends the data and cautious analysis of it to begin to probe into what is to be made of them.

Using an only slightly more prescriptive formula, Huberman and Miles (1994) link three subprocesses -- data reduction, data display and conclusion drawing and verification. Data are reduced in anticipatory ways as conceptual frameworks are chosen and as instruments, cases, and questions are refined. Then the data are summarized, coded, and broken down into themes, clusters, and categories. Data displays include the diagrammatic, pictorial, or visual forms to show what the data imply, laying the groundwork for the last process. Writing conclusions is where interest and meaning are drawn.

With appreciation for the complexity of the original research problem and the rich data I collected, I followed the general guidance of Wolcott's three ingredients, description, analysis, and interpretation, as well as several of Miles and Huberman's

suggestions for data displays (1994). Grounded theory provided a clear several-step process, including initial and selective coding, described below. Narrative analysis, also described, helped to focus the lens in a slightly different position, adding capacity, through storylistening and storytelling, for understanding and relaying the conceptual density of this data.

Grounded theory analysis

Grounded theory takes the researcher into and close to the real world so that the results and findings are "grounded" in the empirical world (Patton, 1990, p.67). In the initial analysis that began to take place even during data collection, I queried myself about "What is happening here?" -- what Charmaz (2000) describes as the driving question of grounded theory analysis (p. 675). Grounded theory pursues emergent themes through early data analysis, discovery of basic social processes within the data, inductive construction of abstract categories through comparative processes, and integration of categories into a theoretical framework that specifies the causes, conditions, and consequences of the studied processes. Most grounded theory studies are directed at development of substantive theory with conceptual density and the emphasis on rich theory development is a major difference between grounded theory and other approaches. A central feature is a general method of constant comparative analysis (Strauss & Corbin, 1994).

Coding

Coding, affixing codes to a set of field notes drawn from observations or interviews, is the "pivotal first analytic step" (Charmaz, 2002, p. 683). The "stuff of analysis" (Miles & Huberman, 1994, p. 56), it reflects, according to Coffey and Atkinson (1996), a subtle process of "having ideas and using concepts about the data" (p. 29). The recommended line-by-line coding keeps researchers thinking about the meaning and it facilitates making comparisons (Charmaz, 1999). Selective or focused coding is then used to sort, synthesize, and conceptualize the still-large volumes of data by adopting

frequently reappearing initial codes. This allows a more refined process for developing categories from the focused codes and then generating broader conceptual frameworks (Coffey & Atkinson, 1996).

I began the process of data analysis initially by listening to and transcribing the audiotapes and then placing in one loose-leaf notebook the typed transcripts into an order with the case identification known only to myself. In the initial or open coding of each individual interview transcript, I assigned to each line or few lines a shorthand designation to aspects of the data so that specific pieces of the data could be retrieved (Merriam, 1998). In this initial coding the researcher is discovering participants' views and making analytic decisions about the data. Following Charmaz' example, I focused on the action in the data, penciling in the right hand margins, phrases such as "seeking healing," "describing how people took care of sick," and "recounting events of flooding." As I noticed certain related items in the conversations, such as the frequent mention of preparing and eating soups, I made simple notes (e.g., "soups") to quantify these.

I conducted focused coding using an informal system of color coding key items such as "cultural practices" in red, "narratives" in green and frequently occurring concepts such as "water" in blue so I could easily retrieve them. Then I created a type of index for each interview with the identified themes coordinated to pages so I would be able to locate them later as I compared cases.

Constant comparison method

Constant comparison consists of finding patterns, making comparisons, and contrasting one set of data with another (Krueger, 1998). Although these comparisons actually began during data collection, it was assisted by getting to the point of having covered the transcript pages' right hand margins with penciled-in initial and selective codes and selective codes marked with colored adhesive notes. In earnest at this point, I looked for common themes, comparing one segment of each interview with others and

comparing it all to the literature – looking for similarities and differences. My whole being felt immersed in the data while I was coding and indexing and then making comparisons across cases, but it was only when I "stepped away" from the data and then returned, often after more reading, reflection, or a member check, that I was able to see similarities, distinctions, and integrations that I would have missed without additional theorizing.

Analysis according to dichotomizing attributions for diabetes

As noted in Chapter 2, diabetes is seen by many American Indians to be a "new" disease (CDC, 1997), an "unnatural" (Joe & Young, 1993, p. 6), "outside" disorder (Huttlinger, 1995, p. 14). It has been called a "white man's sickness" (Garro & Lang, 1993, p. 299; Morgan & Weedon, 1990, p. 19) which requires "white man's medicine" (Acton & Fiore, 1996).

Knowing this, I have been interested in the universal, dichotomizing concept, particularly in naturalistic systems, of illness due to natural, or disharmonizing, internal forces involving the individual, or unnatural, externalizing forces imposed from the outside (Helman, 2000; Wing, 1998). I anticipated that attributions for diabetes would largely be viewed as externalizing, or from the outside. This concept served as an organizational way of categorizing these responses so they could be further analyzed. Using short phrases that illustrated the concepts of externalizing, or unnatural, origins and internalizing, or unnatural, origins, I case ordered these in matrices.

Narrative analysis

Personal narratives illuminate the intersection of biography, history, and society (Reissman, 2002). Folk narratives are usually conventional, widely shared cultural representations mediated by the narrative community at large (Narayan & Georgie, 2002). Telling and listening to stories is at the heart of social and cultural life for many communities, serving as an indirect, non-threatening communication strategy to communicate moral and messages by a teller who remains polite and allows the listener

to interpret the material in their own way (Carter et al., 1999). Narrative analysis can serve as an especially valuable approach to analysis of stories which draw from the metaphors, language, and legends of a culture, or "cultural documents" (Helman, 2000, p. 96), looking beyond the data itself to the ways in which the stories are socially and culturally managed and constructed (Coffey & Atkinson, 1996). A strength of looking at data as narratives is that it abandons the treatment of participants' accounts as true or not, opening up for analysis the culturally rich methods through which interviewing researchers and participants together make sense of events and generate plausible accounts of the world (Denzin & Lincoln, 2000).

Storytelling is frequently a feature of explanations for ill health because it provides a way of giving meaning to the experience of illness, placing it in the context of the life history of individuals or of communities (Helman, 2000). Illness narratives, the stories that always surround episodes of illness and healing for those who live through them, are not limited to the autobiography of the person but can include the experience and healing of a collective social body, or community, that has been put asunder (Kleinman & Seeman, p. 237). They can be viewed as a triangle composed of collective experience, cultural representation, and subjective experience. Kleinman's work in explanatory models, (1988) an approach to gain understanding of the ways in which an illness episode is interpreted and understood by patients, healers, and other members of the local social world, has been used by a number of diabetes researchers (Garro & Lang, 1993; Paterson & Sloan, 1994; Paterson, Thorne, & Davis, 1999; Paine-Jackson, 1999).

Because this study is about the phenomena of diabetes in the context of the community and the participants in this study are elders known for their collective experience and concern for the health of their communities, I analyzed their narratives as illness narratives, the stories people have around episodes of illness and healing they have lived through (Kleinman & Seeman, 2000). The genres of illness narratives help to

determine the meanings that underlie the narratives, state Kleinman and Seeman, citing Arthur Frank's work (1995) in identifying these genres:

1) restitution narratives - emphasize positive responses and outcomes; stories of coping with illness, rebuilding the body-self, and remoralization;
2) chaos narratives – stories told of disorder, distortion, and fragmentation. Anguish, threat, and uncontrollability are characteristics of this type of story;
3) quest narratives - emphasize either a search for cure or for meaning and transcendence within and through illness; and
4) testimony narratives - explicitly moralized forms of stories that seek to bear witness, or to give voice to, those who suffer.

When codes are raised to analytic categories as I have attempted with the analysis and conceptually ordered matrices, some will be found to be incomplete or have insufficient evidence, notes Chavez (2001). The vivid integration of personal and collective experience of these elders was very useful in transforming the rich data generated by the interviews and observation. However, I found that the narratives offered by these participants also included a genre of more specific recommendations, or wisdom, for health protection. This genre was added in the findings and displayed in the matrices presented in Chapter 5.

Display of data in matrices and diagrams

Extended text, a more traditional form for displaying qualitative data, has been minimally used in the presentation of findings, in favor of matrices, which are recommended by Miles and Huberman (1994) as a major avenue to valid qualitative analysis. In addition to assisting analysis and displaying data in an organized assembly for interpretation, the matrices also helped to reduce the data. The case ordered rows, sorted by themes, do contain long texts that can be cumbersome to read. However, for the following reasons I believed it was important to include the women's words, in context, as much as possible, in the illustrations selected:

1) The nature of the narratives is holistic and contextual grounding, one of the functions of storytelling (Banks-Wallace, 1998), can be lost when text is reduced or interpreted in solely the words of the researcher.
2) Consistent with a feminist standpoint, I am sensitive to domination (Abu-Lughad, 1993), which can include privileging or ignoring certain voices or messages, representing a type of imperial translation (Fine, 1994) and the "thorny" problem of speaking of the experience of "others" (Duran & Duran, 1999, p. 292).
3) Shared stories can help groups to resist oppressive situations and develop solidarity (Banks-Wallace, 1998). I believe the stories, should they be used for this purpose by the tribe or by program planners, need to be retained in the context in which they were told.

To display the data I case ordered and conceptually ordered it according to the research questions, creating four matrices – one for attributions for diabetes, one for chaos genres of illness narratives which were largely externalizing attributions, and one case-ordered matrix illustrating statements or narratives reflecting concern for the health of the people To assist the reader to distinguish the themes elaborated in the text and to match these with the illustrations in the matrices, I underlined in the text the themes that emerged.

CHAPTER 4

RESEARCH SETTING, PARTICIPANTS, AND EXPLORATORY FIELDWORK

For land-based tribal people, definitions of “reservation” are not limited to historical and legal meanings but encompass concepts and values relating to the land and the people, and beliefs about the permanence of the reservation and of tribal sovereignty (Schneider, 1994). The following sections provide an overview of some aspects related to the research setting in the broad concept of the Standing Rock Sioux Reservation including the people and a description of the study participants and their integral place in the setting as well as in this study. Also included is a brief glimpse of my exploratory fieldwork for the previous four years before data collection and some examples of excerpts from field notes that give a glimpse of the contributions of this experience to the overall research.

The Standing Rock Sioux Reservation

Often the name by which an indigenous tribe or group referred to itself can be translated as "people" or human beings (Schneider, 1994). The people we now call the Sioux, prior to European contact, referred to themselves as Lakota or Dakota or Kota, meaning friends or allies, and were members of three different, but related, groups, the Dakota, Lakota, and Yankton-Yanktonai, sometimes called the Nakota. The word Sioux comes from the term Nadouesseiou used by the Chippewa and related tribes to refer to the Dakota and shortened by the conquerors. Whereas the word's exact meaning is no longer known, it is believed to mean "lesser snakes" or enemies (p. 8).

The great Dakota nation was originally composed of seven major bands or council fires. The easternmost division was the Dakota, sometimes also called the Santee, although this is actually the name of one of the bands. The four main groups of the Dakota were the Mdewakanton (Spirit Lake People) who occupied seven villages along

the Missouri, the Wahpekute (who had a single village on the Minnesota), the Wahpeton living in seven villages, and the Sisseton who were organized into 12 villages. The Lakota were the westernmost division. There were seven bands of the Lakota: the Hunkpapa; the Mnikonju or Minneconjouuu; Sihasapa (Blackfoot); Oohenonpa; Sicangu; Itazipcho; and Oglala. Most of the Lakota people of the Standing Rock Tribe are Hunkpapa Sioux (Schneider, 1994).

The Standing Rock Sioux Tribe, like many other North American tribes, is experiencing high rates of diabetes among their people, including seven cases among teenagers. They have initiated a number of efforts to try to reduce the impact of diabetes, including in 1995, a community organization course and beginning in 1997, ongoing diabetes-focused education for CHRs. The Tribe has a Diabetes Program, funded by a federal grant for qualifying American Indian and Alaska Native communities by the Balanced Budget Act of 1997, which is actively providing educational and support messages and culturally-relevant programs. The CHR office and the Diabetes Program office are part of a nucleus of tribal offices located in the seat of the nation, Fort Yates, North Dakota. There are 8 communities and these are pictured on the map in Figure 4.1

History

The history of the Dakota and Lakota bands of people is long, rich, and marked by unresolved grievances. Although the Treaty of Fort Laramie, 1851 and 1868, had guaranteed the security of the Great Sioux Reservation, in 1876, in pursuit of gold and partly in retaliation for the Battle of the Little Big Horn, the US government annexed the Black Hills from the Sioux. In 1980, the U.S. Supreme Court ruled for the Sioux, stating, “a more ripe and rank case of dishonorable dealing will never, in all probability, be found in our history” and awarded $106 million (N.D. Dept. of Public Instruction, 1995, p. 40). The Sioux tribes have refused to accept the compensation for this land, center of the Great Sioux Nation was the Black Hills, the "paha sapa," sacred to all Lakota and Dakota people (N.D. Dept. of Public Instruction).

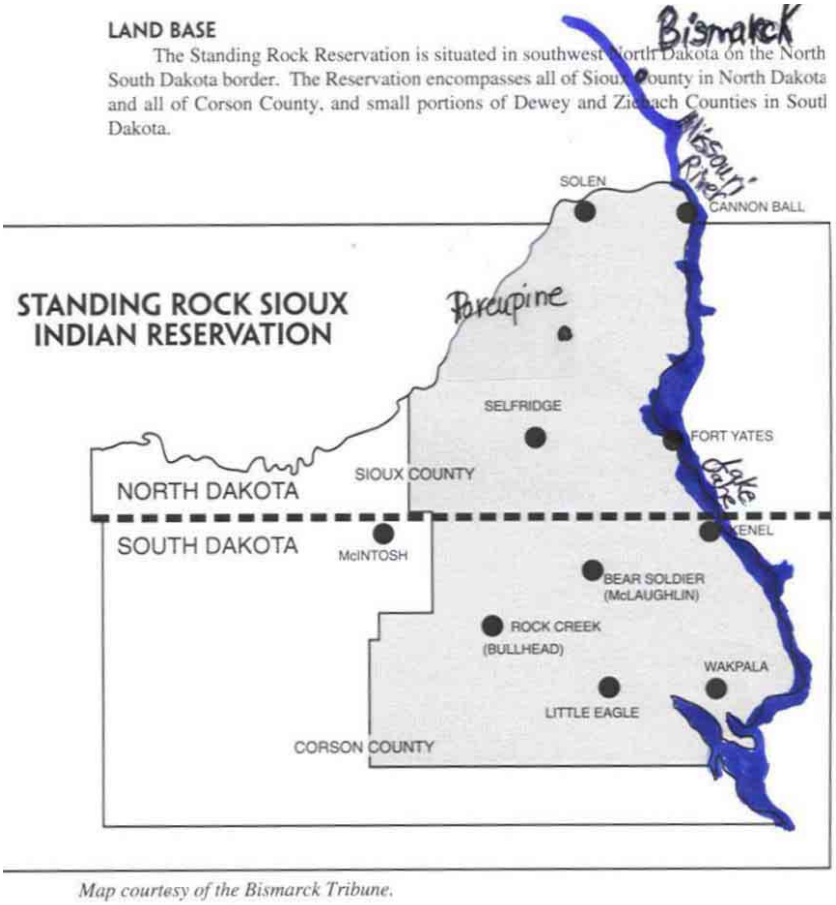


Figure 4.1 . Map of the Standing Rock Indian reservation. Adapted, Schneider, 1994.

In 1887, the Dawes Allotment Act allotted Indian lands to break up the Indian land base or the reservation. Individual allotments of land, "most of very poor quality," were made to Indians and the remainder was opened to non-Indians for homesteading. In the face of starvation, a new religion, the Ghost Dance, emerged with hopes for return of the old ways, but on December, 1890, over 300 Lakota people planning to practice this dance were massacred at Wounded Knee, S.D., by the U.S. seventh cavalry, the military unit that had been annihilated by Sioux and Cheyennes at the Battle of Little Big Horn in 1876 (N.D. Dept of Public Instruction, 1995).

As described in the next section, 25% of the reservation population had to relocate out of flood areas because of the building of the Oahe Dam, which began in 1948. It was not considered feasible to relocate the city of Bismarck, so the Corps of Engineers decided to move small communities including Cannonball and Kenel. Along the river great stands of dead cottonwood trees are found in the water, “constant reminders of the changes that have been brought by the White man's struggle to control nature” (Schneider, 1994, p. 149).

Termination, a government policy developed in the 1950s aimed at ending reservations, removed Indian status from a number of tribes on the basis that they no longer needed Federal services. The impact was economically and culturally disastrous with many tribal land holdings were allotted to individuals or sold off and the land becoming subject to taxation (Schneider, 1994).

In 1975, the Indian Self-Determination Act was passed, favoring the retention of the protective role of the federal government while increasing tribal control of important areas of local government (Lacey, 1995). The 1975 Self-Determination Act is particularly relevant to health issues because it gives tribes the option of staffing and managing Indian Health Service (I.H.S.) programs in their communities or choosing or developing alternative health service programs (U.S. Public Health Service, 1996).

The American Indian Religious Freedom Act was passed in 1978, reversing official government policy prohibiting the practice of spirituality passed in 1863 (N.D. Dept of Public Instruction, 1995). The 1988 Indian Gaming Act (American Indian Digest, 1995), allowed establishments like casinos to operate on tribal lands. In 1983, President Reagan restated in a policy statement on Indian affairs, the “government to government” relationship of the United States to tribal governments (Lacey, 1995).

Land base

The Standing Rock Reservation, home of the tribe, straddles the central border of North and South Dakota. The size of the reservation is over 2.3 million acres, as of 1994,

of which about 980,000 acres are Indian owned, trust land and the remainder is fee land of over 1.5 million acres constituted primarily by non-Indian owned lands, school and township lands, and about 50,000 acres is reservoir-taking area, created by the creation of the Oahe Reservoir (N.D. Dept. of Public Instruction, 1995), which was part of the plan to control the Missouri River and to provide water for electricity and irrigation that brought about the building of Garrison Dam and other higher up on the Missouri (Schneider, 1994). In 1948 the Army Corps of Engineers started constructing the Oahe Dam though they faced intense opposition from the tribe. One quarter of the reservation population had to relocate from their homes in the flood areas, flooding 160,889 acres of "prime agricultural lands" (N.D. Dept. of Public Instruction, p. 39).

The topography of the reservation varies but most of the plains consist of rolling hills and grass lands, described by some as looking like the ocean because of the great sweeps of land cut into swells and hollows with the grass rippling like waves (Norris, 1993). There are areas along the Missouri usable for agriculture and stock ranching and "badland" type areas further away from the Missouri River (Schneider, 1994).

Language

Lakota and Dakota languages are distinct but both are from the Siouan language family, as are the Mandan and Hidatsa languages of people who live on the Fort Berthold Reservation (of the Three Affiliated Tribes, Arikara, Hidatsa, and Mandan) in the west central part of North Dakota. Lakota and Dakota languages are so close that speakers of the different dialects can understand each other, allowing for differences in pronunciation (Schneider, 1994). For the elders of the Standing Rock Sioux Nation, Lakota or Dakota is their first language, though all speak English as a second language (Schneider, 1994). Younger generations typically speak only English fluently, although some schools have recently established programs to help students learn their native languages.

Population

According to 1995 statistics, the reservation had about 11,672 enrolled members with about 5,860 living on the reservation. Since that time, many members have returned to the reservation and currently about 9,000 reside there. To be enrolled in the tribe, members must be able to document a blood quantum of at least one-quarter, based on lineage from this particular tribe (N.D. Dept. of Public Instruction, 1995).

American Indian populations tend to be younger than for the U.S. population in general. In 1990, 33 % of the AI/AN population was younger than 15 years compared to 22% for the U.S. "all races" population. However, the percentage of people 64 years or older was only 6%, compared to 13% for the U.S. "all races" population (I.H.S., 1997).

In 1995, there were 269 people who were 65 years or older living on the Standing Rock reservation, about 4.4% of the population total (N.D. Dept. of Public Instruction, 1995). The low numbers of elderly people probably reflect lower life expectancies among AI/AN people, particularly for Indian people in the Aberdeen area. The U.S. life expectancy for males, for example, was 72.2 years in 1993, compared to 67.2 for I.H.S. service users, and 60.5 years in the Aberdeen area, a difference of 11.7 years. The life expectancy for females in all U.S. "all races" population was 75.5 in 1993, contrasted to 71.1 among I.H.S. users, and 64.3 for those living in the Aberdeen area (I.H.S., 1999).

Economic status

The per capita income for Standing Rock Indian adults was $3,421, according to the 1990 census (Schneider, 1994). The median household income in 1989 was $12,310 for people living in the Aberdeen area compared to $30,056 for all US populations. While 13.1% of the total U.S. population lives below the poverty level, the rate is 49.6% in the Aberdeen area. Unemployed males age 16 and older represent 26.5% in the area, versus 6.5% overall for the US (I.H.S., 1999). Unemployment among people 16 to 64 years was 70% (N.D. Dept. of Public Instruction, 1995).

Education

Boarding schools and religious mission schools have provided much of the education for Standing Rock adults over age 40. Current generations of youth can now attend schools on the reservation run by the tribe. The first boarding school was Carlisle Indian School, which opened in Pennsylvania in 1879, with the motto, "To kill the Indian and save the man" (N.D. Dept. of Public Instruction, 1995, p. 37). Boarding schools were established in other cities including Hampton, Virginia, and, closer to home for the Lakota and Dakota people, in Rapid City, South Dakota. In the 1880s a Catholic boarding school moved to the Standing Rock agency. Boarding schools were established to "civilize" Indian children (The Heard Museum, 2001).

Health

The general health of the Indians of the Northern Plains appears to have been satisfactory before contact with the Europeans, who described them as vigorous and strong. Because there was little or no immunity to contagious diseases, exposure to diseases the Europeans brought, including whooping cough, influenza, diphtheria, measles, chickenpox and cholera, had devastating effects on populations. Smallpox was the greatest scourge, killing thousands of native people and reducing several tribes to 25% or less of their original number. While there is no evidence that blankets containing smallpox were intentionally given to Indian people on the upper Missouri, there is some evidence that a blanket taken from a man ill with the disease started the smallpox epidemic in 1837 (Schneider, 1994).

Destruction of traditional sources of food, especially the buffalo, which represented not just food but symbolic strength, created famine and starvation in 1889 (Schneider, 1994), when deaths exceeded births (N.D. Dept. of Public Instruction, 1995). The changes in diet that occurred with reservation life have continued to influence tribal health. Some new foods introduced as staples, beginning in the late 1800s, particularly salt and sugar, were detrimental. Rations, later called commodities, usually consisting of

meat of low grade or salted pork, flour, sugar, coffee, candles, and soap, were distributed regularly but meagerly because these were considered by the government to be supplemental until the Indian people turned entirely to agriculture for a living. To ward off hunger, staples were used to create “fry bread,” flour deep-fried with lard (Hill, 1997).

In 1955, tuberculosis, pneumonia, and other respiratory diseases, enteric diseases, accidents, eye and ear diseases, dental disease and mental illness were described as urgent problems of Indian people (Schneider, 1994). Diabetes was rare but since then has become epidemic in the majority of American Indian tribes, including those in the Aberdeen service area. From 1988 to 1996, the Aberdeen area saw a 14 % rise in the rate of diagnosed diabetes, including a 52 % increase among 15 to 24 year old members (Burrows et al., 1999). Age-adjusted diabetes death rates represented 12.4 per 100,000 in all U.S. populations, versus 60 per 100,000 in the Aberdeen area. In March 2001, the Standing Rock Diabetes Program documented a prevalence of 749 people of all ages with diabetes, a rate of 8.9 %, based on an I.H.S. user rate of 8,427. Seven youth between the ages of 15 and 17 are known to have diabetes. The audit revealed that 47.6 % of males and 53.8 % of female members are overweight or obese (I.H.S. Diabetes Audit, 1999).

Values

Everything is related, interwoven, interconnected, and related in Lakota and Dakota ways and these are reflected in the values (Sanchez, Plawecki, & Plawecki, 1996). Although naming of the values varies with the speaker, the inherent relatedness of all things is integral. Beatrice Medicine, a member of the Standing Rock Sioux Tribe and an anthropologist, stated that people brought up in strong families (tiyospaye), with strong Lakota beliefs, are able to function in two worlds because they have a good sense of who they are. Lakota people as parents, whether biological or sociological, are embedded in the tiyospaye, and through this all are related, hence the prayer, “mitakuye oyasi’in,” “relatives all” (1987, p. 160).

Four cardinal Lakota virtues are: 1) sharing and generosity; 2) wisdom; 3) fortitude; and 4) bravery, according to Medicine. The tiyospaye and the intrinsic values and beliefs are tied to the native language and to key rituals like the Sun Dance, a ritual three or four-day dance in which the entire Tribe gathers to ensure renewal of individuals, and of the Tribe itself and the world in general (Brown, 1995). The Sun Dance reemerged in the 1950s and about 1963 began to function as a revitalization movement for the Sioux, Medicine noted.

The value of generosity and helping among Lakota people, defined as wawokiye, has been well documented (Sanchez, Plawecki, & Plawecki, 1996; Schneider, 1994; Stead, 1987). "One should give not only one's possessions to people in need, but also one's time and energy to help others," observed Schneider (1994, p. 17). At ceremonies, some tribal members have a "give away" in honor of a prayer granted, a vow honored, or in gratitude for the recovery of someone's health, giving away collected or home-made gifts – a practice that was outlawed, along with religious ceremonies, because the government thought it reckless (Long Standing Bear Chief, 1992). Generosity is still so strongly identified with the culture that an Indian, and sometimes an outsider, is said to have "heart" if they share in Indian beliefs and attitudes, emphasizing generosity (Schneider). People brought up in the Lakota way were instructed never to be stingy, Medicine recalls (1987). In contrast, Whites are often viewed as greedy, wanting bigger homes, newer cars, and expensive possessions (Schneider).

Generosity in sharing wisdom is a value reflected in elders, and respect for elders is itself an important value (Sanchez et al., 1996). The elders of experience serve as repositories for the oral lore of the people, sometimes through storytelling which also helps to maintain their' position of respect and importance. (Brown, 1995).

Wisdom refers to heightened mental capacity and foresight to avoid harmful events, according to Basso, therefore embodying insight and prevention (1997). Among elders of many indigenous peoples there is an ethos that decisions should be made with a

"long view" toward their impact on future generations, illustrated by metaphors including, for Tewa Pueblo elders, "look to the mountain" and for the Lakota, "for the next seven generations" (Cajete, 1999).

Perceptions of the mysterious, sacred, and universal creative force, the "wakan," are intimately connected to all aspects of the culture and to respect. The term Great Spirit is translated from "Wakan Tanka," "Big Holy" (Stead, 1987, p. 213), "the great incomprehensibility" (DeMallie & Parks, 1987, p. 42). The name for children, "wakanyeja," "the sacred ones," emphasizes their wakan aspect (Medicine,1987, p. 169).

Health is a primary virtue in the religion of the Lakota society, notes Kenneth Oliver (Stead, 1987), and included in the concept of health is the mental aspect. The Lakota word for health is "wicozanni" with "wiconi" referring to "life" and "humans" and "ni" to "life."

A list of Lakota and Dakota values was recently provided to me by the CHR program from notes they made at a workshop. These values listed are:

1) Woc'ekiya -- prayer -- finding spirituality by communicating with your own higher power, this is communication between you and Tunkas'ila without going through another person or spirit.
2) Wao'hola -- respect - to consider worthy of high regard, for self, higher power, family, community and for all life.
3) Waon'sila -- caring and compassion -- love, caring and concern for one another (in a good way), especially for the family, elderly, youth, orphans, those in mourning, the sick and ill, and the ones working for the people.
4) Wowijake - honesty and truth -- with yourself, a higher power, and others with sincerity
5) Wawokiye - helping -- without expecting anything in return
6) Wah'wala - humility; unpretentious, we have a spirit, we are no better nor less than others

7) Woksape -- wisdom - practice with knowledge, insight and judgment comes wisdom.
8) Wacacintanka – generosity, giving from the heart
9) Woohitika – bravery
10) Wowayuonihan – honor
11) Wowicala – belief, trust
12) Wakoazuzu - forgiveness

Another important virtue, according to Oliver is "wowahwala," which refers to peace, calmness, and the will not to be aggressive (Stead, 1987). Also well known among Indian people is a relaxed attitude toward time, often referred to, with humor, as "Indian time." This attitude reflects a value that things should not be done too quickly, "people need time to think, to discuss and to ponder alternatives" before action is taken (Schneider, 1994, p. 17).

Description of Participants

The community's elders are respected as "the teachers" who also carry a "burden of goodness" (Eagle Shield, 2001). The CHR program was instrumental in identifying information-rich elders respected in the community for their wisdom and moral standing. The CHR program director, in collaboration with the staff, made a list of a dozen women elders he thought would be resourceful on the subject of health and diabetes, noting that these women were primarily "traditional" in their knowledge and practices. In their selection, the program also tried to provide geographic representation of the eight communities in the nation's 2.3 acre land base (e.g., Fort Yates, Kenel, Cannonball, Wakpala, Little Eagle, Porcupine, McLaughlin, and Selfridge). See Figure 4.1. The interviews were conducted in Fort Yates, Little Eagle, Rock Creek, and Wakpala; participants lived in these communities and in Porcupine and Kenel. Four interviews were conducted in the participants' homes, three in their community centers, one in the Diabetes Program office and one in the tribe's casino and lodge 16 miles north of Fort Yates about 7 miles south of Cannonball.

The participants were nine Lakota and Dakota tribal women elders whose ages ranged from 67 to 84 years old; the mean age was 72.5 and the median age was 69 years. Eight of the elders are members of the Standing Rock Sioux Tribe. One elder is a member of another Lakota tribe whose tribal lands are based in the Southern central region of South Dakota; she has been living on the Standing Rock reservation for many years and is accepted as an unofficial member of this tribe with a lot of wisdom to offer, including insights based on her experience with diabetes.

All of the participants were experienced in living with diabetes by having close family members with diabetes and, in four cases, also having diabetes themselves. The elders who have diabetes have been identified by the presence of a star (*) next to their coded identification in the matrices presented in the next chapter. The elders with diabetes have had it for a long time; one for more than 30 years, two more than 20 years and one was diagnosed about 10 years ago. All are presently well controlled and appear to be in good health. In fact, I have wondered if their success in controlling their diabetes and being willing to share their stories for others' learning has contributed, in some way, to the perception by their communities of the contributions these elders have to offer. One of these elders had a diabetes-related kidney transplant 6 years ago, an experience that she uses as a platform from which to speak to people on and off the reservation about diabetes care and prevention; she is in much demand as a speaker and as a visitor in homes of people who are facing this uncertainty, often connected, by her CHR, to people in need of information and support.

All of the participants lived as youth "in the country" in log homes, or, in a few cases, tipis on the Missouri River or its tributaries or creeks, including the Grand River and Cannonball Creek. Most of these women had attended religious or government-run schools at least for a few years, but for several elders, these were within a distance that they could walk or ride horses, so boarding was not required. The first off-reservation Indian boarding school was begun in an old army barracks in Carlisle, Pennysylvania, in

1879, with the mission to "kill the Indian to save the man" (Archuleta, Child, and Lomawaima, 2000). Several of the elders had relatives who had attended this school or the Hampton Normal and Agricultural Institute, in Hampton, Virginia, a school for African Americans and many added the boarding school established in Fort Yates.

All of the elders were married although only one of the husbands is still living. Five husbands of the elders had diabetes, including the one man who is living. All of the widowed elders spoke very highly of their husbands, typically highlighting traits of leadership such as keeping treaty issues alive and wisdom they had shared with their families and others. One of the elders, widowed in 1999, spoke quietly of her husband's life and passing in a way that made me realize, and later my daughter who helped me by transcribing the audiotapes, that her sadness was still very much with her on a daily basis; she had resolved to "do something to be of use in my community," in part to honor his legacy.

Eight of the elders had biological children and all had helped to raise their own or others' children. All referred to grandsons, granddaughters, nieces, and nephews, many of whom I knew. When people heard I was to interview a particular elder, I often noticed several different people told me how they were related to that elder. In an unexpected surprise, one of the elder's sons had been removed from her home by adoption when he was very young before the Indian Child Welfare Act prohibiting such actions was passed in 1978. They had been reunited when he was an adult and we realized during the interview that I happened to know him because he lives in the South – a connection we have enjoyed recognizing in the time that has elapsed since.

The elders selected for interviews carried "the burden of goodness," said the CHR Director, a term I also heard at a tribal conference, "Young Minds – Young at Heart: A Gathering of Youth and Elders" held at the tribe's casino and resort, June 6 and 7, 2001, when councilman Jesse Taken Alive spoke of how the elders carry the knowledge needed for future generations – the "burden of goodness" of the hope and of

the prophecies that someday things will be returned to Indian people. Chosen by the CHR program director and staff because these elders were well respected in their communities, represented various geographically diverse communities and were "traditional" in knowing and still observing traditional "foodways" (Garro & Lang, 1993), and therefore information-rich for the purposes of this study.

I made quite a few observations, while on the reservation, that confirmed the respect these elders had earned among tribal people. As I drove the long distances to various communities, I listened to the tribal radio station, KLND, and happened to hear the hosts mention or feature four of the elders who participated in the study because of some counsel they had given or traditional ceremonies including powwows and memorial ceremonies in which they were involved as leaders. One of the participating elders was an invited guest on a several hour talk program about an important tribal issue.

One day I met another researcher constructing several life histories on the reservation. She knew through word of mouth that I had interviewed two of the elders and she said to me, "Those are the two best storytellers on the reservation," she said. Two CDs on traditional stories have been produced by one of these participating elders and I noticed that one of the stories of gathering beans told by the other elder recognized as one of "the best storytellers" was featured on the CD.

Although I did not realize it at the time, two of the participating elders with diabetes had previously been interviewed by the Indian Health Service (I.H.S.) Diabetes Program based in Albuquerque, New Mexico, for a report to Congress submitted in the year 2000. Smiling pictures of these two women and a quote from each of them were presented in a slide show by the I.H.S. in a national conference, reinforcing my own gratitude that I had been able to interview them and also stay in touch with them afterwards by mail and messages relayed through CHRs.

Also, three of the participating elders, two of whom do not have diabetes themselves, were featured in a series of educational videos for tribal members produced

by the Standing Rock Diabetes Program. Some of the same messages they relayed on the video were conveyed to me during the interviews, further emphasizing their stance on certain issues.

While I was in residence on the reservation, I met several other women elders who would have been well qualified as information-rich sources, who I would really have liked to interview. The CHR program was in agreement, but the study was limited, of course, to the scope of my proposal to interview nine participants so this was not possible.

Language and linguistics

Lakota or Dakota is the first language of all of the participants, though all also speak English fluently. Most of the elders learned to speak English in their youth in schools. Several elders used their native language when they were describing dialogues in stories, which had taken place in the past. Sometimes they described an item first, deliberately, in their native language - probably because it was best said in that way. However, each time an elder spoke words or sentences in Lakota or Dakota, they immediately followed them with the English interpretation so that I could understand.

Although the elders spoke English fluently, a number of them used verb tenses in a manner that would be considered incorrect in most English classes. In particular, I noticed a tendency to use present rather than past tenses. For example, three of the elders spoke of relatives, who I knew to be deceased, in present tenses, so that it would seem that the person they were speaking of was alive today. Similarly, verbs describing actions, like “we get our water,” were in present tense even though they were describing past actions. There was a tendency to use “you know” fairly often in the dialogues, along with thoughtful pauses as next words were considered.

Kindness to the researcher

Several of the elders expressed gratitude to me, at the end of the sessions, for asking their thoughts about these issues. One had prepared braided fry bread and

juneberry pudding, “wakpoli,” that we shared at her kitchen table. Another served me cookies and coffee. Five of the elders asked to hug me after the interviews and one said, “If I had moccasins made I would give them to you.”

Since the data collection period, I have received two personal letters from the elders and several messages passed to me from CHRs and other friends. One of the elders wrote in her letter about her sadness in the passing of her dear brother whom she had described to me, showing also his picture on her wall. I remembered how concerned she was from him at the time of the interviews.

Exploratory Fieldwork and Time in the Field for Data Collection

My actual field experience included six exploratory visits in concert with my work at CDC or to help the tribe and the University of North Dakota College of Nursing (UND) conduct CHR diabetes education courses. Each visit involved several days’ residence; they took place from August 1997 through August 2000. Between visits I maintained phone and mail contact with friends from the C.H.R. program. We collaborated on the presentation of three sessions for national conferences including one in Atlanta, Georgia, in October, 1997, Albuquerque, New Mexico, in October, 1999, and Louisville, Kentucky in October, 2001. We also put together a poem based on the CHR’s words entitled, “I Want to Help My People,” which has drawn a great deal of attention from people who understand the power of the work and commitment of community workers. This poem has been read by CHRs or the researcher in 5 national presentations including the American Public Health Association in 2001.

During my fieldwork for data collection (May 20 – June 17, 2000), I stayed first at United Tribes Technical College (May 20-25) to help the CHR program and UND with an Aberdeen area CHR diabetes program and then at the tribe’s casino and lodge, 16 miles north of Fort Yates. My stay took place during “powwow season” and Memorial Day activities, which gave me additional opportunities to observe the participants in their natural setting. I attended three weekend community powwows, a 2 mile walk/run and an

honoring ceremony memorializing a young athlete, a memorial day community dinner, a 2 mile walk for health sponsored by the CHR program, a health fair, three church services, three family dinners, and a youth and elders conference. I listened to the tribal radio station, KLND, as I traveled long distances by car between communities and while in my room at the lodge.

I have kept field notes in a log in my laptop computer, sporadically, since 1999. Preliminary observations made during the exploratory visits and the early weeks of fieldwork for my data collection provided contextual grounding that helped me to later connect meaning to the data as I interpreted it. The following subsections include some of my exploratory observations, supported by examples from my field notes.

Sadness and humor

A Northern Cheyenne friend told me in 1999, as we were discussing the loss of John F. Kennedy, Jr. and his family, that many Native people relate to the Kennedy's continued legacy of loss - "a cloud of tragedy just hangs over us," he said. In my experiences in knowing CHRs and others on the reservation and also in the larger Aberdeen area through the CHR courses I've assisted in since 1997, I have seen that this must be true. There have been many heartbreaking events I have known to happen among people I know and their families, including fatal car accidents, suicides, and deaths from chronic illness like cancer and diabetes. In one small graveyard in Kenel, I visited in July 2001, two recent graves of people special to me. At one grave, marked with tobacco patches to honor the young athlete killed in a vehicle accident, I could only cry for my friends who had lost such a dear relative, an inspiration to other young people in the community. Yet, at the other grave, I had to smile through my tears as I saw the cup of hard candies placed there on the rocks for the man whose gruff voice belied his kindness. I remembered the many stories told, with tears of laughter, in the CHR office of our colleague, including the time he smeared his lips with a glue stick rather than chapstick $_{tm}$ from his pocket and tried to tissue it off before anyone could see.

When I come to the reservation, I always experience "culture shock," not so much because of the difference in my culture and theirs as in the tragedies I must catch up on and the people I must remember to express condolences to. Part of the shock, too, is just again being with people who are very warm, accepting, and love to laugh. The first night of my data collection period, May 20, 2001, I was staying at United Tribes Technical College in Bismarck, North Dakota, with friends in a dorm home, and I wrote in my fieldnotes, "It takes me a few hours to get over the shock of just being again with such good people. Not that people at home are not also good. But the feeling I have with my friends here is not easy to explain. They go through so much and they are still just so good."

One of the best memories I have on my fieldwork during data collection was having dinner at a casino restaurant with two elders and one of their daughters. The stories about dear people who had done some pretty funny things were so hilarious that I laughed throughout the meal and smile every time I think of the stories shared that night.

Protocol and politeness

Participant observation during the early part of my fieldwork for data collection helped me to gain an understanding of the importance of protocol that I had not understood before, even though I had thought I had knowledge about the culture from my previous experiences and from readings. It started when staying at the college with a CHR friend, the daughter of one of the participants, as it turned out to be, who helped me review and revise the interview questions so that they would be most respectful.

At that time I had planned to interview men as well as women (see "Research Design") but later realized that, for several reasons including protocol, it was best to conduct this study among women rather than from mixed genders I gained more understanding about protocol and propriety in talking with the Diabetes Program Director, the CHR Director, and other CHRs I spent time with. Attending the community events enlightened me, by observation, about the manner for showing respect for elders,

for those honored as veterans, and for the flags (e.g., U.S., military branches, the tribe, and Prisoners of War). Observations about protocol and politeness included this note on June 3, 2001:

> Things fell together for me at church today – I'm learning so much about politeness and protocol. This is probably why the church was acceptable to many – the ritual and protocol were there. Respect is tied into this, too, as people respect anyone who is on a quest for understanding and spirituality. (My daughters Dara and Arin came from Georgia for the weekend) After church, Dara mentioned she had noticed the gentle handshakes she received and how she'd learned, after the first few, to reciprocate with gentle shakes. I explained to her that I thought that this was because people don't try to show power or dominance; they respect people. Ethics is a huge undergirding issue with very high standards. Respect for Wankan Tanka and people is paramount. I almost never hear cursing, either, and I think it's because of respect for words and for people (p. 14).

I participated in a memorial walk/run for a well-loved athlete on June 9 at the invitation of one of the young man's sisters, a friend of mine who is a CHR. The family held a ceremony afterwards on the community powwow grounds to award gifts to the race winners and to people who had helped with the event. I was impressed as I watched each recipient of a handmade star quilt and a jacket, in the case of the race winners, be received with a handshake in a long line of family members. I was stunned when the announcer called my name and said that I was on the reservation working with people to address diabetes. I received a star quilt and was greeted warmly in the family line by each member as my friend introduced me.

<u>Discouragement and validation about being there</u>

At one point during the early part of data collection, the scheduling of interviews appeared to be moving very slowly and I began to question my "right" to be there as a white person, a "washihu" in Lakota, who stood to benefit from the data collection by

being able to pursue an advanced degree. I had tried to contribute to the tribe by providing technical assistance for the previous 3 years and felt there was a perception of reciprocity within the CHR program and through them, extension to others who knew of my work and interest. However, I began to wonder if many people who observed my presence did not know why I was there and if I was being seen as just one of a string of "wannabes" who visit reservations such as this. With no interviews firmly scheduled, I was sitting in the room of the casino and lodge where I stayed, despairingly and reflexively typing these sentences in my field notes for June 7, 2001:

> Leaving the conference today, ("Youth and Elders – Young Minds, Young at Heart" held in the banquet room of the casino), I had to keep my composure long enough to get to my room and cry. I think I said "goodbye" to the kids but am not even sure. The comment made to me in the lunch line (by an acquaintance) that two white ladies had come to the powwow (the weekend before) with many questions about the culture hurt me because I didn't know why I was being told this. I spoke with (a friend who also is a friend of the tribe) about it who said he may have been just making conversation or letting me know that I was different – that instead of being perceived as a "helicopter researcher," not invested in the welfare of the people, I was a continuous and caring presence. I don't know. One of the topics today was the historical grief of the Lakota people from situations like the Wounded Knee massacre, dishonest land dealings, and boarding schools. There was much tension in the room, I realized after hearing people respond to the speaker on the subjects. While several talked about resilience, moving on, hope, and having a positive focus others felt like it was important to deal with the pain and its aftermath among the people. One elder, a traditional healer, said that the victims were in a safe place now and people should just remember them -- not feel sorry and hold a grudge or get mired in this because that would cause heart attacks and strokes. Then he added that the people had been studied relentlessly. I

> tried to leave at the end of that session, thinking maybe I shouldn't be there, but I could not leave because some of the kids followed me to my room and if I had stayed there they would have missed the other sessions. I want to pack up and go home. Between being tied to relational restrictions, feeling so out of place from another culture that has been the oppressor, and having no self esteem now, I am ready to give up 3 years of work. It is too easy to be misunderstood (p. 15).

The next morning the CHRs had an open-air discussion on the local station, KLND, about their roles in health promotion and care as a public awareness effort. I was in my room typing field notes. Unexpectedly, one of the CHRs added to his comments about their roles, "We have a friend here, visiting from Atlanta, Georgia, who came, at her own expense, to listen to people talk about diabetes… when it started and all that. She's going to talk with my aunt tomorrow – she'll tell her about the first time diabetes came to people here. I want to thank Dawn Satterfield for coming."

My spirits renewed, I went back to the CHR office that day and thanked the worker who had spoken so kindly on the radio. I have no doubt that this validating statement had a great deal to do with the fact that interviews became easy to line up at that point. The radio station is a key source of information, entertainment, and even tribal identity to people, perhaps especially to elders who spend more time in their homes. Word of mouth was probably a factor in elders wanting to meet me after hearing the radio message and communicating with each other on the telephone.

The day of the radio program (June 8), I wrote this at the conclusion of my field note entry, "What a day! Have been in such a spectrum of experiences - personal reflections, complete despondence, sadness, gratitude - and this just from today's events and conversations and reflection on observations of being in meeting of youth and elders' conference. This experience is at once rich, deep, and draining " (p. 15).

Summary

This chapter offered an abbreviated overview of the research setting a holistic view of the land and the people. Description of the participants was provided, as well as some notes about the exploratory fieldwork and the experiences during data collection. The next chapter will describe the findings of this small study.

CHAPTER 5

FINDINGS: WOMEN ELDERS' DISCOURSE ABOUT DIABETES

The purpose of this ethnographic study was to document, understand, and support Lakota and Dakota women elders' ways of knowing and teaching about health protection and diabetes prevention. To construct an understanding of the meaning that diabetes, health, and preventive practices hold for the participating elders in terms of helping their people, I conducted in-depth interviews and afterwards analyzed and interpreted the data using grounded theory and narrative analysis. Field experience and an ongoing relationship with many of the tribe's health workers over the past four years has helped to provide additional naturalistic depth to this study.

This chapter provides presentations and displays of within and cross-case analysis, built through a process of constant comparison of the similarities and differences across cases for the purpose of deepening understanding and explanation of what has happened. The research questions were conceptually clustered so that meaning could be generated more saliently (Miles & Huberman, 1994). The research questions were:

1) To what connected factors do Lakota and Dakota elders attribute diabetes?
2) What narratives do these elders offer that reveal health protection and diabetes prevention as culturally constituted practices, both in the past and the present?
3) How do these elders express their concern and share their wisdom?

Conceptually ordering the data was a critical analytic step, which assisted to compress, organize, and display it in four matrices. Sorting data that is intrinsically holistic in almost every area of expression was challenging, however, and there are categories and illustrations of overlap and "fuzziness" (Nazarea, 1997, p. 64) in each framework.

Participants

The participants for this study were nine Lakota and Dakota tribal women elders whose ages ranged from 67 to 84 years old; the mean age was 72.5 and the median age was 69 years. Using "purposeful" sampling in which participants were identified based on the purpose of the study (Krueger, 1998), the tribes' CHR program staff identified these elders because of their wisdom, knowledge and willingness to share, as well as living in geographically diverse regions of the tribe's land base. All of the women were experienced in living with diabetes by having close family members with diabetes and in four cases, having it themselves (these are marked by * star symbols in the matrices). A lengthier description of the participants is found in Chapter 4.

Introduction to Presentation of Findings Clustered by Research Questions

Since qualitative data is thick and rich (Geertz, 1973, p.6) and its interpretation subject to questions of validity (Miles & Huberman, 1994) and the influences of subjectivity, I represent these data in ways that do not suppress the words of the participants as I project my own voice of interpretation. The meanings constructed were, in many ways, collaborative between the participants and the researcher so as I try to make sense and order of the data for publication, I have been anxious to represent their voices in ways that would honor our alliance. I established this section to discuss the nature of the holistic dialogues, with examples, as it relates to the presentation of data, the choices I made in terms of documentation of narratives verbatim, the conceptual and thematic ordering of the data by research questions, and the development of theory that emerged.

The holistic nature of elders' dialogue

Health is never just the absence of disease in the worldview of Lakota and Dakota people, as described in Chapter 1. Health and well-being are interconnected and integrated spiritually, mentally, emotionally, and physically in continuous ways that cannot be fragmented. The holistic orientation to health, illness, and prevention for these

elders is evidenced in the stories and the language of the participating elders. As one elder (# 5) said when referring to various categorical tribal programs, “It all should be inter-related – just like the spoke of a wagon wheel; if you have one thing broke in it, it can’t go around. It’s like that.”

The experience of illness was also not bounded by personal experience but included the life-world of their tribal network of people. All of the elders used the words “we” and “our” often, and some specifically referred to “my Indian people,” (#2) and “our people,” (#4, #6, #7).

Diabetes was not consistently distinguished in the interviews from other threatening conditions and health, in general. While these elders seemed intent on trying to respond to my questions about diabetes, about which they were all familiar, some responses were comprehensive of other conditions, including alcoholism. Dimensions of health in emotional, physical, spiritual, and mental domains underpinned all of their dialogues. Remembering that the subject was primarily diabetes, the elders sometimes pointed out the relationships between things to help me understand. One elder (# 6) stopped in the middle of a story and said, “I’m not only talking about sugar (diabetes), but I’m talking about what’s going on. It causes heartache, you know?” Another elder (#7), talking about attributions for diabetes, added, “….maybe some of these stress factors and some of this grief (are involved in causing diabetes). We need to know what really does cause diabetes. Just trying to be healthy is what we have to strive for. It’s so much a part of our general health… I don’t know if we can focus on it (diabetes) and be realistic.” Nevertheless, while not clearly separated from other issues related to health in terms of attributions and prevention, diabetes was known to be singularly destructive; as one elder (#6) said, “I don’t want to have diabetes because I’ve seen a lot of this diabetes. It’s not good for our people.”

Clustering of the findings within research questions and organizing concepts

The findings were conceptually clustered within the research questions and thematically organized according to two concepts familiar to cultural anthropologists. Naturalistic communities tend to view illness origins as dichotomous in that they come from externalizing, or unnatural, forces, or from internal, natural, forces which have gotten out of balance (Helman, 2000; Wing, 1998; Adelson, 1998; Huttlinger, 1995; Garro & Lang, 1993). The other concept is that of illness narratives, grounded in cultural representation and collective and personal experience (Kleinman & Seeman, 2000); to these genres of illness narratives – restitution, chaos, quest, and testimony, I have added a fifth of protective practices. I displayed illustrations conceptually ordered according to these themes in three matrices. A fourth matrix featured case-ordered illustrations of the elders' interest in contributing to health protection in their communities. Finally, I developed models for the findings that evolved first from creating a pictorial display for the first research question and then making more explicit a conceptual framework based on the summary of the findings.

Research Question #1: Attributions for Diabetes as Originating From Natural and Unnatural Forces

The views these elders held about factors connected to high rates of diabetes in their people were integrated throughout the interviews and included both explicit and implicit observations, usually expressed through narratives. It was apparent from observation of the comments and voice inflections after the first few interviews that the elders tended to think of diabetes as an "outside" or external disorder," which is consistent with the literature described in Chapter 2 in which Native people tend to view diabetes as "unnatural" and "outside" (Joe & Young, 1993, p. 6; Huttlinger, 1995, p. 14), a "new" disease that requires "white man's medicine" (Garro & Lang, 1993, p. 320). The elders' attributions for diabetes were in agreement with biomedical explanations in terms of physiological causes; however, they extended beyond these to unnatural causes.

The dichotomizing concept of illness is described in the following section as it relates to the data. To represent the themes that emerged in relation to attributions for diabetes as natural or unnatural, I case ordered and illustrated these in Table 5.1. To further illustrate these conceptual concepts, I provided illustrations of particularly salient narratives accompanying the themes of attributions for diabetes in Table 5.2. Because they are narratives of attributions and many of the attributions were externalizing, or unnatural, most of these stories are illness narratives in the genre of "chaos," which often describes disorder and fragmentation, according to the Frank's typology cited by Kleinman and Seeman (2000), outlined as part of the planned data analysis in Chapter 3.

Factors connected to diabetes origins that are "natural" or "internal"

Multiple internalizing or natural factors related to personal disharmony contributing to the development of diabetes were also offered and much of the explanation for diabetes was placed on individuals who developed it. In fact, although diabetes was often dissociated from the culture and history as an outside disorder, participants in each case acknowledged early in the interviews the contribution of obesity, poor nutrition, and physical inactivity to diabetes. The themes of not being active enough and eating indiscriminately appeared in every interview.

Metaphors for physical inactivity, "couch potato," "being loggy," and living in a "push-button generation" were employed by one of the elders (#2), whereas all of the other elders talked about this in terms of the words "active," "work," "hard work," and "manual work." The metaphor commonly used for unhealthy food choices was "junk food." Drinking pop, a practice abhorred by eight participants who brought this issue up, was seen as a personal, implicitly disharmonizing, choice by adults or by children whose parents allow this; however, several participants indicated that these choices are mediated by societal trends from the outside.

Three of the elders (#3, #5, #8) specifically mentioned enticing advertising on television shows and in stores that present temptations to people and to children. I had

noticed this as well in the small food markets found in the communities where sugar-sweetened drinks are prominently displayed. At one such market, I noticed that the sweetened drinks were advertised "on sale," while the sugar-free drink of the same size and brand cost more. Several elders added that it takes "a strong mind," to recognize and resist temptations such as enticing advertising. One of these elders expressed her hopes that her grandchildren would steer away from "that messy road of eating junk food."

The four elders with diabetes have had the condition for many years (the shortest time was 10 years) and are physically and mentally very active. In fact, based on my experience in diabetes care, I could surmise that they were all in excellent control of their diabetes which probably accounts, in some ways, for their standing as elders leading active lives with wisdom to share about maintaining balance with diabetes. In every case the elders with diabetes told first their own stories of diagnosis or dealing with diabetes before speaking to their collective experience with diabetes risk among their people.

These elders assumed responsibility for having developed diabetes and their attributions were internalizing, related to disharmony in their lives. Two elders with diabetes said they were overweight when they were diagnosed, with one (#1) saying she was eating, "anything I wanted." Although she considered herself physically active in caring for many young children with few resources, another elder (#9) said she had gained a lot of weight during her years of mothering, which was implicitly tied to being overwhelmed with the responsibilities of raising children after the early death of her husband. This elder ended a narrative about her diagnosis by saying, in a low tone, that she was "ashamed" that she had developed diabetes. Although she is in excellent health now except for arthritis she returned her transcript by mail to me recently with a personal letter in which she wrote, "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."

The elder who had a kidney transplant six years ago (#2) clearly blamed herself for not taking diabetes seriously when she was diagnosed over 20 years ago. She talked

about forgetting the values and teachings from her own elders "in the rush of life" (see Table 5.2) and not realizing until she had to go on renal dialysis the extent to which she had compromised her health.

All of the elders with diabetes spoke of currently being active and eating good foods, including traditional foods. These elders attributed their present good health to these lifestyle habits and having dealt with their own diabetes by following medical recommendations (e.g., taking insulin injections or pills). For each of these elders, their current high level of physical activity was a subject emphasized as an attribution for their good health. Two of these elders (#1, #2) mentioned that they are tending gardens. One said (#1), "I just keep myself, and I still do what I want. I still have a garden…. We don't have exercise machines but I work outside, you know. Or I took a walk a lot of places. I have to walk, twice a day." I observed that this elder mentioned exercise machines as if this might be considered a desirable way to exercise, however, she had realized that walking and working outside is just as effective. Three of the four elders mentioned that in addition to their medical regimens, they use home remedies for their diabetes, including sage tea. The oldest elder (#8), who does not have diabetes, gave me some sage tea to drink, made from sage she had laid out to dry.

Lack of food preparation was seen as a major contributor to poor health including diabetes mentioned by most of the study participants. "We don't cook our food anymore," said two of the elders (#2, #5). "We depend on the can opener," said one of these (#2). Included in this theme, the majority of the elders recalled that foods they felt helped to protect health were "simple foods." I placed the theme of lack of food preparation in the category of largely internal attributions, though it was indirectly tied throughout the narratives to external attributions that have contributed to this situation. The ways of gathering, preparing, and storing foods are part of many narratives including those featured in Tables 4.2 and 4.3. Six elders spoke of gathering wild turnips and using these and other vegetables including squash and onions, along with lean meats like

venison and pheasant, in “soups.” Three elders described gathering wild beans by the riverbanks. A narrative about gathering beans (#9) is found in Table 5.3. As we talked at her kitchen table, this elder pointed out her “drying stick” positioned across the top of her kitchen cabinets for hanging vegetables, fruit, and meat (“papa” in Lakota) to dry; with her encouragement, I took a picture of this stick (Photograph #1). The oldest elder (#8) proudly showed me her garden (Photograph #2) and her turnip chips, which her children had helped to gather, cut, and hang to dry draped across the branches of a tree in her front yard (Photograph #3).

Respect is a strong cultural value and it is to be shown for all things, including the animals, the land, and food. Lacking respect was woven through many of the interviews when elders considered factors connected to health problems like diabetes. In most of the other interviews, lack of respect was most connected to internal attributions for sicknesses and other problems related to straying from the ways that are “true,” as one elder (#1) put it. Lack of respect for food was specifically mentioned by an elder (#7) who then tied in external attributions focusing, first, on habits that were learned in boarding school. Another externally located attribution for sickness, related to respect, was the recurrent theme of not using the land as it should be because of lack of respect. An elder (#3) concluded the narrative in Table 5.2 about the dead catfish in the Missouri River by adding, “… they are not really thinking and having respect for Mother Nature.”

Related to respect for all things is gratitude to the Creator for life and all that has been given as part of “giving back thanks,” as an elder (#5) said. Relying on God for help and guidance was a prominent theme. Terms for “God” included “the great power,” “the Great Spirit,” “the Creator,” “Lord,” “Jesus,” “Wakan Tanka,” and “Tunkinsila.” Several of these terms were used interchangeably throughout each interview without any effort to distinguish between Indian and Christian beliefs. Three of the elders brought up their faith in the Lakota religion’s Sun Dance, congruent with their Christian beliefs. One of these elders (#3) stated that this religion, “correlate(s) with the Bible.” Another elder

(#5) said, “There’s only one God,” an implicit, underpinning concept in the interviews of the majority of the elders who mentioned not only their traditional but also their Christian faith. Another elder (#9) said, “God Creator is the One that created us all to help each other.”

Elders were humble in making attributions; they generously offered their observations after I asked, but several added statements about their lack of qualifications to make judgments. One elder (# 6), for example, concluded a story of healing by saying, “I’m not a doctor. I don’t even know anything about medicine.”

Factors connected to diabetes origins that are “unnatural” or “outside”

Allusions to diabetes as an unnatural, externalizing disorder – outside of the history or culture of the people – were implicitly woven throughout all of the interviews and evidenced by the many statements to “this diabetes” or “that diabetes” by seven of the elders, one of whom also spoke of “this manmade diabetes.” The researcher’s introduction included mention of the rarity of diabetes until relatively recent years (i.e., the 60s), a fact which all of the elders appeared to be in agreement with, based on their nonverbal affirmations. The sudden onset of diabetes was a specific theme brought up by two elders and illustrated by statements including “an attack of that diabetes on us Indian people” and “it just came all of a sudden and it was like it went to everybody.”

Unnatural, or externalizing, causes of illness included an emphasis on the “outside” environment. Water was a recurring theme in all of the interviews, with both good and sad comments and narratives. As far as attributions for illness, participants referred often to water resources being contaminated and the ways of living on the riverbanks as “all washed away.” Disappointment and sadness about the ways the Missouri River had been altered and fears about the safety of the water supply were recurrent themes identified as water/air/food is not pure and sadness about flooding of the river homes and foodways. On the other hand, water was also referred to as a valuable nutrient and a resource people should drink a lot of as an individual, internalizing, choice.

One participant said, “water is life” and another “water is the source of life.” Drinking of water as a healthful practice was often displaced in modern times by drinking sugar-laden products such as “pop” and “koolaid.,” the elders said sadly.

Indirectly related to externalizing attributions for diabetes in terms of water was the theme of losing their river homes and foodways for flooding as it affected people’s physical and emotional health, which was brought up by eight of the nine elders. This loss began in 1948 when the Corps of Engineers began controlled flooding of waterways and plains on the reservation to accommodate the building of several dams in North Dakota (See Chapter 4. The loss of fertile lands where wild beans and other vegetables grew along the river, as well as many medicines that “went under,” (#1, #9) accompanied the loss of ways that were remembered fondly for their hard work and family togetherness. One elder (#7) spoke of lingering “grief” and “stress” and another of “sadness and hurt” (# 5) in relation to the loss of foods, activity, and cultural ways associated with living on the riverbanks. All of the elders who mentioned these losses told stories of their memories of living in earlier times, with five describing the loss of the log homes they lived in with their parents and grandparents and how, when these homes were displaced and people had to move to higher ground, the free electricity promised for the newly built government homes never materialized. A picture of the Grand River banks is found in the section entitled “Photovoice and cognitive mapping.”

Many problems were associated with moving people, “here together,” as one elder (#1) described it, to higher ground with cluster homes now provided through Housing and Urban Development (HUD) grants. One elder (#4) mentioned returning with her aunt to see her former homeland soon after the water rose over it in the early 50s, saying, “we just cried.” Several elders questioned the fairness of the decisions to allow controlled flooding and subsequent tribal decisions about compensation for the flooding. One elder (#9) described confronting the Corps of Engineers when she was younger about the damage they were causing. In relation to environmental impacts such

as this, as well as to other issues that require autonomy, three elders (#3, #4, #5) talked about the need to teach their young people about tribal sovereignty and the importance of respecting and not forgetting their treaties.

Several elders mentioned the related, continuing effects on health in terms of the loss of the buffalo and reservation life. The buffalo were brought up by 4 elders with respectful rhetoric describing their character and resourcefulness as a source of lean meat, shelter, and tools. Two elders told stories (#2, #9) of communicating with buffalo, using their native tongues followed by interpretation in English for my benefit.

While reservation life was fraught with problems including isolation and joblessness, noted by several elders. One of the elders (#7) stated that she disliked the brainwashing that reservation land was the worst. The goodness of the land is important to understand, she said, and the land, she added, can "always sustain life." This belief was echoed by several elders, one of whom said "the land is the provider" (#3) and another (#2) who 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." Not making use of the land was an internalizing, natural though disharmonizing attribution for diabetes. In spite of the emotional and spiritual sadness and the physical losses of the land (e.g., homes, medicines, wild plants, impurities) and associated foodways (Garro & Lang, 1993), the "goodness of the land" and the need to respect it was a prominent theme that represents hope and resilience.

Boarding school experiences, which involved many Indian children since the movement began in 1879, were "mixed," as one elder said, with both good and bad legacies. The educational opportunities were valued, noted several participants, but three elders noted that habits learned in boarding schools were at odds with their cultural values and they believed these had directly contributed to intergenerational problems with food, including "eating fast" because of the ways they were taught to guard their possessions and the scarcity of food. Stories told by two elders (#6, #7) displayed in Table 5.2, illustrated the adoption of traits being carried through subsequent generations

that have altered cultural habits and attitudes towards food, including "stinginess" and lack of respect for food. The sadness of the isolation students felt being away from home was illustrated by stories told by three elders, two of which are displayed (see Tables 4.2 and Table 5.3). Two of the elders (#3, #7) mentioned that the goal of the schools was to "civilize" them when their people were, in fact, "already civilized."

Alcohol or liquor was mentioned by several elders in terms of the larger picture of health that cannot be restricted to specific illnesses. However, this was viewed by three elders in an "outside" context since it was introduced by the dominant culture; one (#1) asked, "Why did United States Uncle Sam make this liquor?" and a very old elder (#8) noted that habits learned in the military service, including drinking alcohol for her sons in the Korean War and World War II, contributed to illness and sadness. On the other hand, drinking liquor was also included on the list of "natural" or "internalizing" attributions in the case of this elder and another (#3) who implied that abusing alcohol is a personal choice that can be associated with not having a "strong mind" tied to not relying on God.

Another interesting finding included as an external attribution for diabetes was found in a narrative told by one of the 84 year old elders about her stay in a sanitarium for tuberculosis where people were also receiving instruction for special diets related to diabetes. "I wanted to get big and fat, too…… so I could be strong," she said.

Words are powerful in this culture and three of the elders (#3, #5, #7) suggested that being told you had diabetes or were likely to get it actually predisposed one to develop diabetes. The diagnosis of diabetes is sometimes not even correct, noted one elder who told a story of diagnosed diabetes in a man who failed to take the biomedical regimen recommended and was said later by another doctor he did not have diabetes anyway (#3). The risk factor of inheritance or family history, commonly listed in diabetes literature, was not believable said several elders.

Table 5.1

Themes identified for Research Question #1, attributions for diabetes (Question # 1: To what connected factors do Lakota and Dakota elders attribute diabetes?)

	Natural, internalizing, attributions	Unnatural, externalizing, attributions
Elder 1*	Eating indiscriminately: "anything want" Being overweight: 300 lbs.at diagnosis Drinking pop: "pop is no good" Not being active enough Lack of food preparation: boil, gather Lacking respect: "no respect, no love" Not relying on God Ignoring traditional early feedings	Sudden onset of diabetes: "an attack" Losing river homes & foodways for flooding Water/air/food is not pure: sicknesses Societal trends: "modern life today" Liquor: "Why did Uncle Sam make this liquor?"
Elder 2*	Eating indiscriminately: "junk food" Drinking pop Not being active enough: "couch potato" Forgetting the values & teachings Adults not teaching children values Not making use of the land Lack of food preparation: boil, gather Ignoring traditional early feedings Not relying on God: Jesus	Societal trends: "push button generation" Habits from boarding schools: " stinginess" Water/air/food is not pure: "all polluted"
Elder 3	Eating indiscriminately Drinking pop Not being active enough Forgetting the values & teachings Adults not teaching children values Drinking liquor: affects health of many Not relying on God: "can't live without" Not giving thanks to Great Spirit	Societal trends: "messy road of junk food" Reservation life: meat rations fed to dogs Loss of buffalo: main source of survival Un/under employment: can't afford good diet Loss of language: one of greatest things lost Being told have diabetes: will come true Water/air/food is not pure: fuel, insecticides Lacking respect: manmade land destruction Habits from boarding schools: "stinginess" Losing river homes & foodways for flooding Helplessness imposed by government Treaties not kept: "our treaties are still here"
Elder 4*	Drinking pop Eating indiscriminately: "not natural" Lack of food preparation Not being active enough Not making use of the land: gardens Not relying on God: Creator	Sudden onset of diabetes: "… catching it" Losing river homes & foodways for flooding Habits from boarding schools: white bread Water/air/food is not pure Treaties not kept: "treaties must be kept alive" Water/air/food is not pure: "preservatives"
Elder 5	Eating indiscriminately: "junk food" Drinking liquor: affects health of families Drinking pop Not being active enough Not relying on God Lack of food preparation	Societal trends – "instant gratification" Being diagnosed with diabetes prematurely Un/under employment: low self esteem Helplessness imposed by government Reservation life Treaties not kept Losing river homes & foodways for flooding Sadness, grief, hurt: "alcoholism… too"
Elder 6	Not making use of the land: gardens Drinking pop Eating indiscriminately Lack of food preparation Lack of fiber in foods Being overweight Not being active enough Not relying on God: Tunkansila, Jesus	Being told have diabetes Water/air/food is not pure: chemicals Loss of buffalo Losing river homes & foodways for flooding Sadness, grief, hurt

Table 5.1 (Continued)

Themes identified for Research Question #1, attributions for diabetes (Question # 1: To what connected factors do Lakota and Dakota elders attribute diabetes?)

	Natural, internalizing, attributions	Unnatural, externalizing, attributions
Elder 7	Lacking respect: "… deep respect for food" Ignoring traditional early feedings Eating indiscriminately Being overweight Lack of food preparation Not making use of the land	Habits from boarding school: eating fast Reservation life Loss of buffalo Losing river homes & foodways for flooding Sadness, grief, hurt Stress factors Brainwashing that reservation was worst land
Elder 8	Eating indiscriminately Drinking pop: and koolaid Not being active enough Being overweight Not relying on God Ignoring traditional early feedings Lack of food preparation	Societal trends: " they advertise on t.v." Loss of buffalo Losing river homes & lifeways for flooding Water/air/food is not pure: chemicals Habits learned in military service Liquor Needed to be strong to face tuberculosis
Elder 9*	Lacking respect: for all things Eating indiscriminately Being overweight Not being active enough Ashamed of developing diabetes herself Ignoring traditional early feedings Lack of food preparation Not relying on God	Loss of buffalo Losing river homes & foodways for flooding Water/air/food is not pure Reservation life

* Elders who have diabetes

Finally, the majority of the elders felt that ignoring traditional early feedings of infants, and breastfeeding in particular, was related to development of health problems like diabetes later in life. One of the elders (#9) referred to it as "the sincere milk." Another #2 told a narrative of her role in convincing her niece to breastfeed, with good results. These elders expressed strong beliefs in the value of breastfeeding, not only for physical effects but emotional bonding between the mother and the child. Several elders mentioned the taboo against sexual intercourse while a child was nursing, seemingly as a limitation to this practice. Two elders added that the practice of mothers and grandmothers teaching older children to taste good foods even when they were only a few months old was a way of teaching respect and good memories of food.

As noted at the beginning of this chapter, attributions about diabetes were holistically woven throughout the conversations. Each of the participants in this study

shared narratives, particularly in answer to this question about attributions, and the themes identified from the narratives and occasionally, shorter statements, were featured in5.1. The most revealing narratives related to the origins of diabetes are illness narratives with externalizing attributions, all of the chaos genre, illustrated in Table 5.2.

Table 5.2

Case-ordered narratives (of chaos genre) addressing Research Question #1

	Research question #1 narratives of attributions for diabetes
Elder 1*	**Sudden onset**: "It seemed like everybody was healthy… Some people walked long places, from out there to this town … and back again. But when we got that attack of that diabetes and it seemed like it all attacked us Indian people, that seemed like every family had it." **Drinking pop**: "I'm always telling my grandson who drinks pop, `go easy on that, because you might get that diabetic, too. I heard that some 8 year olds have it, too, so I don't want you to have it.' So I had to watch them, too, and other people. Like some places I go, they'll be sitting drinking pop. They showed to us a can of pop… there's that much sugar in a can of pop. So then, it's no good to drink pop." **Lacking respect**: "... a good clean life... true... not today. They don't have no respect and no love, no nothing. It's too bad today. That's where a lot of trouble starts all over this place." **Liquor**: "Why did United States Uncle Sam make this liquor?...I've been a lot of places when a person died with this liver disease. Ohhh..., it's a terrible death. I stayed with a lady to that boy, that night... He was going to die.. he was just scared, "help me, help me" and he started crying... Liquor is the one. And that's where a lot of people got their diabetic, too." **Not being active enough**; "a long time ago, as I grew up, nobody had diabetic at that time, nobody didn't have it. We lived 10 miles east; the Missouri water was what we were drinking, nice, clear, soft water... And my mother and dad, we gardened all kind of vegetables, potatoes, squash, corn, everything, beans, and so we had plenty vegetables to eat. My dad had to milk 4 cows everyday so we drink milk from there and wild fruit we picked down the creek, down the hill, cherries, plums, lots of berries, buffalo berries, whatever. And then my mother had to make jelly; she canned it or she dried some up and all that. On the hill is where she go to dig turnips and dry that up too, and dry squash and all that. And that's what we eat, ...they go out hunting for deer, even prairie chickens and pheasants. It seems like we wasn't sick at all." **Losing river homes and foodways for flooding**: Narrative 1: "...but they put us together like this, in a community, not out in the country and no exercise or nothing. And they bring us commodities... Prone to get us into diabetic." Narrative 2: "the Corps of Engineers come and ... use the water for electricity or something and they took the land, they send crewman people, they took the land and they said they were going to build us some houses because the water is going to back up, up there, so many feet high, you know, so many thousand feet, so we have to move out of our place where we live, and now it's all under water. That's why they had to move us up here. Here together."
Elder 2*	**Not being active enough; Eating indiscriminately:** Narrative 1: "...you know, some things that I was taught long time ago I forgot in the rush of the life, from one fad to another, you might say, you lose track of that. But when you get down and get sick like I do, and then you think back, how come grandma wasn't sick? And then you remember, oh yeah, we ate like this, we didn't have salt... she made bread over the fire, she didn't have all those sugars and stuff in. We bake, we add sugar and salt and different things in. But back there it was just flour and lard and baking powder. And she made her bread and that was good enough then, so why not now? So I used to bake a lot of things. I used to make cookies and stuff. (Now) I make them, but I learned how to use this Equal (sweetener)." Narrative 2: "I think it's the way we taught ourselves to live, without exercise, without really thinking about what we're putting in our body. About all the mixtures of stuff they put in the meats and we eat fat meat. We don't eat lean meat... we don't watch what we eat, we overeat, we tend to stuff ourselves and when we do that we get how would you say, "loggy" and then we don't want to move and so we sit down ... and then we go to sleep, and we don't exercise none of this carbohydrates off, or work it off, or anything. We just retain it. And we get up and we eat again and we lay down. That's why I said it's a couch potato era... nobody exercises." **Habits learned in boarding school**: "...we were forced to do things that we weren't brought up to believe in. Like, I think we were taught to be stingy. See Table 5.3, testimony:

Table 5.2 (Continued)

Case-ordered narratives (of chaos genre) addressing Research Question #1

	Research question #1 narratives of attributions for diabetes
Elder 3	**Indiscriminate eating; Societal trends; Low incomes**: Narrative 1: "…now to this present day, the commodity has a great deal of improved food items and one of them is fresh vegetables and fruits. So that's one of the things that I look at. And actually how things are now, the things that they make and they sell. Lot of those things I call it the junk food. We have to watch what we eat. And if we didn't pursue that enough in our own life, our way of our own, then naturally our children and our grand-children will get into that messy road of eating junk food. So some of this is how we are caught, because a lot of our families are on food stamps. And when you go to a grocery store the1st thing you see is all the variety of soda. And those are eye catching. And then it comes to all the chips. And they don't really see what is good, which is the vegetables and all the fruits. So a lot of us really maintain a strong mind to try to overcome a lot of these temptations." Narrative 2: "A lot have said they would like to be on a diet if they can afford it. Income-wise, all these things are lacking. So you're not really taking care of your body… you're going to become ill somewhere, one way or another. And maybe this is where the diabetes comes in." Narrative 3: "Look inside our reservation. Are there any jobs you can get?" **Not relying on God; Low self-esteem:** Narrative 1: "…Almighty God, the Great Spirit, the Wakan Tanka, that has put us on this continent. He has given us so much and yet they took it all away from us and put us into small little islands called reservations. And this is where we're full of problems…" Narrative 2: " We must always give thanks back to the Great Spirit. Anything and everything we do, because of Him we are alive. Whatever we take into our body, through our mouth, I say we do that to ourselves. If we're not healthy, we do that to ourselves. If we drink beer…, smoke pot… it ruins inside our holy temple. So we bring that on ourselves. So we really should pray that God will help us not go into the darker ways of life. That's not the way." Narrative 3: "With the help of the Great Spirit - that is the power that we have….we can say "no" to anything that will hurt us…… you can't live without God. You have to know who He is. This is the strong belief that the Lakota people have. This is why we never used to have that diabetes. We didn't know what heart trouble was… We didn't know all these things, illnesses that we have. We didn't know what they were. We just recently, we have, because we felt like we have been let down, we have been put down, and the white society looked at us savages or barbarians or whatever, and we looked down on ourselves. So now, we're beginning to see the light and we're building that self esteem back in us." **Liquor**: "Alcohol has affected every one of our homes. I said (to town people): "Look at our Indian people that are standing on the streets… they're so sick. All they have on their mind is their next drink. `Your society has caused that. This little town has 5 liquor joints in it. What are you going to do about it? Put your liquor joints away. Make some parks…' **Being told have diabetes**: "when you're sick and you go to the I.H.S., they're going to say, `You're diabetic.' They're going to make you believe and you will become a diabetic." **Water/air is not pure; Losing river homes and foodways for flooding; Reservation life:** Narrative 1: "…why is it that our wild fruits are not growing like they used to? We used to really have a lot of wild fruits and everybody was picking wild fruits and they live on that. And you look at the airplanes and you look at these things that spray all these chemicals, and you look at the dams, the reservoirs, full of boats. So there's no pure land, no pure air, nothing is pure anymore. It's manmade. They believe in the modernistic way of life so much that they are destroying what was good at one time. …The water thing (flooding) killed a lot of our wild fruits, most of them went under. It's no longer there and it will never come back. That has a great deal (to do with health and diabetes) among our Lakota people, 'cause we survived on a lot of those good things." Narrative 2: "The reservoirs are a plaything. You sit on the little boats. So what goes under that water from these engines? Have you seen the evergreens lately? They're turning brown. So man is doing all these things to the wonderful Mother Earth that was pure at one time. So that can cause a lot of illnesses in us the human beings. And gee, every year, there's always a different kind of illness…." Narrative 3: "Are they trying to wipe us off from the face of this earth or what? But you know, we were put here first. This continent was occupied by all kinds of Lakota people. They understood each other's sign language. But when the Europeans came, that's when the trouble began. And it's still here. …We want to live our ways of life with the treaties. And the treaties are very strong, because a pipe was used to sign treaties. And those treaties cannot be broken. I guess they tried, but they couldn't do it.

Table 5.2 (Continued)

Case-ordered narratives (of chaos genre) addressing Research Question #1

	Research question #1 narratives of attributions for diabetes
	But 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. This is why, because of treaties, the government promised to provide the … free health, it's not the best health, like the clinics and stuff, and education, and these homes. 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; they're too old. So then they said `well we don't believe in your constitution either; that's too old.'" Narrative 4: "One time we went down to the Grand River that flows down here. And we went upstream, and there was a little bridge and it was kind of deep on the side, you could tell. You look there and I thought, `Gee, look at these fishes,' and I love to eat, what they call, catfish, `and they're floating,' and I thought, `Oh my goodness,' you know, I thought they were playing or something. The closer we got they were all dead. And they were huge ones, about that big, and then they were swept ashore, and some of them are still floating. So what does that tell us? Somebody's throwing some garbage, you know, that has a lot of polluted things, can, sprays, chemicals, and into the river, and that upstream way up there, there was a lot of farmers. So, that killed all of those nice fish. So, they are not really thinking and having respect for our Mother Nature. We call it Mother Nature and Mother Earth. If you have no respect for Mother Earth then all these things will evolve …, and it destroys a lot of things. So, that's why our land is so important because the land is the provider. Mother Earth will provide everything so pure at one time Maybe someday our land will be pure again… But, I heard down the line some place… that man will destroy the earth, not God. Everything will be destroyed by man…Everything that we think that's polluted or is not good, it all has something of man made. All these Corps of Engineers that supposedly are so talented and smart are destroying things…"
Elder 4*	**Sudden onset**: "it just came all of a sudden and it was like it went to everybody…. **Drinking pop; Eating indiscriminately: Not cooking foods anymore** Narrative 1: "It's mostly what we are eating today. I don't know what is in that canned stuff and too many preservatives in the foods. It's not all natural. They give commodities; sometimes it's too salty." Narrative 2: : "… a lot of these young people; they don't care. I keep telling my kids, my grandchildren, `you must be careful about drinking pop and all this sweet stuff. Someday you'll get like that …. you'll be getting shots.' **Water/air is not safe**:"… we lived out along the Missouri River, before this water came, we used to drink that Missouri River water, and it was clear at that time because it runs all the time. We used to take barrels down there and haul it back up to the house and strain it.. That was good water…" " I think they should really check into our water, the water that we're drinking." **Losing river homes and foodways for flooding**: Narrative 1: "it really felt bad. So me and my aunt didn't go out there for a long time. There was a church, and there used to be a cemetery, it was all gone… we just cried…. So sad…I think it did a lot of damage to our people." Narrative 2: "Living on your own land, you can plant your own garden, utilize what's growing there. They used to have some wild beans that grew along the river. My aunt, she used to take a gunnysack and fill those sacks up with those wild beans and through the winter they would cook that. Also wild plums or cherries and she used to do a lot of canning. She used to keep that in her cellar. And dried meat…They also had some medicine they used for cough syrup... Now there is nothing." **Habits learned in boarding schools** "I only went to one boarding school one year. That was '44 and '45. ….During that time we had to eat wheat bread at every meal. The only ones that got to eat white bread was the high school. So we got tired of eating that white bread." "We were only allowed to eat 15 minutes."
Elder 5	**Drinking pop; Eating indiscriminately; Not preparing foods**: "I think that what happens here is that no one takes the time to cook. They all go to fast food. I shouldn't say all, but the most of them buy pop and chips. Everything is `right now' and I do not live that 'right now.' I still cook for my grandchildren. I don't really believe in this, what do you call these, fast foods, or pop, especially. I don't allow pop in my home, and chips and all that. I do not have things like that for my grandchildren. I had to tell them that wheat bread is good for them. All I have in my home is wheat bread." **Societal trends**: Narrative 1: "…we have all these good things that you press and it comes on instantly. And how I see that kind of world we're in is instant gratification…. That's who we are and where we're at, so we are neglecting not only our health but everything that we have."

Table 5.2 (Continued)

Case-ordered narratives (of chaos genre) addressing Research Question #1

	Research question #1 narratives of attributions for diabetes
	"I think instant gratification is self-serving. Always want to satisfy the number one, which is the individual self." Narrative 2: "But my husband got his education through, he was a 2nd World War veteran. At that time, and back in those days, they called it the GI loan or grant. It's a loan but when you're finished, whatever you are, 2, 3 or 4 years college or whatever, when you finish it, it becomes a grant. So you don't need to pay it back. Well, that's how my husband got his education, so we didn't owe the federal monies that come into the tribe. And we always say we earned, everything we do we earned. It's not anything that's been handed to us. So, that's how we are in my family. My children, they think like that too. That's who they are. And so, a person needs to recognize that and realize that what the United States government is doing to our people. They're making them helpless. And that's what all these disease are coming in. Instant gratification is one of them. And the Indian and the white person, or shall I say other race, other than the Indian, we are different. Even our bodies are different, say, who was it that surgery? My sister. My sister had surgery and she healed right away and her wounds were healed. And she told me that the doctor told her that, "You people are made different from the rest of the races. You heal quicker than the rest of the races." **Losing river homes and foodways for flooding; Liquor**: "I grew up along the river and it's been taken away. So if you have people being forced to move out and … relocated on a piece of land. That has a great deal affected your mental, because your environment and what you're used to was being taken away and they try to make you start over here, but it's going to take time and some people, they just give up. And that's where alcoholism comes too, because of depression and because of a lot of hurt." **Being told have diabetes**: Narrative 1: "There's one thing in my mind that I do not believe is that (diabetes is) hereditary. Because that's what they based on nowadays. When you go see a doctor, they want to know your parents, what they had and what they died from and all that." Narrative 2: "We know our own bodies, so when we're sick or don't feel good, we see a doctor. But nowadays, they write down, they take your blood pressure…. And then, so when you go to a doctor, they diagnose you right away as a diabetic and that's wrong." **Helplessness imposed by government; reservation life:** Narrative 1: "..you are being controlled inside the reservation…the majority of our people here on the reservation are poverty people, with no jobs or anything provided for them. So in order for them to have food and stuff,…. They just stop and wait for it to come…. I always call it a handout. And that's what's ruining our people, too." Narrative 2: "And we always say we earned, everything we do we earned. It's not anything that's been handed to us. So, that's how we are in my family. My children, they think like that too. That's who they are. And so, a person needs to recognize that and realize that what the United States government is doing to our people. They're making them helpless."
Elder 6	**Eating indiscriminately; Not preparing foods; Not being active enough; Being overweight**: Narrative 1:"This diabetes (is) caused by sweets, and fats, and I guess being not active, because a person that moves around, makes use of your muscles arms, legs… you could see that there IS a difference. I don't want to have diabetes because (I've) seen a lot of this diabetes and it's not good for our people." Narrative 2: "Junk food is what causes all that, too. I buy junk food for the boys, but on the other hand, I cook meals for them. Junk food isn't good for them and it isn't good for us, too We don't have those junk food when we were young. Who ever heard of those? "Narrative 3: "My nephew (with diabetes) don't take care of himself. He used to be really fat. It's because of that. And he still eats bad foods." Narrative 4: "My mother got diabetes in the 60s. She was active but she got blind (see "Sadness, grief, " and fell and broke both her wrists, kind of handicapped (she became overweight)." Narrative 5: (talking about community cellar) "our people they store their potatoes, and onions, and their canned goods in the cellar. They each have little sections and have padlocks on their doors. They kept their food there in the winter times." **Sadness, grief, hurt**: " my mother had diabetes in the 1960's. But the reason why my mother was blind was because when they were going to boarding school, they used to cry a lot.. because sitting outside in the, it's a boarding school, and they cried and cried and windy, windy…. and then some of the cement blowing, the gravel blowing, one went in her eye and that kind of leave a scar. So younger age she has a scar in her eye, and so, because of that, she kept rubbing her eye every now and then. So she had a scar in her eye. That's what causes the blindness. I guess one side…. She was crying because of loneliness."

Table 5.2 (Continued)

Case-ordered narratives (of chaos genre) addressing Research Question #1

	Research question #1 narratives of attributions for diabetes
	Being told have diabetes: " sometimes I think that when once they're told that they have diabetes, they completely let themselves go, instead of trying to move around and trying to exercise." **Loss of buffalo**: " ..at that time when they have meat, buffalo meat…it isn't rich, some say it is, but it isn't rich. Its' got less fat …but I do this….. I always eat it … when I eat that dried meat, that buffalo meat, not meat, but beef, I always eat that beef marrow, you know that bone inside, I always eat it with that dry meat. Once in a while, I don't do that all the time. But that's too rich. But sugar diabetes people don't like that. But what I'm going to say about diabetes is, my mother says that diabetes people, their intestines, or every place, inside their mouth, or every place, it's coated with something, you know, that's sick, and sometimes they lost, they lost their taste. It's uncontrollable sometimes, and she said, "What's good for that is sardines, you know that soy oil, sardine, with crackers, unsalted crackers." It's good with that, and she said, "Make a thin piece of meat, you call it…. thin it, and you bonfire it with ashes. Put that meat over it like that. Kind of burn it and eat it, and that's going to take out that coating inside your intestines, and you'll have your, kind of like, a new start again." And it's true, I noticed that people with diabetes. Even their sweats are sticky, sugar…" **Lack of fiber in foods**: "Eat fiber, that's what's going to get that, and that coating out. But if you won't eat that, you have to eat it everyday, you know, and if not, why it's going to, and that's what causes the artery clog up, too. That's everything. I'm not a doctor. "I don't know anything about medicine." **Losing river homes and foodways for flooding**: "long ago we used to live in little log houses, and those were ours at that time. But now if you look at them people living in the Districts, those new homes, those good homes, they're not theirs and yet, you know, because they're still paying rent on it, so I think 90% of our people are homeless, probably 98%, because those are all rented houses, HUD homes. So, I considered them all homeless. And you know, at that time when we had those log houses, it's pitiful, it's poor, but at least those were theirs, you know?" "my grandfather was still living. My mother and dad were still young. They lived over this hill on the other side of the creek, and my grandfather, he's a builder, and he's the brain of all that, the whole family, that grandfather of mine. He was a farmer, he was a rancher, and he was a provider. He make sure that his family is ok. So, he had a little field back here. He grows oats, then he grow beans. So he gets hundreds of sacks of beans, northern beans. … my grandfather ordered a house from Sears and Roebucks or one with the catalogs, anyways. He bought a house, ordered, and it came in a chain, box car, loaded. He made it. But my grandfather never went to school. He never was educated in anything, but his own experience, he experienced life. He took that house and brought back in 18 wagon loads, he built the house. There was a blueprint but, what the heck, he didn't even look at it. He just make it the way he feels like it. He even made it 2 story" (laughter).
Elder 7	**Habits from boarding school; Lacking respect for food**:"it's come into my mind several times that one of the reasons our people are prone to diabetes, maybe, is the boarding school experience that they went through. My husband ate in a certain way that was so different from the way I ate. We used to talk about that. My husband would say, "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, on Standing Rock since the 1870's 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, many of our people, which is why when there is food, they all just hurry to eat it. And you know food is really a primitive part of us, something that is essential to our very life. So, we have to treat it in a very good way."

Table 5.2 (Continued)

Case-ordered narratives (of chaos genre) addressing Research Question #1

	Research question #1 narratives of attributions for diabetes
Elder 7	**Ignoring traditional early feedings; Lacking respect for food**: "My mother was a mid-wife. So some of these young mothers would bring their babies to the house My mother would look at them, see them after they were growing up. Of course we always would have food. My recollection is in the summer months, there was always this shade outdoors, a squaw cooler, but no one likes that word, with the green branches on it, my mother would have her cook stove outside, her wood range outside, and she'd be cooking food. This canvas would go down underground there, and an oilcloth on top of that, the plates would be put out, with the food out there in the middle, and we'd all go down and eat. One of the old grandmothers would tell this young mother with this baby, maybe 2 or 3 months old, (Dakota words) which meant 'Hold that baby in your arm, and have it eat' and the mother would take that food off her plate and maybe mash the squash or potatoes and put that on the baby's tongue, and the baby would swallow that. And then say, (Dakota words) meaning, 'cut off a strip of fat, and let the baby suck on it, that way it won't be itching when it gets older," To this day, I like squash. I must have been introduced to squash in someone's loving arms (laughs). I really like squash, and I like corn and all the foods that are ours. But somewhere along the way, someone introduced this business of baby food and the baby having a high chair. And you see what goes on when the baby sits in the high chair and tries to eat. You know, it all goes on top of his head or the floor. Or "I don't like this…" and you know we never said that, "I don't like this." That was never said by us; we had a healthy respect for food. That, I think, has been a very, very serious change and whatever was there, we ate it. But today, from what I see, the children, they don't want to eat this, they'd rather eat potato chips… Perhaps it shows that we care for them when we make this accommodation. But maybe from the earliest time, then, perhaps they should be treated this other way. That way, then they could develop that deep respect for the food, and would eat it, that way, maybe they wouldn't get diabetes." **Reservation life; Losing river homes/ways for flooding**: **Being told the reservation was worst land**: Narrative 1: "I always heard that about having the worst land. That's what I heard when I was young and went to school … the reservations is the worst land. But I always thought about what my mother's grandmother and her father said when they had to cross the river to where they lived…. They had to leave their farmland. They had to come here to this government territory. But they believed it was part of our grandmother the earth and it would sustain life. It sustained their lives." Narrative 2: "They kind of brainwashed us into not thinking something of their land, so they didn't try to hang onto it. Some of us have felt kind of bad… some of these people had large families…when the tribal council got this money that they should have shared with people who actually lost their homes and their land to the Missouri River. They said they would buy land from individuals and all these individuals flocked in there and gave up their land and they had a lot of children; those children could have had 10 or 5 acres somewhere where they could have put their own homes. You know having your own home is really important. The other thing that has strongly contributed, I think, to the health is that prior to the time that this flooding occurred probably about 90 to 95% of the people lived in their own homes. And then after that they got this rented housing business and I think that's an uneasy situation to be in. I grew up in my own home, a real old house; it was just wonderful for me living in our own home; my mother always told me that the reservation is really for those who can't work too well off of the reservation.`I raised you to know that you can compete against anybody and do a good job.' So that I went to work off of the reservation but all those years I rented houses. It was kind of uneasy for me." Narrative 3: "I think about all of these people who lost their homes - their lands along the river. Many of them never again got to live in their own homes, a home they call their own. We tried to get them to pay these people - something for that because I think that must have been damaging." Narrative 4: "... other one is the fact that people who were brought to these reservations….for all of the people in this part of the country, they were forced to come to these places. The old ones… my mother's grandmother was born in 1840 and she came to Standing Rock in 1890. I marvel at how they were… they lived east of the Missouri River here. She said we lived in our earth lodges…. Which the Dakota did….they did not live in tipis like the Lakota. She said "we had all these beautiful things, these backrests, all of them painted, all of the porcupine quill work, decorations for the home and we had all of our painted flesh bags and boxes in which we stored our food. The military came and they told us we had to move to the Standing Rock reservation. We could only take the very, very essential things.

Table 5.2 (Continued)

Case-ordered narratives (of chaos genre) addressing Research Question #1

	Research question #1 narratives of attributions for diabetes
	She said they made the men build rafts out of logs and put the women and children on there and what few belongings we had…" she said the men swam with the horses and guided the rafts across the river. That old grandmother lived …until 1930, so she was 90 years old. But she used to say "You know we don't want to talk about these bad things that happened to us because, you know, they make you feel bad inside," she said, "you know you can get sick from that." I always think there's a lot of wisdom in that- granted we don't bury our head in the sand about these bad things that happened to us - we have to kind of talk about them and see if there's something that can be done about them. That's the other thing I think that we either go one way or the other… we don't want to talk about certain things … I know for me if something's bugging me I just have to see if I can do something about it… at least try it…. And the fact that I tried - then I feel better. That doesn't leave me seething inside – like some of our people – who really try not to look at some of these very, very troublesome things in their lives… I think that contributes to diabetes." **Being told have diabetes**: "People say, `Well, you're at an age where you're gonna get diabetes.' They say it's genetic or inherited that we get diabetes. If people never say that again that would be the best. Like (a man with diabetes) says, "My grandma and grandpa weren't diabetics." So it's not inherited. I think if people never say that again that would be good."
Elder 8	**Losing river homes and foodways for flooding**: "We had log houses. Those homes are ours. These homes are not ours. We have to pay to live in them. We lived in log houses. We had kerosene lamps and wood-stoves, haul our water. That was nice. We didn't have to pay for all this." **Habits learned in military service**: And then the boys joined the Service. We kept them away from drinking and stuff like smoking. Then when they do all that, they enlist and they sent pictures back with cigarette in their hand and beer and we didn't like it but they joined the Service and that's what they got started. I went home crying when we got those pictures. **Needed to be strong to fight off tuberculosis**: "… but you know we lived a long time ago, now everything's different. We all live like this (indicating housing). We all get commodities, food stamps. It starts by eating, we don't eat no wild game anymore. This disease come up that they had to beware of what they eat. Some don't I think. They get worse. Like me, when I was in that sanitarium (for tuberculosis), I had that spot on my lung, and I was to have it cut off. I was in a room with these people, diabetics, that's what they were controlling the disease there. I was in that group laying there with them. They come and show me what I was supposed to eat. They feed those people, that sugar they let you eat, and feed them diet. I didn't have no salt or sugar. I wanted to get big and fat too. (I thought) I'd be strong." **Drinking pop**: "I think that it's too much sweet for her to be drinking. Water would be good but…I know my little granddaughter here drinks Kool Aid, is always wanting Kool Aid. And she likes popsicle, or when she eats that, she doesn't think about eating food. I think that's too much sweets for her. Cause my kids never had it. When we'd come to town, they had candy but not much. We never had children with trouble with toothache…." **Water/air/food is not pure**: I don't know what they put in the water. Then sometimes the water gets rusty…..everything down there, .it all washed away."
Elder 9*	**Eating indiscriminately; not being active enough**: "…they don't care about God. All they care about is their stomachs, and when they eat that pow wow food they're gonna get worse fat. They're `gonna get diabetes…We have to abstain from all those things (soda and bad foods). The Bible tells us to abstain from all evil appearances." "God created us to walk and to do things manually, but that nowadays there's nothing done manually. It's all by machine. It's all by cars, and we just sit. We eat and we sit and that causes us to become diabetic." **Ashamed of developing diabetes herself:** Narrative 1: ".so, I'm ashamed that after I married at the age of 17, and at the age of 34 I got diabetes. … because they all they said that it was a disease and I was full of disease and all that and I was going to church, and I was supposed to be a Christian. I was supposed to be this, and here I am, I'm down with this disease. And oh, I went through a lot of bad words…. after that, everybody's got it. And then when I had kidney problems, they laughed at me then. And now everybody's going through dialysis. And me, I pray to God and everything. I'm not on dialysis. God heals me… and I had heart problems, and people laughed at me said everything, that I was two-timing God and I was dipping into witchcraft when I believed in Indian medicine. They said I was a witch and all that, and that's why I have heart trouble. And oh, you don't know what I went through. But still I just hung on to this prayer life. If they can take the Bibles away from me and keep me out of the churches and everything, but still they can't take this prayer out of my heart and my mind."

Table 5.2 (Continued)

Case-ordered narratives (of chaos genre) addressing Research Question #1

	Research question #1 narratives of attributions for diabetes
	Narrative 2: "I believe I contracted this diabetes because I cooked for a whole bunch of people and the leftovers, I wouldn't want to throw this away. And I'll start eating. And I don't have no husband so I'll be just eating. I hate to throw this away, you know? I didn't want to waste. So I forgot about living. Then I started to use these commodities and that did a lot of it too. I didn't realize it but I thought, "Oh well, that's good and I'll just cook." And oh my, now, my kids, some of them has got diabetes…" **Losing river homes and foodways for flooding:** Narrative 1: "…we lived in a log house, but we didn't have to worry about paying electricity. We didn't have to worry about paying for propane because 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. Don't take much heat. 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 and you know. And along the river, along the banks, along wherever there's, we had natural onions,… not the wild onions on the prairies, but these were along the river, and their blades were three cornered, the blades. They grew about this tall, and on top they had yellow seeds, flowers. And we used them for, like grandpa, for cooking. But grandpa would take that and use that for cold medicine, or to put under, like a poultice under lungs if they're sick in the winter time, coughing, you know. They would use that like sometime, maybe that was high blood pressure, I don't know, but they would cook that and give it that man or make him eat it raw. And then in the spring, all winter and spring they would, a certain man would, (Lakota words)…. They would get a hole right in their main artery and let that bleed …. then for a certain time, and then they would shut it up. They used tobacco to shut that up, that's the only time they bought and used tobacco. Stopped the bleeding. So, see that's what's used for high blood pressure, otherwise, that man said, my grandfather, I went with him that day, his pulse would be just going all the time, and they get dizzy and all that. But after they done that and they used that onions, that wild onions. We lost that. There's nothing now. There's many medicines that we lost, that grew along the river. We could use it. 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 Corp of Engineers, I said, "You guys, you're listening to that President or whoever is giving you the orders to make dams on our poor reservations," I said, "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, you know, "Indian beans" they called them. Narrative 2: "And they, the Army Corp of Engineers, who they listened to, I know it's the …European people, that don't want us Indians here anymore. They want to annihilate us. They're the ones that they took orders from. And they built these dams to annihilate us…. They're slowly doing that because we solely depend upon this ground." **Water/air/food is not pure**: "So, see, we tried to protect our land. The medicine men knew what they were going to do, they're going to destroy the land, the water, the air, and the ground, everything. And it's coming to pass. That's why us Indians are slowly fading away, because they ruined our land now, even the water we drink, they put the running water (in), they stopped…, and they're putting chloride in there. We're getting diabetes from it." **Ignoring traditional early feedings:** "We have to nurse our babies. It's the first milk, the Bible says we have to have "the sincere milk of the word." The true milk of the mother bonds them. They know who their mother is… for life It gives them strength. Where a bottle baby is fed they don't know where their mother is, they're looking for her. That's spiritually and physically we bond. The one who breastfeeds her baby she looks after to them. Whereby when they're bottlefed you don't pay attention to them. You nurse them you've got them with you all the time. Bottle babies … no wonder there's a lot of alcoholism… they learn to nurse the bottle. I always think like that. I have a lot of experience and this is what I see. It's good to breastfeed 'cause you have to have love for that child all his life. Our Indian way. Even now my children are gone and they're away from me but when my breast hurt, my grandmother said, "when you grow up and your breast hurts you you'll know one of your child's is crying. One of them needs help. The Spirit will tell you which one is crying. We are spiritual people along with physical people."

*Elder who has diabetes

Photovoice

While I did not receive current photographs from the elders, there was a great deal of interest expressed in taking photographs to help me to illustrate the issues they thought were relevant to health and diabetes prevention. To help my understanding, and also realizing that pictures might help support their interest in having others visualize the nature of health and diabetes prevention, from their perspectives, various elders said they planned to obtain pictures of powwows, healthful plants found on the plains, and homegardens and send these to me. One elder said she wanted to get a grandchild to take a picture of her as she tanned a deer hide. To date I have not received any photographs but in a member check one of the elders reiterated her interest in me including these and gave me suggestions for obtaining pictures.

Photographs #1, #2, and #3, already described, were taken after the participants physically pointed these items out to me during the interviews as things that were important for health protection. When I asked permission to take a photograph of these things they agreed and helped assisted me as they could by giving me the best position to photograph from. These photographs, of a drying stick, drying wild turnips, and a garden are related to the theme of preparation of foods, the lack of which was seen as an internalizing attribution for diabetes. Storage of vegetables and dried foods in community cellars was mentioned by two elders in the Rock Creek community so I included a picture of this cellar, with their permission, used until the 1950s (Photograph #4).

The theme of the land – both the changes and its basic goodness – was strong and three of the elders stated that pictures of the land “before” (the flood) would be helpful; one elder suggested resources for obtaining such pictures. This elder added that while she had no personal pictures, she felt it was very important to illustrate this and she gave me recommendations for ways to secure old pictures. Another elder said she had especially wanted to bring to the interview a photograph of her childhood log home on the river with her grandfather standing in front and she was disappointed she had been unable to

locate it. Based on these elders' suggestions that photographs could help illustrate these points, I have included Photograph #5 as an "after" picture of the Grand River banks in 2000 pointed out to me by the CHR Director as an example of the environmental damage resulting from the flooding which began at the half-century point. Photograph #6 is a photograph of one of the flooded lands near Fort Yates; dead cottonwood trees with white branches can be seen protruding from the water.

Photograph #1: Drying stick for meats, fruits, vegetables, and medicines. A braid of wild turnips is hanging on the stick.

Photograph #2: Turnip chips drying on strings in tree in front of elder's home.

Photograph #3: Garden of an elder (age 84).

Photograph #4: Storage cellar for food in Rock Creek community used until 1950s.

Photograph #5: Banks of Grand River in 2001.

Photograph #6: A flooded area in Fort Yates, North Dakota with dead cottonwood branches floating on the surface. In the summer, children swim in this unsupervised area.

A number of elders, as noted, felt that boarding schools were a relevant attribution for diabetes because of the habits learned and the sadness, grief and hurt that was generated. It was suggested by an elder that I contact the Heard museum in Phoenix, Arizona, to secure pictures that would illustrate boarding schools. I located a picture on the museum's website of a 15 year old Sioux girl arriving at the Hampton Institute in Virginia in 1897 which reminded me of narratives told by several of the elders describing the loneliness their relatives or of themselves faced as young girls. Another picture of a

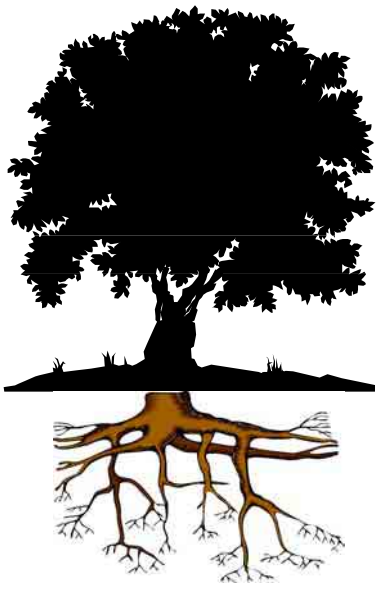
baking class in Flandreau, circa 1900, reminded me of the stories such as the "biscuits hidden in the bloomers" narrative told by one elder (#7). I have not received permission yet to use these pictures so they are not included in the dissertation.

Summary of Findings for Research Question # 1 About Attributions for Diabetes

The externalizing and internalizing attributions for diabetes made by the elders represent some of the "root causes" of diabetes, which are often unknown to practitioners in biomedical science. A diagram designed to illustrate these concepts displays a cottonwood tree (canwakan), a tree that is symbolically very important to the people. Many of these trees that grew along the riverbanks have been uprooted by the flooding of the lands over the last several decades, however (see Chapter 4). To the left of the tree are listed some of the externalizing, or unnatural, attributions for diabetes. Beside the tree's roots are some of the internalizing, or natural, factors described by the elders. All of the attributions are really "roots" that contribute to development of diabetes in particular populations.

"Outside" externalizing, unnatural attributions:

- Societal trends
- Loss of river homes and foodways
- Water/air/food is not pure
- Habits from boarding schools
- Sadness, grief and hurt
- Helplessness imposed by government
- Treaties not kept
- Brainwashing that land is poor
- Needed to be large to avoid tuberculosis



Internalizing, or natural, attributions:

- Eating Indiscriminately
- Drinking pop
- Being overweight
- Not being active enough
- Lack of food preparation
- Lacking respect
- Not relying on God
- Ignoring traditional early feedings
- Not making use of the land

Figure 5.1. Graphic illustrating "root" attributions for diabetes, which are externalizing, or unnatural, and internalizing, or natural.

Research Question #2: Ways of the Past and the Present that Protect Health

Statements and narratives made by the elders during the interviews were analyzed and sorted into conceptual themes of internalizing or externalizing attributions for diabetes to help answer the first research question and illustrated in the first two tables, or matrices, of this chapter. Table 5.1 identified the themes each elder expressed within these concepts and Table 5.2 illustrated some of the chaos narratives related to externalizing attributions. Because the narratives are holistic and inherently interconnected, designations according to the research questions are arbitrary but helpful for making sense of this rich data.

The second research question was about ways that helped to protect peoples' health, in the past and the present, and my interest in this generated thick responses that included good memories of living in earlier times and the teachings they learned from their elders, observations based on their long life experiences, and advice for younger generations. Classifying illness narratives into four genres identified by Frank, cited by Kleinman and Seeman (2000) began with placement of chaos narratives, as externalizing attribution examples, in Table 5.2 for the first research question. This approach helped to lend insight into the meaning in the content and construction of the narratives. Narratives representing the genres of restitution (e.g., positive outcomes, healing, or coping), quest (e.g., search for cures or meaning), and testimony narratives (e.g., moralized stories that bear witness to suffering), described in Chapter 3, are displayed in Table 5.3.

Restitution narratives

The narratives classified as restitution most often dealt with healing, through traditional medicines, prayer, and modern medicines, or combinations of these. One of the recurrent messages offered by five elders, sometimes in short statements rather than narratives, was the observation that people looked after each other and found ways to heal themselves. The way these statements were made, in a sort of quiet, reflective manner of recalling, was striking and constituted an example of how these elders were

constructing meaning, themselves, through the interviews. An example of one of these restitution narratives about helping and healing each other is found in Table 5.3, for elder #4, who talked about hanging a lantern outside when someone was sick so others would know. Another restitution narrative was by an elder (#3) about the "wake up call" that is being heard by Lakota people and how the people are returning to the good ways of their religion which she referred to as the Sun Dance religion which was blended with Christianity, an integration that was very commonly voiced throughout data collection.

Some restitution narratives related to having diabetes or other health problems that ended very positively, such as recovery from profound hypoglycemia with the help of a grandchild (#1), were not included in the table because of space limitations and the fact that they were less reflective of collective experiences in protecting health, although they were culturally quite representative of values like kinship. A story by the elder with diabetes who had a kidney transplant (#2) was included as a restitution narrative, not only because of the hope and restoration that it parlayed, but because it also displayed joy, humor, and a message for others with diabetes about prevention by heeding medical advice and observing traditional ways.

Quest narratives

The narratives classified as quest narratives were some of the most spiritually grounded narratives – in several cases seeking, or hoping others would seek, spiritual intervention for the sake of curing diabetes (#2, #6) and one of these elders' voice rose with passion (#6) as she wished that leader would "Put their whole hearts into and find a cure," going on a vision quest so they could help their people. Quest narratives also included seeking spiritual guidance to help people keep their minds "strong." This theme could be phrased as reliance on God, the absence of which was one of the internalizing attributions for diabetes for the first research question. Quests for health as narratives were also included and these tended to be more the sharing of the wisdom people had gained in their own searches, in case this could be helpful as advice for others. I also

included in this category a narrative about the importance of sovereignty and "keeping the treaties alive."

Testimony narratives

The stories classified as testimony narratives usually made a strong teaching point, sometimes a moral one, at the end. The testimony narrative shared by one of the elders (#1) was about success in helping her granddaughter choose breastfeeding as the traditional way of early feeding. Another elder (#5) told a story of healing, of sorts, but the main point she was making was that doctors are quick to diagnose diabetes too early, sometimes when they don't have it after all, an externalizing attribution for diabetes. The moral tone of these stories made them instructive, as they were intended to be. One elder (#6) gave a short testimony story that involved a metaphor of a garden as a way of viewing and caring for children and teaching them values, which is important for protecting health and preventing illnesses and other problems related to societal temptations. Several strong testimony narratives were offered by an elder who says she "says what she thinks" while also being "humble" (#9); the narrative she told about gathering beans from the cache of mice reflects not only wisdom about preparation of food, mentioned earlier, but cultural values such as giving gratitude, reciprocity and not being greedy.

Health wisdom

Another genre of narrative I heard in the collective narratives about health and illness told by the elders was one I termed, "health wisdom." Perhaps because these participants were elders who had knowledge of traditional ways and because I was asking about this in particular, some of their narratives were rather explicit in providing recommendations or recall of what had protected people in the past. These included narratives of the following: eating simple, prepared foods and soups; gathering, drying and storing traditional foods; staying active and doing hard work; relying on God and keeping a strong mind; and resisting temptations like slick food advertisements. I have

labeled some of the narratives in Table 5.3 as “health wisdom,” and in the summary for this second research question I created Figure 5.2 to show how this wisdom, represented by this genre of narratives and integrated throughout the others, contrasts in language or content to Western messages with similar messages.

Attributions for their own good health

All of the elders who participated in this study appeared to be robust and in good health. Four have diabetes but apparently well controlled, which appeared to lend some additional wisdom to their role as elders who have successfully dealt with this now common condition. The stories, in particular of the elder who had a kidney transplant and has done very well and another elder, now 84 years old, who avoided amputations and dialysis years ago, apparently with the help of traditional healing, are inspiring.

All of the elders attribute their present good health to being active, in physical, mental, and spiritual dimensions although they no longer did the “hard work” they also think is important for protecting health. All of the elders spoke of eating traditional foods, along with modern foods, recognizing that the traditional foods, “closer to nature,” as one said, were the more healthful. Four of the elders mentioned “keeping soup on” in such a casual way that it made me think a pot of soup might be found in their kitchen almost every day. One of the oldest elders was looking forward to preparing for the winter by receiving, she hoped, some deer killed by her grandsons, so that she might dry the meat on her drying stick and tan the hides to make moccasins and a dress.

Table 5.3

Illness narratives offered by elders that address Research Question #2 about ways of protecting health from the past or in the present.

	Research question #2: Illness narratives that illustrate ways of protecting health
Elder 1*	**Restitution:** "…these hot days I'll be outside raking out my yard, and cleaning up my yard, and whatever I can… Just to keep going all the time, moving all the time. I don't sit around, because wh I come over here to visit some elderlies over here, all the elderlies sitting there, and doing nothing, ar sick and all that, and I said "Why don't you get up and just walk around the chair like I did?" That's where I am today, 23 years I have diabetic and I'm still up and around. See like that couldn't hold m down, the way I'm walking and doing something all the time. I'm still up and around. I still garden.' **Health wisdom:**"my granddaughter from way up to Montana, we went up there when she had her first baby. And I was with her until she had the baby. Then the doctors asked her if she's going to breast-feed or bottle? And she looked at me and so I says, "Why don't you breastfeed? You're going to have a nice good healthy baby." `Ok, grandma, I will.' She breastfed her baby. You can take her anyplace where you are, and they don't have to be boiling water or making milk and all that stuff. And so she did; she raised her oldest daughter breastfeeding, 2 of them. And that was good, you know. And it was a little boy here, and she said,`Grandma was telling me to breastfeed him, look how chubby he is, he's a fat little boy.' It was good, you know? I did."
Elder 2*	**Health wisdom:** Narrative 1: "…. long time ago, before diabetes, Indian people looked after each other. Nobody went hungry, nobody, if somebody was sick, they doctored them right away. And I said that's what we should do now. But we don't; we each go their own way. It's like saying, oh take care of yourself, you're the one that made yourself sick. That's not right. And so this diabetes, I said "we can beat it, I said, we can keep it down, because if we don't keep that, our diets, I won't call it a diet, but even in the way we eat, if we watch that, we can live a normal life, we don't have to be sick and so you have to use a strong mind." Narrative 2: "God made these doctors and I said (to woman with poor diabetes control) God wanted to heal you, but he's using these doctors to help you, so don't be afraid of them, and do what they say do. Don't be like me and think you're your own doctor," and I said, "and end up being changed to that dialysis. If you can avoid it, please do what your doctor says." Narrative 3: "We could use the rivers more often. The ones that are not polluted. Fish is good for you, really good for you. And that's what we used to do when we lived along the river, my grandmother used to put, we called it a catch line, put several big fish hooks on there, and put big pieces of meat, and then we'd run with it and go across the river and string it up there and to this side, and she let it…In the morning, when she pull out, she'd have great big catfish. So we'd eat some of that and then go sell some. So we had means including using the water. But if, like, this isn't polluted yet, so a lot of people could get fish, and there's lot of wild fruit along this (land,) too." Narrative 4: "I put my trust in the Lord. That he is either going to heal my kidney, or else he's going to get me one, or if I died and went home, I'd be whole. So I sad these 3…. You know, 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 it along by not taking care, and we hurry along our death, by ignoring people's advice." **Restitution:** Narrative 1: "I had my trust in the Lord. That he is either going to heal my kidney, or else he's going to get me one, or if I died and went home, I'd be whole. So I said those 3…you know, 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 it along by not taking care, and we hurry along our death, by ignoring people's advice." Narrative 2: "when I came out of ICU (after kidney transplant), my sisters were there and I asked for my Bible, so I turned it to my reading, it was in Titus. And then my doctor came over and nurses would rush in and look at my catheter, my bag, and then they look at each other. I said, "What are they worried about?" He said, "He's not putting out." And that's my kidney. And he's like "Got to remember, he rode on ice all the way from California, and he's got to get used to your body before he starts functioning." He kept calling him he, so since my reading was in the Bible I called him Titus. So the next morning the nurses came in "Betty, how are you and Titus getting along?" A couple of days later they came and ask me again, "He's got me on the run," I said. :

Table 5.3 (Continued)

Illness narratives offered by elders that address Research Question #2 about ways of protecting health from the past or in the present.

	Research question #2: Illness narratives that illustrate ways of protecting health
Elder 2*	**Testimony**:Narrative 1: "(my grandmother) cooked in the house, but she lived in the tent. And my grandfather fixed it, and my dad fixed it, so it never, the water didn't go through. It was in the real hot summer time, they take this wax, and they waxed that tent. They put it on it and it soaked through, and so the rain couldn't go through it. And we used to go out there and we used to call it the Indian gum, because as it melted it hang in gobs from the side of the tent, and we take that and we chew it….. And then he took cardboard and then they lined the area up so the wind couldn't come through. So he fixed it pretty cozy and she had in her little tent that Dad made out of a little tin barrel, that what you call it, an iron barrel, or whatever, 10 gallon barrel, he made her a stove. Inside you line it with bricks and keep the heat in. She lived until she was 89, I think. But she was a very active woman. She harnessed her own horses. My grandpa went clear to Oregon to buy her some small, a team of horses so she could train them and he used to say, "Don't mess with them. Let her train them herself." And so she got her little can and then she'd have oats in there, and then she'd go up on the hill and tap it, and pretty soon here they come, you know. She talked Indian to them and tell them to back up, they'd back up. So my grandma raised me, and she's the one who taught me all about the food, and how to prepare them for the winter, how to butcher a deer, how to butcher a cow. And how to make moccasins and stuff like that. How to cure the hide, scrape it…. and that's how I start eating now again. Nothing but vegetables, except that, you know, that when I'm going to make mashed potatoes like I said, I let then soak for a while, to get all the starch out of them." **Testimony**: "… Indians, 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 that was a road that passed our house by the river, the river bed, along there... So she said "there's a wagon coming, go stop them and go over there and bring them back." She'd feed them and then water the horses. So that's the way we were, we grew up. But in boarding school, everything, everything of yours was labeled. Even to 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 sit 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, and we used lots of butter, I know, because on our mashed potatoes, and stuff like that…"
Elder 3	**Restitution:** "…the wake-up call is, our way of life is coming back. And all these programs, they never used to start with a prayer. And all these workshops that I have attended, they begin with a prayer. And then the ways of life has been instilled in the minds of the Indian people now. 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. … Those are coming now and they're eating the right kinds of foods and go to bed early, don't stay out too late. 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. And now, there's a lot of schools that are having called Indian clubs, awareness of our culture ways. This is the first time in history that this school has offered the Lakota language. And this happened, and I'm the instructor there. So these are some of the things that I call the waking call of all Lakota people. And it's going to benefit our young generation."

Table 5.3 (Continued)
Illness narratives offered by elders that address Research Question #2 about ways of protecting health from the past or in the present.

	Research question #2: Illness narratives that illustrate ways of protecting health
	Quest: "…our Great Spirit always gives us something to think about. And that's one of the things when something like that happens, we always resort to God. God has a plan for us. He's the one that made this world. And if we are not appreciative, then he will do something where we're going to suffer. And that's one of the things. So if we're not wise enough, we are going to overlook a lot of these things. You know, your wisdom comes from God. If a person prays a lot, then he'll give you a lot of good thoughts into your mind. And that comes from God. You know, at my age now I've thought about these things, but, especially what our fathers used to say, "Get what you can out of a day." You know, "Learn that God has put us on this earth, that we need to work for the betterment of our health." That's some of the things and a lot of these things that our Indian people have known already, that it just correlates with the Bible. .. It's our way of life." **Testimony:** "even now I say that the buffalo meat is way better than the cow's meat and a lot of those…we used to like to eat tripe. But we don't like that cow tripe. That really smells….has a bad odor. … compared to buffalo and it's very easy to clean. Then when you think about that animal and if it wasn't for that animal we wouldn't be alive today. Because the buffalo provided everything, shelter, clothing, food. And the buffalo was the main source of survival. And then come where we were put on reservation life. And then came the rationing of foods…that we're not used to. And that resulted in illness, caused a lot of illnesses, you name it, what the body can take and cannot take. That was all due to the reservation life. And the commodities that was given to us, I remember receiving commodities at one time and the meat, canned meat, was so terrible, so bad. We used to feed the dogs with it."
Elder 4*	**Restitution:** "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." **Quest**: "I wish they could find a solution to this problem that taking everybody to dialysis…"
Elder 5	**Restitution**: I have a grandfather that died when he was 104 years old, and he had all his limbs. The only thing that he really couldn't, was his hearing, he's completely, he went deaf, but he could still see. And he's got his mentality." **Quest:** "our system, our way of life, it's always the leader, they look up to that leader and they trust that leader. So I think that, in my belief system, is that the leadership that make the difference in change. So that's where I'm at and I don't think that, they call it, in government level, they call it 'sovereignty'. And I always wish that we were sovereign because we could manage our own life. Because the United States Government made treaties with our ancestors, and they broke every one of them. And coming along in 1889 they had an act, not a treaty but an act, that kind of more or less joined to wipe out the treaties that were signed. There's 13 of them, treaties, but 2 of them that stands out is 1851 and 1868. Those 2 treaties stand out. And the act was being done in 1889. And that's where they tried not to honor those treaties, because of 1889 act. So, good leadership could maybe have a President to see our treaties and who we are. Cause we're different. We're very different, like I told you. We know who we are, and our spirituality is so meaningful. We can heal ourselves with prayer. That's what I said is power of prayer is so… I believe in that." **Health wisdom:** Narrative 1I tell my grandchildren to move around, don't sit around, watch TV or those Nintendos. I restrict them from that. I say, "Grandma needs this done. Grandma needs you to vacuum her living room, which it doesn't' need, but I just want them to work. I want them to understand that in this life and this day and age they are going to be responsible for who they are." Narrative 2: "So we're trying to be (like) the society that's doing all this, but our Indian people don't know how, so that they more or less are trying to survive the best way they can by buying instant foods and all this. And they're going on the wrong place but someday hopefully - like we mentioned, the children have got diabetes. I hope all our people will realize that so that our young children, they need a chance in this world, that they need their health."

Table 5.3 (Continued)
Illness narratives offered by elders that address Research Question #2 about ways of protecting health from the past or in the present.

	Research question #2: Illness narratives that illustrate ways of protecting health
	Testimony: "I have permission to tell this. (A relative) broke his leg and went to a public health and they kept him there. He was a heavy-set man, not really call him fat… He went into there and…he was diagnosed as diabetic. And so every time they come in and they give him these pills, he put them in his mouth, with water and all that. But after a while he said (to relative), `I don't take them. I don't even as much as swallow them pills.' And every time they leave, that's when he'll throw it in the wastepaper basket. I don't know how long he was in there, he came home and told them, he said, `I'm diagnosed as a diabetic and look at all the medicine that they sent me home with, so I just want you to witness something that I'm going to tell you. All this will go into the trash can." And that's exactly what he did. Letters are coming, it's time for you to check your blood…Anyway, so, that went on. Finally they quit sending him letters. Well, 3 years later, I think he had pneumonia. So again, she took him to the hospital. Says, "Oh oh... They're going to be giving me pills," he said, "Well you know what to do." So she left. Anyway, … but I think 2 or 3 days…the doctor came in, and said, "According to your chart here you were a diabetic but now," he said, "We cannot find anything wrong with you. You do not have the disease. What did you do?" He said, "'Nothing,' I didn't want to tell him that all the waste that I did, cause it cost them money to buy all those medicines. I threw them away. 'Nothing'. So he said, "You're a clean man, you're not a diabetic." So that's very important. And that's how seem like they're diagnosed with diabetes right away. And like you said it's all over the world now. But I think that, if you know your body, you can prevent that. Because we, I know my body. I know who I am; I can take care of myself. So, if I go to a clinic I know why I went there. So I think it's very important that we know our bodies, so we don't have to go along with what they tell us right away."
Elder 6	**Restitution:** "the doctor told my mother there's nothing we can do for your daughter because she had a heart trouble, enlargement of the heart. And she had tuberculosis, and that's why she's going skinny. She's going to die… I was skinny, but then my fingertips and my toes were swelled up. And I just don't feel good. I don't even want to eat. And so my mother don't know what to do, and, just them my grandfather was going by. He was a medicine man; she called him over. He came and said, "She's sick and she's going to die, so she's going to be sent to a sanitorium, and … they'll send her back when she dies…" But my grandfather didn't say anything, that's his natural way, remember, he never says anything. So he was standing there and then he went back and so my mother was kind of mad at him. But that time my dad was home. "Told your dad and he doesn't even say anything." Next day, evening came, and here, towards evening …"I think there's a horseback coming", my dad said, "I think my dad's coming. He came and my dad went down there and tied his horse and he came up and he brought a quart jar of medicine. It was foamy like… He gave it to my dad, and here "give it to her… make it so she takes it 4 times,"… There was no taste or nothing, but it was really just foamy and I drank it up. And next morning…I will get one again…and next evening… before I even get it, I got hungry. Boy, I really ate, and from that day on I took all that medicine and I got well. And … and all my body went back to normal." **Quest:** "These people that are going to Sundance… "Why don't they put their whole heart in it and find a cure for diabetes?" "Prayers and the people that are going through a vision quest… they could find a cure for their own people, for the benefit of their people. If they ONLY put their whole heart into what they're doing." **Testimony**: "my mother used to tell me, `your children come first. They are your valuable gift, so you should raise them right.' So when I talk to my nieces and nephews, I always say, "those are your crops. It's growing, so you better, if it's getting weedy, kind of fix it, get the weeds out, the bad weeds out. And let it grow by itself." And this is what I always tell them. "If your crops grow, so you're doing ok. You're going to get a good crop. Take care of it, and you'll have a better, in a way I would say, a garden…." That's what I told them.

Table 5.3 (Continued)
Illness narratives offered by elders that address Research Question #2 about ways of protecting health from the past or in the present.

	Research question #2: Illness narratives that illustrate ways of protecting health
Elder 7	**Testimony: "**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 that, how they never had enough meat to eat at the boarding school. We used to also visit some of her friends older than her. Some of them were there when she went to boarding school in Fort Yates in the 1880's or somewhere around in that time. I'll never forget what she (a friend) 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." "And another one of my mother's friends said when she went to boarding school, she said, "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."
Elder 8	**Testimony:** "My dad used that (the community cellar). They had potatoes, squash, rutabagas and carrots, and my step-mother, she canned so she had all kinds of like cherries, plum jam, and all these different berries, and buffalo berry jam. Puts it all in boxes and my dad made a shelf so they put those on the shelf and they'd padlock that root cellar. When he'd go back there, he'd have to light up …and he has potatoes and other things, covered up with dirt. I don't know how they planted there when they didn't have this water, grow great big carrots. But now we use this water from the house, we have gardens."
Elder 9*	**Health wisdom:** "And I have a pole that you see up there. I use that because when I get meat, I always dry it, you know? I dry it. There's no fat on it, that dried meat. In the summertime when I get corn, I dry the corn and I go out in the prairies and I get tispinna, you know, or Indian turnips. I dry that and I use that for potatoes and the corn and there's no fat in there. So I use that and you know why they call me "an old Indian", and "an old lady" and all that, but you know that did something for me. And I've lived a long life because of eating the traditional way." **Quest:** "… the way my grandfathers taught me to pray….that way and God answered my prayers. So there is a God. And He's the only one that can help us in this day and age." **Testimony:** Narrative 1: ("Indian beans" grew in the ground)... and these little mice, they collected them.. They … gathered them for the winter. They grew here and there, but the mice knew where to get them, so they would gather them and take them.. .in mounds. They would carry them. They had little roads, like that. And when you go in the winter time with grandmother… when she finds a road, she follows it, and she gets to that mound. But before she goes, she would say, "Grand-daughter, today we're going to visit my sisters, and I'm gonna trade with them." And she would pack kidney fat or either corn, or the real beans that we have. She would pack some in there, in her pack, when she'd be going. When she finds a road, she would be singing to them sisters and brothers that's she going to visit, because if she don't sing and pray to them, if you open that mound and if they're in there, they're going to bite you, and you'll die, see? They would go away and then they would let, and then she would trade, you know? She only took so much, you know, but the rest she would put her trading stuff in there, cover them back up. And so she would sing, she would sing a song (sang in Lakota) "My sister, my sister, I'm hungry, so I'm coming". Yeah, and they would listen to her, and then she would, oh, the beans, they are about this big. And she would gather some… She would make me stay away. But if they didn't sing, people that don't sing, they get bit. So she would trade them and cover it up. I learned that from my grandmother." Narrative 2: "And I was a huge woman and I'm not afraid of anything. In other words, they said I'm a true, true bull, buffalo.. things that I do kind of reminds me, "Gee, maybe my grandmother is telling the truth." … going along when I see this herd of buffalo. There's just a big old dust storm coming…. I was driving the car and I stopped and I looked. There these 2 buffalo were fighting. Boy, they're quick. They bump their head and spin around, you know. They were trying to gore each other, but they had their heads together. And all these other ones were around them like this. I was looking at them. I looked at them. I don't know what got into to me. I jumped off the car and I went over there, and I said in Indian, "(Lakota words) "My, why

Table 5.3 (Continued)
Illness narratives offered by elders that address Research Question #2 about ways of protecting health from the past or in the present.

	Research question #2: Illness narratives that illustrate ways of protecting health
Elder 9*	are you doing this? Why are you fighting? There's just a little bit of us and here you're trying to kill each other. Stop that!" And them 2 fighters they just stopped, and they looked around at me, like that…" I said, "Go on, go eat, and live peaceably," I just said that, and here they looked at, and here they both put their nose up in the air, they made some kind of a noise. They turned and went, so all the rest of the buffalo followed them. So, I thought, and then it didn't dawn on me until I got in the car. Then I start shaking. What did I do, what happened? And I remembered… You gotta try all things and see if it's of God. Another time, I was going, they were all standing at the West side and they were just looking so forlorn. Again I stopped and I went, and I said, "Oh you poor brothers and sisters. How come you're standing there looking?" I was talking in Indian, " How come you're standing there looking West? You're looking for food that the white man took away from you. Like us, they took you away. Now they're bringing you back. But they're feeding you something wrong, that you don't like. You want to go back. Is that right?They put a fence around you. Well, us too. We got a reservation. We can't look for the foods that we need. We're cooped up in that reservation. We're eating the wrong foods too," They just looked at me and kind of bellowed… They understood me. "I'm sorry," I said, "but just pray. Me, too, I'll pray."… Then one by one they turned and went… so things like this happen to me. And I realize that we have power, us people, with God. But if we turn away from Him, we have no power. We don't respect God, so He don't respect us. He won't listen to us because we don't cry out to Him… So, that's not right. We need to do our work on earth…"

* Elder who has diabetes

Summary of findings from research question #2 about culturally constituted health protection practices and beliefs

The findings clustered in the second research question about culturally constituted practices and beliefs that helped to protect peoples' health were presented with the assistance of analyzing the illness narratives in the genres of restitution, quest, or testimony. This process was made easier by the detailed analysis of the first question because this question was in many ways reflections of, or in some cases reversals of, the attributions for diabetes already described. Like the attributions for illness, the discussion of protective practices and beliefs and things that could be done to help prevent diabetes were grounded in cultural beliefs and norms, many of which were outlined in Chapter 4.The narratives in answer to the second research question were more positive and hopeful than the first question about attributions for diabetes. This may be in part because many protective health practices were related to good memories of growing up with their families and practicing cultural ways that they also attributed to the peoples' good health. Since many of the narratives in answer to this question fell into a more

practical, “health wisdom” genre, this category was added to the four previously identified genres of restitution, quest, chaos, and testimony narratives.

The quest narratives were very earnestly delivered, reflecting these elders’ genuine concern for their people and reflections on how the paths people were taking that lead to health problems like diabetes might be averted. I was particularly moved by the quest narratives beseeching traditional leaders to seek spiritual intervention for a cure. Some of the testimony narratives, like those of restitution, were also hopeful and restorative, while others delivered moral points about colonial practices or biomedical errors in diagnosis or treatment.

The figure of the two worlds, first presented in Chapter 1, has been applied as a figure to illustrate examples of communications based on indigenous knowledge and those more commonly offered by conventional science. Some of the similarities and contrasts may be evident in the messages related to indigenous knowledge, shown on the left side, and conventional science, represented on the right hand side.

Health Wisdom:	**Conventional Health Advice:**
Respect food	Choose proper foods
Gather, store, boil, make soups	
Work hard, stay active	Get regular exercise
Keep a strong mind	Seek support
Stay off “messy” roads	Moderation
Stay away from ‘pop’	
Keep balance and harmony	Balance food, exercise & medicine
Water is a gift of life	Drink plenty of water
Use the land as should be	
Give gratitude to God	
Be generous, not stingy	
Respect all things	
Feed infants traditionally	

Figure 5.2. Similarities and contrasts of indigenous health wisdom and conventional science health recommendations – examples.

Research Question #3: Caring and Sharing for the People's Health

People who are viewed as elders in American Indian communities are typically trusted because of their knowledge and wisdom of traditional ways and for practicing the cultural values in their own lives. Responses to the previous research questions, as with this question about ways these elders have expressed their concern and willingness to share knowledge for health protection, are integrated throughout and are culturally grounded, as has been noted. Because the cultural values, described in Chapter 4 are so inherent in answering this question, I have underlined some of these as themes in reporting the findings for this question and in the summary. Specific statements that were generated by a question about the participating elders' beliefs about sharing knowledge are featured in Table 5.4.

Generosity and sharing is considered to be a cardinal value among Lakota and Dakota people, documented in Chapter 4. The way in which a person becomes regarded by many as an elder involves generously, in part, sharing wisdom and useful experience, typically in a patient, instructive manner that does not impose on the learner but rather shows respect for their experiences and encourages them to seek their own understanding, which is another cultural value.

The elders who have diabetes have been called on to participate in a number of educational venues including videotaped interviews and community programs, and they have been anxious to tell their stories in ways that could help others avoid some of the earlier sadness they had known related to diabetes. Elders who did not have diabetes were also anxious to help; several of the quest narratives were about searching for cures or for meaning to help their people with this challenge.

One of the most striking observations related to this question was watching one elder after another come to a point where they, in constructing their own reality, said quietly statements like, "seems like we took care of each other," was unforgettable. This observation was followed by stories of generosity and caring for others, such as hanging

out the lantern outside a house when someone was sick so that people would know to help or stopping wagons of travelers to offer them food and shelter.

The many stories that were told are implicit evidence of the generosity and willingness to share and give hope. Stories are a rhetorical strategy, often used by elders, as a way of communicating cultural values and lessons that need to be learned without attempting to impose these beliefs on others (Carter et al., 1999) because of politeness and humility as well as the respect for words that leads to an economy of words (Momaday, 1996). Illustrations of these are documented in the chaos narratives of Table 5.2 and the narratives of restitution, quest, and testimony in Table 5.3. The cultural values of caring and compassion for their people, including children, are prominently displayed in the narratives, including the ways of caring for each other whenever anyone was sick, sharing the medicines that were needed, the teaching of young mothers about early feedings (Table 5.2, #7), and the generosity observed in their own elders (e.g., stopping wagon trains to bring people in to be fed as told by elder #2 and illustrated in Table 5.3.

Some of the participating elders are known for telling traditional stories with implicit moral lessons from which others can learn. One of these stories, found in Table 5.3 for elder #9 is a testimony narrative about "Indian beans" that reflects cultural values of reciprocity and respect for all creatures. In this story the elder was taught as a girl by her grandmother to go the riverbanks where wonderful beans are stored for the winter in mounds by little mice. She learns to explain her intentions to trade fairly with the mice, not being greedy, and leaving for them corn and fat to help them have adequate winter stores of food in exchange for the beans.

However, there was, among some of these elders, resistance to accepting any type of designation as someone with special communication ability or as having a position of moral authority, even when acknowledged by the community as respected elders. I believe this standpoint is reflected in the cultural values of humility, which includes equal regard for all creatures without thinking oneself above any other creature, and honesty

and truth in the way people represent themselves. One elder (#1), for example, stated that she was not trying to "be somebody," when she shared advice with people. Another elder (#9) said, "I want a turn to be humble." For these reasons, too, statements in response to beliefs about the importance of sharing their knowledge tended to be answered in short statements or narratives, rather than long and multiple stories.

Finally, one of the oldest elders (84 years) relayed a narrative featured in Table 5.4 using metaphors of water and of roots, both of which had been threaded through her entire interview, ending with a message about sharing wisdom - "like water that stays, it will become stale. But a stream is always giving life."

Summary of findings for Research Question #3 about evidence of concern for their community and willingness to share to help their people

Responses to this research question about ways that elders expressed, implicitly and explicitly, their concern for and interest in helping their people prevent problems including diabetes were reflected in earlier discussions in this chapter. Like the responses to the first two questions, these too were culturally grounded in the tribe's values, particularly of generosity and sharing. This concern was relayed through a traditional method of communication - storytelling - which speaks indirectly to people while trying to teach values. Many of the narratives gave additional evidence of this, which strongly reflected the values of generosity and sharing. The metaphor of the stream that always gives life as long as it is allowed to flow illustrated a view of caring and of sharing for the people. The personal stories of coping told by elders with diabetes also revealed generosity in sharing so that others could benefit from their experience. The frequency of the statements made by the elders about how people used to "help each other" and "heal ourselves," was enlightening in both the content and the quiet reflection during which participants constructed the meaning of this in terms of health protection in modern times.

Table 5.4
Case-ordered themes representing interest in sharing knowledge and caring.

	Research question #3: How do these elders express their concern and share their wisdom?
Elder 1*	"I just want to (tell them how to avoid diabetes), but when I say that, some people say, `You shouldn't be saying that. Mind your own business.' Some people, they need help and nobody telling them. They're not diabetic, but look I'm living with it 23 years. I'm still living today. I still have my legs. I want them to know that."
Elder 2*	"I hope I have helped people because I don't want them to go through what I did. I had to go the full nine yards to discover that life is worth living, especially when you have grandchildren, and especially if you want to live for them to grow and for them to live without dialysis, without facing that disease. Because there's ways and means of keeping from it, and that's watching your diet and exercising. `Watch what you're eating, watch your intake. You can eat some of the things, but….watch how much you eat, it's the main thing.'"Also see Table 5.3, testimony narrative.
Elder 3	"Water is the source of life. And that's how our Lakota people, centuries back, that's how they were so healthy. They didn't drink coffee, tea, or all the sodas and what have you that we drink nowadays. So (we) need to really be careful and encourage, like I encourage my grandchildren, you know, `drink juice, you know, instead of soda; drink a lot of water.' That's what I always do, so when we go to a powwow or something, I carry a lot of water. If we can do that, if our parents, and the young mothers, and the grandparents can encourage that to their children, in turn they can encourage, and it goes on. And we can get back our health again."
Elder 4*	"It's kind of sad how everybody is catching it. I hear young people are getting it more and more. I was wondering what caused that. Is there a way to find it, to stop it? … I don't know how anybody is going to find out where this diabetes comes from. Because a long time ago, a lot of our people, they never had that. I see a lot of our people on dialysis…" "I'm trying to make myself useful in the community – helping." Also see Table 5.3, restitution narrative
Elder 5	"I always wish that we were sovereign because we could manage our own lives…. (Today) maybe 90% of our Indian people speak the white man's language and I think all our young people, most of them, have their education. So the time is here now to make the change and if we can talk like this to our young people; it has to come from the heart, to know how to make these things happen." "And I always remember what my husband said, "we're survivors, no matter what the United States government will do to us, remember we are survivors."
Elder 6	"that's how I lived (see restitution narrative, Table 5.3) and when my grandfather said to me, he said, "Ok, you were going to die, but you were spared because of, you know, your taking medicine and you're going to live to be an old lady." And now I'm an old lady, I'm 69 years old. So, I was very glad. That's why I said you have to help the people that are less fortunate, people that need your help."
Elder 7	"It doesn't always work out… still you have the satisfaction that you tried. To mention (things)…. Then see if someone wants to help do something about it."
Elder 8	"When they come to my house, I tell them…." Long time ago we used to do this and that…" "Oh, that's your day, but that was a long time ago," they say. "Those were good days."
Elder 9*	"A willow or ash grows tall and the leaves grow on top because of the storms and winds that make the roots grow deep. Sometimes those roots have to hold onto a rock, which is Jesus. The winds came to me and almost blew me over, but my roots grow deep. It's doing God's work. If you don't share it (wisdom), it will spoil. Like water that stays, it will become stale. But a stream is always giving life."

Summary of the Findings Across Questions and Cases

Underpinning all of the dialogue and emerging themes of this study, and crosscutting questions, the cases, and the conceptual ordering were five primary cultural themes, "the land is always good," "water is life," "respect for all things," "gratitude to

the Creator," and "we helped each other" (generosity and caring). These led to identification of an overarching theme, "the 'place' of place," in health.

In choosing to highlight these prominent themes, and in leading to this the smaller themes already presented, I realize that I must be careful to represent the voices I heard with justice and clarity. Having been instructed by gatekeepers and to some extent, published literature, as well as by these elders and others I have met in the Nation about the values of the people (see Chapter 4). I was struck by the ability of people to be able to identify root causes of problems like diabetes, which often involve tragic history and trauma, and balance these stories with those about the positive, hopeful aspects of an issue and honorable remembrances of the resilience and survival of their ancestors. The key themes that emerged are briefly discussed:

"The land is always good."

Based on my familiarity with Native studies literature and my field experience, I had postulated that the interviews would elicit statements about the land in relation to health, although I tried to bracket my assumptions that the land changes resulting from alterations to the Missouri River for dam building would be included in the attributions for diabetes. Connections of the land to health were rich and plentiful throughout the interviews -- relayed primarily through narratives in chaos and testimony genres.

Land-based attributions for diabetes were unnatural, or externalizing, and included: losing river homes and foodways for flooding, water/air/food is not pure, loss of buffalo, reservation life, and intimately related to these, sadness, grief, and hurt and stress factors. These themes were largely consequences of colonialism and post-colonialism, around which other themes of attribution were also related including: treaties not kept, societal trends, un/underemployment, loss of language, lacking respect, helplessness imposed by the government, liquor, and habits learned in boarding school.

On the other hand, a more internal attribution to which individuals were seen to bear some responsibilities was not making use of the land as it should be used. This, like

a number of larger themes, was tied to key cultural values of respect for all things and gratitude to the Creator.

In spite of the losses involving land and present concern about damage and inappropriate use, the goodness of the land was a prominent theme, to which water and food were related, that was brought up by a number of the elders. “The land is always good,” one elder said as she was winding up a narrative about the move to the reservation in her grandmother’s time and the more recent environmental changes. Another said, “the land is the provider.” The emphasis on the goodness of the land, in spite of all the things that have happened, brought balance to the discussions and reflected not only cultural values of respect and gratitude to the Creator for the gift of the land, but also hope and resilience for which the Sioux people are known. Several elders expressed their appreciation for tribal health programs that promote drinking water, getting outside and walking, and respecting their culture.

“Water is life”

Water or “mni,” has to do with “life” in both the Lakota and Dakota dialects, and is used in related words, such as “wicozanni,” for health. Water was a thread that ran through all of the dialogues and narratives. Although the waters that flooded the river homes, beginning in the 1950s, were a source of great sadness and desolation, and the current water supply is not believed to be pure, the priority of respecting water resources and personally drinking a lot of water, was clear. Water, like land, even when it has been injudiciously manipulated, is still always basically “good” and a supporter of life.

Longing for the “clear” water of the Missouri River was expressed and remembered by a number of participants. Although I did not hear much evidence of hope for being able to restore the water to its former health, the concept of “hope” was present in some of the dialogue around water. The fact that several tribal health programs were promoting good things like drinking a lot of water and walking was seen as a good sign, and according to one, part of the “wake up” call of the return to Lakota values and

practices. Some of the elders I interviewed have taken this on politically, being involved in treaty meetings and speaking to the tribal council to share their advice.

The abhorrence of "pop" was a universal theme across the interviews. It was seen as a detrimental societal influence with harmful consequences, particularly for younger generations who may not yet have the "strong mind" needed to resist temptations like enticing advertising for pop, "junk food," and other aspects of a "manmade" society. "Pop" was both an attribution for diabetes and, I believe, a symbol of the elders' concern for deteriorating respect among younger generations for cultural knowledge and values.

"Respect for all things"

Respect for all things, "waohala," is a key value that underpinned every aspect of the responses. Lack of respect was seen as a key attribution for diabetes and illness, both on the part of individuals, especially in regard to lacking respect for food, and for more powerful forces, that, without foresight or understanding of the environment, destroyed land and water that played a role in the people's health and sovereignty. While there was attribution for diabetes and health problems caused by loss of land by flooding and the related sadness that accompanied that, there was also a theme about the goodness of the land, and it was seen as a bountiful gift for survival that must be wisely used.

"Gratitude to the Creator"

Related to respect and the goodness of the land and water was prayer ("wocekiye") and gratitude to the Creator. This value, spoken by some as spirituality, is considered to be essential to health by the majority of the elders. The words "attitude of gratitude" aptly describe this value in English.

"We helped each other:' generosity and sharing"

Generosity and sharing (wawokiye) are considered to be primary cultural values of the Sioux people, as described in Chapter 4. The compassion of the elders for their people and the desire to help to prevent problems like diabetes, if they could, was evident

throughout my field experience, data collection, and analysis as I came to understand the centrality of this value as it relates to health.

"The place of "place:" an overarching theme

The "place of place" includes the realization that "place" is not only inclusive of the placement of people on reservations, stories about the land and the water, and the taking back of the Black Hills by the government (see Chapter 4) but also of the loneliness and forced acculturation of the boarding school experiences most children and termination policies of the 50s that moved people to the cities. The "place of place" in health and well-being may be a uniquely understood concept of indigenous people and people forcibly brought to these shores that is little understood by the larger American society for whom decisions to leave their homelands represented personal choices.

An insightful member check took place when I called one of the elders on the telephone on October 21, 2001, to share with her some of the key findings of the study. In context with the key themes that I shared with her, this elder brought up the tragedy of the loss of life and the "home" of the World Trade Towers, on September 11, 2001. She said she was sure that this was a place of meaning to many people – a type of "homeland." She then tied to this concept of "home" the displacement of students from their homes in boarding schools, the loss of her peoples' homelands and ways to the flooding of the Missouri river, and finally, the meaning of the loss of homelands for all people, including those who have perpetrated violence against innocent people, in part to protest these losses. This member check helped me to make a broader connection to the importance of the land, or of "place," in general and led to identification of an overarching theme for the final analysis that connects many of the themes with values rooted in the cultures of the people of the Standing Rock Tribe. In addition, this conversation caused me to reflect on the resilience of the people and how their cultural values must have helped to ground them through repeated losses.

A conceptual model of the findings

The culturally-based themes and the related attributions and narratives have been displayed in a model that illustrates the findings of this study, with the chaos stories contributing understanding and acknowledgement of the root causes of outside disorders like diabetes, while the personal and collective stories from the genres of restitution, quest, and testimony, as well as traditional stories, lean toward hope and the use of the positive power of words to create new visions for future generations and hope for diabetes prevention.

Moving in view of the left side of the model to the right, the unnatural attributions for diabetes (e.g., environmental, habits learned) that generated chaos narratives based in fact of loss and survival are shown first. While these stories of chaos may be sad reminders, they are important for understanding the root causes of diabetes, acknowledging grief and pain, and finding ways to draw attention to things that can still be addressed at various levels of influence (e.g., social, political, environmental). The Lakota and Dakota values are shown in the rootedness of the trunk of the cottonwood tree. The families include those that were the major themes in this study (i.e., “the land is always good,” “water is life,” “respect for all things,” “gratitude to God,” and “we helped each other: generosity and caring”), as well as other values integral to the ways of the people. These values were reflected in the stories of restitution, quest, and testimony, many of which have to do with hope for the future and for prevention of diabetes.

Summary

The findings of this study were related to the three primary research questions about attributions for diabetes and for health, based on the culturally constituted ways of knowing and doing that the elders maintained were important for health protection and diabetes prevention, and their more implicit beliefs about the responsibility for sharing their knowledge. Although diabetes appears to be largely viewed as an “outside” disorder, the attributions for diabetes categorized as unnatural, externalizing, factors and

as natural, internalizing, factors were balanced within and across cases. Narratives describing the externalizing attributions for diabetes tended to fall into a genre of memorable illness narratives identified as chaos narratives.

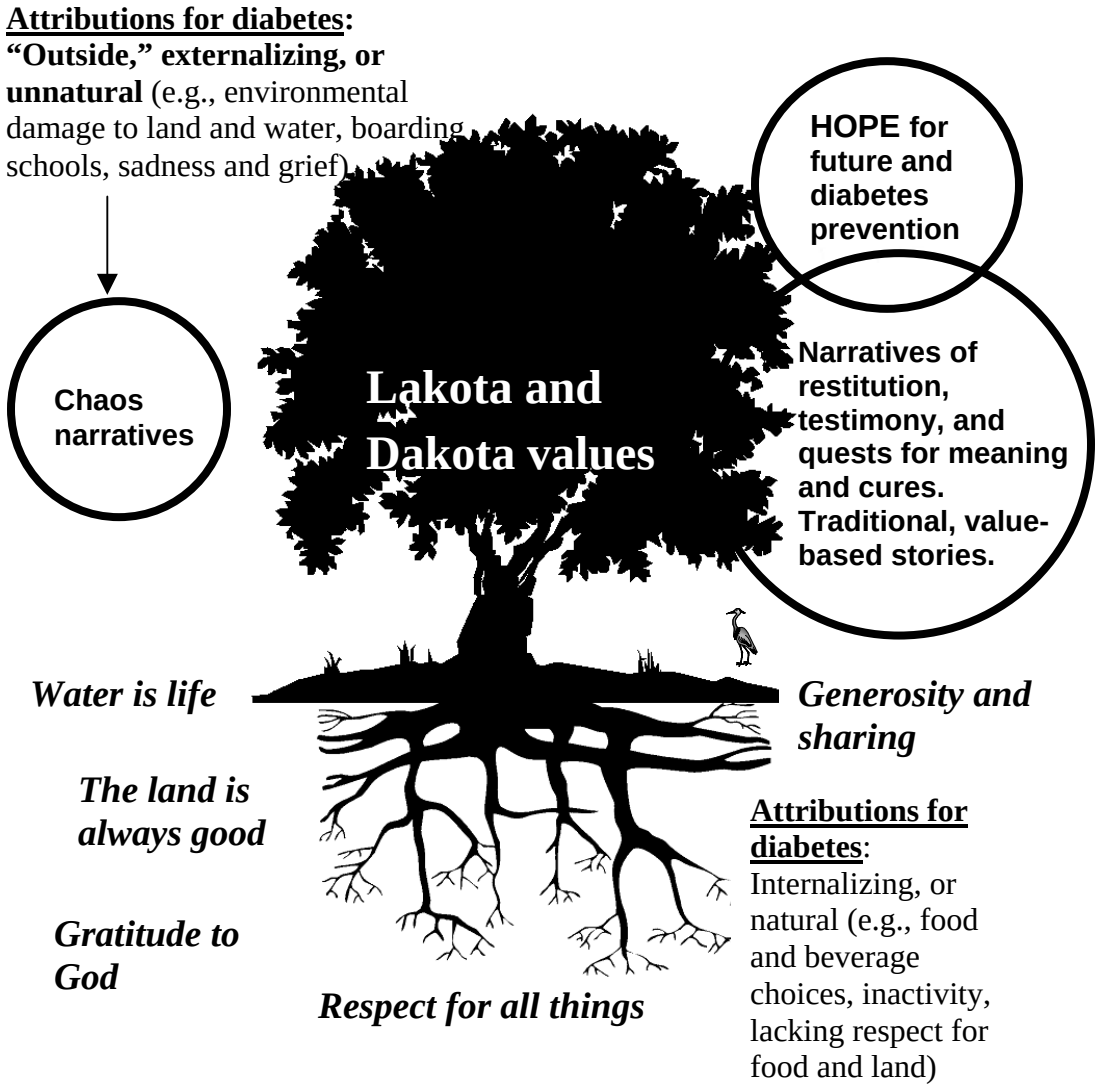


Figure 5.3. Conceptual display of study findings including for attributions for diabetes, illness narratives of health protective cultural practices and beliefs, and use of stories to reshape picture of diabetes with hope.

Narratives revealing beliefs about ways that protected health and prevented disease in the past were classified into genres of illness narratives of restitution, quest, and testimony. Many attributions for good health were recalled and elders indicated these should be restored in adaptive ways (e.g., preparing foods, gathering wild foods, being physically active by doing hard work, shopping for good foods). A number of the examples of health wisdom offered by the elders have been contrasted to similar health messages offered by conventional scientists. Elders' concerns for their people were exhibited implicitly and explicitly throughout the interviews and examples of these are included in all of the matrices. "The 'place' of place" was an overarching theme, built, as were the narratives, on themes that included: 1) "the land is always good," 2) "water is life," 3) "respect for all things," 4) "Gratitude to the Creator," and 5) "`We helped each other:' generosity and sharing." These value-based themes and stories of restitution, quest, health wisdom and testimony balanced tragic stories recalling losses and the contributions of these to development of chronic illnesses like diabetes.

CHAPTER 6

DISCUSSION OF FINDING AND IMPLICATIONS

The previous chapter presented the findings of this study clustered conceptually by the research questions and thematically by dichotomizing concepts of illness and by illness narratives. The integrated responses to the key research questions were supported by observations made in earlier fieldwork. Key themes were identified, grounded within Lakota and Dakota cultural values. A conceptual model of a cottonwood tree illustrated the rootedness of the values as well as the importance of acknowledging the root causes of conditions such as diabetes.

This chapter will discuss the major findings of the study, the implications of the study for community organization and health communications about diabetes prevention and health promotion, researcher bias and the research methodology. It is organized by presentation of an overarching theme, the "place" of place, and subsequently the place of hope and resilience, of power, of local knowledge, of politeness, of values, of storytelling, and of memory and of meaning. Implications of the study are highlighted, followed by recommendations for health program planners, for tribal leaders, and for future research. A brief discussion of the research methodology and limitations is followed by a final summary.

Summary of the Findings

This study generated rich findings and instructive lessons, organized by the research questions: 1) To what connected factors do Lakota and Dakota elders attribute diabetes? 2) What narratives do these elders offer that reveal health protection and diabetes prevention as culturally constituted practices, both in the past and the present? and 3) How do these elders express their concern and share their wisdom?

The attributions for diabetes, a disorder perceived to originate from "outside" forces, were both natural, or internalizing, and unnatural, or externalizing factors. Internalizing factors representing personal imbalance were sometimes related to being unable to keep a "strong mind" to resist temptations including overeating, inactivity, and drinking pop or other substances including alcohol. Externalizing factors included land losses, environmental damage to the land including flooding and pollution, and forced assimilation policies including boarding schools where students were isolated from their homes and families and where they learned poor eating habits and nontraditional ways of thinking about food. Stories around these "outside" factors were typically chaos stories, laced with sadness.

Protection from diabetes in the past was attributed to "hard work," traditional foods that were prepared including soups, respect for all things including food, being generous rather than stingy, gratitude to God, and prayer. There was considerable agreement on these factors among the elders and on the attributions for their own good health, which were the same protective factors. The majority of the elders appeared to have adapted their still predominantly traditional ways with modern conveniences as they were useful. For example, some elders use crock pots for soups and artificial sweeteners to flavor some foods. The vibrancy, health, and generosity of all of the elders provided a lesson itself in the resiliency of the human spirit and the strength of the elders' cultural and spiritual values. An interesting observation was that the elders with diabetes were so healthy and all appeared to have their diabetes in good control, suggesting to this researcher a picture of balance and wisdom for others based on their own experiences.

A key finding of the analysis of the interviews, triangulated with other observational experiences, was the way the narratives and the interview time were balanced with sad and hopeful themes. While many unforgettable chaos stories were told, mixed with sadness and often humor, and the elders were very serious in acknowledging historical trauma that had contributed to illnesses like diabetes, there were

also expressed memories of resilience and resourcefulness and appreciation for good things that were taking place like returning traditions and the Diabetes Program and the CHR Program reinforcing things they believe in – like community walks, encouraging water and respectful views of food and activity. Many of the narratives were of restitution with positive endings of healing or hope. There were quest narratives appealing for wisdom and spiritual guidance for addressing health problems like diabetes, alcoholism, and suicides among youth. Testimony narratives were completed, typically, with a moral ending.

Another key finding was that, in spite of the unnatural factors contributing to health, economic, and welfare problems and major issues like uncertainty about the safety of drinking water, a majority of the elders pointed out that the land is always good and water is connected to life and health. The land and water, gifts given by the Great Spirit, Creator, or God, are always to be appreciated and respected. When the respect is absent, "manmade" problems abound, affecting people's health and spirits.

The cottonwood tree (canwakan) was used for this report as a symbol of the rootedness of cultural values and knowledge for health protection, as well as the need to understand better the roots of "new" problems like diabetes, so that relevant actions might be taken. The key cultural themes related to health protection were: "the land is always good," "respect for all things," "water is life," "gratitude to God," and "generosity and sharing." The sum of the data collection, which informally encompassed ethnographic experience of the previous four years and post-data collection including analysis and member checks, led to a deeper understanding of the rootedness of the values and "the place of place" in understanding health issues and needed actions.

Discussion of the Findings

The "place" of place

"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 Lakota author from the Standing Rock Tribe (1999). As noted in Chapter 2, health for Native people is "located within a text of historical accountings, land, and the production and interpretation of traditional activities" (Adelson, 1998, p. 5). The "place" of people is territory lightly charted by anthropologists said Basso (1996) and exists largely in spatial distribution of illness for social scientists (Catalano & Pickett, 2000). For this discussion I adopted a panoramic view of "place" that includes "where groups of people have invested themselves - their thoughts, their values, their collective sensibilities and to which they feel they belong" (Basso, p. xiii, xiv). These investments by beloved ancestors have endowed "places" with meaning. The "places," "the commons," or "the land" of indigenous people tend to emphasize group survival over self-interest and long-term sustainability over short-term gain (Nazarea, 1999, p. 14).

Although I had anticipated, based on my total field experience, that land changes including the flooding and reservoir-making for dam building would be included in the attributions for diabetes. I had tried to "bracket" these so that I could listen closely for any themes that emerged. The land changes did, in fact, account for a key attribution for diabetes prevalence. However, the sustained investment in the land and belief in its inherent goodness is a concept I had known to expect. This belief in the goodness of land and water, I believe, reflects strong cultural values including respect, gratitude, wisdom, and probably also forgiveness as well as "overlapping from behind" in the web of interconnectedness "from the influence of generations of elders" (Turner, 1989, p. 3). See Chapter 1.

The place of hope and resilience

It appears that hope and resilience were at the heart of the words elders used to balance chaos narratives and attributions for diabetes with stories of healing, positive outcomes and quests for help based on faith. Observations about hope and resilience were reinforced when I reviewed my field notes about the youth and elders'conference I attended in June in which I witnessed elders acknowledge sad historical events and

discuss unresolved grief but follow this with reminders of the Lakota ways of looking forward not behind and with forgiveness (See Chapter 4).

Resilience has been defined as the capacity to bounce back from adversity. Researchers emphasize that resilient adaptation comes about as a result of an individuals' situation in interaction with protective factors in the social environment (USDHHS, 2001). I believe these protective factors may have a lot to do with cultural values, personally and collectively for the Lakota and Dakota people. For the people, collective loss and resulting struggles are real and continuing but it is noted that their outcomes are very different than another community for which the "ground was taken out from under them," as well, in the Buffalo Creek Flood in West Virginia in the mid-point of the previous century said Kai Erikson, who chronicled the aftermath of this ecological disaster, noted that this community succumbed to the "psychic numbing" depression, survivor guilt, and isolation and has never recovered (1976, p. 204).

Paulo Freire, a pioneer in health promotion who focused on liberation of people through dialogue, listening, and action, said, "without a minimum of hope, we cannot so much as start the struggle. But without the struggle, hope …. dissipates, loses its bearings, and turns into hopelessness" (1996, p. 9). For the Standing Rock people, the sadness, the rage, and unresolved grief are there, but this is balanced with memories of resilience and survival and with hope that the good ways and the land can be returned.

<u>The place of power</u>

Formal power in a tribal nation rests with the elected tribal council, an issue of sovereignty that is closely guarded and protected from infringement by state or local governments. The tribal land base or homeland is the sine qua non of sovereignty, which in addition to a secure land base includes interdependent factors of a functioning economy, self-government, and cultural vitality (Wolfley, 1999). Less formal power, a type of moral authority, rests among elders, including some of the participants of this study.

As a student researcher developing a dissertation, it was not feasible for me to conduct a study fully aligned with participatory research. However, several of the elders were quite engaged in this work and some actively encouraged me to find photographs from historical sources that illustrate the devastation to their land as well as current photographs illustrating the protective things people are still doing. Judging by this interest, I believe this type of representation using photovoice could spark dialogue among community people leading to action (Freire, 1996).

In designing and conducting this study, I was very concerned about issues of power and representation, afraid I would not be able to report what I learned objectively and fairly. Mid-way through the analysis, however, I was almost completely reassured when I realized that my limited understanding of the linguistics, the placement of the native language in the dialogue, and cultural values was allowing me to hear the balancing, underlying theme of refusal to dwell solely on grief and the resurgent use of hope that prevails among many traditional people. Their representation, not only in their words but in their rhetorical strategies using stories and balance, was already just, honest, and powerful and all I had to do to mitigate any power I might have had to distort things was to "listen with clean, clear ears" (CDC, 1997, p. 48) to the discourse and remember what I had learned through the rich gifts I have enjoyed in collaboration with many Lakota and Dakota people over recent years.

The place of local knowledge

For most constructionists, the types of knowledge brought to bear on health and illness can be seen as collections of beliefs created through human interaction and preexisting meanings. With local ecological knowledge, grounded in lifetimes of intimate daily observation, this knowledge is especially fragile because of its local nature (Hunn, 1999). The importance of local knowledge, said Kunitz (1996), was thought by many scientists to have been made obsolete by developments like the germ theory in the late 19th century. However, with illnesses like type 2 diabetes, in which both prevention and

treatment are based in activities of daily living and choices rooted in values and knowledge, rather than pharmaceutical regimens or technological treatments, conventional practitioners may yet come to a deeper understanding that illnesses are shaped by different contexts and do not act independently of other forces in the web, including environmental, social, historical, and political strands.

Local knowledge of health and diabetes articulated by the elders in this study was profound in the breadth and depth of its reach. Conventional scientific knowledge around the causation of diabetes (e.g., obesity, physical inactivity), as well as its care, appeared to be well known to the participants. A few participants relayed stories of doubt about diagnoses of diabetes, particularly when they seemed prematurely given or, in one case, diabetes appeared to go into a type of remission and these stories need to be heard by conventional practitioners. Knowledge about the protection of health afforded by traditional foods and activity levels was enlightening, as was the realization that the elders felt that helping each other, including finding the needed medicines in the hills, was an important explanation for their past health. The insight they offered about additional etiologies, though, was very insightful. I had certainly not understood so completely the connection of health to the land and water or the historical contributions to weight gain among people that include assimilating habits of stinginess, fast eating, and isolating loneliness in boarding schools and overeating to get strong enough to avoid the "new" illnesses like tuberculosis.

The place of politeness

Politeness on the reservation is an undergirding theme I came to appreciate much more during my recent field experience for data collection. It is probably related to avoidance of dominance, as evidenced by the gentle handshakes given, consistency in avoiding imposing one's own ways on another, and regard for people who are searching for understanding and wisdom, even if they are sometimes outsiders like this researcher. The acceptance of tobacco pouches by elders to convey their willingness to participate

and to acknowledge the researcher's sincere attempt to show respect provides an example of politeness and honor.

In the health communication literature, politeness accompanies "face work" providing a way to understand the context of interaction based on perceptions of both speakers' attempts to support their sense of self esteem, autonomy, and solidarity (Spiers, 1998). This interesting area of study is also related to speech accommodation theory in which the initiating speaker, often a health care provider, accommodates their voice and words to those of the other person in a gesture of politeness, respect, and solidarity. I have noticed over the last several years that my own speech, when talking with Native people, is quiet and low and non-assuming. During the interviews I conducted, I noticed at one point I was myself referring to "this" diabetes, an example of speech accommodation at work.

The place of values

Related to politeness and all other located issues are inherent cultural values and virtues of the people. Respect, according to Fredericks and Hodges (1999) is the most fundamental of these for American Indian and Alaska Native peoples, operating at all levels. Respect underpinned every aspect of the responses to the research questions posed in the interview method of data collection. The opposite of respect - lack of respect - was seen as a key attribution for diabetes and illness, both on the part of individuals, who may lack respect for food, and for more powerful forces, that, without foresight or understanding of the environment, destroyed land and water that played a role in the people's health and sovereignty. Related to respect was prayer and gratitude to our Creator. Spirituality appeared to be regarded by the elders as essential to health in all dimensions.

The Lakota and Dakota values are honorable and admirable. Since they form a rooted network for the elders' insights about health protection and diabetes prevention, I believe they should form the basis for intervention efforts. This type of communication

approach fits the health communication strategy of internalization, which can include identifying concepts and designing messages that are consistent with existing values (Kelman, 1958). A growing number of programs have incorporated this approach (Narayan et al., 1998; Cook & Hurley, 1998; Carter et al., 1999).

The place of storytelling

The stories of chaos, restitution, quest, testimony and health wisdom were integrated by the inherent values. Many of these stories were personal ones that serve as witnesses for strength and survival in the face of struggle. The elder with the experience of surviving renal failure has told her stories in community forums and, with her CHR, visits people with diabetes to deliver these messages at their kitchen table; her passion for helping people to understand so they can avoid her experiences can serve as a springboard for action as people listen and realize that she cares about them.

Cultural legends can also carry powerful messages that help remind people of lessons that help to protect health and balance. I recently purchased a compact disk produced by a Dakota woman, Mrs. Mary Louise Defender Wilson, entitled “My Relatives Say” (Makowke Music, 2001). She tells a traditional, captivating tale of a “blue heron” who decides to forego his natural winter migration to the South because it seemed smaller birds, like the wren, fared well through the winter and it was inconvenient to leave -- -- with near-disastrous consequences. He barely survived the winter because he could not fish in the frozen lake and then only with the help of the prairie chickens, who treated him as one of their own, inviting him into their warm circle and persuading the wren to bring in an early Spring. The tale has “stories within the story” with many lessons about traditional knowledge, reciprocity, inclusion, and respecting all things are consistent with some of the values identified in this study as well as the message about the value of traditional ways for health.

Personal stories, historical stories of resilience and survival and cultural legends related to health and diabetes prevention, told by knowledgeable elders who may choose

to teach, in turn, health workers to tell such stories could illuminate messages in non-threatening, traditional ways that respect the hearer's ability to interpret the meaning for themselves. Some of the most inspirational stories I know, for example, are of community health representatives who have harnessed their own personal grief and found meaning within their losses so they can go on to help others. Stories about struggles and survival may lead people on a path to find meaning in their suffering and losses and the positive personal experiences of elders who live well with diabetes can use the positive power of words to reshape the way people think about an illness and create a new empowering vision for the future (Carter et al., 1999).

The place of meaning and memory

"Communities of memory," said Sergiovanni (1997, p. 220), are rare ones in which members share a sense of belonging, of common identity, of history and shared goals and values along with an enduring understanding of the intrinsic meaning of these things. In such communities, bound by kinship, place, mind, and memory, the sources of authority for leadership are found in shared ideas, communicated and reinforced by the connections of people to each other because this in itself has meaning and importance for the community's health and well-being.

With expanding globalization, industrialization, and the contractual arrangements these entail, values have shifted from viewing communities as sacred with kinship responsibilities to more technically rational societies based on contracts. These newer societies have brought many gains and conveniences, but they lack moral authority, moral ties, and the connection to meaning; decisions are based instead on rational will, notes Sergiovanni (1997). A continuum of societal trends, ranging from communities of memory thickly laden with meaning to technologically sophisticated societies can be illustrated by movement from "gemeinschaft," a German word related to community and "gesellschaft," which refers to society (p. 223).

Moral authority and kinship relationships may be very important when trying to communicate health messages to a greatly affected community by a condition such as diabetes or in other areas needing collective assurance, such as watching out for a community's children and even national airport security. This study has led me to a greater understanding of the importance that meaning and moral ties had for these elders in the dialogue and the manner in which they shared their knowledge. While there were many personal narratives of having diabetes and living with others who have it, the real meaning for these elders seemed to be in translating memories and knowledge, and questing, on behalf of their people, for ways to prevent diabetes among their people. Transcending conventional population-based approaches, the co-construction of the findings of this study among community health representatives, participants, tribal health leaders, and other elders I've been privileged to meet have revealed reservoirs of knowledge grounded in meaningful values, validated by the elders' memories of and faith in the teachings from generations of elders.

Implications and Recommendations of This Study

This study, with its key findings in the importance to these elders of place and of values, the researcher's observations about the importance of hope, of power, of politeness, of local knowledge, and of storytelling, and the observed skill of these elders' in telling stories to indirectly and meaningfully communicate messages has led me to new paths of discovery in considering strategies for communication of messages and engagement of communities in preventing diabetes. Discussion of the implications and possible applications of the messages and the rhetorical strategies of the elders, followed by consideration of recommendations for health program planners, for future research, and for tribal leaders in light of this study is provided in the next subsections.

The natural and unnatural attributions for diabetes were consistent with other qualitative literature about Native people's views of diabetes as originating from the outside, brought by the oppressor, as was smallpox and other "new" diseases (Hill, 1995).

Externalizing attributions tended to lead to the telling of chaos stories, which included graphic tales of loss and grief. However, these observations and stories were balanced with values about the goodness of the land and water and stories of resilience and survival for which the underlying theme was hope. Therein lie several implications for those who care about diabetes prevention and health protection, whether at program planning, research, or tribal leadership levels. Awareness of the "root" causes of illness phenomena, so often unrecognized, once displayed in a coherent form such as a slide show or an academic size poster could serve as a springboard for action on the part of community people to mobilize various levels of policymakers, including those at local, state, and national levels. Social action could involve new tools of public health such as "photovoice," with a grassroots group like these women elders to present policymakers with a collective, respected voice and memorable images.

For example, the perception that the water is contaminated is currently influencing people to substitute sugar-laden pop for drinking water. It might be possible to work collaboratively to write grants for projects that would create awareness among tribal members and policymakers (e.g., high school science students and environmental agencies could be supported to test the purity of the water) or obtain reusable water bottles that contain filters for chloride and other chemicals. At a local, more immediate, level, the internalizing attribute of drinking pop instead of water could be addressed by working with the tribal council and other entities (e.g., youth leaders, schools, stores) to minimize inappropriate advertising (e.g., selling sugar-free pop at higher prices) and promote bottled water until the issue of unsafe drinking water is addressed. Tribal people who understand the deep meaning of water, "mni" to the Lakota and Dakota people, would have insight into meaningful ways to promote drinking water. For example, one of the CHR groups I worked with to design a health message developed a poster with a shimmering waterfall and the message, "All-natural, pure and refreshing. Lakota drink of all time. Drink WATER."

A powerful story can engender a shift from hopelessness to a new empowering vision for the future (Carter et al., 1999). It is helpful to understand that the power of positive words similarly constitutes the didactic component of the healing ritual in which traditional healers reshape or reconstruct the way a supplicant thinks about the illness afflicting him and by describing the healing effect of the medicines chosen (Wing, 1998; Tall Bull, 1999). A positive, meaningful personal story or a relevant legend allows the listener to recreate their own "story" for meeting new challenges, allowing internalization of knowledge involving adopting messages because they are consistent with one's existing values (Kelman, 1958). We will not always know what story may have meaning for a particular person, so some experimentation if required.

The elders participating in this study grounded all of their responses to questions about health and diabetes in their Lakota or Dakota values and culturally constituted practices. Cultural values, it would seem, as well as traditional foodways, are at the heart of healthy behaviors. Communication messages about health and diabetes prevention in Indian communities should probably be linked to cultural values and delivered by people whose subjective norms are valued, particularly elders, who are known in some Plains communities as carriers of "the burden of goodness."

Implications and recommendations for health program planners

Health program planners should know that dialogue is the first ingredient in Freire's process for community action, which he maintained was the birthright of all and for which "liberation of hope" is a possibility (Pegler, 1995) and dialogue cannot exist in the absence of a profound love for the world and for people. It requires humility and "a deep faith in humankind, faith in their power to make and remake, to create and re-create, faith in their vocation to be more fully human" (Lupton, 2000, p. 71).

Resilience programs take a "strengths-based approach" to human development and functioning. Rather than focusing on deficits and illnesses, the program planners seek to understand and promote "self-righting tendencies" in individuals, families, and

communities (USPHHS, 2001, p. 14). The work of Kretzmann and McKnight, co-authors of Building Communities from the Inside Out (1993) has pioneered this approach in health communication.

Kretzmann and McKnight (1993) point out, too, that communication between communities and academia is one of the biggest barriers to collaborative intervention planning and implementation, according Academic institutions often do not understand the knowledge and belief systems of communities, and assume that the rest of the world collects and interprets information the way they do. Elders of land-based tribal nations who have experienced both the unknown and all-too-well-known disease of diabetes in their lifetimes have available to them a specialized knowledge based on generations of observation and adaptation that has not been acknowledged or respected by conventional scientists. This knowledge is consistent with modern health knowledge but it deserves the validating recognition that these knowledge and practices were most healthful in the first place.

Community views often include perceptions of "helicopter" or "safari" research (Macaulay, 1994), reinforced by researchers who come and take without reciprocity, and "tumbleweed" programs (McLean & Warm Springs Healthy Nations, 1997), which come and go as funding expires and as medical or program staff rotate to new positions. At the beginning of program development planning in collaboration with the tribe, assure that the leadership lies within tribal members and issues of sustainability and funding are addressed. Work with tribal members to identify and honor artists in the community who may choose to help reinforce messages and programs with their skills in painting, poetry, storytelling, or other forms of artistic expression (Kretzmann & McKnight, 1996). A painter, for example, may be able to create designs for the program to be used on materials and t-shirts or hats.

Politeness and protocol are very important. They show respect and some understanding of related cultural values including patience in waiting for people to seek

answers for themselves and avoiding imposing knowledge or interpretations on others. Strive for reciprocity in dealings with people.

Program planning and implementing interventions rest with tribal health leaders, in most cases. An outside health program planner, when invited by the tribe, may suggest seeking understanding and counsel from elders on issues regarding attributions of illness and health protection to gain an understanding and to identify some of the root causes, if this knowledge is not already being sought. Themes generated by learning attributions for diabetes may lead to solutions that would otherwise have been hidden from view because there is much reliance of scientific but superficial etiological explanations for causation of illness.

In culturally-relevant ways, find documentation of positive attitudes towards actions known to help prevent diabetes and its complications. Messages that are consistent with cultural values, for example, may be accompanied by positive behaviors towards the related actions and communication of these attitudes could serve as positive subjective norms, a construct in the Theory for Planned Behavior (Montano, Kasprzyk, & Taplin, 1997).

Program planners should try to gain understanding about and acknowledge the importance of place, or of lands, to health. In collaboration with groups of tribal members, actions to help preserve and protect homelands may be important endeavors to help promote health in physical, mental, spiritual and emotional dimensions. Consider asking elders to explain in community forums, their ways of understanding and promoting physical, mental, spiritual, and emotional health, and how this relates to the critical concept of balance in diabetes prevention and control (Dunning, 2000; Satterfield & Davidson, 2000). Some of these issues might serve as “sparks and triggers” that open the way to dialogue and action, Freire’s formula for engaging people in finding their own solutions (1996).

It is important to have an understanding of the capacity for stories to reshape the way people think of illness like diabetes (e.g., a "wake up call" with messages we need to hear). Identify people who tell personal illness narratives of restitution that chronicle how they learned to live well with diabetes or overcome an obstacle. Gather a forum of elders to identify several traditional stories that they could tell at health fairs or other places to serve as a springboard for awareness and education about diabetes prevention and health promotion.

Implications and recommendations for tribal health leaders

Some of the "root" or contributing causes of diabetes, which were identified by elders in this study, may be helpful in determining issues to address. These causes, until they are listed, may not be visible or validated. Consider finding a "champion" for the cause and mobilizing a group for action. It may be necessary to assist them to deal with political issues they may want to address, such as approaching local stores (e.g., with advertising or availability of pop), state governments, or elected state and national legislators. Tools such as "photovoice" can be very useful for building solidarity among community members and influencing policymakers and news media sources (Wang & Burris, 1997) because they have more understanding, sometimes through a little "shock" treatment that photographs can provide.

Tribal leaders may want to consider asking the elders to develop a menu of personal and collective stories and cultural legends that may be useful in communicating messages about health promotion. Also, consider words of spiritual leaders for messages that may help remind people of health protection strategies. For example, Sitting Bull is documented as saying, "I have advised my people thus; when you find anything good in the white man's road, pick it up, but when you find something bad, or that turns out bad, drop it, leave it alone" (Nerburn, 1996).

Leaders may want to consider asking elders to talk about, in a group, the culturally constituted practices and values that were protective of health in the past and

can be adapted for application today. Consider asking elders to serve as consultants for activities involving traditional gathering and preparation of foods and broadcast this at intervals throughout the day on the tribal radio station, along with messages that explain the known bioscience about why these things were healthful (e.g., the value of fiber in slowing absorption of glucose). There needs to be additional scientific evidence about things like the value of traditional foods; it may be that students could be encouraged to pursue scientific research in these areas that would likely confirm traditional knowledge. Perhaps the elders could hold a community forum about diabetes with planned stories, demonstrations of food preparation of traditional foods (e.g., drying, making soups, preparing breads, making berry puddings) and work with a physical trainer to calculate facts like the number of steps people made per day 50 years ago before diabetes became common.

In this study, it was noted that elders of different generations offered some insights that were based on their age. Older elders held some memories of struggles or events and the adaptive responses made that younger elders had not understood because they were seasoned adults at the time. It is very important then to preserve the wisdom of elders of all decades, perhaps particularly when looking at a particular phenomena, because the this knowledge is nor replaceable.

Implications and recommendations for future research

Research that provides some explanations may be helpful for intervention planning in a particular setting. However, the next step for research if it can continue in the original setting would be for a study of the process and outcomes of social action, the next steps for addressing the findings of this study. For example, application of the attributions for diabetes as groundwork for planning community intervention steps through participatory research with the tribe is a recommendation for action and evaluation. Whether or not these “unearthed” attributions could serve as a pivot point for

action, guided by a group of elders, for example, is not known but the potential would seem to be there.

The concern mentioned by a number of elders that one could get diabetes by being told you have it as well as the stories of some members who have been told they have it but are later found not to have diabetes needs to be addressed with additional qualitative research. Focus group methodology may help at this point to learn more about the perceptions of being "named" with a particular illness.

The cultural values underpinning all of the responses of this study, including attributions for diabetes, may serve as the basis for social action led by group work in designing and fieldtesting health communication messages. Groups could be led through an instructive process in message design, with suggestions that cultural values, stories, and historical messages may be helpful for content development. The messages could be created on poster boards and displayed at community centers with community members voting on those that are most appealing.

Storytelling as a teaching tool for diabetes prevention could be formatively tested with theater-style participant interviews following a community forum that included stories. Community participants at risk for diabetes could be enrolled and followed in a study that included storytelling in the intervention plan and at intervals throughout the follow-up period, participants could be interviewed about the stories or other messages that connected with them and offered meaning to their efforts.

Also, while cultural values, consistent health messages, and stories were very important findings in this study among female elders, little research has been done among youth. Research that explored youth's perceptions and values about health and prevention could be valuable in helping their elders and tribal health leaders to plan interventions to help protect their future. It may possible, after exploratory work is completed, to "sample" some of the findings of this study among elders, as well, to identify any shared values or protective factors.

Discussion of Research Methodology and Limitations

Ethnographic methods, honed by the discipline of anthropology, were employed for the questions of this study about attributions for diabetes and for health in a particular community. This was the most appropriate methodology for the research questions posited and the local knowledge sought. Although the actual data collection period was only one month, the field experience of recent years greatly informed the study. However, for the primary data collection method of in-depth interviewing and secondary method of photovoice, a longer residential stay on the reservation would have helped in a number of ways. For example, it could help to fill out gaps in the early analysis of the study, provide an opportunity for onsite member checks and allow the time needed to help participants gather or take photographs.

Realizing as I did in the early part of my observation experience on the reservation that it was best to interview women elders solely might have happened sooner if I had had a longer residential stay. The issue of protocol and politeness was one I had superficially understood before data collection began and, in fact, I had been more interested in interviewing women from the beginning but had incorrectly thought that excluding men as sources of wisdom about health might seem impolite. In reality, the aspect of protocol was more important in this situation. Discussing participant selection according to gender in more depth with the gatekeepers I knew as I wrote the proposal would probably have helped to distinguish this preference.

Gitlin (1994) noted the challenge for those working in alternative research methodologies to work simultaneously at the level of method and within the community. I was known in the community first for my work with community health representatives in diabetes education. It has been important that the level of working within the community, rather than that of conducting research in the community, was most visible to community members. Had this combination not been in operation, I doubt that I would have been given permission or access to conduct the research. Although I can only

operate in a reflexive, caring stance with personal comfort, I realize that this colors the findings in favor of community capabilities that may be beyond the reach of reality.

In many ways, the actual process of getting to the point of scheduling and conducting the interviews, as well as the plans for sharing the findings with the community at a later date, reflect elements of participatory action research, defined as a systematic investigation with the collaboration of those affected by the issue being studied for the purposes of education and taking action or effecting social change (Green et al., 1995). For a longer study on the reservation, I would work with tribal members as equal partners in investigation, with collaboration in all aspects of research design, implementation, and analysis.

Pelto and Pelto (1978) suggested that one of the limitations of ethnographic interviews is that persons selected tend to be unusually eloquent and sensitive in their presentation of personal and cultural wisdom and their collective concern for their people. In answering my research questions, the vivid integration of these elders' cultural representatives and collective experience, along with their subjective experience, was powerful in explaining the causes of this epidemic, the cultural ways of health protection, and strategies for communicating these things to future generations. Their selection, I believe, was justified by the unique information they could offer to this subject. To learn more about local knowledge in the future, I would again elect to interview the people's elders or wisdom keepers, rather than people who are less traditional in their beliefs and practices.

Extending the data beyond a descriptive point, as Wolcott had observed (1994), provided a key movement toward transforming this data, which had at first seemed so culturally specific and rich that I, as a non-tribal member, may not be able to interpret it. The processes of grounded theory and narrative analysis, however, were useful in making sense of the data and leading to generalizations of larger, more macro structures for this study. Inherent in the required immersion in the data and conducting the processes of

analysis was also an almost continuous state of theorizing, which occurred not only when looking at the descriptions displayed through my work, but standing in the line at the grocery store or explaining to my oldest daughter what I was coming to understand. The reflective part of the analysis constituted a much deeper and lengthier process than I had imagined, with the larger themes emerging only after I had written up and revised the findings many times and then discussed some of these with one of the participating elders by telephone through member checks.

The codes that were raised to analytic categories in this research are still incomplete or have insufficient evidence, as Chavez (2001) claims is usually the case with grounded theory data analysis. For this reason, the researcher needs to return to the field or find new cases to further develop the analytic process through theoretical sampling to give them more analytic power. I would like to discuss all of the themes with the elders and with tribal health leaders to learn if these hold up with additional thought and scrutiny. The secondary data collection method of photovoice, a participatory action tool based on feminist perspectives and aimed at social action, would, I believe, be fruitful for initiating dialogue and bringing certain environmental issues to the awareness of policymakers if issues such as extended time and physical support including transportation to particular sites could be addressed. Also I believe there is more to learn from elders about their perceptions of the role of storytelling for communicating messages about health protection and diabetes prevention.

Both of these types of inquiry require more time and reflection on the part of the participant and this study, limited as it was, did not allow for extensive theoretical sampling, although the depth of richness of the data suggest to me that additional work in a theoretical sampling type of data collection would be very useful, now that I have finally gained some understanding for the questions asked.

Conclusions

The onset of diabetes beginning at the mid-point of the last century and its rapid incline represents a phenomenological illness experience for the people of the Standing Rock Sioux Nation. Unbounded by the experience of those who are actually ill with diabetes, the experience of tribal communities living with this relatively recent epidemic reminds us that the social course of illness, the personal and collective experience of illness, and awareness of the illness' potential impact on future generations are inseparable (Kleinman & Seeman, 2000).

Reducing the illness experience to one of individuals with a focus on cognitive processes to effect individual behavior change has contributed to a regime of knowledge in which the actual social, historical, and environmental roots and distribution of disease are "misrecognized" and overlooked (Kleinman & Seeman, 2000, p. 232). While training the lens on individuals permits a microscopic view of the problem and perhaps protects the hegemony of bioscientific knowledge, it displaces the likelihood of lifting a telescope that would allow a wider view of the problem and the solutions.

The elders who participated in this study provided information and contextual understanding about the interrelated sociological and historical roots of "manmade" disorders including diabetes. They grounded their dialogue about health protection and diabetes prevention in their cultural values and practices. Themes that underpinned the narratives of restitution, quest, health wisdom, and testimony in the discourses reflected not only the cultural values, but also the respectful, hopeful manner in which these concepts were communicated.

The attributions for diabetes were both natural and unnatural. Unnatural or externalizing attributions for diabetes, which were often accompanied by chaos stories, included the loss of homelands to the flooding of the Missouri River for dam constructions beginning in 1948, habits learned in boarding schools, and sadness related to these things. From the internalizing attributions and questions about protective factors

came stories of restitution and healing, quests for meaning and for cures, and testimonies about lessons that should be learned. The importance of people's homeland also included the isolation of children away from home in boarding school. These were connected to an overarching theme of the "place" of place in health and illness with related discussions of hope, values, politeness, power, storytelling, meaning and memory.

Identification of the attributions for diabetes may provide insight for needed interventions that would be unlikely to be considered by conventional health practitioners. The rhetorical strategies the elders used of telling stories to communicate these concepts have relevant implications for communication about steps that can help prevent diabetes. With the understanding that these elders have provided, along with their help in sharing their personal and collective stories and cultural legends, new avenues of health communication have been suggested.

Both culture and genes are repositories of information about survival and health. "Slippery as gems," (Nazarea, 1997, p. vii) this coded knowledge should not continue to be marginalized. Conventional scientists need to rise to their full stature of intellectual honesty and integrity, acknowledging the wisdom, prevention, and ecological knowledge that has served to protect people from chronic diseases for thousands of years. Only when conventional science can make this respectful move, will there be potential for consilience of knowledge domains of science and learning so that all can be brought to bear to face the growing global challenge of diabetes.

Perhaps this web of data, literature, and story may help to create a platform to support the deep wells of local knowledge and community strengths and bravely face the enemy of diabetes (DeCora, 1999). To effectively confront diabetes, people will need to rally around a common goal, "so the people may live" and unite in solidarity to begin the "hard work of hope" (Warrior, 1997). And at the same time we are learning new lessons from old tools, we may need to ask one more question about story and about the choices

we are making in our world for the land we live on, the food we eat, and the norms we accept for our children and their children to come. “Is diabetes trying to speak to us?”

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APPENDIX A

LETTER OF INVITATION FROM STANDING ROCK

STANDING ROCK SIOUX TRIBE
TRIBAL HEALTH ADMINISTRATION

June 5, 2000

Dawn Satterfield, RNP, MSN, CDE
Division of Diabetes Translation, K-10
National Center for Health Promotion and Disease Prevention
Centers for Disease Control and Prevention
Atlanta, Ga. 30341

Dear Ms. Satterfield:

We are pleased to offer you an opportunity to conduct your dissertation research with the people of the Standing Rock Nation. We understand that as a doctoral candidate at the University of Georgia and as a member of CDC's Division of Diabetes Translation, you have an interest in the "traditional knowledge" about health of older native people of the Northern Plains, particularly as it relates to health promotion and protection. The Standing Rock people have many strengths. The project you are proposing will acknowledge the wisdom and capabilities we have within our culture to address our health concerns from the perspective of these strengths. Our ways of knowing can broaden and inform the "western" model of health, and together, may potentially be used to create a more effective and culturally relevant model for health promotion among our people.

We would be willing to allow you to conduct and record interviews among our elderly people, individually and in groups, using dialogue as well as photographs and geographical mapping, if these prove to be helpful. Afterwards, you could convene a focus group of community health workers to discuss the these identified and consider possible actions. We would wish to assure the following understandings: 1) each person who agrees to participate in your study would provide individual informed consent in writing prior to being interviewed and recorded, and 2) any individual who is asked to participate would be free to decline or withdraw consent to be interviewed and/or recorded. Also, as you probably understand, we would expect that confidentiality will be assured and maintained throughout all phases of your project, and that participants' names will never be attached to the data. It is also assumed that your report of the study will not include names or other identifying information that could be used to link individuals to specific data. Data from the interviews will also need to be secured in a locked file, and it is understood that no one will have access to the interview data except yourself. In accordance with usual research procedures, all of the original data will be shredded within three years. We will allow you to work with the Community Health Representative (CHR) program to assist you to make contacts, and to provide

introductions to elderly people who live within our communities on the Standing Rock reservation.

Ms. Satterfield, at this time, we would also like to take the opportunity to thank you for being helpful as a resource and advocate for our CHR Program in their diabetes prevention initiatives over the course of the past three years. It has been heartening to see that you have had the commitment to maintain good relationships with our CHRs, and that you have continued to participate as a teacher and facilitator in a number of training sessions for CHR groups in the Dakotas. The poem, "I Want to Help my People" that you encouraged our CHRs to write last year has received attention from a number of people outside our region and we are glad for others to know of the dedication of our people. As American Indian people, we face unique challenges in dealing with a complex array of health issues, and it is good to know that there is a special interest to reach out to us. Your respectful support has allowed us to see evidence of early interests in addressing the President's initiative to reduce disparities in health among racial and ethnic groups. We have valued the time you have spent here and the work you have done with us during your visits to North Dakota, and we hope that we will continue to have the support of the CDC in addressing our many health concerns, especially in the prevention and control of diabetes.

We will offer you whatever assistance we can through the CHR Program in organizing the logistics of conducting your dissertation project, and we look forward to your sharing the results of the study with us. Our policy would be to have our Health, Education, and Welfare Committee of our Tribal Council review the final results of the study, and to review the final written report of the project before approval would be given for public distribution of the study results at conferences or in journal publications. Please keep me informed of the progress of your study as it progresses.

Sincerely,

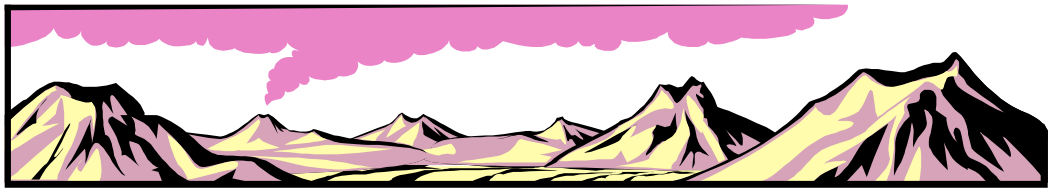
William Sherwood
Standing Rock Sioux Tribal Health Director

APPENDIX B

CONSENT FORM

CONSENT FORM

The Web in the Story of Diabetes: Listening to Wisdom of Standing Rock Elders about Protecting Health and Preventing Diabetes



This research study involves putting into writing the words and insights of a number of Lakota elders of the Standing Rock Nation. The purpose is to understand and honor these ways of knowing about health and how to protect people from diabetes. After the study is complete, a report will be given to the Health, Education, and Welfare Committee of the Tribal Council and this may help the Nation to talk about answers to diabetes.

Dawn Satterfield is the person who is asking for time to talk with me. She has made these points to me:

1) I can choose a time to talk with Dawn that fits my schedule.
2) I can choose not to be part of this study. I lose nothing if I do.
3) I can choose to take away my consent at any time and not be part of this study.
4) The risks to me could include getting tired or feeling sad about things I talk about.
5) I will have the chance to tell stories, show or take pictures of our land, and draw maps to help Dawn understand my words.
6) My name will not be linked to our talks. The talks will be taped so that Dawn can later write down my words as they were said.
7) If I choose to have a copy of the tape or the words of our talks, I can have them.
8) I can choose to give my copy of the tape or my words to any person I want to, but Dawn will not share the tape or the transcript of my written words with others.
9) If I have questions about the study I can call any of these people: Dawn (phone 770-425-3974), Dr. Laura McCormick, under whom Dawn is working (706-542-4956), or Mr. William Sherwood at the tribal health office (701-854-7206).
10) I will receive an instant camera and film and another small gift as part of my participation in this study and I can keep these even if I decide to stop participating in the interview at any time.

It is my choice to take part in this study

_____ _____

Signed to take part in study Date **Signed, Dawn Satterfield Date**

Questions or problems regarding your rights as a participant should be addressed to Chris A. Roberts, PhD, Institutional Review Board, Office of the Vice President for Research, University of Georgia, 606A Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone 706- 542-6514; E-Mail Address JDA@ovpr.uga.edu.