

CHAPTER XX

Battling a New Epidemic: American Indian Elders and Diabetes

Linda Carson Henderson

CASE 1: WHAT IT'S LIKE TO BE A DIABETIC AND AN INDIAN

Jacob is a substance abuse counselor with a southeastern American Indian tribe in Oklahoma. He is an elder and more experienced than the other counselors, a veteran of the Vietnam War. More importantly, he is the acknowledged spiritual leader of his tribe. The sweat lodge is used extensively by Jacob to help those who want to free themselves from dependency and other ills of the spirit, and for those on spiritual quests. He has had diabetes for about five years. I interviewed Jacob in his home and asked him about his illness, attitudes towards medical directives, and problems he and other Indian people have encountered in adhering to these directives.

There is no support from family to stay on the diet. Family support is ... they're killing each other. They won't be very good support. They want people to be happy and eating makes people happy ... so they feed them. Education is needed in lots of areas for the family.

(For example ...) there was a sweat at Mom's house over the weekend. It was a good sweat too, it was 102° in the lodge. There were fried foods, fry bread, all kinda cakes, watermelon. Big cookouts are always a big thing. If you went and there was just peas there, it wouldn't be right.

"Most of, well, we all diabetic, now, me and my brothers and sisters, and we all eat. My mom (also a diabetic), they feed her whatever she wants ... makes her happy. One thing that's hard to do is change in life. I guess I just Indian (laughs).

Jacob's testimony begins to help us understand why among American Indians and Alaska Natives (AI/AN), diabetes constitutes a devastating epidemic of monumental proportions with unacceptable levels of excess disability and death (Indian Health Service, 1999; Meneilly and Tessier 2001; Lieberman 2004; American Diabetes Association 2005). The diabetes mellitus prevalence

rate ranges from 17 percent among northern plains American Indians to 80 percent in Alaska.¹ In comparison, the diabetes prevalence for the general U.S. population is 6.3 percent, for African Americans 11.4 percent, and for Latinos 8.2 percent. Additionally, the degree of severity of diabetes among American Indians and Alaska Natives is higher than the general population. AI/AN diabetics are four times more likely than their white counterparts to experience an amputation as a consequence of diabetes and six times more likely to experience kidney failure (Roubideaux and Acton 2001; American Diabetes Association 2005; Ferreira and Lang 2006).

Paradoxically, in spite of today's advanced medical treatments, prevention, and health promotion strategies, prevalence rates for diabetes mellitus among American Indians are persistent, excessive, and rising. In the presence of potent drugs and health education information, diabetes prevalence should be abating. Since it is not, other factors accelerating rates of diabetes must be operating. Preliminary research suggests that one possible source for persistent and increasing diabetes prevalence is that nonobvious sociocultural factors are present that impede the productive application of existing therapeutic efforts. Few projects have addressed conflicting cross-cultural models of diabetes causation, prevention, and treatment as a source of persistent excess disease burden. This omission is notable because divergent culturally constructed concepts of disease are known to impede care-seeking, communication, and adherence (Kleinman 1980; Henderson 2002b; Henderson, Finke and McCabe 2004). Conditions such as diabetes are the grist for health communication barriers, defensive behaviors, and treatment nonadherence, leading to patients and providers losing a sense of partnership in combating this complex disease. The research presented in this chapter examines the cultural construction of disease concepts in terms of their impact upon diabetes care-seeking, self-care, and adherence.

CROSS-CULTURAL HEALTH COMMUNICATIONS

Cultural factors profoundly affect ways in which symptoms are identified and given meaning, how, when, and to whom these symptoms are expressed, and whether an illness episode is ignored, stigmatized, or accepted (Tripp-Reimer et al. 2001). The study of patient "explanatory models" provides information about how patients make sense of illness episodes, and how they choose and evaluate medical treatments (Kleinman 1980; Henderson 2002b; Henderson, Finke and McCabe 2004). These explanatory models are heavily influenced by the culture of the patient, which serves either to facilitate or impede health care-seeking and medical adherence.

Professional and lay explanations for disease, treatment, and prevention can vary radically, and nonobvious sociocultural factors operating to impede effective health care may be found in the culturally based models of diabetes held by patients and practitioners. Explanatory models held by providers and patients may be similar, and in that case facilitate health communications with resulting increased adherence to treatment recommendations and sufficient patient/provider

satisfaction. However, models that are *discordant* between practitioners and patients are prone to reduce effective health communications, reduce adherence to treatment recommendations, and negatively impact health outcomes.

The research delineated in this chapter was preceded by two preliminary studies in the populations of American Indian diabetic elders and their health providers. The pilot study findings indicated that elder diabetics held varying explanatory models of diabetes, and that tribal providers also held divergent practice models, some highly discordant with those of the elders. These models, along with the cultural identification of both elders and providers, influenced care-seeking and diabetes self-care behaviors among the elders (Henderson 2002a). The research delineated here expands upon the initial pilot studies and elaborates on the varying models of diabetes and resultant care-seeking and adherence behavior within this population of AI elders. It underscores the differences between cultural constructions of disease by patient and provider and illustrates the importance of identifying personalistic and medically inconsistent models of disease within culturally diverse patient populations.

DIVERGENT MODELS OF DIABETES

In regard to diabetes research and the cultural construction of diabetes among American Indians, perhaps the most directly relevant is Goforth-Parker's study of American Indian diabetics in rural Oklahoma. Her research provided a vivid description of the life experience of patients with the disease and underscored cross-cultural differences in the diabetes experience in terms of sociocultural factors that negatively influence adherence (Goforth-Parker 1994). In another American Indian context, Ferreira explores the life of a Yurok elder and writes of the cultural construction of diabetes as the perceived result of neocolonialism and oppression (2006). The graphic depictions of traumatic experiences at the hands of colonial powers illustrate the power of life events and stress on the construction of illness narratives.

Many American Indian and other minority elders experience "multiple jeopardy." They are members of a minority group, are often poverty-stricken, and are in poor health when compared to their counterparts in the general population (Henderson 2002b). When we speak of multiple jeopardy in terms of American Indian elders, the term in actuality encompasses much more than is contained in a strict definition of the phrase. When we look at these elders as the descendants of a long history of structural violence at the hands of colonizing nation-states, then we expand the multiple jeopardy conceptualization exponentially. Indigenous governments and scholars attribute structural violence, with its associated social and physical suffering, traumatic memory, community destruction, and nutrition trauma, to dramatically higher chronic disease morbidity and mortality exceeding that of the mainstream population (Roubideaux and Acton 2001; Ferreira 2006; Korn and Ryser 2006). While health care for American Indians is an entitlement that previously was administered by the Bureau of Indian Affairs (B.I.A.), it should be noted that the BIA

once fell under the auspices of the Secretary of War. Because studies of Indian health status showed such extensive morbidity and mortality, the Indian health program was transferred from the BIA to the Public Health Service in 1954 (Johnson and Rhoades 2000).

A study in a nonindigenous context identified divergent explanatory models of diabetes among patients and providers in a large Midwestern university diabetes clinic (Cohen et al. 1994). The study revealed differences between patient and provider explanatory models of diabetes in terms of etiology, pathophysiology, and severity. Differences were significant, even though the patients and providers in the study all were highly educated and had similar backgrounds. Within populations in which patients and providers are not of similar backgrounds, it is likely that a much greater degree of incongruence would be noted.

CASE 2: EXPERIENCES OF STRUCTURAL VIOLENCE AND COLONIALISM

Betty is eighty-one years old, has diabetes, and like Jacob, is one of the “traditional” members of her tribe. I interviewed her in her home and asked her about her diabetes management, attitudes toward providers, and past experience with health care under entitlement of her tribal membership. She related a history that was horrifying in terms of the rampant prejudice against American Indian people that existed at the time of the episode she relates (1940s).

She talks first about her personal history. This is customary in all social interactions with others, a give and take about one’s “people.”

My daddy had allotment lands,² but my mother sold them and moved into town. Granddaddy came over from Mississippi (he was a preacher) to see if Oklahoma would be a place to be. He settled at Bethany. There is a graveyard there that he designated that Indians and whites could be buried there. So it got all filled up and you have to go to Bentley to be buried now. The Indian meetings last a week at a time. There are pots of food, a roast pig or goat, and shelters made out of grass. My uncle was a school teacher and his white wife was a school teacher.

I have a fringed shawl. I used to dance at Bethany. I remember an old lady who could barely move, could get up and dance and not stop.

In regard to the provision of diabetes education, she relates:

“I learned from my mother. I learned that you didn’t have feeling in your feet real good. I knew what to do and what to watch for. And what not to do. I learned all of her knowledge about diabetes from taking care of my mother. I never go to the Indian clinic. Only to get my toenails trimmed. Sometimes the nurse comes here to do foot care. I still believe in some of the old-timey remedies, sassafras tea ... some herbs I stay away from.

At this point, she starts to speak of past experiences with the medical system:

I went to get my tonsils out at Talihina (the location of an Indian Health Service hospital). I only got put part to sleep. The nurse came and got me. I stayed for two weeks to

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guard against bleeding. I also stayed at Talihina two weeks before having a baby. My first husband ran off; he was “noholo” (white man; literal translation: person without a soul). I had to stay one month due to complications. There was a German doctor who told me when I was in pain that horses and cows don’t have anything for their pain so I got no anesthesia. I tore badly. He was an awful man. The same one who took out my tonsils.

I was in a room with five other women. The woman across from me was a large Indian lady, and she didn’t speak to anybody. Then one day, I looked across and she was squatting on the bed and was about to have the baby. She said, “leave me alone, I’ll have this baby by myself,” but I called for the nurse and they took her off, bed and all, and she was hollering at them. Her people would bring her a glass of herbs for her to drink every day. I think that had something to do with it. She didn’t cry out or anything. But my granddaddy said that Indian women don’t make any noise when they’re in pain.

THE CULTURAL CONSTRUCTION OF DIABETES IN AMERICAN INDIAN ELDERS: THE RESEARCH

In developing this research project, I hypothesized that there would be visible, diverse, and unacknowledged models of diabetes within the population of AI elders. Various culturally constructed concepts and explanatory models of diabetes would be used by AI elder patients to respond to the disease, possibly as a function of acculturation status. Furthermore, if present, and unrecognized by health care providers, these culturally constructed concepts and attendant explanatory models could constitute a communication and behavioral barrier to optimal management of diabetes. Consequently, the research identified cultural models of diabetes within a population of AI elders as a function of acculturation status, and examined how differing cultural models of diabetes among these AI elders contributed to nonadherence and delays in health care-seeking behaviors.

The Elders

Interviews were conducted with thirty American Indian elders with Type 2 diabetes, in a large Oklahoma American Indian tribe. Type 2 is diagnosed most often in adulthood, and is due to insulin resistance, a consequence of weight gain and dietary changes, especially increased consumption of processed sugars. Type 1 is usually diagnosed in childhood, and involves the absence of insulin production. It is a sad fact, however, that children are increasingly being diagnosed with Type 2 due to the rising rates of obesity among persons in all age groups.

In this study, an eligible subject was fifty-five years of age or older,³ had a diagnosis of Type 2 diabetes, and was American Indian as evidenced by a Certificate of Degree of Indian Blood (C.D.I.B.).⁴ In this research, a nonrandom intensity sample was used. Intensity samples are composed of those who are “experiential experts” and who are “authorities about a particular experience.”

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All were fluent in English, but many also spoke the tribal language. Observation indicated that the majority of the subjects were subsisting at poverty level, or slightly above. Some resided in "Indian houses" (tribally sponsored) on purchased land or original allotment lands, three lived in federal housing developments, and others resided in privately built homes. Participants were contacted by either tribal Community Health Representatives (CHR),⁵ physicians, and other health care providers, and asked if they would consent to be interviewed for the study.

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The Interviews

The semistructured interview included: (1) social history, (2) medical history (self-report), (3) care-seeking assessment, (4) adherence assessments, (5) explanatory model elicitation, (6) cultural identification assessment, and (7) a contact summary form used to record interviewer impressions of the subject and the affective content of the interview. The interviews were conducted face-to-face and administered in the homes of the respondents, in the tribal hospital, tribal health care clinics, and other places convenient for the subjects.⁶

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Cultural Identification

Due to the high degree of cultural heterogeneity in this population of AI elders, the cultural identification of participants was elicited in order to validly assess the impact of this variable on the cultural construction of diabetes, as well as care-seeking and adherence behaviors. "Cultural identification" in this research refers to acculturation status in terms of identification with either traditional indigenous life ways or identification with white mainstream life ways.⁷ Cultural identity domains were based upon a review of the literature, pilot study findings, researcher observations, and very importantly, lived experience with members of the tribe.

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Based on these factors, subjects were placed in either an "indigenous" or "mainstream" category.⁸ Cultural identification questions addressed religious affiliations and beliefs, language used in the home, attendance at traditional American Indian functions, knowledge and use of traditional medicine, including sweat lodges, knowledge of folktales, wearing of traditional dress, consumption of traditional foods, and participation in communal tribal sporting events. Additionally, homes of the subjects were observed for markers of traditionalism. These included such things as decorations and personal adornments, photographs of participants in traditional dance regalia, burning rocks used for spiritual ceremonies, and the presence of sweat lodges on the subject's property.

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RESULTS: THE MODELS

Two divergent culturally based models of diabetes were found among the elders. One model is designated the Indigenous Model and is characterized by

strong valuing of cultural insularity. Behavior is consistent with valuing a strong traditional American Indian cultural identity reinforced through cultural membership, friendship, and kinship networks. This sometimes was accompanied by derogatory remarks about the unwanted authoritarianism of the white mainstream including “white doctors” and their directives. The Indigenous Model thus is characterized by nonadherence to biomedical dietary guidelines, medication use, delays in care-seeking, and a strong identification with the more traditional life ways of the tribe.

The other AI elder diabetic model is the Mainstream Model. While there is value placed upon AI cultural ties, this model is characterized by more pronounced identification with white mainstream culture. There is more acceptance of the biomedical model of diabetes as characterized by early care-seeking, greater adherence with dietary guidelines, greater adherence with medications, and greater trust in health care providers.

Indigenous Model

Indigenous Model elders postponed care-seeking in the presence of recognizable symptoms, and demonstrated considerable nonadherence with medical advice. These health behaviors were positively associated with strong identification with traditional AI culture on the cultural identification questionnaire.

Additionally, nonadherence with medical regimens was perceived in such a way that it was socially acceptable, even desirable, to ignore and/or deride medical advice. Following the recommendations of the “white” medical authority placed the elder outside of their peer group. Diabetes has become increasingly endemic among American Indian populations, and this has resulted in a construction of the disease as commonplace and benign. Indeed, the disease and attendant noncompliance may create a sense of solidarity with other American Indian diabetics within the culture.

Complicating matters further, acknowledgement of the connection between the biomechanisms of diabetes, adherence, and complications was limited. Most elders had received very little diabetes education, and what was received was in many cases not culturally acceptable in terms of the way that the elders live their lives in the context of AI traditions and mistrust of white biomedicine. The traditional elder mistrusts white medical authority, and this results in an unwillingness to ask important questions about self-care. In addition to mistrust, this reticence may be due to shyness, not wanting to be a burden to the provider, or not wanting to admit to lack of knowledge.

When tribal health care providers were interviewed, both AI and non-Indian, varying provider models of care delivery were elicited (Henderson, 2002a; 2002b). Interviews with providers elicited the following quotes that additionally inform us about the Indigenous Model of care-seeking and adherence:

I have to explain changes over and over. I wonder sometimes if they understand me. The patient wasn't getting what the nurse on the phone was saying. So, the patient got

the CHR on the phone to interpret to her what the message was. A lot of elderly full bloods don't understand what the doctor is saying. The doctors talk fast and use big words. Even if written, the patient needs interpretation. Elderly American Indians aren't very assertive. Patients say the doctors are in too big a hurry. They're afraid to ask (questions). They don't want to offend the doctor. (Henderson 2002b:97)

The cultural construction of the elder holding the Indigenous Model is crafted from a history that includes prejudice, access to care barriers, and absent or culturally inappropriate diabetes education. It is this history that engenders symptom tolerance, the normalization of the disease and its symptoms, and the devaluation of adherence. It is this context that inspires these additional quotes from providers:

They're traditional. They may want to seek alternative types of treatment. They don't understand the extent of the disease. (Henderson 2002b:100).

She would deny it at first. She's not going to give up her favorite foods. She would go to the doctor but that doesn't mean she would abide by what the doctor would say. Just the Indian way, you could say. They don't like people telling them what to do, don't like being told how to live, what to eat, what not to eat. (Henderson 2002b:100)

Mainstream Model

Within the group of elders who held the Mainstream Model of diabetes, analysis indicated the predominance of early symptom identification, early care-seeking, and adherence to prescribed treatments. The elders holding this model of diabetes were more likely to be more acculturated into the white mainstream culture. The behavior of the elders in this group, in terms of the issues here, was aligned with the expectations of the white mainstream medical community. This does not suggest that they are perfect patients, but in comparison to the more traditional elders, there was trust in formal medical providers and an expressed intent to "do what the doctor says." It was considered to be socially incorrect not to comply with medical recommendations that were perceived as gifts of knowledge from health care providers. In this group of elders, as in the more traditional group, cultural identification predicted health behaviors. The elders who had received formal diabetes education were in this group of elders, and this variable would also contribute to increased adherence to treatment recommendations. Seeking out and accepting this education would also align the elder with the mainstream biomedical paradigm.

In summary, the elder holding the Mainstream Model may be likely to seek care early in the disease process, and may be likely to adhere to dietary guidelines and medication use. There is a value placed on continuing health and maximal functioning. Health care providers are seen as helpful persons, and there is no inclination to "rebel" against health care directives. The diabetes education has been instructive to this group of elders. There is a possibility that the elder who more closely identifies with the white mainstream has an

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increased chance of internalizing diabetes education that was crafted to meet the teaching needs of the white mainstream.

CASE 3: MUCH SUCCESS AND GOOD FORTUNE

I interviewed Jack at his home in Lukfala, Oklahoma. He was a man of eighty-seven years who closely identifies with mainstream white culture, as opposed to traditional American Indian culture. He has been hugely successful over time in controlling his diabetes. He was diagnosed with the disease thirty-four years ago. He states that at that time, he had numbness in his hands, as well as excessive thirst, and he sought care immediately. His blood sugar was 400 (any value over 127 is considered to be abnormal, and 400 is very high).⁹ When asked if he was surprised to be diagnosed with diabetes, he said that he wasn't because it "runs in my family" and he has a "lot of cousins that have it." He does not know much about the disease because there were "no classes back then." He just knows that diet and exercise control it. He gardens and that is his exercise. At first, he was on oral medications for the diabetes, but was able to achieve control, and now takes no medications. He lives with his spouse in a privately built home in a rural area. He does not participate much in tribal activities. He states that he was "in heavy construction" before he retired, and attributes his success in controlling his diabetes to diet and exercise. He says, "There's a lot of them don't do that (what the doctor tells them to do). I say 'You can live a normal life or you can die young.'" The day before the interview, he had just finished planting four hundred tomato plants. When I left his house, he gave me gifts of freshly picked summer squash and green peppers.

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ELEMENTS OF THE AMERICAN INDIAN DIABETES MODEL

Postponement of Care-seeking

In this research, elders who held the Indigenous Model of diabetes postponed care-seeking even in the presence of recognizable symptoms, while those holding the Mainstream Model sought care early in the disease process. The "late care-seeking designation" used in this research was assigned only to those subjects who stated that they recognized symptoms of the disease, but decided to wait before seeking care. There are differences in perception between Indians and non-Indians about the physical symptoms of illness. Cultural systems vary in selecting which symptoms are considered serious enough to send the person to a health care provider, as well as the manner in which the symptoms are presented and evaluated by the provider (Weaver and Sklar 1980; Cohen et al. 1994).

Grandmother would rather get some weeds or roots to treat her. Everybody who goes (to the tribal hospital) gets cut on and dies. (Henderson 2002b:85)

As indicated in this quote, traditional American Indian people seek to avoid contact with the “white” medical establishment. Some relate bad experiences from the past, both their own and that of friends and relatives. The traditional elders in my research postponed care-seeking even in the presence of illness they knew could be due to diabetes. They frequently ignored symptoms, delaying diagnosis, or because of lack of education (in my research, only four of the elders had had diabetes education), or attributed them to causes such as old age (Evaneshko 1994; Tom-Orme 1994; McCabe 1999; Henderson 2002b).

Due to the high prevalence of the disease within the population, and the high morbidity and mortality rates, there has been a “normalization” of diabetes and its complications within the AI population. In the group of elders that more closely identified with traditional culture, there was little alarm at both the possibility and reality of being diagnosed with diabetes:

Well, I’ll have to learn to live with it. Not scary sounding. Father had diabetes. (Henderson 2002b:79)

Well, you see, I been with mama about 50 years with it and she didn’t have any problem with it, except she lost a leg. (Henderson 2002b:81).

These reactions may indicate a perceived inevitability. For the traditional elders in this research, while extensive problems with vision, circulation, and episodes of fainting resulted in care-seeking, earlier symptoms were minimized and/or ignored. Many elders spoke of diabetes being “caused” by life events such as loss of a spouse, or moving to another job or home location, and correlated the appearance of the disease with these perceived life stressors. This was also a feature of diabetes patients’ explanatory models as indicated in the study by Cohen et al (1994). As in that study, AI elders minimized the seriousness of their disease, concentrating instead on the social and personal effects of the illness.

Adherence Issues

The elders in this study who more closely identified with the indigenous culture were less adherent to diet, exercise, and medication use than culturally mainstream elders. Because of the lack of diabetes education, there was an inability among the nonadherent group to connect poor adherence to disease complications. There were also social pressures mitigating against adherence, and notable derision attached to discussion of the “white man’s diet” and the “white doctor’s” instructions:

I didn’t know how serious it was. Then there weren’t too many people who had diabetes. At first, I didn’t take it serious. They wanted to put me on insulin, but I wouldn’t do it. I quit taking insulin for over two years because my sugar wasn’t over 200. (Henderson 2002b:79).

I know more than they do. They ain’t said nothin’ to me. I done lived it. I do fine as long as I take my pills. (Henderson 2002b:80).

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Medication adherence was higher than dietary adherence, due in part to utilization of medications to attenuate dietary indiscretions. Ironically, among some traditional elders, use of insulin was perceived as making one “sicker.” Accounts were given of family members who were placed on insulin, only to die or worsen after starting the medication. In actuality, the family member was placed on insulin only after extensive disease progression. The insulin was an attempt to halt the cascade of medical complications, but was usually unsuccessful, and was perceived as being extremely harmful.

CASE 4: WHAT NOW?????

Chris Billy is sixty-five years old, and was diagnosed with diabetes mellitus twenty years ago. At the time, she thought she could “out-run it.” Now, as I interview her in her home, she sits in a wheelchair. Due to her diabetes, both legs have been amputated below the knee. A dialysis bag lies at her feet, as the insulin she takes is no longer sufficient to maintain a blood sugar level that is safe for her body. Due to her diabetes, she suffered a heart attack two years ago, and has lost vision in one eye. She awaits a prosthesis, which will be delivered to her in a few days. She must learn to walk again. When she has grown used to using one artificial leg, then she will be fitted with the other leg. I asked her questions about what she thought when she was first diagnosed, the reaction of her family, and what she felt about her medical care.

Commenting on when she was first diagnosed with the disease:

I didn't pay any attention to it. I just kind of ignored it, but I got so I had to pay attention to it. All the family has it.

I asked her if she had problems following the doctor's recommendations:

I do those things. They don't interfere with my life, now. In the past, taking the pills and the insulin was a problem. Sometimes I didn't take my medicine. Maybe a week would go by without insulin. It just wouldn't bother me. It just didn't matter. Then I'd get a real bad headache and crave sweets, then I'd check my sugar and take my shots. I quit partying, smoking and traveling. Sometimes I was gone a week or two weeks, then I would come back. But I stopped all that, 'cause it started affecting my eyes.

Chris pauses, looks at her friend, seated on the couch. Her friend also has diabetes. She has had the disease for four years. She is already having trouble with one foot. Chris looks over at her and says:

Look at me. Watch what you do.

Her friend just shakes her head and says:

I guess I just don't want to accept it, maybe. Sometimes I just don't feel like “diabetic,” I guess. I just feel normal.

Chris shakes her head. Her niece also sits nearby, helping her aunt with tasks around the house. She has just celebrated a birthday:

When I blew out the candles, I wished that my aunt would get her new leg soon, and that she will be able to walk again.

Distrust of White Authority

Indigenous Model elders did not trust medical providers and were reluctant to ask questions of them. These elders appeared to subjugate themselves to medical authority in the clinical setting, but shed many of the medical recommendations at home. For many people who are illiterate or marginally literate, the oral discourse of the health care provider is confusing and results in the patient feeling demeaned by the experience.

The history of interaction with the white community must also be considered an important factor. Elders are a repository of memories from times past, both from their own experience and that of their parents. The history of contact with whites can be seen as one of extermination (“the only good Indian is a dead Indian”), expulsion from lands, exclusion from mainstream society through reservation internment, and attempted forced assimilation through removal of children to boarding school facilities (Holmes and Holmes 1995). Within the traditional culture there is considerable distrust of white persons, and there exists within the population a history of nonadherence passed down from the preceding generation. This antecedent context has exerted influence over this cohort of elder diabetics. One subject said that she would not take her (changed) diabetes medicine because she felt the doctors were experimenting on her.

As previously mentioned, within the peer group of traditional elders, adherence to medical directives is not valued. Rebellion against white authority was cited as one reason that persons do not comply. Physicians, nurses, and other health care providers are perceived by traditional elders as “white” even though they most likely are tribal members (twenty-one out of thirty providers in this study are AI/AN). Providers who are Indian might be referred to by traditional patients as “white Indians,” because they have been placed in a position of authority that has been defined by the tenets of the biomedical mainstream. Such perceptions are seen in the following commentary on doctors, the first from an amputee, also on dialysis for kidney failure, both conditions consequences of uncontrolled diabetes:

It’s my body. I know what I can do and what I can’t do. Coming from the Indian side of the car, you’re going to a white man doctor (you say) “That white man don’t know it.” (Henderson 2002b:84)

A Indian in the white man’s way will jump right on the meds. The “real” Indian will be harder to get them to understand how diabetes works.... The “real Indian-Indian” will stay at home and say the doctor did not deal with them right. (Henderson 2002b:84).

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We've done heard about this. If it wasn't for the white people, we wouldn't have all these problems. They refer to traditional cooking as good, white cooking as bad. The wild game is gone (due to whites). (Henderson 2002b:84)

Diabetes Education

For most of the AI elder subjects in this research, there was a regrettable lack of formal, culturally relevant, diabetes education in both quantity and quality. Only four AI elders interviewed had received formal diabetes education. All of the elders who had diabetes education more closely identified with mainstream culture. For these elders, then, symptom recognition and care-seeking was facilitated by this experience and the positive reception of non-Indian ideas. It is notable that many elders were diagnosed before diabetes education services were available from tribal health care. The elders, as a generational cohort, had little exposure to this knowledge at the time of diagnosis. It was possibly assumed by the health care establishment that the elders had received diabetes education, but in fact, they had not. Moreover, there was no apparent effort to convey culturally appropriate education over the years following diagnosis:

I thought it would last only one or two years and I'd be OK. Meds decrease the symptoms and then you don't take the medicine until you have a problem, and this leads to amputation. (Henderson 2002b:79)

Honey, I been with it for 50 years. I pretty well know how it works. You got blood sugar. The doctor said about her mother that her mother ate anything she wanted to. If she wanted to eat it, she ate it. (Henderson 2002b:85)

COMPARATIVE ETHNIC PERSPECTIVES ON DIABETES AND ELDERS

In the United States, as well as worldwide, diabetes is on the upswing among virtually all populations. This is due mainly to health behaviors that have diverse underlying causes strongly related to socioeconomic, political, and cultural contexts (American Diabetes Association 2005; Ferreira and Lang 2006). According to the Centers for Disease Control and Prevention (CDC), the prevalence rate for the Vietnamese population living in this country is approximately 7 percent. For the African American population, it is approximately 11.3 percent (ADA 2005; CDC 2007). These prevalence rates exceed that of the non-Hispanic white population (around 5.0 percent), although all population groups have seen an escalation of the disease in recent years (CDC 2007). How do the findings of the research presented here compare with other research on diabetes in elders from other ethnic communities within the United States?

Mull, Nguyen and Mull used ethnography to examine the cultural context of diabetes in a California Vietnamese community (2001). Ideas regarding cause

and treatment, as well as suggestions for improving diabetes self-care within this population, were elicited from first-generation immigrants to the United States. In contrast to the American Indian elders, among whom one-half had achieved control over their diabetes, three-fourths of the Vietnamese elders did not have good control of their diabetes.

Concepts about causation were culturally shaped, as were “proper” treatment regimens. Causation was often related to “sadness” brought on by stress, as well as perspiring less in the United States than in Vietnam. Perspiration was seen as a desirable way to rid the body of toxins. Treating diabetes included the use of Eastern herbal medicines by two-thirds of the sample to restore balance. Indeed, these persons lowered their doses of diabetes medicines while taking the herbal medicines in an effort to restore “balance.”

Few American Indian elders spoke of using traditional medicines or consulting with practitioners of traditional medicine. Within the Vietnamese population, elders with diabetes extensively used Eastern medicines and home remedies:

Eastern medicine is much safer than doctors’ medicine because it cools your body and brings it back into balance. Doctors’ medicine has a lot of strong hot chemicals ... you can get really bad side effects if the dose is too high for you ..., I’ve been using different things from the market to bring my sugar down ... bitter gourd, guava leaf tea, and banana tree sap. If those don’t work, then I’ll think about taking doctors’ medicine. (Mull et al. 2001:309).

Low use of professional medicine was also connected to not wanting to be a burden to adult children: “I’m old, and I don’t want to bother my son with taking me to the doctor, so I just drink tea and pray I won’t get any worse (Mull et al. 2001:308).” However, if they saw a doctor, they preferred neighborhood doctors trained in Vietnam: “We go to them because they understand our language and we don’t have to wait as long as in the clinic, but we can’t really ask them any questions. Some of them seem to be just rushing through” (Mull 2001:309).

Like their tradition-oriented AI counterparts, Vietnamese elders spoke about an aversion to insulin: “If you have to take insulin, for sure you’re going to die soon. Also, they say that some people go blind because of it” (Mull et al. 2001:309).

It was apparent that within this sample, many of the Vietnamese immigrants with Type 2 diabetes lacked knowledge of this disease. This is partly because it is not common in their home country, where high levels of physical activity and low-fat diets are the norm.¹⁰ There is also the factor of the low literacy, especially among women, found in this Vietnamese population of elders. Most were indigent, advanced in age, and non-English speaking. Diabetes education for them in the United States was lacking, difficult to access, or not understandable due to language differences and low literacy.

African Americans in Florida

In an exploration of diabetes self-management techniques in an African American community in St. Petersburg, Florida, Rahim-Williams (2006)

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elicited behaviors and beliefs about acceptable management and treatment among women diagnosed with diabetes. As among AI elders, the cultural construction of the disease in the population of African American women encompassed both lay and biomedical perspectives. The main reasons given for lack of treatment compliance were difficulty in giving up favorite foods, the high cost of medications and supplies, weight loss, daily testing, and stress. As in the AI population, there was a belief that if diabetes runs in the family, it is inevitable.

Half of the respondents thought that it was easy to manage the disease. Behaviors utilized for management included changes in diet and exercise, use of prescribed medications, and close monitoring of blood sugar by themselves and their doctors. However, many did not check their blood glucose every day. And one-fourth indicated that they did not exercise because of health problems, social factors, and unsafe environments. There was the understanding that weight control was a good way to manage the disease. As in the other populations discussed previously, most reported that they struggled with the dietary changes:

“I do the same thing I always have done. I eat the same things ... diabetic sugar, I’m not working with that because I don’t want it. It doesn’t taste good. I just eat what I like to eat. But, the only time I know that the diabetes is going to bother me is when I don’t eat. I get weak and dizzy” (Rahim-Williams: 21).

As in the American Indian and Vietnamese populations, there was a feeling that stress reduction was important in the control of diabetes. A distinct factor that stands out in the African American community was the connection between diabetes and religious activities in terms of diabetes control:

Religion is a part of your life. Diet is a lifestyle, but your Christianity is even more than that because it’s who you are and who you pattern your life after.... The connection between my religion and my belief and my health or my diet or diabetes is that I am ... going to need to have my supreme being in order for me to stay on track because I am too weak for this. I can’t do it all by myself” (Rahim-Williams:13).

Whereas among the Vietnamese elders, diabetes was a relatively “new” occurrence within family systems, in the African American sample, similar to the AI sample, the majority of women studied had a family history of the disease. However, unlike the indigenous American Indian elders, whose families and peers devalued adherence, within this ethnic community family networks constituted a key support system for adapting to this disease:

“I have 100% support from my family. They watch me like a watchdog. They ask, Momma, are you supposed to have that? I say, don’t come in here with that today ... but they are only looking out for me” (Rahim-Williams:18).

In contrast, in both the Vietnamese and American Indian populations, all of the women in this study had attended a diabetes self-management education class. Over half, however, had not received a referral to these classes from their physicians, nor did they receive referrals to a nutritionist.¹¹ Rather, the women sought out diabetes education on their own.

While the women knew the self-care regimens recommended, and utilized them, the utilization was sometimes spotty, and depended upon the circumstances in the person's life. Monitoring and response occurred primarily with symptom recognition and was not consistent. Mediating circumstances included barriers such as costs of medications, environmental concerns such as unsafe walking environments, and lack of insurance. Based on these identified themes, a "Model of Interruption" was delineated that explained the inconsistent use of recommended behaviors due to multiple interruptions by sociocultural, structural, and/or environmental factors that lead to lack of consistent appropriate self-care.

CONCLUSION

Efforts to effectively combat diabetes by the medical community and American Indian tribes have been substantial in the past several years. Actions to decrease the prevalence of diabetes have thus far concentrated on disease etiology, the biology of the disease as it exists within varying segments of the population, and the infrastructure of care delivery. However, the existence of a health care delivery system is insufficient unless it is underpinned by appropriate prevention and education strategies crafted to effect changes in human behavior (Johnson and Rhoades, 2000). Education regarding prevention and management of diabetes must have cultural relevance to the target population in order to be maximally effective.

The practice of medicine has two players: the patient and the physician. By focusing on both these sides of the health promotion equation, the research presented here has implications that could impact current practice. The Traditional AI patient has a stereotype of Western non-Indian providers in which the health worker is viewed suspiciously and is critiqued through the filter of the patient's culture. This stereotype may view the provider as having an insensitive nature, being greedy, arrogant, untrustworthy, and intrusive (McCabe 1999; Rhoades and Rhoades 2000). It is notable that in the research presented here, to more traditional elders, the majority of medical providers were seen as symbols of "White authority," even if the providers were American Indian. In the research with Vietnamese elders, access to culturally relevant health care practitioners was lacking, such that Vietnamese elders sought out same-culture lay providers, rather than North American-trained physicians (Mull et al. 2001).

One of the implications of our findings for current practice is that due to the nature of the Indian Health Service directives regarding standards of care, most of the AI elders in this research receive the same general type of *ongoing* diabetes care, but that the care may not be effective because differences in cultural identification are not adequately addressed. The research also revealed that many elders had received no diabetes education (except the small amounts given during clinic visits), possibly because at the time they were diagnosed, there were no education programs. The health care system has neither recognized nor alleviated these gaps.

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In the population of American Indians, as well as in other culturally diverse populations, elicitation of social and cultural histories by health care providers becomes crucial in identification of models of illness operating in patients and their families. It is necessary to evaluate each person regarding his or her inclusion within a culturally traditional support system, attitudes towards chronic illnesses such as diabetes, and to what extent the family will influence decision making regarding health care. Degree of cultural immersion should be assessed along with additional factors such as literacy and socioeconomic status. In terms of optimizing health status in populations of culturally diverse elders, in whom long-standing traditions exist side-by-side with contemporary mores, the impact of efforts made to truly understand the cultural context of aging and health for individuals cannot be underestimated.

NOTES

1. The high prevalence rates noted in Alaska are due to a number of factors. Changes in the diagnostic categories for type 2 diabetes, and increases in the number of screenings conducted, may contribute to this increased prevalence. Also implicated are the changes in Alaskans' diet, from primarily subsistence hunting and fishing to a "modern" diet with its attendant high sugar, fat, and sodium content.

2. Allotment lands were those parcels of land deeded to AI persons when lands that previously belonged to tribal nations were opened to white settlers by the U.S. government. A typical parcel consisted of 160 acres.

3. The age group of fifty-five years and over was chosen to designate elder status, consistent with Indian Health Service guidelines (I.H.S. 1997). AI/AN elders experience more comorbidities at younger ages than their counterparts in the white population.

4. The Certificate of Degree of Indian Blood (C.D.I.B.) card is issued to members of American Indian and Alaska Native tribes by the Bureau of Indian Affairs (B.I.A.). The issuance of the card is predicated on the enrollment of ancestors with the B.I.A., and designates the AI blood fraction of the individual. The B.I.A. calculation of AI fraction is based on blood derived from both federally recognized and nonfederally recognized tribes. The C.D.I.B. card entitles tribal members to those trust benefits offered by the federal government that are specific to AI/AN persons, and which fulfill the trust responsibility of the federal government toward AI/AN tribal members.

5. The Community Health Representative (C.H.R.) program is a unique community-based outreach program, staffed by a cadre of well-trained, medically guided, tribal and Native community people, who provide a variety of health services within American Indian and Alaska Native communities. A Community Health Representative (C.H.R.) may include traditional Native concepts in his/her work and is funded with IHS-CHR appropriations.

6. Responses to questions were transcribed by the investigator and placed into the ethnograph software program in order to facilitate analysis. Utilizing the ethnograph software, codes can be defined, text data can be coded, and response frequencies calculated.

7. Addressing cultural identification (CI) is crucial for contemporary AI research due to the high degree of cultural heterogeneity within tribal populations. Questionnaires assessing CI cultural identification often use an "immigrant model" for question selection. "Immigrant model" questions are relevant to persons first coming to the

United States, but irrelevant to those in residence here. The “immigrant model” obviously does not apply to American Indian populations (c.f. Stephenson 2000). Consequently, CI life experience domains were based upon a review of the literature, pilot study findings, researcher observations, and very importantly, lived experience with members of the tribe.

8. CI assessment results placed subjects in either an “indigenous” or “mainstream” category. These are terms of convenience for description and analysis. However, the technical limits of the use of these dichotomous terms must be understood. At the individual level, the existence of absolute, dichotomous designations cannot experientially exist (Hill, Fortenberry and Stein 1990). For example, the “Acculturation Continuum” has positions along a line, at one end of which is the identifier “Traditional” and at the other “Assimilated.” The middle is designated “Bicultural,” and movement from one pole to the other reflects processes of “acculturation” (Valle 1989). People can be said to exist at any point on the continuum based on changing social and cultural environments, and movement can be due to situational social environment variance. It is not possible in today’s global cultural environment to be completely shielded from diverse cultural influences. Thus, individual experience in the sense of absolute encapsulation in one and only one cultural environment does not occur (Hill et al. 1990). The use of *indigenous* and *mainstream* to refer to the cultural identification of the elders is not perfect, but does not necessarily supersede an agreed upon “convenience usage.”

9. According to the 2007 Clinical Practice Recommendations from the American Diabetes Association, a diagnosis of diabetes can be made when the fasting blood glucose level is equal to or over 126mg/dl. A level of 400 would be considered an extremely urgent medical condition (American Diabetes Association 2007).

10. In this population, referrals to formal diabetes education classes were lacking for some of the women interviewed. The women sought information from other sources such as relatives, friends, nurses, and books.

11. Regarding culturally based dietary habits, it was said to be difficult to avoid sugar, as the people liked their coffee very sweet. The admonition to cut back on the large amount of white rice in the diet also presented an adherence problem.