

Divergent Models of Diabetes among American Indian Elders

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Published online: 8 October 2010
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Abstract The purpose of this study was to examine belief systems about diabetes in American Indian elders, and the effects of culture on care-seeking, adherence, and diabetes self-care. Health belief theory predicts that care-seeking and medical adherence are a function of culturally mediated beliefs that result in behaviors that effect health status. In order to elicit cultural meanings of diabetes, in-depth interviews were conducted with an intensity sample of 30 American Indian diabetic elders (55+). Two models of diabetes were identified, divergent in terms of 1) health behaviors, and 2) cultural identification. One model was characterized by delayed care-seeking, and a non-valuing of adherence to diabetes self-care. Non-adherence to medical recommendations was perceived as being socially desirable, because adherence placed the elder outside their peer group. The second model was characterized by early care-seeking and improved adherence to diabetes self-care. These divergent models of diabetes, in which care-seeking, diabetes self-care, and adherence vary as a function of cultural immersion, has implications for health education and disease management and may contribute substantially to health disparities.

Keywords American Indian elders · Cultural construction of disease · Diabetes

Introduction

Among American Indians (AIs) diabetes constitutes an epidemic of monumental proportions with unacceptable levels of excess disability and death (American Diabetes Association (ADA) 2007; Lieberman 2004; Meneilly and Tessier 2001; Indian Health Service 1997). The diabetes mellitus prevalence rate in tribal areas ranges from 17% to as high as 80% (Ferreira and Lang 2006). In comparison, the diabetes prevalence for the non-Hispanic white population is 6.6%, for African Americans 11.8%, for Hispanics 10.4%, and for Asians 7.5% (Centers for Disease Control 2007). The prevalence rate of diabetes

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increases with age. The total prevalence of diabetes for those persons aged 60 and over is 23.1% (American Diabetes Association 2007).

Additionally, the degree-of-severity of diabetes among American Indians is higher than the general population. AI diabetics are four times more likely than their non-Hispanic White counterparts to experience an amputation as a consequence of diabetes and are six times more likely to experience kidney failure (Ferreira and Lang 2006; American Diabetes Association 2007; Roubideaux and Acton 2001:).

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. Research has addressed the high morbidity and mortality as due to insufficient education about diabetes, and structural, social, and economic barriers to health care access. 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. Conditions such as diabetes are the grist for health communication barriers, defensive behaviors, and treatment non-adherence, leading to patients and providers losing a sense of partnership in combating this complex disease. This is of concern because culturally constructed concepts of disease that are condensed into disease-specific explanatory models often impede care-seeking, communication, and adherence (Henderson and Henderson 2002, 2004; Kleinman 1980). The research presented here examines the cultural construction of diabetes in a sample of American Indian elders in terms of the impact of these beliefs upon care-seeking, diabetes self-care, and adherence.

Background

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. The study of patient "explanatory models" provides information about how patients make sense of illness episodes, and how they choose and evaluate medical treatments. These explanatory models are heavily influenced by the culture of the patient, which serves either to encourage or impede health care seeking and medical adherence (Henderson and Henderson 2002; Henderson *et al.* 2004; Kleinman 1980).

Additionally, professional and lay explanations for disease, treatment, and prevention can vary radically. Sometimes obscure socio-cultural factors are operating that impede effective health care (Henderson 2002a, b; Garro 1996). These may be identified by examining the culturally based models of diabetes held by both 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 increased patient/provider trust. However, models that are discordant between practitioners and patients are prone to reduce effective health communications, reduce adherence, and negatively impact health outcomes (Cohen *et al.* 1994).

For example, Hunt and Arar's (2001) research examining patient and provider perspectives in a Texas diabetes clinic found that provider perspectives were grounded in clinical terms, with nonmedical considerations only secondary. For the patients, the experience of diabetes was inextricably woven into, and influenced by, daily life experience.

Research in another non-indigenous 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.

In regard to the experience of diabetes among American Indians, one of the most revealing 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 diabetes and underscored cross-cultural differences in the diabetes experience in terms of socio-cultural factors that negatively influence adherence (Goforth-Parker 1994). In *Indigenous Peoples and Diabetes*, Ferreira explores the life of a Yurok elder and writes of the cultural construction of diabetes as the result of neocolonialism and oppression. The graphic depictions of traumatic experiences at the hands of colonial powers illustrate the power of life events and prolonged stress on the construction of illness narratives (Ferreira 2006).

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 (Sokolovsky 2009; 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 interpretation of the term. When we look at AI 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 connect 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 non-indigenous 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 (the 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).

The Cultural Construction of Diabetes in American Indian Elders

The research presented here examined models of diabetes held by a sample of American Indian elders. Additionally, the cultural identification of the respondents was assessed because prior research suggests that the models would be culturally-mediated. Furthermore, if unrecognized by health care providers, these culturally constructed concepts and attendant explanatory models could serve to either facilitate or impede optimal management of diabetes. Consequently, the research 1) identified models of diabetes within a sample of AI elders as a function of cultural identification, and 2) examined why these differing models might contribute to delays in care seeking and poor adherence to diabetes self-care.

Methods

Sample

Interviews were conducted with thirty American Indian elders with Type 2 diabetes, in a Southeastern 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 55 years of age or older,¹ 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.).² In this research, a non-random intensity sample was used. Intensity samples are composed of those who are “experiential experts” and who are “authorities about a particular experience,” in this case, diabetes (Morse 1994). All were fluent in English. Participants were contacted by either tribal Community Health Representatives,³ physicians, or other health care providers, and asked if they would consent to be interviewed for the study.

Data collection

Both structured and semi-structured interviews were used and included the following information: 1) social history, 2) medical history (self-report), 3) care-seeking assessment, 4) adherence assessments, 5) explanatory model elicitation, 6) degree of cultural identification, and 7) a contact summary form used to record interviewer impressions 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, and in tribal health care clinics.

Data analysis

Data from the structured and semi-structured interviews were transcribed by the investigator and placed into the Ethnograph v6.0 software program for analysis. Utilizing the Ethnograph software, codes can be defined, text data can be coded, and response frequencies calculated (Seidel 1998).

Specific topics of interest were initially identified by conducting an extensive review of the literature about American Indian populations and diabetes, and patient/provider cross-cultural communication in regard to the delivery of healthcare. For example, topics included correlates of diabetes self-care, cross-cultural explanatory models of chronic disease, and provider perceptions of patients with chronic diseases. Identified topics from the literature review and interactions with the tribe became a “start-list,” providing a framework for data analysis. After topics were identified, coding proceeded from these.

¹ The age group of 55 years and over was chosen to designate elder status, consistent with Indian Health Service guidelines (I.H.S. 1997). A/AN elders experience more co-morbidities at younger ages than their counterparts in the white population.

² 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 A/AN from both federally recognized and non-federally recognized tribes. The C.D.I.B. card entitles tribal members to those trust benefits offered by the federal government which are specific to A/AN persons, and which fulfill the trust responsibility of the federal government toward A/AN tribal members.

³ 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.

Major groups of like codes were defined in detail. From these grouped codes, data of interest were more specifically refined. After interviews were fully coded, common themes could be identified across interviews (Luborsky 1994; Miles and Huberman 1994). Thematic analysis resulted in the diabetes models described in this study.

Cultural identification

Due to the high degree of cultural heterogeneity⁴ in this sample of AI elders, the cultural identification of participants was elicited in order to 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 indigenous life-ways (traditional) or identification with non-indigenous life-ways (mainstream). The questions were based upon a review of the literature, input from tribal members, pilot study findings, and researcher observations. Based on the answers to the cultural identification questionnaire, respondents were placed in either a “traditional” or “mainstream” category.⁵

Limitations

As with any field research, limitations exist that impact research methodologies and the findings. Objectively quantifiable measures of diabetes control were unavailable for this study. The tribe preferred that medical records not be accessed for this research because their Institutional Review Board was not yet established. If medical records had been used, the HbA-1c levels which measure blood sugar control would have been evaluated in order to make a more precise assessment of diabetes control over time. Medical history was self-reported, and blood sugar control was assessed by the elder’s health care provider.

In attempting a dichotomous assignment into cultural identification groups (traditional vs. mainstream), there is a possibility of misclassification. In today’s world, the existence of “pure” cultural categories cannot exist. Within varying situations an individual may alter his expression of cultural identity in order to adapt to current circumstance. Discrete categories were used in this research in order to facilitate analysis.

The sample of American Indian elders was taken from only one tribe in Oklahoma. There are major cultural and other differences between many American Indian tribes. Therefore, the findings presented here should be generalized with caution.

⁴ The sample for this study was taken from a population of southeastern American Indian elders who live in Oklahoma, a state in which tribal boundaries are delineated but in which there is comparatively little reservation land legally held by the tribe. There is more intermarriage with non-indigenous people when compared to isolated reservation communities (Henderson and Henderson 2004).

⁵ The cultural identification assessment placed respondents 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 terms must be understood. At the individual level, the existence of absolute, dichotomous designations cannot experientially exist (Hill, Forenberry 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” (Vallé 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. The use of “indigenous” and “mainstream” to refer to the cultural identification of the elders is not perfect, but does not necessarily preclude an agreed upon “convenience usage.”

Findings

Models of diabetes

Indigenous model This model is characterized by strong valuing of traditional American Indian culture, and a strong traditional cultural identity reinforced through cultural membership, friendship, and kinship networks. Non-adherence was perceived in such a way that it was socially acceptable, even desirable, to ignore and/or deride medical advice. Notably, following the recommendations of the “white”⁶ medical authority placed the elder outside of their peer group. Elders holding this model sometimes made derogatory remarks about the unwanted authoritarianism of the biomedical community, referred to as the “white doctors,” and their directives. This was accompanied by non-adherence to diabetes self-care recommendations, to include dietary guidelines, medication use, and follow-up care. Diabetes has become increasingly endemic among American Indian populations, and this has resulted in a perception of the disease as commonplace and expected. Indeed, the disease and attendant non-adherence may create a sense of solidarity with other American Indian diabetics within the community. 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 which engenders symptom tolerance, the normalization of the disease and its symptoms, and the devaluation of adherence. Jacob’s testimony below begins to help us understand the nature of the diabetes epidemic:

Jacob’s experience

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, in order to help those with substance abuse who want to free themselves from dependency, and for those on spiritual quests. He has had diabetes for about 5 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.”

⁶ The terms “white man,” “white doctor,” “whites,” and so on, are those used by respondents in this study. The use of these terms by the respondents is demonstrative of the extent to which past abuses, discrimination, and disenfranchisement have instilled in American Indians a distrust and often active dislike, for “white” people, and those that are symbols of the “white” authority. Abuses from the past have affected the health of the generations of American Indians.

“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).”

In a prior study, when both Indian and non-Indian tribal health care providers were interviewed, two models of care were elicited. One group of health care providers held what was termed the “Negotiated Practice Model” and the other the “Uniform Practice Model.” Those holding the Negotiated Practice Model were able to discern that culturally traditional elders may require different types of diabetes education and care. Uniform Practice Model providers held that all AI diabetics should be treated the same, regardless of cultural immersion (Henderson 2002a, b). These findings would serve to propagate distrust.

None of the elders holding the Indigenous Model of diabetes had received diabetes education. Therefore, there was a lack of knowledge about how delayed care-seeking and poor diabetes self-care contribute to diabetes complications. But the distrust of health care providers resulted in an unwillingness to ask important questions about self-care. It is this context which inspires these quotes from tribal health care providers:

“...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 (Community Health Representative) 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).

“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 The model of diabetes held by elders who were more assimilated was termed the “Mainstream Model,” and was more closely aligned with western biomedicine. While there was value placed upon cultural ties, elders holding this model had a pronounced identification with non-indigenous culture. There was more acceptance of the biomedical model of diabetes, and this influenced care-seeking and diabetes self-care.

Within the group of elders who held the Mainstream Model of diabetes, analysis indicated the predominance of early symptom identification, early care-seeking, and improved diabetes self-care (diet, medication, and follow-up). There was more trust in formal medical providers and an expressed intent to “do what the doctor says.” It was considered to be socially incorrect not to adhere to medical advice that was perceived as a gift of knowledge from health care providers. In this group of elders, as in the more traditional group, cultural identification predicted health behaviors. The few elders who had received formal diabetes education were in this group of elders, and this variable contributed to increased adherence to treatment recommendations. It should be noted, however, that the elder who is more assimilated also has an increased chance of internalizing diabetes education that was crafted to meet the teaching needs of the non-indigenous population.

Jack's experience

I interviewed Jack at his home. He was a man of 87 years who closely identifies with non-indigenous culture. He has been successful over time in controlling his diabetes. He was diagnosed with the disease 34 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).⁷ 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. He was at first 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. The day before the interview, he had just finished planting 400 tomato plants. He states:

"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.'"

Discussion

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, sometimes waiting until the diabetes resulted in complications that could not be ignored. 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. They frequently ignore symptoms, delaying diagnosis, or because of lack of education, attribute them to causes such as old age (Evaneshko 1994; Tom-Orme 1994; McCabe 1999; Henderson 2002b). The traditional elders in my research postponed care-seeking even in the presence of symptoms they knew could be due to diabetes. Those holding the Mainstream Model sought care earlier. The "late care-seeking" category used in this research was assigned only to those respondents who stated that they recognized symptoms of the disease, but decided to wait before seeking care. This was sometimes related to the distrust in health care providers:

"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).

That being said, 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). Due to the high prevalence of the disease within American

Indian communities, 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, alarm was not expressed at either the possibility or 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 culturally 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 non-indigenous elders. There were social pressures mitigating against adherence, and derision attached to discussion of the "white man's diet" and the "white doctor's" instructions.

Medication adherence was higher than dietary adherence, due in part to utilization of medications to attenuate dietary indiscretions. 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 other efforts failed. The insulin was an attempt to halt the cascade of diabetes complications, but was sometimes unsuccessful, and therefore was perceived as being extremely harmful.

Distrust of white authority

Indigenous Model elders did not trust medical providers and were reluctant to ask questions of them. Some elders appeared to agree with healthcare providers in the clinical setting, but shed many of the medical recommendations at home. Additionally, for many people who have difficulty understanding medical terminology, the advice of the health care provider may be confusing and result in the patient feeling demeaned by the experience.

The lack of trust may be due to the history of interactions with the non-indigenous community. Elders are a repository of memories from times past, both from their own experience and that of their parents. The history of contact with non-indigenous colonialists 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). There may exist, then, based on past abuses, a history of discounting the "white doctor's orders," and this may be passed down from the preceding

⁷ According to the 2010 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 126 mg/dl. A level of 400 would be considered an extremely urgent medical condition (American Diabetes Association 2007).

generation. It was apparent that this antecedent context had exerted influence over the sample of elders in this research. For example, one subject said that she would not take her (changed) diabetes medicine because she felt the doctors were experimenting on her. Therefore, within the traditional culture there is sometimes considerable distrust of “white” persons, to include “white doctors” and their perceived authoritarianism.

Betty's experience

Betty is 81 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 the Indian Health Service (I.H.S.). 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 (1940's).

“My daddy had allotment lands,⁸ but my mother sold them and moved into town. 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.”

“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 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, sassafas 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 (the location of an Indian Health Service hospital). I only got put part to sleep. The nurse came and got me. I stayed for 2 weeks to guard against bleeding. I also stayed at 2 weeks before having a baby. My first husband ran off, he was 'noholo' (term for white man, literal translation: person without a soul). I had to stay 1 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.”

⁸ Allotment lands were those parcels of land decided 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.

As previously mentioned, within the peer group of traditional elders, adherence to medical directives was not valued. Rebellion against non-indigenous authority was cited as one reason that persons do not follow the orders of the health care providers. Physicians, nurses, and others are perceived by traditional elders as “white” even though they many times are tribal members (21 out of 30 providers in the study of providers cited earlier were American Indian). Providers who are Indian might even 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 biomedical mainstream. Such perceptions are seen in the following commentary on doctors, the first from an amputee, also on dialysis for kidney failure, complications 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).

“We've done heard about this. If it wasn't for the White people, we wouldn't have all these problems.” The respondent referred to the diabetic diet in the following way: ‘traditional cooking is good, White cooking is bad. The wild game is gone (due to Whites)’ (Henderson 2002b: 84).

Diabetes education

For most of the elders, there was a lack of formal, culturally relevant, diabetes education in both quantity and quality. Only four elders interviewed had received formal diabetes education. For these elders, then, symptom recognition and care-seeking was facilitated. It should also be noted that many elders in this sample 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.

Conclusions

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 have concentrated on disease etiology, the biology of the disease as it exists within varying segments of the population, and the infrastructure of care delivery.

Fortunately, there has been an increase in studies and initiatives which emphasize the importance of community-based, culturally appropriate interventions. Education regarding prevention and management of diabetes must have cultural relevance to the community in order to be maximally effective.

The practice of medicine has two facets: the patient and the health care provider. The research presented here addresses one side of the equation. Medical providers' practice

models reflect both their personal construction of the disease as well as the bio-medical construction acquired through medical training (Stein 1990). Stereotypical paradigms of culturally diverse populations may significantly interfere with patient education and care (Loewe *et al.* 1998). Health care providers must be able to make an assessment of the role that culture plays in individual patients, as well as for themselves. They must assess potential conflicts between their own cultural identifications and perceptions, the established bio-medical model of disease, and those of the patient (Kleinman 1980; Hill *et al.* 1990).

As previously indicated, the author has conducted research on health care providers' practice models, and perceptions of the role culture plays in health care practice. The two practice models identified were discordant with each other, and one was at odds with the model of diabetes held by the traditional American Indian elders (Henderson 2002a, b). Given the history of past abuse, and viewed through the filter of the traditional culture, providers may be seen as having an insensitive nature, greedy, arrogant, untrustworthy, and intrusive (McCabe 1999; Rhoades and Rhoades 2000). 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.

Due to the Diabetes Quality Improvement Project, the American Diabetes Association, and the Indian Health Service, accountability and quality improvement measures are utilized, and expected standards of care met in most tribal diabetes centers. Therefore, most of the AI elders in this sample received the diabetes care that meets these accepted standards, provided they accessed clinic services. However, one of the implications of my findings for current practice is that the care may not be maximally effective because cultural differences 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.

While the findings presented in this research represent "uncomfortable knowledge" regarding the relationship between traditional culture and diabetes adherence, the responses to the questionnaires underscore the need for health care strategies that are based on an acknowledged and understanding of culturally-mediated health beliefs, and the reasons for these beliefs. In the population of American Indians, as well as in other culturally diverse populations, elicitation of social and cultural histories by healthcare 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 immersion in traditional culture (to include age cohort), attitudes towards chronic illnesses such as diabetes, and to what extent the traditional family will influence the success or failure of health care. In terms of optimizing health in culturally diverse populations, in whom longstanding cultural traditions may exist side-by-side with contemporary lifestyles, the impact of efforts made to truly understand the cultural context of aging and health for individuals cannot be underestimated.

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