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Ethnogenetics: Interpreting Ideas about Diabetes and Inheritance

DIANE WEINER

INTRODUCTION

Genetic inheritance is a multilayered concept enveloped by cultural assumptions, given diverse meanings by physicians who serve American Indians and by their patients. Unfortunately, providers and clients are often unaware of the different perceptions each have. Ethnographic data about perceptions of inheritance enhance an understanding of notions about diabetes and its causes. A broader view of this topic reveals that subtle and explicit cross-cultural misunderstandings are common to individuals and to topics of all sorts, consequently affecting associated prevention and treatment courses.

The words *genetics* and *inherited* are used frequently during discussions of diabetes, which is a common subject of communication between providers and their American Indian clients due to the prevalence of Type 2 diabetes among the Indian Health Service population.¹ The age-adjusted Indian Health Service-diagnosed diabetes prevalence rate for American Indians is 69 per 1,000,² whereas the overall U.S. rate is 24.7 per 1,000.³ Recent results from the Strong Heart Study reveal that among Arizona American Indian participants, for example, the age-adjusted rates of Type 2 diabetes are 65 percent in men and 72 percent in women.⁴ Diabetes is the second leading cause of outpatient visits to Indian Health Service facilities, after the common cold.

When confronted by medical information and technology, lay people rarely remain passive. They tend to interpret and evaluate illnesses and treatments actively.⁵ Interpretations are greatly impacted by historical, social, linguistic, cultural, and educational factors as well as by the genders of providers and clients. In interviews, California and Arizona tribal members often explain inheritance as a part of biological, social, and cultural ethnic identity,

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while their providers define inheritance in a biological context. Multiple interpretations of a single concept by professional and lay people alike may represent underlying disagreements about etiologies which in turn influence health care behaviors.

Doctors, nurses, and physician assistants seemed stunned by clients' notions of diabetes causation. They were particularly surprised that Native people interpreted "genetic inheritance" to have social or learned aspects. Similarly, clients are often unaware that medical professionals do not interpret inheritance the same way they do. To complicate matters, geneticists themselves have multiple views of the relationships between genetics and particular medical conditions; scientists create and negotiate competing perceptions due to institutional, political, and economic conditions.⁶ Nevertheless, notions of genes are perceived and presented by scientists and health professionals as "facts" rather than social constructs. Even though there exists "no fixed agreement" among biological scientists "about what a gene is and how genetic control works,"⁷ information about genetics is passed to biomedical practitioners as if non-negotiable truth exists. Challenges to a particular scenario or theory concerning genetics will only occur if and when a competing alternative gains notice.

Using the study of the terms *genetics* and *inherited* as an example, one can assess conditions of power and authority as part of cross-cultural communication processes. An analysis of the various interpretations of inheritance enables us to understand intricate constructions of diabetes etiologies. Examining doctor-patient communication about diabetes helps to account for offered, requested, and enacted treatment behaviors. At a macroanalytical level, this study investigates two scientific systems: professional and lay theories of etiological knowledge. These "two ways of knowing" are based on observations, empirical tests, and validated responses.⁸ Furthermore, they are dynamic—based on paradigms that are influenced by ideas internal and external to the distinct knowledge systems.

To identify the ways in which doctors and American Indian patients define genetics and inheritance, this work will examine who creates particular definitions, what makes definitions persuasive or unconvincing, and the processes and factors that motivate people to develop, ignore, or act in particular understandings. This analysis will aid in the establishment of a framework for assessing competing realities of biomedicine.

METHODS AND SAMPLE POPULATION

This paper is based on six years of research on chronic illness beliefs and behaviors among two Indian communities—one in Southern California and one in Southern Arizona. In order to secure the privacy of tribal members, the author and the elected tribal council officials prefer that the described communities remain anonymous. All names included in this article are pseudonyms.

In the California study, 121 individuals between the ages of 18 and 91 years participated in face-to-face, open ended interviews; 91 of 121 people were female. All interviews were in English. Thirty people, 9 males and 21

females, claimed to have diabetes. These individuals were members of the same American Indian tribe, who resided on, or were enrollees of, three neighboring reservations. Data collection techniques included an epidemiological questionnaire, informal interviews, combined genealogical and medical history maps, and participant observation.

In the Arizona study, 33 people between the ages of 45 and 71 years were informally interviewed. Seven of the 33 people were male. Three of the men and seventeen of the women had diabetes. These individuals, who are members of the same tribe, were contacted through a tribal diabetes clinic for senior citizens that met weekly. In addition to conducting interviews, I participated in and observed clinic and senior center activities two to three days per week for thirteen months. Participants who did not have diabetes were contacted through senior center events such as daily meals, arts and crafts, and exercise programs. Interviews were conducted in both English and Spanish. Frequently, one of two trilingual women would assist as interpreters for interviews that included the Native language.

My observations of and informal interviews with medical providers from American Indian health programs in California (ten individuals) and Arizona (fourteen individuals) enabled me to garner data about practitioner and client communication practices. All of the providers from California are, or were, affiliated with a single Indian Health Service contract branch facility. Three of these practitioners were doctors, although none of these physicians were American Indian.

In contrast, all but two of fourteen providers with whom I had contact in Arizona were American Indian. These individuals are currently based at different facilities, not all of which directly serve the clients of the senior diabetes clinic. The two physicians I interviewed were career public health service doctors who have each had contact with the research population for several decades. These doctors are stationed at two separate Indian Health Service facilities in Arizona. Both doctors reportedly maintain social and medical service contacts with their former clients. Two other providers interviewed were associated with nonprofit health organizations that serve indigenous populations throughout the nation. These providers have designed and implemented diabetes programs for the research populace.

SETTING

California

Members of the three California reservations live in a rural area approximately sixty miles from a metropolitan area. Most members sixty-five years of age and younger speak English in public. Although the majority of tribal members embrace the tenets of two religions, their Native religion and Catholicism, Christian evangelical churches attract congregants. Due to geographic remoteness, employment opportunities are often limited to seasonal and/or part-time tribal programs and businesses and local non-Indian-operated services.

The diet of these people has changed drastically during the past two hundred years. The consumption of wild foods, including game, fish, nuts, fruits, and vegetables, was supplemented by horticultural and ranch practices throughout the early part of this century. Access to water and land for agriculture is currently quite limited. Since World War II few people hunt, fish, or collect wild foods on a regular basis for personal consumption. However, some individuals, especially retirees, maintain household gardens of varying sizes.

Historically, members of this ethnic group tended to attribute illness to accidents, sorcery, and the transgression of social rules, believing that reactions to events may occur instantaneously, or take place weeks, months, years, or generations later. The intentional or inadvertent social transgressions of kin of one generation could influence the health of an individual of the same or subsequent generation. Like many aspects of life, certain illnesses were considered to have mysterious etiologies and courses. The American Indian physician, John Molina, explains

Native American people are a spiritual people. Their lives have meaning and a purpose. Events are hardly ever random or accidental and many times warrant an interpretation.... Knowing the meaning of an illness may then guide the performance of a ritual or ceremony.⁹

The goal of most preventive and curative therapies performed by “Indian doctors,” diagnosticians, and herbalists is to address the social, physiological, and emotional imbalance of a person and members of his or her social network.

In this view, contemporary analyses of health are often causal. These cause-effect linkages are frequently said to impact many acute and chronic health conditions. Some health problems have observable causes, while others do not. Similarly, some health situations may be traced to accidents or mysterious circumstances.¹⁰ Mystery may be perceived as a sacred, willful, and humanly uncontrollable power or object that may at times aid in the creation of social system violations. It is not uncommon to hear parents state that when a child cuts her foot while bicycling without shoes, the child or her caretakers are deemed to be responsible for this injury. This episode is analyzed as a circumstance of visible causal relations. These same parents may also attribute this accident to the improper social behavior of the victim or her kin, or to mysterious causes. Because each action may create a distinct reaction, astute members of this tribe learn to make connections throughout their lives. Not everyone chooses to react in similar manners to a situation; distinct, deliberate approaches mirror the varied actions of the primordial beings, or First People.

Arizona

Unlike California, tribal members in Arizona reside on and near a “suburban” reservation, in close proximity to a city. Everyone interviewed spoke English and Spanish, and at least eleven of these individuals were trilingual, also speaking their Native language.¹¹ Like their neighbors to the west, almost all

the individuals from Arizona say that they practice both their Native and Catholic religions. Two exceptions are members of Protestant denominations. Senior Center clients tend to be retirees; they are former agricultural, manufacturing, or domestic laborers.

These seniors often proclaim that their diets have changed little since their youth, although more hunted meat was reportedly eaten in the past. Diets tended to consist of store-purchased foods and items grown in household gardens. The population density and size of this reservation seem to constrict individual or collective agricultural practices. Wild foods, such as cactus fruits, are still collected for personal use and sometimes traded, given, or sold to other seniors.

Traditionally, members of this group shared many illness etiologies with tribal people interviewed in California. All illnesses had causes, and multiple etiologies were commonplace. Treatment was provided by lay individuals through prayer, ritual song, dance, vows, and/or herbs. Professional herbalists, divinely inspired healers, masseurs, saints, and guardian spirits also assisted the ill members of their social networks. Health in all its facets was and continues to depend on familial support and care. According to Senior Center clients, social, emotional, physical, or spiritual isolation greatly contributed and continues to contribute to unwellness.

Health Care Resources

Both in California and Arizona, tribal members have many treatment options from which to choose. Most utilize medical providers associated with local community-operated programs and Indian Health Service facilities. People also seek the care of practitioners associated with Veterans' Affairs hospitals, urgent care units, and private practice physicians. In California, health maintenance organizations were also used. People often obtain additional assistance from lay persons, clergy, herbalists, masseurs, or "Indian doctors" or healers. It is not uncommon for individuals to utilize several health care systems at once. One Arizona woman, Cora, in her mid-sixties and diagnosed with diabetes approximately twenty-two years ago, regularly attends the tribally operated senior diabetes clinic, receives additional aid from a general practitioner contracted through her tribe, and uses a ritual masseuse.

The Indian Health Service has operated a variety of diabetes prevention projects throughout the United States since 1979. People with whom I had contact in California were able to receive care from an Indian Health Service contract branch clinic operated by a consortium of reservations. This clinic offers dental, medical, social service, nutritional, psychological counseling, and pharmaceutical care.

In contrast, Arizona tribal members with whom I had contact had access to services operated by the tribal health department. The tribal health department employed nurses, social workers, psychologists, and community health workers. All other needs were referred to specified contract care facilities. These programs offer those with diabetes their only direct contact with doctors associated with the tribal health care delivery system.

MEDICAL PERCEPTIONS OF INHERITANCE, GENETICS, AND DIABETES

Basic scientific assumptions about genetic inheritance equate this idea with biological heredity. Yoxen asserts that constructions of biological heredity depend on the ability to perceive organisms both as individuals with distinct characteristics and as members of sets of like individuals. If all organisms were regarded as utterly distinct, or as similar in all essential respects, it would make little sense to try and explain patterns of resemblance between them.¹²

Other analysts view the body as divided into minuscule discrete parts rather than as a whole entity or a human being.¹³ Genetic mechanisms serve as bodily codes or texts that may be interpreted in distinct manners by different individuals.¹⁴ Various constructions of genetic diseases are continuously negotiated and described by groups of research specialists who offer their knowledge to clinicians. Information about genetics and associated conditions may be distributed in a variety of forms such as journal articles, videos, or educational forums. These interpretations are purportedly reassessed by clinicians and then dispersed to clients and sometimes members of their health and social support networks as scientific, value-free, and authoritative information.

From 1993 through 1995, The Indian Health Service distributed the *IHS Physician's Introduction to Type 2 Diabetes*¹⁵ and its *Standards of Care* to diabetes control officers and coordinators¹⁶ in each of the twelve Indian Health Service area offices.¹⁷ In California, all Indian Health contract facilities are annually sent these items as well as patient education curriculums.¹⁸ According to one of the authors, this "concise booklet" was developed in order to: (1) familiarize providers with American Indian experiences of Type 2 diabetes; and (2) standardize diabetes treatment practices.¹⁹ In California and throughout the nation, Indian Health Service staff attrition rates are relatively high, with the average stay of doctors approximately two years. The authors considered this book to be an orientation aid. Tribal health employees in Arizona who are community members claim to be unfamiliar with *IHS Physician's Introduction to Type 2 Diabetes*. Instead, they read *The Diabetes Forecaster*.

Based on twenty years of medical and epidemiological research with members of the Pima tribe of Arizona, the 1993 guide defines Type 2 or non-insulin dependent diabetes mellitus (NIDDM) as a "genetic disorder characterized by insulin resistance and subsequent relative deterioration of insulin secretion.... Recent studies suggest that insulin resistance is inherited in a codominant fashion."²⁰

The "thrifty gene theory" embraced by the majority of Indian Health Service doctors and nurses argues that myriad indigenous populations underwent feast and famine cycles.²¹ A so-called thrifty gene would have a selective advantage, increasing the body's ability to store fats to be metabolized later during times of food shortages. This gene purportedly becomes detrimental with a more consistent food supply high in sugars and carbohydrates in association with decreased physical activity, weight gain, and obesity.²² Data suggest that the Arizona Pima may increase their risk of diabetes if the mother or

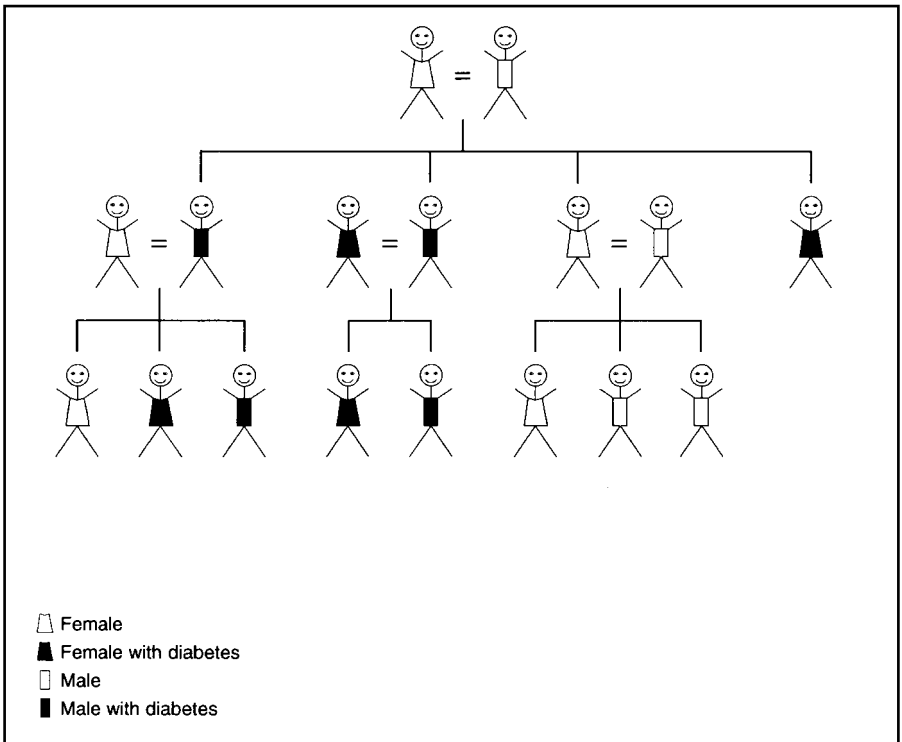
both parents have diabetes, in addition to a personal high waist-hip circumference (see fig. 1).²³

The 1993 and 1995 *Indian Health Service Introduction to Type II Diabetes* guides both note that environmental factors including obesity, age, family history, blood quantum, impaired glucose tolerance, and a parental or personal history of gestational diabetes purportedly increase an American Indian's risk of developing diabetes. In the 1993 physician's guide, genetic processes are represented as the central feature of this mixture. Environmental components are described as elements that interact with genes in the development of Type 2 diabetes. However, in the 1995 general providers' guide, a model of diabetes represents genetic tendency, inactivity, obesity, and levels of insulin in blood as discrete factors that all aid in the development of insulin resistance.²⁴ Ideas about genetics and diabetes are partially updated through a packet distributed to physicians in California as part of their ongoing "orientation," including articles on the pathogenesis of diabetes that decree the significance of genetic events.²⁵

PROVIDERS' EXPLANATIONS OF DIABETES AND GENETIC PROCESSES

Figure 1

Providers' Perceptions of Diabetes Inheritance



Providers communicate American Indian genetic predilection to diabetes in two ways: through verbal interactions with clients and through the distribution of written materials. Although each facility has its own education programs and protocols, the *Physicians' Guide* states that "it is very important that all health care providers have the same message for the patients."²⁶

During a visit to the California clinic in 1996 I asked a physician to explain the relation between diabetes and genetic inheritance. This doctor said:

I usually say [to clients], if there's a lot of diabetes in the family, there is a predisposition to get it—that's genetic. [Through] dietary habits and care for one's self, they may never get it, but if they do, they can control it. The genetic part of it is—if a lot of family members have it the [clients] are more predisposed.

And obesity [has a role]. A couple of 100 years ago it was good to be able to put weight on in a hurry. It was good to have low metabolism. If a person had that ability, she could survive. The skinny ones died. It was good 100 years ago, but not now with unlimited fast food.

This explanation demonstrates a linkage between genetics and what is often referred to in the Indian Health Service-sponsored literature as environmental factors. Dietary habits are often felt to be especially critical by providers in California and Arizona, who note the connection between obesity and the consumption of carbohydrates, sweets, and fast foods among their clients. According to practitioners in California and Arizona, this situation is exacerbated by limited exercise and physical activities performed by adults, especially women.

Physicians are requested by Indian Health Service diabetes control officers and coordinators to inform their patients that diabetes is a disorder in which the body is unable to use food properly. Requests are also made for providers to teach clients, among other things, the ways in which family members can prevent diabetes.²⁷ Apparently, no mention is made to providers to tell their clients that diabetes is genetic or that diabetes is inherited genetically.

In addition to informing their patients verbally about diabetes, providers distribute a variety of written materials, which are generally in English and designed for national or regional distribution. These items are rarely developed for a particular ethnic, age, or language group. Pamphlets, flyers, and books are usually geared toward the fourth- or fifth-grade reading levels. The authors of these materials often link the onset of diabetes to food consumption and physical activity and focus on symptoms and treatment methods, such as food preparation and choice. Passages about diabetes etiologies are also included. *Diabetes and American Indians*, found in clinics in Arizona and California, explains that diabetes "is mainly due to changes in eating and exercise" and is attributed to high blood sugar, which according to this text,²⁸

you are more likely to get ... if you are heavy,... inactive, over age 30, have family members with high blood sugar, had high blood sugar during pregnancy.

... Brothers, sisters and children of people with diabetes tend to get high blood sugar.

Doctors, nurses, dieticians, and community health workers distribute other education tools with similar information. California providers with whom I have had contact claim that they discuss the ideas expressed in these materials with their patients. During the few clinical encounters between health professionals and patients witnessed by the author, providers did not distribute written materials.

Nurses and community health workers in Arizona tended to hand out items during diabetes clinics. Sometimes information was discussed at the individual level, while at other times groups of ten to thirty people were asked if they had any questions. In such situations, questions rarely arose from the participants. Similar scenarios occurred when health care presentations were made one to two times per month by guest speakers. These rarely generated public inquiries made by members of this ethnic group. Instead, individuals tended to make public responses in the form of declarations and commentaries; Native people saved their questions until after the presentation in one-on-one or small group interactions.²⁹ For instance, a diabetes educator who is a member of this tribe made a presentation about the interaction between dietary practices and blood sugar levels. During and after the slide presentation comments by lay audience members such as “I love to eat” a particular food were made. However, no questions were asked by the audience. Later, almost all the people in attendance approached this presenter and made inquiries about ways to obtain and prepare a variety of foods.

Written health education materials that I have seen circulated among American Indian lay people do not use the term *genetic*. Instead, diabetes is reported to “run in families.” The term *genetic* is used by some providers and is found in public health and medical literature. In these forms, *genetic* is a synonym for biological inheritance. Users of this social construct seem unaware that lay explanations of the term encompass additional and varied meanings.

LAY EXPLICATIONS OF GENETICS

Among Native people interviewed in California, diabetes is often reported to be genetic or inherited. In this vein, these terms refer to an object, idea, or condition that is passed between or within generations. Since interviews were open-ended and unstructured, not everyone discussed diabetes etiologies. Due to the nature of these interviews, people had the opportunity to discuss more than one cause of diabetes.

As in Arizona, members of this California tribe also may associate the onset of diabetes with weight gain,³⁰ collective dietary changes of the past century,³¹ and/or alcohol consumption. Aging is thought to be a possible cause of diabetes by certain people interviewed in California.

Although several people in California claimed that pancreatic disruption is a function of diabetes, only one woman, a diabetic from Arizona, reported that her pancreatic malfunction caused her diabetes. Another person in

Arizona stated that pollutants contributed to diabetes. A daughter of a former cancer patient said that tumors caused diabetes. And only in Arizona did individuals assert that they did not know what caused diabetes, but two seniors from Arizona with diabetes did not respond to this question.

Diabetes was also attributed to emotional conditions. In California two people said that stress and depression, provoked by pressures to perform numerous activities, caused diabetes. In Arizona, two people claimed that stress, depression, frustration, and fears related to social isolation caused diabetes.

People from both states felt that diabetes has multiple causes. For instance, it may be perceived to be affected by genetics and weight gain. In total, individuals from California mentioned five causes of diabetes, whereas people from Arizona noted eleven different causes. Clearly, Arizona seniors have relatively more idiosyncratic perspectives of diabetes causation than do people in California. Table 1 shows the diversity of etiologies described by interviewed individuals from California and Arizona.

In California, the *biological* consequences of diabetes are frequently mentioned by lay people with reference to genetics. Yet this term appears to be quite confusing. A person may state during an interview, "diabetes is genetic," but within minutes the person will then inquire "what does genetic mean"? The speaker will inevitably follow this question with the message that diabetes

Table 1
Lay Etiologies of Diabetes³²

Causes of Diabetes	California Natives		Arizona Natives		Total
	Diabetics		Diabetics		
Weight gain	12	13	2	1	29
Inheritance	11	33	5	2	51
Emotions	1	1	1	1	4
Aging	2	2	0	0	4
Alcohol	4	8	0	1	13
Diet	17	21	5	4	47
Don't know	0	0	2	2	4
No response	0	0	2	0	2
Pancreas	0	0	1	0	1
Pollutants/					
Pesticides	0	0	0	1	1
Tumors	0	0	1	0	1

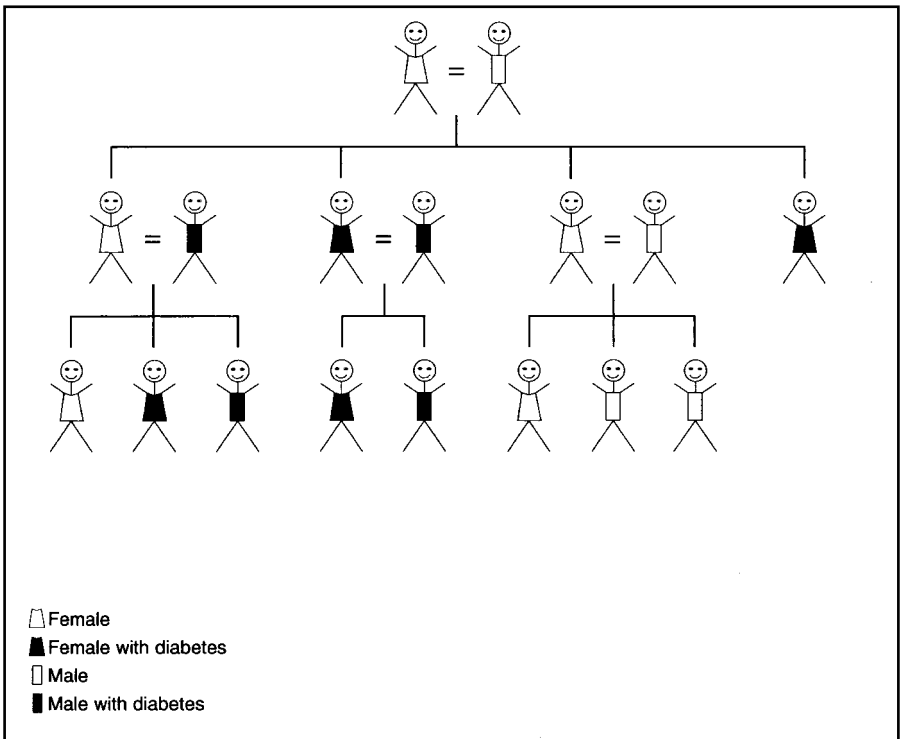
*Responses by those who have diabetes are in bold lettering.

is, according to doctors, inherited. Indeed, four people who have and five people who do not have diabetes mentioned the biological transmission of this condition. Twenty-nine individuals, seven of whom are diabetic, as well as seven others from Arizona, feel that diabetes “runs more or less through families” (see fig. 2a). On the surface, this view mimics that of the health education materials; in-depth interviews reveal a wealth of information on this notion. One woman claims, “diabetes is something [the doctors] say is inherited, it’s something we can get if all our ancestors, or all our family has it.” Other people propose that even if one ancestor has or had diabetes, this illness may be passed to members of the next generation.

Diabetes is thought to pass from members of one generation to the next and is viewed as similar to a viral contagion spreading through the populace. Indeed, diabetes is sometimes called “contagious” because it may be “caught” from a family member. In this context, contagious refers to something that is easily passed from a person in one generation to an individual in the next generation.

Diabetes is also perceived to have a *social* basis for inheritance. Social lines are said to bind people between and across generations through blood, marriage, and adoption. In addition to those people who believe that diabetes “runs in families,” four people without diabetes note the relationship between familial ties and the advent of diabetes. The idea commonly espoused that “all

Figure 2a
Lay Perceptions of Diabetes Inheritance

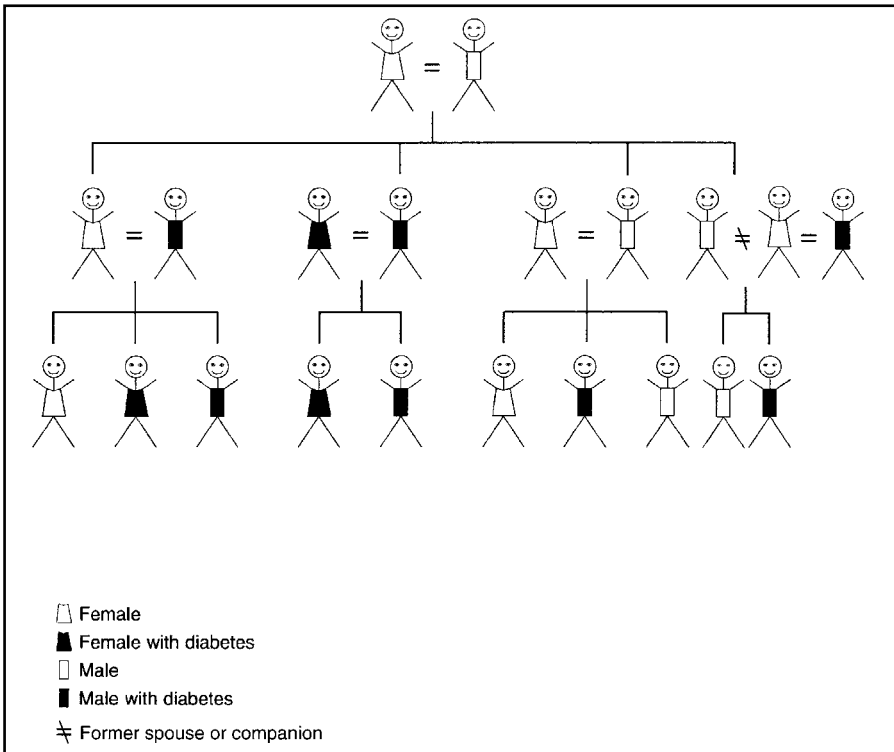


[members of our tribe are] related somehow,” suggests that “if one person has [diabetes], you’re gonna get it.” Diabetes is considered to be quite commonplace. Sometimes this condition is clustered among members of a social geography; other times diabetes appears to be scattered throughout the group. The transmission of this condition is linked to collective social ties (see fig. 2b).

These social aspects are represented by individual and communal perceptions of identity. Individuals who believe that “to be Indian is to be diabetic” (to quote one man in California) assert a symbolic identification with American Indians throughout the nation, but more specifically with the collectivity of other tribal members. Ethnic relations become entwined not merely with physiological markers³³ but also with invocations of distinct history, lineage,³⁴ and immersion into the nation state.³⁵ One elder, Margaret, is the only one of nine siblings who does not have diabetes. She and many of her peers feel that diabetes is partially a result of being economically, politically, and socially dependent upon outsiders. Margaret claims the major problem, health or otherwise, among members of her reservation is:

a lack of proper nutrition due to economics. If you only have three dollars in your pocketbook, you’ll probably go buy potatoes and flour

Figure 2b
Lay Perceptions of Diabetes Inheritance



and maybe that will feed your family for five days.

I think [diabetes is] just a weakness of the system to me of digesting processed food. I think there's definitely ties to the modern times of packaged food. In my grandmother's time they were eating wild, they were eating rats, birds, they were eating possums, wild things. I think this was in the 1860s when they started bringing food and Indians were sent to the reservations.

In this perspective, the advent of diabetes is linked to communal dietary changes. Stories about the relationship between food, politics, and history are repeated during anthropological interviews as well as during conversations among band members of different generations.

Social bonds concerning diabetes are partly framed by health circumstances that are delineated by medical providers who initially make diabetes diagnoses. If, as another person claims, "very few people here [on my reservation] can say they aren't diabetic," then issues of medicine, illness, and well-being perceptually link one person to another. These bonds are both infiltrated by and embrace changes in the health status of group members. For instance, those with diabetes may discontinue certain jobs such as farming and domestic service due to neuropathic damage. These same individuals may instead babysit grandchildren, nieces, and nephews. Households may expand or contract as chores shift. Modifications in employment, household responsibilities, and residence reflect the fluidity of these social networks.

The intergenerational transfer of diabetes purportedly also has *cultural* components. Interest in and taste for foods are said to be acquired by seven persons, three of whom have diabetes. Arizona seniors frequently agreed with this notion. Knowledge of diet and food preparation is also thought to be learned. In the California population, beef, potatoes, rice, tortillas, tacos, enchiladas, and "sweets" are all publicly acknowledged by those with diabetes as desired foods. Favored luxury food items reportedly include deer, rabbit and wood rat, acorn, and particular wild mushrooms. In Arizona some of the favorite foods of the interviewed seniors include wild spinach, flour tortillas, enchiladas, potatoes, beans, sodas, candies, and cakes. Foods such as jackrabbit and cactus fruits are also extremely well liked but sometimes difficult to obtain due to physical infirmities and collection restrictions.³⁶

The views of many men and women, non-diabetics and diabetics alike, are reiterated by one woman's description of diabetes: "Bad food habits, I think that's what it is. They say it's inherited, right? You inherited it from your mother. Well of course, you watched your mother cook and all the things she gave you to eat, and now you serve yourself that and the kids that. And they say it's inherited. Yes, it's inherited that way." In this context, susceptibility to diabetes is learned from members of prior generations. One does not inherit diabetes *per se*, but rather one inherits the dietary habits that increase the possibility of developing diabetes. Teaching cultural knowledge is part of the pathway of diabetes. Elders pass down recipes, and youth use these recipes. Nathan is a California man in his mid-fifties who has had diabetes for more than ten years. He asserts that diabetes is clearly linked to the cooking and eating practices of family members. One day he offered a recipe for breakfast and for impending diabetes.

You grew up eating tortilla rolls and fried potatoes, and you fry bacon. You get out the bacon, you leave your grease in there and you fry your potatoes in the bacon grease, when they're fried, empty the grease into another pan, put a lid on that pan of fried potatoes and let the grease roll off into another pan and you fry your eggs. So your eggs, potatoes, and bacon are all cooked in bacon grease. That starts from day one.... Oh, does that taste good!

Four elders from one reservation discussed another "cultural factor" that purportedly contributes to the onset of diabetes. These two men and two women described the importance of serving food to guests and the demonstration of respect offered by guests who accept such food. Those with diabetes often find themselves in difficult situations. They do not want to feel physically sick by consuming certain foods, yet they do not wish to place themselves or their hosts in cultural or spiritual jeopardy by refusing food. Earl, who has had diabetes for more than twenty-five years, remarked that even when "you stick to your diet, someone hands you a candy bar and you feel you can eat it, cause he *gave* it to me. You can eat a candy bar, but just a bite of it." Gifts of food are offerings. To refuse food is insulting. Many other people taught me this lesson, but only these elders verbally linked this cultural more to the advent of diabetes (see fig. 2c).

The intergenerational distribution of knowledge is apparently one of the pathways of diabetes. Inheritance also involves biological and social modes. Importantly, these lay models of inheritance stress transmission from one person, or whole being, to the next. This view differs from that of the Mendelian slant, which describes the passage of coded messages created by and delivered to body parts. None of the providers with whom I spoke were aware of these multifold interpretations of inheritance by their clients. Clients' assumptions about inheritance apparently are not shared with providers.

SOME ROOTS OF COMPETING REALITIES

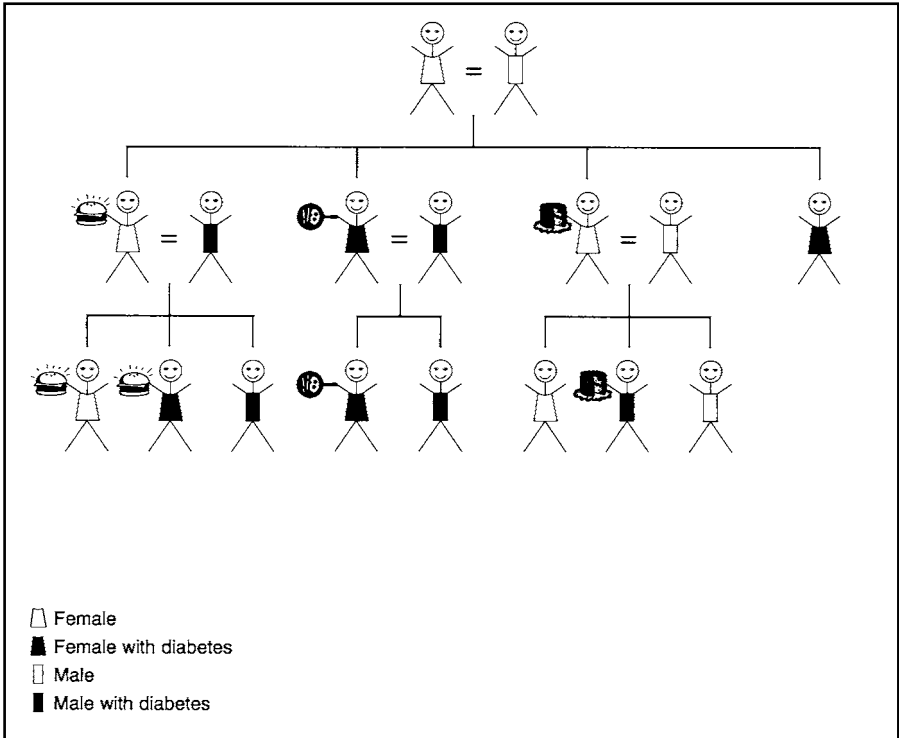
What might account for these seemingly subtle differences in understanding and expressing the transmission of diabetes? Numerous factors may contribute to belief systems; however, two interconnected possibilities are considered: health care communication practices and education approaches.

Communication Practices

Many sociolinguists have noted the differences between physician and client communication practices. Providers and their clients tend to form two speech communities. Agreement on the interpretations of words and associated social values may be limited.³⁷ This disagreement may be due in part to the marginalization of social contexts during patient-provider interactions.³⁸ Discussions between providers and patients about food preferences and preparations may occur, although talk about associated cultural meanings and behaviors may be absent.

In some cases, efforts may be made to incorporate cultural information into a medical encounter. One physician from California suggested to a dia-

Figure 2c
Lay Perceptions of Diabetes Inheritance



betic patient, Joy, that she attempt to lose weight by forgoing some of the food on her plate. “In your tradition,” he remarked, “you leave some [food], a little offering, you don’t have to lick your plate clean.” Interestingly, Joy, who was in her mid-seventies, countered this statement, responding that this task was “kind of hard after all these meals and years.” Joy was not asked why she considered this approach to be difficult. The provider assumed that his understandings of local cultural practices might be a means to solve a problem; the cause of the problem, as defined by the patient, remains unclear. In this way, the patient’s thoughts are disregarded by the earnest attempts of this physician to include his perceptions of local cultural practices into the medical encounter.

Bewilderment on the part of both parties may exist as a result of conversational flow. Medical practitioners generally control information exchange through their manipulation of topic shifts.³⁹ Prior studies reveal that during medical speech events women and ethnic minorities rarely direct the flow of communication.⁴⁰ When the patients’ speech is interrupted by a provider’s topic shift, there may be two consequences. First, like Joy, the views of patients may be neglected; this situation eliminates what the patient may perceive as useful information from the conversation.⁴¹ Second, topic shifts, especially relatively rapid ones, may disrupt the ability of a patient to explicate an idea

or term, such as genetics, posed by a physician. Confusion may be increased if the provider and patient do not speak the same native language.

According to lay individuals, miscommunications occur when unfamiliar terms are not clarified, diagnoses are not precise, and details are not offered. "Sometimes," one woman explained, "you have to go look up terms in the dictionary or ask [another] person." Physicians, even when attempting to translate medical jargon into lay terms, have a tendency to frame their ideas in complex professional language.⁴² In some cases, terms are understood by participants in a dialogue but topics are incongruent. At other times, similar vocabulary may be used, such as the word *inherited*, but meanings are not shared.⁴³ If participants in a speech event are unaware of linguistic and cultural differences or methods to mend splits, disjunctures will continue.

During interviews, physicians in California report that they often ask clients if they understand what is being taught. One doctor relates that after his explanations, he often requests clients to state in their words what he has said. Frequently blank stares are the response. Unfortunately, even if patients understand directives, providers may not be able to interpret the cues of silence or gaze made by clients. Silence may mean many different things. As used by local elders, silence may represent agreement with a statement, or it may reflect utter confusion. Health care practitioners may also not recognize that comprehension of treatment directives by clients does not infer mutual understanding of underlying meanings of cause and/or therapy.

If a client is stumped by a provider's ideas, the hierarchical nature of their relationship may sway clients from making inquiries. To do so might displease the practitioner.⁴⁴ Among many California and Arizona Indians, it is considered improper behavior to question people directly who offer knowledge and assistance.⁴⁵ However, according to many interviewed Californians about fifty years of age and older, it is deemed appropriate to ask questions to garner precise explanations about information offered by practitioners.⁴⁶ This situation reflects the status attained by these older persons.

In his study of Bengali health care complaints, Wilce explains that nonwestern patients rarely expect an egalitarian relationship with their providers.⁴⁷ Historically, the health care specialists of tribes in California and Arizona were considered to have distinct expert knowledge.⁴⁸ Other Natives considered tribal healers to be very powerful people. The authority of these individuals has been and continues to be represented by their ability to direct the health care encounter. Verbal input, especially in the form of patient inquiries or challenges, may be frowned upon or considered culturally irrational by clients. Even though power may not be evenly distributed in this relationship, providers and patients shared and continue to shape broad cultural knowledge, language, and associated goals. Medical personnel who have "earned power" through evidence of training and healing will frequently be accorded polite behaviors that often include client silence and reticence. Individuals in Arizona often report that they have "trust in the doctors and the pills and shots for diabetes." This view is shared by others in Arizona and California who frequently contend that diabetes is a relatively new ailment, mainly diagnosed and treated by physicians.⁴⁹ In this context, trust and confidence are established and maintained through provider

demonstrations of efficacious care, not necessarily through verbal skills.⁵⁰ This stance may reflect shared health care objectives but divergent linguistic and cultural orientations, whereby clients entrust their bodies to others in order to alleviate suffering.

Professional Education Approaches

The construction of competing realities may be due to the separate reasoning and language methods that professional and lay individuals employ, which are influenced by informal and formal education. Indian Health Service providers have undergone years of medical training in which the culture of biomedicine is espoused and ingrained. Through observation, interaction, memorization, and discussion, medical students learn medical categorizations. Body parts, functions, and conditions are classified through sequenced lists and contrastive modes.⁵¹ This education enables students and providers to develop images and associated contexts to which lay individuals are rarely privy.

Unlike the overwhelming majority of their clients, these practitioners have access to distinct expert and lay language and thought systems.⁵² In clinical practice, doctors and other health professionals have access to jargon and data that are perpetually updated in relation to new medical procedures, technologies, and research. I interviewed physicians who report that they draw on medical literature and their experiences as both providers and as possible patients throughout the course of their training and practices in order to enhance their practices.⁵³ Unique experiences lead to varied interpretations, insights, and guidance. Four doctors who participated in the interviews, two of whom are of American Indian descent, are career public health service physicians. They use the knowledge gained from their work with members of other tribal and rural communities to care for their patients. In fact, these doctors may be rather unique in that three of them have traveled and worked throughout the United States and other nations. Experiences and interpretations of cultural, social, and medical variation expand the knowledge bases of these doctors, who use this information to resolve clinical problems.⁵⁴ One doctor said:

Since I was a little kid I just was intrigued in far away places with strange sounding names—kind of the anthropology of human experience and other cultures, and so actually I traveled a lot around this country when I was younger and I took a year off from medical school and traveled around the world—going to many different cultures in Africa and Asia—that just whetted my appetite that the Western model is not the only way of living—there’s a lot of advantages to it ... but there are many other ways to live.

All of the providers I interviewed perceived socioeconomic conditions as partial influences upon diabetes treatment approaches. They frequently cited poverty, limited infrastructural resources, household size and density, and substance abuse among community members as factors that may affect the health of an individual. Yet I did not observe health literature or talks direct-

ed toward clients that focused on socioeconomic, cultural, or historical conditions.

Practitioners may be able to grasp and empathize with some client language and cultural beliefs. For example, agreement on diagnoses and the utility of a particular therapy may exist. However, the ability to switch between professional and lay languages does not infer that all underlying meanings will be expressed or shared.⁵⁵ This situation may reflect the ability of medical workers to learn parts of lay health languages, but not have full immersion in such. These providers have, as Lave and Wegner note, learned to talk about a subject but not always within a subject. This mode may unwittingly increase the transmission of skewed information by speakers.⁵⁶

Lay Health Education Resources

Lay health care training about diabetes may take many forms. In addition to interactions with medical practitioners, some people claim to read popular and public health literature. Others obtain information from radio and/or television programs or forums and conferences on diabetes. The most common educational method is discussion with and observations of extended family members, neighbors, and members of the tribe. In particular, conversations with and observations of diabetics who have visible symptoms are reported to be a major source of pertinent information. These individuals become teachers who engage others in a communal experience of education.⁵⁷

Bits and pieces of information garnered over a number of years mixed with commonsense cultural knowledge generally forms the experiential model of lay individuals.⁵⁸ This model includes empirical evidence noted by lay persons. Among individuals in California, diabetes information is generally requested in order to solve a particular problem.⁵⁹ For instance, a person may display concern about dizziness or "the shakes." Personal therapeutic approaches are then created or this knowledge is integrated with previously obtained information. People who do not have diabetes tend to acquire knowledge about diabetes during conversations with and through observations of diabetics.

In California, only one of thirty people with diabetes interviewed stated that she initiated a conversation with a biomedical provider concerning the causes of diabetes. Nevertheless, physicians offer etiological information in the context of treatment descriptions. The apparent objective is to link the cause of diabetes to its control, much in the same vein as in the literature. This information is not necessarily offered so that clients have a part in treatment decision-making, rather so that patients may be more easily persuaded to pursue a particular treatment approach.⁶⁰

In the case of diabetes etiologies, doctors often employ physiological explanations while lay people are more likely to describe life events that might have made them the target of an illness.⁶¹ Clients and their families often discuss the meanings and circumstances of their experiences.⁶² Indeed, as Jennie Joe has stated, providers frequently offer mechanistic data about *how* diabetes

may develop, while patients and family often describe causal information regarding *why* it develops.⁶³ Both types of explanations are rooted in the distinct cultures of the speakers. Providers initiate discussions of genetics and inheritance as vehicles for care options. Patients and their family members address genetics and inheritance as part of personal, collective, and cultural stories and histories.

Lay understandings of technological and medical terms may be incongruent with scientific meanings if the ideas have no strong foundation in daily experiences.⁶⁴ As a participant in Emily Martin's study of the immune system aptly noted, lay people are not included in the conversations of scientists.⁶⁵ Thus, many people reinterpret ideas based on historical and cultural experiences.⁶⁶

Inheritance may have biological, social, and cultural components because interpretations of these terms are based on lived experiences. Coupled with statistical and observational evidence that, as one person claims, "diabetes is an Indian disease," diabetes and its causes are not surprisingly linked to local histories and cultures. In this perspective, diabetes is an illness that members of a group may have, share, discuss, teach, and live; it is not merely a biological condition influenced by social features.

CONCLUDING REMARKS

I contend that these differences in perceptions espoused by providers and their American Indian clients are due in part to attempts by health professionals to assert authoritative control. According to Jordan, authoritative knowledge, frequently disseminated by those who control a dominant power base, is considered to be information that is objective, convincing, natural, official, notable, and consensually constructed.⁶⁷ Providers argue that biological explications of genetics and inheritance are the foundations of diabetes causation theories and treatment approaches. Genes and the environment create problems for individuals' bodies. Providers appear to propose such arguments for altruistic purposes; health professionals, believing in their version of truth, feel patients will be healthier if they understand the causes of their illnesses.

Lay people develop alternative models of diabetes causation, thereby partially revamping medical control of health care knowledge. In some cases, people appear to accept the views of their providers. In other cases, clients seem actively to resist and reinterpret ideas espoused by medical practitioners. In still other situations, lay and professional people have translation problems. Breakdowns in the communication process encourage both providers and patients to create and adhere to separate truths. Lay people think and act in a variety of manners. When lay individuals try to understand genetics and inheritance, they give expert knowledge legitimacy but not complete authority.

Providers may attempt, though not always successfully, to render their knowledge authoritatively to clients. Indian Health Service diabetes researchers, control officers, and coordinators distribute data about Type 2 diabetes, presenting it as value-free, official facts. As the Indian Health Service

declares, all providers are to deliver similar messages concerning the etiology of diabetes. Providers associated with the Indian Health Service do not seem to question openly this purportedly objective and expert knowledge. These practitioners tend to disseminate etiological descriptions as produced and disseminated by the Indian Health Service. Providers who discuss genes and genetics with patients may be, in a way, quite individualistic in a bureaucratic system. Whether or not these communication approaches are truly isolated remains to be clarified by additional research.

Diabetes is a medicalized condition. It is an illness that is labeled, defined, diagnosed, and treated by medical professionals. In their efforts to explain diagnoses, prognoses, and treatments to clients, Indian Health Service providers must intellectually and physically mediate the relationships between technology and bodies.⁶⁸ A hierarchical arrangement certainly exists whereby patients are offered parcels of information to aid them to control blood-sugar levels and associated metabolic conditions. However, the providers in this project seemed willing to share additional knowledge with their clients. The former are willing to answer questions, and the author has witnessed that they will occasionally negotiate therapies. Clients rarely initially informed or developed diabetes treatments. Instead, providers rely on patients' views and behaviors as guides in the management of therapies. Perhaps due to their training,⁶⁹ these providers seem not to realize that some clients wish to participate in therapeutic decisions.

The hierarchical nature of diabetes care becomes compounded by verbal impasses. Health care professionals are prone to obscure causes and associated solutions in technical language, thereby consciously or unconsciously exerting the need for additional technical and expert assistance.⁷⁰ Control is thus still exerted, even though it may be expressed in an empathetic or friendly manner.

Lay responses to diabetes etiologies are diverse. Etiological sources are based upon technological screenings, the results of which are used by providers for diagnoses. Clients and the general health service population tend to consider technological data to be reliable and authoritative.⁷¹ For instance, urine and blood tests that reveal diagnoses are rarely doubted. Only one person interviewed refuted a medical diagnosis of diabetes. Months later this test, done in a local hospital, was also rebuked by Indian Health Service personnel. Nevertheless, clients, especially in California, counter the absolute influence of authoritative knowledge concerning diabetes causation through the creation of parallel or opposing knowledge. They cast doubt upon and, at times, redefine medical expertise. People interviewed in California in particular actively and consciously produce, validate, and distribute ethnically and culturally based etiologies. Ideas about inheritance are reshaped in an effort to demystify the talk of medical professionals.

Perceptions of inheritance are embedded in individual and collective genealogies and culture. As the anthropologists Garro and Lang, who worked with other American Indian communities, state,

Biomedical health care practitioners are important sources of information; lay accounts of health problems often draw on biomedical concepts and terminology.... [I]t is not the case that lay accounts of ill-

ness are simply impoverished biomedical accounts. Professional and lay models of illness develop to meet different objectives. Biomedical explanations of disease are geared to constructing a causal etiological model. Although lay accounts also address causal issues, they are perhaps more appropriately characterized as ways in which individuals attempt to make sense of the disorder that they are experiencing.⁷² Thus, individuals faced with illness develop explanations of how they have come to be that way, explanations which frequently range beyond the medical realm.⁷³

Indeed, both California and Arizona Indians tend to incorporate and reshape ideas and behaviors to fit into their lives and social identity. Personal and group dynamics of cultural, historical, political, and ethnic relations are reflected and, at times, forged.⁷⁴ This turn of events may illustrate community efforts to demystify and gain ownership of information and care.⁷⁵ Unlike the mainly middle-class participants in cancer and AIDS advocacy movements, Indian Health Service clients have little political, social, or economic clout on their health care delivery systems. However, assertions of locally and ethnically based social knowledge, intellect, and history provide a basis for ownership of the illness, the etiology, and the treatment.

Lave and Wegner explain that individuals create identities that are influenced by participation in a community of practice. People obtain the abilities to exchange information both about a topic or practice and within the topic or practice. With the latter, a person acquires, through stories and community lore, ways to engage, focus, and coordinate approaches of communal memory, reflection, signals, and membership.⁷⁶ Similar to medical students involved in schooling,⁷⁷ lay people whom I interviewed are all participants in a communal understanding of diabetes. People gain a form of ownership, not merely as “people who have diabetes” or relatives thereof, but as those who create, shape, and/or comprehend local and shared views of etiologies. For certain individuals, from these ideas of causation, theories of treatment are established and/or understood. For some, the situation may resolve a frustration with the inability to control or cure their diabetes. And, if biomedical experts cannot cure diabetes, why should they have intellectual ownership over this condition? As Margaret suggested, ideas about diabetes may be based on social interactions between members of her ethnic group partly because medical resources can only alleviate problems—they cannot resolve them. This woman maintained:

I think that's there's so much of [diabetes] it's not unusual for someone to come across another and say, “How are you?”

“You know I've got diabetes.”

And they're young, maybe in the twenties....

Myself, I don't go to the doctor and how would I typically say that? Cause I'm not interest in suppressing symptoms. Now if I crushed the tip of my finger here and it wasn't gonna work anymore I'd go to the doctor and have him cut it off or do whatever had to be done. I'd always do that, but I wouldn't be interested in having it hang there and take pain killers and aspirins and stuff that's going to—it's still there, but it's not cured.

I think maybe that's the part that hasn't convinced my people, they're not cured. But you could go to some wise person, and there's a lot of people that just talk to one another and minister to their mind and let them know they're all right and yet they could feel well.... I think the experience [with doctors' treatments of diabetes] is pretty well repetitious and ... I don't think [my relatives] really see any hope of change.

Lay explanations expand upon the medical sphere, but people can only negotiate data to which they are exposed. Garro and Lang contend that most of the individuals in their diabetes studies were "well informed about standard medical explanations."⁷⁸ Perhaps due in part to the prevalence of diabetes among American Indians, individuals seem willing to participate in medical discourse. Indeed, American Indian people in California pride themselves on their abilities to negotiate cross-cultural information and their associated meanings and behaviors. Remarks about etiologies are often made in assured and declarative tones. In contrast, in Arizona a sense of bewilderment was common when discussing diabetes etiologies. Several seniors commented that they rarely ask their providers to explain confusing terms or ideas. I have observed that in group settings, health care inquiries tend to be made only in the hearing of adopted or biological relatives. As Cliff Trafzer notes, these individuals may not wish to expose their ignorance to a doctor or to anyone else.⁷⁹ Perhaps for this reason, one woman claimed that "we all have diabetes and we don't even know where it comes from."

Some people may actively resist or reinterpret the beliefs of medical providers. As often, lay individuals do not understand the language, ideology, and culture of providers.⁸⁰ The former thus explicate and expand upon terms and ideas. Medical and scientific views of genetics are not always reproduced by clients. Technical knowledge which is not directly and observably tied to efficacious diabetes screening and care is not necessarily equated with fact or authoritative information. Limited access to scientific and medical discourse through literature, lecture, and conversation obstructs public understandings of medical constructs of genetics and inheritance.⁸¹ Communication becomes disrupted when sociocultural knowledge and linguistic tactics are not shared.⁸² Clearly those interviewed in Arizona are restricted participants in medical discourse. The case of genetics and inheritance partially represents an error in translation. Within this context, ideas about genetics may be a consequence of diverse realities but not of realities in competition for authority. Significantly, although this paper has focused on genetics and inheritance, other concepts and terms that providers and clients use are often confusing to participants in health care encounters.

Discourse about diabetes and its etiologies embraces more than one language and system of knowledge. Both the professional and lay perspectives have truths based on "scientific" observations and trial-and-error experiments. Neither perspective is culture-free, and a key to understanding treatment objectives and courses relies on this "fact."

Treatment Implications

What impact do perceptions about diabetes etiologies have upon treatment practices? Many. For providers, ideas about genetics and environmental factors shape causation theories. Practitioners are able to separate their etiological theories from the therapeutic practices of clients. However, patients intertwine the causes and resolutions of health problems. Prior to the completion of this manuscript I informed several Indian Health Service-associated doctors and nurses of their clients' views. Although lay opinions were deemed by providers to be unique and even a bit bizarre, these perspectives were classified as pertinent to the health of clients and potential patients. These practitioners realize that individuals tend to develop strategies and enact procedures based on personal and group meanings of genetics.⁸³ Knowing this information, several therapeutic situations should be addressed.

Of major consequence is that people who have diabetes *do* utilize medical services. Lay persons consider medical perspectives to be meaningful. These perceptions seem to need cultural adjustments. Among these American Indians, medical treatments may be delayed and even altered by certain clients who insist that either the views of medical professionals are obscure or inaccurate or that lay etiological and treatment beliefs have value.

Thus, distinct constructs may partially influence the use of therapies. Interestingly, the acceptance of new belief systems and associated behaviors does not imply the abandonment of prior ideologies and actions among members of either American Indian community. For instance, among people in California or Arizona the use of insulin does not preclude the use of prayer or plant remedies as treatment methods. Perceived efficacy greatly influences choices. Medical pluralism expands the opportunities for beneficial outcomes, either immediate or long-term.

As Brooke Olson suggests in her article in this volume, one way to facilitate the management of diabetes is to create mutual understandings of different constructs. The overall objective is to share insights. It is not necessary for providers or for clients to forsake their diverse views. Instead, providers who will probably maintain dominance in the communication event should explain their views and encourage clients to do so.⁸⁴ The use of questions, diagrams, examples, images, and analogies by providers and clients alike will be helpful. For instance, providers might describe a term, such as insulin, and ask her client what she imagines that insulin does in her body. Conflicting messages proposed by one or several individuals should be clarified in order to deflect confusion and possible curtailments in care.⁸⁵ Perceptions of etiologies must also be tied to therapies.

Clients should also be requested to tell their stories. The allotted length of time for provider-patient interactions may curtail continuous in-depth discussion. However, even infrequent inquiries and probes by practitioners may provoke patients to state their opinions and reveal their life stories. Such information might be enhanced by limited interruptions on the part of providers. Moreover, practitioners need to reflect upon their personal and cultural biases and their possible impact on care. For example, a health professional might define a family as an individual, his companion/spouse, parents, and children.

In contrast, his client may assert that family includes everyone on her reservation and that is why if diabetes is familial, then diabetes onset is inevitable.

Numerous individuals, those with and without diabetes, have stated that they desire additional resources about diabetes. Information in the forms of literature, support groups/talking circles, videos, games, and presentations can all be offered. A biweekly diabetes clinic operated in California by an interdisciplinary team of providers offers clients a class on different diabetes topics throughout the year. Between three and twenty men and women attend presentations on subjects such as “Why Can Diabetes Hurt the Kidneys” and “Holidays Again! How to Manage and Still Enjoy” while visiting with one another. Clinical visits also take place.

In a perfect world, the sociopolitical roots of power imbalance would be addressed. These suggestions provide just a few means to adjust this imbalance. Treatment and associated delivery policies will benefit from additional cultural studies of diabetes etiologies. Data that explore the relationship between health constructs and therapeutic strategies will illustrate that miscommunications occur in multiple health care encounters. Furthermore, such research should enable providers and clients alike to compose and expand upon health conversations.

EPILOGUE

Due to recent amendments to the Indian Self-Determination Act (1998), the contracting and compacting structure of American Indian health care is changing. Regional Area and Headquarters Offices, previously the recipients of funds directed toward the development and distribution of diabetes education materials, may not continue to receive moneys for these purposes. Instead tribes and tribal health consortiums may decide to direct their funds to other programs. It is difficult to determine what type of immediate or long-term impact this situation will have on providers and their clients. Practitioners may have to rely on different sources of training or create their own. For many providers who are already overburdened or who are new to American Indian health care, decreased access to pertinent information may create gaps in knowledge. Health care communication with patients and their families may be adversely affected. Let us hope that this legislation offers tribes, tribal consortiums, lay people, and providers opportunities to create special tribally unique education approaches.

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NOTES

1. Prior to July 1997 this condition was classified as Type II or non-insulin dependent diabetes mellitus. For additional information see: Anonymous, "New Recommendations for the Diagnosis and Classification of Diabetes Mellitus," *The IHS Primary Care Provider* 22 (August 1997): 121–122.

2. This rate does not include individuals who chose not to use Indian Health Service facilities, people who have not received a medical diagnosis, or members of tribes that are not federally recognized.

3. Dorothy Gohdes, "Diabetes in North American Indians and Alaska Natives," in *Diabetes in America*, ed. National Diabetes Data Group (Rockville: National Institutes of Health, 1995).

4. Elisa Lee, et al., "Diabetes and Impaired Glucose Tolerance in Three American Indian Populations Aged 45–74 Years: The Strong Heart Study," *The IHS Primary Care Provider* 20:8 (1995): 97–109.

5. For more about this subject, see Linda C. Garro, "Continuity and Change: The Interpretation of Illness in an Anishinaabe (Ojibway) Community," *Culture, Medicine, and Psychiatry* 14 (1990): 417–454; Linda C. Garro and Gretchen Chesley Lang, "Explanations of Diabetes: Anishinaabeg and Dakota Deliberate upon a New Illness," in *Diabetes as a Disease of Civilization: The Impact of Lifestyle and Cultural Changes on the Health of Indigenous Peoples*, eds. Jennie Joe and Rob Young (Berlin: Mouton de Gruyter, 1994), 293–328.

6. See Max Charlesworth, Lyndsay Farrall, Terry Stokes, and David Turnbull, *Life Among the Scientists: An Anthropological Study of an Australian Scientific Community* (New York: Oxford University Press, 1989); Monica J. Casper and Marc Berg, "Introduction to Special Issue: Constructivist Perspectives on Medical Work: Medical Practices and Science and Technology Studies" *Science, Technology & Human Values* 20:4 (1995): 395–407; Laura Nader, ed., "Anthropological Inquiry into Boundaries, Power, and Knowledge," in *Naked Science: Anthropological Inquiry into Boundaries, Power, and Knowledge* (New York: Routledge, 1996), 9.

7. Charlesworth, Farrall, Stokes, and Turnbull, *Life Among the Scientists*, 49–51; see also Rayna Rapp, "Accounting for Amniocentesis," in *Knowledge, Power, and Practice: The Anthropology of Medicine of Everyday Life*, eds. Shirley Lindenbaum and Margaret Lock (Berkeley: University of California Press, 1993), 55–79

8. For additional analysis of this topic, see Laura Nader, "Anthropological Inquiry into Boundaries, Power, and Knowledge," in *Naked Science*, 1–25.

9. John Molina, "Cultural Medicine," *Journal of Minority Medical Students* (Spring 1997): 32.

10. As Elaine Jahner notes for the Lakota, "direct and explicit acceptance of the mystery of origins characterizes all the statements we have from Lakota who lived according to tribal beliefs." Jahner, "Lakota Genesis: The Oral Tradition," in *Sioux Indian Religion: Tradition and Innovation*, eds. Raymond J. De Mallie and Douglas R. Parks (Norman: University of Oklahoma Press, 1987), 46. See also Raymond J. DeMallie, "Lakota Belief and Ritual in the Nineteenth Century," in *Sioux Indian Religion*, 25–43.

11. Due to my limited knowledge of their native language, it was unclear to me if other participants were fluent in their language. These eleven people all self-identified as speakers of their indigenous language; they also consistently held conversations with other speakers.

12. Edward Yoxen, "Constructing Genetic Diseases," in *The Problem of Medical Knowledge: Examining the Social Construction of Medicine*, eds. Peter Wright and Andrew Treacher (Edinburgh: Edinburgh University Press, 1982), 145.

13. Ruth Hubbard and Elijah Wald, *Exploding the Gene Myth* (Boston: Beacon Press, 1993).

14. Charlesworth, Farrall, Stokes, and Turnbull, *Life Among the Scientists*, 41.

15. Indian Health Service Headquarters Diabetes Program, *IHS Physician's Introduction to Type 2 Diabetes* (Albuquerque: Indian Health Service, 1993).

16. A control officer is someone who operates an Indian Health Service Area program, whereas a coordinator manages a designated diabetes model program.

17. The *IHS Physician's Introduction to Type 2 Diabetes* was updated in 1995 as a guide for health care providers; much like the earlier guide, the recent version emphasizes the differences between Type I and Type 2 diabetes as well as criteria for diagnosing and managing the latter among American Indians.

18. Kathy Kobus, personal communication, October 1996.

19. Beth Dabrant, personal communication, November 1996.

20. Indian Health Service Headquarters Diabetes Program, *IHS Physician's Introduction to Type 2 Diabetes*, 2.

21. J. V. Neel, "Diabetes Mellitus: A 'Thrifty' GenoType Rendered Detrimental by 'Progress'?" *American Journal of Human Genetics* 14 (1962): 3091; J. V. Neel, *The Thrifty GenoType Revisited: The Genetics of Diabetes Mellitus*, eds. J. Koebelerling and R. Tattersall (New York: Academic Press, 1982).

22. E. Benjamin, et al., "Exercise and Incidence of NIDDM among Zuni Indians," *Diabetes* (Suppl. 1) 42 (1993): 203A. W. C. Knowler, et al., "Determinants of Diabetes Mellitus in the Pima Indians," *Diabetes Care* 16:1 (1993): 216–227. Kenneth Weiss, Jan Ulbrecht, Peter Cavanagh, and Anne V. Buchanan, "Diabetes Mellitus in American Indians: Characteristics, Origins and Preventive Health Care Implications," *Medical Anthropology* 11 (1989): 283–299.

23. M. Prochazka, et al., "Linkage of Chromosomal Markers on 4q with a Putative Gene Determining Maximal Insulin Action in Pima Indians," *Diabetes* 42 (1993): 514–19. Peter Bennett, "Non-Insulin Dependent Diabetes Mellitus and Its Complications," Third International Conference on Diabetes and Indigenous Peoples: Theory, Reality, Hope (Winnipeg, Canada, 1995).

24. Beth Dabrant, Kelly Acton, and Bernadine Tolbert, *IHS Introduction to Type 2 Diabetes* (Albuquerque: IHS Diabetes Program, 1995), 3.

25. Hannele Yki-Järvinen, "Pathogenesis of Non-insulin Dependent Diabetes Mellitus," *The Lancet* 343 (1994): 91.

26. Indian Health Service Headquarters Diabetes Program (1993), 5. The revised edition expands upon this theme. The authors state, "every facility should work towards providing systematic mechanisms to make culturally-relevant self-care information available for patients." Dabrant, et al. (1995), 21.

27. Indian Health Service, *Indian Health Service Basic Series Diabetes Curriculum* (Rockville: Public Health Service, 1996).

28. Portland Area Indian Health Service Diabetes Program, *Diabetes and American Indians* (Bellingham, WA: Indian Health Service, 1987).

29. These “small groups” tended to consist of luncheon table groupings that were basically rigid. Groupings of biological and social kin sat at the same tables during almost every visit to the Senior Center. About five different individuals seemed to move from table to table without social compunction. Seniors asked questions of presenters who visited table groupings.

30. See also Garro and Lang, “Explanations of Diabetes: Anishinaabeg and Dakota Deliberate upon a New Illness.”

31. See also Joan Marie Roche, *Sociocultural Aspects of Diabetes in an Apache-Choctaw Community* (Ann Arbor: University Microfilms International, 1982). Garro and Lang, *ibid*; Benjamin Kracht, “Diabetes among the Kiowa: An Ethnohistorical Perspective,” in *Diabetes as a Disease of Civilization*, 147–168.

32. This table does not include data on gestational or Type I diabetes.

33. For additional discussion on this topic, see Anthony Giddens, *The Constitution of Society* (Berkeley: University of California Press, 1984); Linda C. Garro, “Continuity and Change: The Interpretation of Illness in an Anishinaabe (Ojibway) Community.”

34. Fredrik Barth, ed., “Introduction,” in *Ethnic Groups and Boundaries* (Boston: Little, Brown, and Company, 1969).

35. See also Mathew C. Snipp, “The Changing Political and Economic Status of the American Indians: From Captive Nations to Internal Colonies,” *American Journal of Economic and Sociology* 45:2 (1986): 143–155; Eric Wolf, *Europe and the People without History* (Berkeley: University of California Press, 1982).

36. A frequent topic of conversation among women, especially, was their inability to obtain permits from federal, county, and intertribal agencies to collect wild foods. Political restrictions purportedly decrease access to desert fruits and nuts that often grow on lands other than those of the reservation.

37. Joel Kuipers, “Medical Discourse in Anthropological Context: Views of Language and Power,” *Medical Anthropology Quarterly* 3:2 (1989): 99–123.

38. Stephany Borges and Howard Waitzkin, “Women’s Narratives in Primary Care Medical Encounters,” *Women and Health* 23:1 (1995): 29–55.

39. Robert Hahn, *Sickness and Healing: An Anthropological Perspective* (New Haven: Yale University Press, 1995); H. B. Beckman and R. Frankel, “The Effect of Physician Behavior on the Collection of Data,” *Annals of Internal Medicine* 101 (1984): 692–996; Candace West, ed., *Routine Complications: Troubles with Talk Between Doctors and Patients* (Bloomington: Indiana University Press, 1984).

40. Alexandra Dundas Todd, “Exploring Women’s Experiences: Power and Resistance in Medical Discourse,” in *The Social Organization of Doctor-Patient Communication*, 2nd ed., eds. Todd, Alexandra Dundas, and Sue Fisher (Norwood, NJ: Ablex Publishing Corporation, 1993), 267–285.

41. See Alexandra Dundas Todd, “Exploring Women’s Experiences: Power and Resistance in Medical Discourse,” 275; Kathy Davis, “Nice Doctors and Invisible Patients: The Problem of Power in Feminist Common Sense,” in *The Social Organization of Doctor-Patient Communication*, 243–265.

42. V. M. Henzl, “Linguistic Means of Social Distancing in Physician-Patient Communication,” in *Doctor-Patient Interaction*, ed. Walburga von Raffler-Engel

(Belgium: John Benjamins, 1989): 45–60; Peter A. Ubel, “Doctor Talk: Technology and Modern Conversation,” *The American Journal of Medicine* 98 (1995): 587–588.

43. See also Veronica Evaneshko, “Presenting Complaints in a Navajo Indian Diabetic Population,” in *Diabetes as a Disease of Civilization*, 357–378.

44. See also Dianna Garcia-Smith, “The Gila River Diabetes Prevention Model,” in *Diabetes as a Disease of Civilization*, 471–494.

45. See also Tamar Kaplan, “An Intercultural Communication Gap: North American Indians vs. the Mainstream Medical Professions,” in *Doctor-Patient Interaction*, 45–59. In a study of Midwestern urban and rural patients, 60 percent were found to want an active role in medical decision making, yet only 47 percent of patients claimed to have challenged the ideas or recommendations of their doctors. M. R. Haug and B. Lavin, “Practitioner or Patient—Who Is in Charge?” *Journal of Health and Social Behavior* 22 (1981): 212–229.

46. Individuals interviewed both in California and Arizona who are or have been cancer patients or who are in the field of education also tend to feel at ease making inquiries.

47. James Maclynn Wilce, “Repressed Eloquence: Patients as Subjects and Objects of Complaints in Matlab, Bangladesh,” Dissertation, University of California, Los Angeles, 1994, 37–38.

48. Lowell John Bean, “Power and Its Applications in Native California,” in *Native Californians: A Theoretical Perspective*, eds. Lowell John Bean and Thomas Blackburn (Socorro, NM: Ballena Press, 1976), 407–420. Lowell John Bean and Sylvia Brakke Vane, “California Religious Systems and Their Transformations,” in *California Indian Shamanism*, ed. Lowell John Bean (Menlo Park, CA: Ballena Press, 1992), 33–51.

49. Other studies reveal similar views. See Martin Hickey and Jannette Carter, “Cultural Barriers to Delivering Health Care: The Non-Indian Provider Perspective”; Garro and Lang, “Explanations of Diabetes: Anishinaabeg and Dakota Deliberate on a New Illness”; Scott Camazine, “Traditional and Western Health Care among the Zuni Indians of New Mexico,” *Social Science and Medicine* 14B (1980): 73–80.

50. Steven Epstein, “The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials,” *Science, Technology & Human Values* 20:4 (1995): 408–437.

51. Byron and Mary-Jo DelVecchio Good, “‘Learning Medicine’: The Constructing of Medical Knowledge at Harvard Medical School,” in *Knowledge, Power, and Practice: The Anthropology of Medicine and Everyday Life*, eds. Shirley Lindenbaum and Margaret Lock (Berkeley: University of California Press, 1993).

52. See R. Y. Bourhis, S. Roth, and G. MacQueen, “Communication in the Hospital Setting: A Survey of Medical and Everyday Language Use Amongst Patients, Nurses, and Doctors,” *Social Science and Medicine* 28 (1989): 339.

53. See also Robert Hahn, *Sickness and Healing: An Anthropological Perspective*.

54. *Ibid.*, 151; E. Friedson, *The Profession of Medicine* (New York: Dodd, Mead, 1970), 170.

55. Anne Burson-Toplin, “Fracturing the Language of Biomedicine: The Speech Play of U.S. Physicians,” *Medical Anthropology Quarterly* 3:3 (1989): 283–293; Cecil Helman, “Communication in Primary Care: The Role of Patient and Practitioner Explanatory Models,” *Social Science and Medicine* 20 (1985): 923–931; Kathleen Huttlinger, Laura Krefting, Denise Drevdahl, Phillip Tree, Elaine Baca, and Anita Benally, “‘Doing Battle’: A Metaphorical Analysis of Diabetes Mellitus among Navajo People,” *The American Journal of Occupational Therapy* 46:8(1992): 706–711.

56. Jean Lave and Etienne Wenger, *Situated Learning: Legitimate Peripheral Participation* (Cambridge and New York: Cambridge University Press, 1991), 109.
57. *Ibid.*, 95.
58. See also Cecil Helman, *Culture, Health and Illness: An Introduction for Health Professionals*, 2nd ed. (Boston: Wright Publishers, 1990); Arthur Kleinman, *Patients and Healers in the Context of Culture* (Berkeley: University of California Press, 1980); Robert Hahn, *Sickness and Healing: An Anthropological Perspective*.
59. See also I. J. Benett, "What Do People with Diabetes Want to Talk About with Their Doctors?" *Clinical Practice* (1993): 968–971.
60. See Robert Hahn, *Sickness and Healing: An Anthropological Perspective*, 152; C. Lidz and A. Meisel, "Informed Consent and the Structure of Medical Care," in *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: Making Health Care Decisions*, vol. 2: *Appendices (Empirical Studies of Informed Consent)* (Washington, DC: U.S. Government Printing Office, 1983).
61. Linda M. Hunt, Miguel A. Valenzuela, and Jacqueline A Pugh, "¿Porque Me Tocó a Mí? Mexican American Diabetes Patients' Causal Stories and their Relationship to Treatment Behaviors," Unpublished manuscript, 1997, 6.
62. Stephany Borges and Howard Waitzkin, "Women's Narratives in Primary Care Medical Encounters," 41.
63. Jennie Joe, "Sociocultural Factors in Diagnosis and Treatment," in *NIDDM and Indigenous Peoples: Proceedings of the Second International Conference on Diabetes and Native Peoples*, eds. Jennie Joe and Robert Young (Tucson: Native American Research and Training Center, 1993), 47–49.
64. See Hickey and Carter, "Cultural Barriers to Delivering Health Care: The Non-Indian Provider Perspective," 613.
65. Emily Martin, *Flexible Bodies: The Role of Immunity in American Culture from the Days of Polio to the Age of AIDS* (Boston: Beacon Press, 1994), 180. See also Rayna Rapp, "Accounting for Amniocentesis," in *Knowledge, Power, and Practice*.
66. See Brigitte Jordan, "Cosmopolitical Obstetrics: Some Insights from the Training of Traditional Midwives," *Social Science and Medicine* 28:9 (1989): 925–944; Brigitte Jordan, *Birth in Four Cultures: A Cross-Cultural Investigation of Childbirth in Yucatan, Holland, Sweden and the United States*, 4th ed. (Prospect Heights, IL: Waveland Press, 1993; rpt. from 1978), 154.
67. See Casper and Marc Berg, "Introduction to Special Issue: Constructivist Perspectives on Medical Work."
68. Arthur Kleinman asserts that physicians are taught to consider the illness narratives and causal beliefs of clients with skepticism. Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988), 17.
69. See Edward Yoxen, "Constructing Genetic Diseases."
70. See also C. H. Browner and Nancy Press, "The Production of Authoritative Knowledge in American Prenatal Care," *Medical Anthropology Quarterly* 10 (1996): 141–156.
71. Gareth Williams and Philip Wood, "Common-sense Beliefs about Illness: A Mediating Role for the Doctor," *The Lancet* (Dec. 20/27, 1986): 1435–1437.
72. Garro and Lang, "Explanations of Diabetes: Anishinaabeg and Dakota Deliberate on a New Illness," 294.
73. See also Libbett Crandon, "Medical Dialogue and the Political Economy of Medical Pluralism: A Case from Rural Highland Bolivia," *American Ethnologist* 13:3 (1986): 463–476.

74. See also Susan DiGiacomo, "Biomedicine as a Cultural System: An Anthropologist in the Kingdom of the Sick," in *Encounters with Biomedicine: Case Studies in Medical Anthropology*, ed. Hans A. Baer (Philadelphia: Gordon and Breach, 1987), 316; Steven Epstein, "The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials."

75. Lave and Wegner, *Situated Learning: Legitimate Peripheral Participation*, 109. See also Aaron Cicourel, "Hearing Is Not Believing: Language and the Structure of Belief in Medical Communication," in *The Social Organization of Doctor-Patient Communication*, eds. Todd and Fisher (Norwood, NJ: Ablex Publishing, 1993), 64.

76. Robert Hahn, *Sickness and Healing: An Anthropological Perspective*, 157–158.

77. Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition*, 44, 48.

78. Garro and Lang, "Explanations of Diabetes: Anishinaabeg and Dakota Deliberate on a New Illness," 321.

79. Clifford Trafzer, personal communication, January 1998.

80. See also Epstein, "The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials"; L. M. L. Ong, et al., "Doctor-Patient Communication: A Review of the Literature," *Social Science and Medicine* 40:7 (1995): 903–918.

81. Rapp, "Accounting for Amniocentesis," 73.

82. John Gumperz, "The Retrieval of Sociocultural Knowledge in Conversation," in *Language and Use*, eds. John Baugh and Joel Sherzer (Englewood Cliffs: Prentice-Hall, Inc., 1984), 129.

83. See also Jordan, *Birth in Four Cultures: A Cross-Cultural Investigation of Childbirth in Yucatan, Holland, Sweden and the United States*.

84. Among some cancer patients, for instance, the sharing of patients' views seems to increase adherence to medical recommendations. W. B. Carter, et al., "Outcome-based Doctor-patient Interaction Analysis: 2. Identifying Effective Provider and Patient Behavior," *Medical Care* 20 (1982): 550; D. L. Roter, "Which Facets of Communication Have Strong Effects on Outcome—a Meta Analysis," in *Communicating with Medical Patients*, eds. M.A. Stewart and D.L. Roter (Newbury Park, CA: Sage Publications, 1989).

85. Browner and Press. "The Production of Authoritative Knowledge in American Prenatal Care," 145.