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Community Participation in Tribal Diabetes Programs

CAROLYN SMITH-MORRIS

In the past five years, there has been a surge in the attention shown to community and community-based health programs among Native Americans, particularly for chronic health problems such as diabetes. New Mexico's Native American Diabetes Project, a diabetes education and gardening project in the American Northwest, and the Daya Tibi health center in Poplar, Montana are just a few of the programs to report outcome success using a community-based model. What do these projects have in common, and to what does *community-based* refer? Is community participation, as Bell and Franceys declare, just a euphemism for unpaid labor?¹

Community participation in health programming—from the efforts of community health workers (CHWs), to participatory research, to the impact of politics on community health programs—has been a popular approach in anthropology and public health since the late 1970s and is now a hackneyed expression in health programming. As part of a comprehensive edited volume on the subject, Barbara Israel et al.² declare community participation to be not a method but an orientation based upon nine principles such as the facilitation of collaborative, equitable partnerships in all phases of the work; promotion of colearning and capacity building among partners; and the involvement of systems development through a cyclical and iterative process.³

This discussion offers a view of community participation from Indian country. One major impetus behind this resurgence of “community”-developed programs for Native Americans is the momentum of self-determination. The era of tribal self-determination, stemming from the 1975 Self-Determination Act among other pieces of legislation, is nascent in its capacity to produce

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novel, culturally relevant, and community-minded programs in health. Tribal councils and other governing bodies have increasingly demanded participatory methods of research, health care, and education from both Native and non-Native professionals.⁴ It is little wonder, then, that these terms fill the titles of public health, medical anthropology, and even diabetes care literature on tribes. Tribes have motivated this transformation.

My goal is to consider the resurgence of community-based programs in Native American communities in the United States and to explore in particular the meanings, benefits, and potential dangers of this trendy model in diabetes programming. As community participation has been considered thoroughly before, I have focused my attention on its recent popularity for diabetes treatment and education.⁵ I begin with an historical overview of the objectives of community participation as it has grown out of the first agriculture extension and international development projects into medical anthropology and particularly public health practice. I then consider the fundamental aspects of community participation. These fundamentals organize my analysis of community participation in Native American communities and point to the inadequate transformation of the social and economic structures that sustain high prevalence and incidence of diabetes in these groups. As a case study, I draw upon ongoing fieldwork in the Gila River Indian community. Undergoing a transition from crisis to epidemic (or disproportionately large) rates and finally to endemic rates of diabetes (in which diabetes is characteristic among a population), the Gila River Indian community demonstrates an evolution of disease interventions. This evolution has involved a predictable progression in the community's reaction to widespread disease, including relatively late attention to structural barriers and the need for community-based approaches. I conclude by exploring the possibilities for the culturally transformative and structural changes that might produce the elusive reduction in diabetes prevalence for Native Americans.

A BRIEF HISTORY OF COMMUNITY PARTICIPATION

A participation movement began in western industrialized nations with cooperative education programs in the mid-nineteenth century. By the 1920s, important structural investment was being made into rural education and support, such as the US Agricultural Extension Service and other social welfare programs. Yet, through the 1940s, local culture and goals were largely overlooked both in the United States and in international health projects. An exception is the work of Kurt Lewin, a founder of action research. The first community development program launched in India was in 1952, followed by the "Village Aid" project in Pakistan in 1953. These projects exemplified many efforts in the 1950s and 1960s, including volunteer programs developed by the United Nations Children's Fund (UNICEF) to teach people in urban slums about health and sanitation. A more detailed discussion of the historical roots of community-based research—which includes the development of ideas, after Paulo Friere, that communities are active subjects in their own experiences and examinations—has been made by Wallerstein and Duran.⁶

When in the late 1970s community participation became a fundamental element in the primary health care movement and the Alma Ata initiative, we began to see more creative and critically applied ideas for fostering community involvement in health programs.⁷ It was during this period in 1979 that the Indian Health Service (IHS) established its “model programs” aimed specifically at improved diabetes care, prevention, and treatment. These included “culturally sensitive materials and community outreach efforts” in keeping with the methodological standards of that day.⁸ As many new approaches were tested, researchers recognized trends in programmatic views of culture as an obstacle⁹ or as local knowledge that could be tapped for programmatic use.¹⁰ These notions came to be seen as “static”¹¹ and uniformist¹² and more flexible treatments of culture were proposed. Also within the first decade of the primary health care movement came increasing recognition that health is not above politics. The idea of culture in health programming facilitated a shift away from exclusive focus on local cultural details to a concept that included the “culture” of health care organizations, health bureaucracies, and even international development. Morgan’s work offers several case studies on the interplay between international, state, and private agendas in health care initiatives.¹³ Structural factors of health systems and the ways in which these interface with social and political structures, therefore, came to the foreground of community participation ideals. Importantly, some community “development” models have operationalized participatory goals by focusing on basic services that are prerequisites to disease prevention.¹⁴ Likewise, local beliefs about illness and curing came to be seen as more flexible and changing and the community participation model has correspondingly improved.¹⁵

But only recently has the community participation momentum reached tribes. Its current applications in Indian country almost certainly index the insistence of tribes and nations to participate fully in program development, implementation, and evaluation. The significance given to community-based perspectives by those working in Native America has been particularly fruitful, especially in recent decades of tribal self-determination and administrative takeover of previously IHS-model health care structures. But we are also seeing the revival of an old buzzword. Does the term *community* mean the same thing to different parties? What can tribes and nations expect from programs under this banner?

A large collection of literature employing the terms *community participation*, *community based*, and *community owned* shows little agreement on the concept of a community. While some authors directly address the methodological and structural considerations necessary for community participation in health programs,¹⁶ others use the term *community* as simply a descriptor for programs located in some geographically defined population center.¹⁷ It is hard to develop meaningful and reasonable generalizations even from expertly collected data. Data quickly become dated and, through sampling errors or analytical overgeneralizations, false communities can be created from pilot information.¹⁸ Researchers and programmers must be mindful of these dangers as we increase the use of the participation model. Israel’s

work provides the single most comprehensive discussion of the principles of community participation not as a method, but as an orientation to collaborative work with communities.¹⁹

FUNDAMENTALS IN COMMUNITY PARTICIPATION

Now in our third decade—nay, our second century—of community participation, the core elements of a constructive community participation model are familiar. I offer the following discussion not as a comprehensive review of effective and unproblematic applications of the community participation model but as a view on noteworthy achievements and lessons learned from attempts at community participation in health programming, particularly for Native Americans. The sections that follow consider some of the main challenges and strategies for community participation among Native Americans. Organized into four sections, this discussion summarizes much of the current best practices. These choices undoubtedly reflect my bias toward applied medical anthropology and health programming, but they still inform efforts in clinical and public health programs and even non-health programs.

Parameters of the “Community”

The first and most difficult task in community participation is the identification of a manageable yet meaningful target “community.”²⁰ The identification of a community can be based on a variety of things:

- geographic boundaries or spaces
- politics of identity and ethnicity
- demographic or other variables determined relevant by a particular research question
- any number of other fabricated ties that ignore diaspora, globalization, media, and the multiplicity of self-identification

Foster reminds us that while development projects work best in communities with shared needs and goals, homogenous communities are a myth.²¹

Are anthropologists and other researchers working among Native Americans cautious about forcing assumptions of homogeneity on unnatural or impossible groups? *Community* implies a special focus on locally identified concerns in which services are somehow tailored to the needs, strengths, and resources of that group. There is a reasonable danger of co-optation of this terminology by programmers unwilling or unable to invest in meaningful local participation from planning through evaluation.²² Some degree of community organization or homogeneity is ideal.²³ A homogenous community being nonexistent, we may prefer Hood et al.’s rhetoric of “geographically compact and culturally strong communities.”²⁴ Certainly, identification of too large or amorphous a community will yield a program that caters to an impossibly diverse set of needs and expectations. Use of preexisting assumptions—for example, that a given Indian reservation naturally constitutes a complete and cohesive community—are also inappropriate. As we “make” these communities through our

inclusions and exclusions our aim is to be maximally inclusive while recognizing the economic and cultural constraints on the program.²⁵

Well-tested methods for exploring the parameters of the community exist. A substantial amount of information about a community is necessary before even the most fundamental project decisions can be made: local demographic and epidemiological information; political and social structures, alliances, and rivalries; environmental factors that influence health, nutrition, work seasons, and financial cycles; geography; and intercultural relations, just to name a few. These and more variables will have significant impact on the health needs of the community and the resources available and barriers to any health project. For this reason, several researchers promote models of formative or diagnostic research as the basis for health interventions.²⁶

Local community members are also most likely to know these variables. In preliminary research intended to inform a community health project, strenuous efforts were made by Schoenfeld et al. to recruit a large and representative sample of community participants.²⁷ While these efforts are tried and to some extent true, Nichter calls for deprofessionalization of the research team to take advantage of the skills and knowledge of local researchers even in the formative stages of the project.²⁸ Local researchers share a culture of common sense with fellow community members, have intimate knowledge of culturally appropriate rhetorical styles, and are more readily able to negotiate meaning with villagers by placing issues in the realm of the experimental.²⁹

Because health care projects initiated from the “outside” may be viewed as peripheral, CHWs with minimal training but ample community knowledge and familiarity can be crucial intermediaries for community-based projects.

Not Involvement, but Collaboration

A second fundamental tenet of community participation is the active involvement of community members in all phases of the project, from conceptualization to implementation and revision. But here too we must be careful of hollow ideology. Increasingly, successful community-based projects are ones in which community members and outside advisers have equal roles in project planning, implementation, review, and revision. This equality better fosters the right types of involvement by different people, as one can easily distinguish several possible types of involvement for diabetes programming including individual, family, peer groups, households, and community.³⁰ Typically, multiple forms of involvement exist at any given time within these collaborations.

Individual patients, for example, must help author treatment plans through meaningful dialogue with providers. As Burden makes clear at the outset of her article, “Tailoring Diabetes Education to Suit the Individual,” treatment and education can be tailored to the lifestyle and needs of each patient without making any sacrifice to the ultimate goal of care.³¹ In absence of this personalized care, we encounter treatment failure and “noncompliance” due to therapeutic barriers, lack of knowledge, lack of social or family support, and insufficient economic means.³² Self-efficacy—the patient’s belief that she or he has the ability to complete a task or action—has been proposed

as the essential characteristic of “successful” managers of diabetes.³³ Relatively few researchers promote the kind of compromise necessary on the part of providers that would promote self-efficacy and produce a treatment plan “within the individual’s range of acceptability.”³⁴ Mechanisms for feedback, correction, and program revision must be tied to these individual sources of information, as well as to significant others identified by those individuals. Mechanisms must also be in place that make adjustments and changes to treatment a feasible and fluid possibility.

Youths are a source of understanding and expression that are often neglected in diabetes research and programming. With some notable exceptions, the unique obstacles to diabetes prevention faced by teens and youth, the role that peers play in these “age communities,” and the harnessable power of youth identity are relatively unseen in typical hospital-based programs.³⁵ Elders and grandparents,³⁶ persons with mental illness,³⁷ and youth have unique barriers and resources, as would any specific demographic or cultural group that coheres in a shared or even imagined community. Participation by and within any of these groups will certainly take on different forms and an anthropological or ethnographic approach to these groups is very well suited for promotion of a mutual learning process.³⁸

When individuals from different backgrounds and experiences come together, it can produce a dramatically positive effect on the intervention.³⁹ While mediated or organized as necessary by “outsiders,” open community meetings constitute a principal leveling mechanism in community participation: the doorway through which *all* community members can enter into discussions about health care needs, expectations, and ideas. Certainly a great deal of knowledge about community needs and priorities as well as community buy-in are essential for the successful health education or treatment program but participation may or may not include these. Several examples from the literature show that the term *participation* can be used to mean a single, preplanning focus group, the hiring of community members to enact a plan developed without their input, and the use of community members as clerical or support staff to a program rather than integral members of an intervention team.⁴⁰ Well-intentioned but inadequately prepared efforts at community participation have produced a dramatic array of impotent proxies for involvement. Further criticism of the community participation model points to the values of self-reliance and individualism as Western cultural values not necessarily appropriate for many communities.⁴¹

CHWs are by far the most well-documented version of community participation and theirs is the principal outreach function of the primary health care movement. But their position is also most easily left without professional support, funding, decision-making power, or other information and resources necessary to be effective in communities.⁴² Conversely, turning over the reins to community members who are not prepared, informed, skilled, positioned, or inclined to manage a program can be equally disastrous.⁴³ These efforts at participation and inclusion also assume that informed, appropriate, representative, timely, well-recorded or documented, and otherwise *good* participation is obtained. Quite often and quite easily, this is not the case.

Wang et al. used focus groups to identify the programmatic needs of a sample of Pacific Islanders with type 2 diabetes.⁴⁴ Focus groups also helped Roubideaux et al. contribute a broad base of Native American perspectives on the National Diabetes Education Program.⁴⁵ This fundamental anthropological tool is a middle point between open community debates and designated or appointed participants. In many situations, designated spokespersons, liaisons, or experts will be necessary, thereby placing limits on the concept of *total* participation. But interventions must be guided by those most capable of success: namely, community members.⁴⁶ And as the number of mediators increases, the difficulty in maintaining broad community participation also rises. Thus, the critical balance between participation and nonparticipation will depend on the degree to which mediators accurately and responsibly can and do manage the concerns of the broader group.

In recent improvements to the community participation model, several inspiring terms and points have been added to our program of study on involvement. Among them are *control*, *embedding*, *‘made’ communities*, and *integration*. What Rowley called “community control” reflected that well-balanced measure of involvement and control by community members and assured the ultimate success of the program.⁴⁷ The “embedding” of the program within existing social, economic, and planning structures resulted in services that, through necessary and constant review and revision, would remain responsive and meaningful to that community.⁴⁸ Beneficial programs might also successfully “make” communities out of their participants, as the Diabetes Prevention Program did in its randomized clinical trial of medication, activity, and intensive support for persons with diabetes.⁴⁹ In their article describing the construction of a new health clinic in a Guatemalan community, Paul and Demarest state bluntly that local forms of representation and decision making should be well understood and respected from the outset, lest even widely endorsed participatory efforts (for example, a representative committee of community members) meet with antagonism and failure.⁵⁰ And diabetes services should, at a minimum, be well *integrated* with all other aspects of social and medical support.⁵¹

Prioritizing the Local

Culture is another hackneyed term, and by stressing an attention to and application of local culture and language I must also stress the term *local*. For while the exploration and application of local symbolic systems has become more common in programs among Native Americans, the essentializing of Native Americans into a pan-Indian prototype can be counterproductive.⁵² Reification and essentializing of what are “traditional” or other cultural identifiers is not necessarily effective.

Conflicts between local and biomedical knowledge systems have been a larger focal area in research. In a discussion of chronic disease self-care that has important implications for diabetes in Native Americans, Miewald reviews the assumptions often made by biomedical providers about patient motivation and attitudes toward disease.⁵³ Michielutte presents a short list

of basic conflicts between Native American and Western cultural values, and then goes on to explore the specific cultural considerations impacting the North Carolina Native American Cervical Cancer Prevention Project.⁵⁴ For example, in hiring interviewers to collect baseline data, the initial approach was to recruit individuals with previous experience and relevant, formal education. After considering the “strong sense of group identification, and mistrust of majority white culture” present in local culture, that approach was revised to emphasize lay health educators (hiring and training local Native American women).⁵⁵

The American Diabetes Association (ADA) developed a Native American advisory group (Awakening the Spirit—Pathways to Diabetes Prevention and Control) for the express purpose of developing a diabetes curriculum with appropriate pan-tribal education material.⁵⁶ This group partnered with the New Mexico Native American Diabetes Project to build a new curriculum for diabetes education among Native Americans (“Strong in Body and Spirit”).⁵⁷ The curriculum is made up of traditions and stories that incorporate health messages. In this context, *community based* refers more generally to the centrality of community in the planning or focus—more to the point, community seems here to be more focused on pan-Indian culture than on addressing local needs and drivers.

For community participation to have meaning, our notions of culture must become local. We must discover the local meanings of disease processes and how epidemiological statistics become *real* in the lives of community members. In this way, we find in the individual both immediate and larger contexts. Through the individual we can “recognize and attend to, for example, biomedical, social, economic, cultural and physical environmental factors as determinants of health and disease.”⁵⁸

Sustainability and Colearning

The most critical reviews of the participatory and community development models focus on unsustainable programs:⁵⁹ those that provide only initial funding with no mechanisms for project modification and change; disperse funds too thinly across an unreasonably large target population; or are simply ill conceived for the time, place, problem, and resources given. Girding these criticisms are many shrewd political analyses⁶⁰ that demonstrate competition over resources, the perils of deep bureaucracy, and (especially important for Native Americans) the paradoxical nature of health care tied to politicized funding.⁶¹

The fourth fundamental trait of the community participation model is its insistence on management of the political and economic realities for the community. Operationalizing this goal, Tripp-Reimer calls not simply for culturally sensitive but for culturally *transformative* interventions.⁶² Programs must not only use locally meaningful metaphors and models delivered in local languages and settings, but also become part of the fabric of the community, interwoven into existing social structures. Participation must involve a “collaboration among members, organizations, donors, and government” so that “widespread political support” is mobilized.⁶³

The Daya Tibi house⁶⁴ and the community gardening project described by Armstrong⁶⁵ aim to weave themselves into the daily life of the community. Glasgow et al. provide another model; as the title (“If Diabetes Is a Public Health Problem, Why Not Treat It as One?”) intimates, their approach treats diabetes as a public health concern rather than a “clinical” concern similar to other chronic illnesses.⁶⁶ They offer a task list for community-based programs, discussing every stage including planning, adoption, implementation, and maintenance.

A community-based intervention that aims to transform cultural models surrounding diabetes will take time. Programs should be expected to fail, and mechanisms must be in place to discover and discuss those failures and resources devoted to revising the program.⁶⁷ If a pan-tribal attitude toward time (“Indian time”) exists, as Miewald and others have suggested, then that attitude may help these communities weather the frail and poorly planned projects that are here today, gone tomorrow.⁶⁸ Without a solid base in community goals and ongoing advocacy across members, institutions, and tribal and federal government, community participation risks a collapse into Francey’s unpaid labor.

EXAMPLES OF COMMUNITY PARTICIPATION AMONG TRIBES

The community participation model is axiomatic in (at least some circles of) development work.⁶⁹ The truths inherent in this approach—cultural appropriateness, community involvement and buy-in, sustainability—are unquestionable. But why are we seeing a resurgence of this model now in Native American communities? And what impact is it having on diabetes treatment and prevention efforts? I have already made the claim that community participation is a natural partner to the self-determinist actions now being taken by tribes, particularly in the realm of health care. As the IHS moves from being the center point of Indian health care on reservations to functioning as a support and monitoring body over tribes that plan and manage their own health care, tribal health structures are changing. Reservation communities are actively seeking models for community mindedness in these new structures.

Native American diabetes programs reflect substantial success at achieving the fundamental characteristics of community participation, with the most important work still to be done in structural change and community-wide transformation. One of the oldest and best-known examples of community-based programming for diabetes is the Zuni Diabetes Project.⁷⁰ Begun in the summer of 1983, this program boasted significant weight loss and improved glucose control among participants and showed that competition could be an effective health-behavior change motivation. The program began humbly with two weekly aerobics classes for persons with Non-Insulin Dependent Diabetes Mellitus (NIDDM, now called *type 2 diabetes*). Participants were recruited using word-of-mouth, community ads, and referrals by their medical providers. That program grew to support up to twenty Zuni volunteers and almost fifty aerobics sessions offered weekly. The successes of this program have since been considered a benchmark: a mean weight loss of four kilograms for participants with diabetes and a

mean fasting blood glucose value drop from 13.2 to 10.8 millimoles per liter. Additionally, seven of twenty-four participants were taken off oral hypoglycemic agents, and nineteen (63 percent) decreased their dosage. The term *community based* was used in the Zuni Diabetes Project to mean programmatic intervention that occurs within and is open to members of the community—as opposed to being an individualized treatment regimen or a program that is based in a clinic or hospital.

Stemming directly from the importance of participatory approaches for tribes and their current state of readiness for such efforts, the ideas (and ideologies) of participation are now being invoked by many programmers and researchers. Unfortunately—but predictably—many of these would-be participatory actors are unable to invest in meaningful local participation. Daniel et al. describe their own such program that, while attempting a “participatory approach” in the planning of education and treatment, did not allow sufficient time for this type of participation.⁷¹ They can be applauded for revealing the difficulties in this work and for sharing some important insights.

Readiness for Community Participation

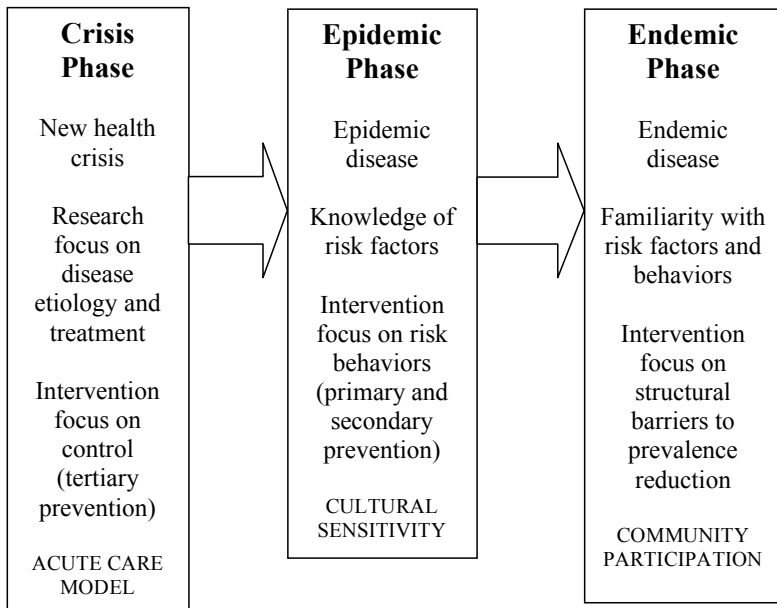
Much has been said about the meanings and validity of community participation. But the readiness of a community for a structural and community-wide response to health problems may also have much to do with the magnitude and longevity of the problem at hand. Depending on the severity and character of the health crisis, communities will be invested in different forms of intervention. Bamber, Hewison, and Underwood perceived a similar progression in the public response to acquired immunodeficiency syndrome (AIDS) in Thailand since the 1980s. They identified three phases including an initial but strong denial during the first six years of increased prevalence; a second phase of more rigorous monitoring, public education, and legislative attention; and a third phase in which resources have been committed to improved monitoring, education, counseling, and community support. They describe the transformation in this way:

By 1991, more realistic AIDS policies were being implemented. The impetus for this change came largely from strong international pressure, staffing changes within the MOPH [Ministry of Public Health], and increased domestic pressure, especially from nongovernmental organizations. There were signs that the phases of denial and then paralysis had begun to be replaced by more positive, *community-based* initiatives, many of them highly innovative.⁷²

The Thai example confirms that community response to epidemic disease involves structural, community-based elements *only in later phases*. Whether this hesitation is due to denial, as Bamber et al. suggest, or to other reasons (for example, the absence of convincing etiological information) must be evaluated for each idiosyncratic case.

The degree of crisis created by a disease helps determine not only the focus of research but also the target of intervention. The progression (see table 1) suggests a normal and expected movement of community attention from proximal to distant hazards, from immediate and tangible symptoms to the more pervasive, intangible causes. In the first or crisis phase of a new disease, energies are invested in building etiological, clinical, and epidemiological knowledge of the disease. By the time the disease reaches epidemic rates in a community, there is likely a growing body of knowledge about its etiology, clinical manifestations, and—ideally—its risk factors. The movement to an endemic phase of disease brings a growing familiarity with risk factors and a potential dulling of public fear into attitudes of inevitability⁷³ or surrender.⁷⁴ After long periods of epidemic prevalence, programs must be increasingly creative and constructive, targeting risky behaviors and prevention even while they battle public disenchantment or declining support. Such programs, similar to several of those described in this article, function well to manage individual cases of disease (including delaying onset and reducing complications or severity). *But these programs do not reduce community prevalence rates.* Only in the best of circumstances are the necessary structural (that is, political, economic, social, and institutional) changes made that would eventually produce a *decline* of prevalence.

Table 1
Evolution of Endemic Disease Interventions



Case Study: Diabetes and the Gila River Indian Community

I offer a case study on diabetes among Pima Indians, which has been at epidemic proportions for several decades. A comprehensive discussion of diabetes as a disease of development among Native Americans has been offered,⁷⁵ as well as a detailed ethnography describing symbolic, intergenerational, and economic barriers to diabetes health.⁷⁶

Diabetes is a condition arising from a body's decreased ability to metabolize glucose. It can develop in childhood or later, and may or may not produce exogenous insulin dependence. Type 2 diabetes is the most common form of diabetes among Pimas. It increases in prevalence with age until a "plateau" is reached during older ages.⁷⁷ Diet and exercise may work to lower blood glucose levels and improve the body's use of insulin in type 2 diabetes. For many, insulin may need to be added, either through shots or an insulin pump because the insulin hormone cannot be ingested in pill form.

Native Americans suffer from higher prevalence than whites of several chronic diseases, including heart disease, infections, and diabetes.⁷⁸ Diabetes can occur with and sometimes cause a variety of chronic diseases including heart disease, kidney disease, neuropathy, eye problems, and depression—all of which occur in Native American populations to a disproportionate extent.⁷⁹ And because diabetes prevention and management require so many behavioral changes (for example, eating and activity level), diabetes can be one of the most medically, emotionally, and socially devastating of the chronic diseases common in many Native American groups. Diabetes is a leading cause of extremity amputation and acquired renal disease among the Pima and is also associated with an increased risk for ischemic heart disease and infections.⁸⁰ Diabetes and its related conditions contribute to higher risk for depression and, in turn, are made worse by depression and alcoholism.⁸¹ Diabetes-related conditions account for 19.5 percent of all Pima deaths, which is four times that of whites and two times that of blacks.⁸² Also, tribal identity is intimately wrapped up in diseases of development including alcoholism, depression, diabetes, and obesity.⁸³

In my work at the Gila River Indian Community, there has been ample evidence of a conceptual shift in the focus of interventions. Diabetes here has been at epidemic proportions for decades; more than half of all Pimas over age thirty-five now have diabetes.⁸⁴ The Pimas have participated in a longitudinal diabetes study continuously since 1965.⁸⁵ From these data, we have observed the incidence of type 2 diabetes to increase for three successive decades in both men and women.⁸⁶

Elsewhere I have summarized three realms influencing the diabetes epidemic at Gila River.⁸⁷ First are political economic factors including the change in subsistence activities from farming to wage labor. This transition resulted in increased sedentism and an eventual reliance on government commodities and other processed foods. Commodities, especially fatty and sweet foods and drinks, made available first through government rations and later in the fast-food market, have had a highly negative and steadily worsening impact on Pima health. Second are genetic factors. James Neel provided seminal work that described a "thrifty" genotype suited to the feast and famine

conditions of early hunter-gatherer existence, either through a “quick insulin trigger,” fewer receptor cells for glucose, or enhanced fat metabolism.⁸⁸ Benyshek et al.,⁸⁹ however, suggest that diabetes is an “acquired characteristic” beginning in utero.⁹⁰ Third are cultural factors, which have mainly to do with foodways, but also include styles of communication, attitudes about disease prevention, and practices related to personal autonomy and advice giving.

One practical question of my research at Gila River was whether the continuing high rates of diabetes, its complications, and comorbid conditions in the Pima could be attributed in part to ineffectual treatment and prevention programming. Treatment and prevention services for diabetes include those at the Hu Hu Kam Memorial Hospital, the Diabetes Education Center, public health nursing, research programs sponsored by the National Institutes of Health, and other IHS programs. These programs offer cutting-edge treatments and prevention strategies, including culturally sensitive and individualized care from enthusiastic and highly qualified professionals. But overall the diabetes treatment and prevention efforts among Native Americans have had only moderate success with the Pima since World War II. Prevalence and incidence rates continue to rise while treatment participation and completion rates are often poor and go unexplained.⁹¹

The progression from a new health crisis to endemic disease is relatively rare but has been the case for many Native American communities suffering from high rates of diabetes. In the historic progression of diabetes in Native Americans, we began by understanding the disease and its prevalence (crisis phase), moved to a phase of risk awareness and behavior modifications (epidemic phase), and only last are turning to the structural elements that created the environment for the continued epidemic (endemic phase). A recognition of this historical transition sheds light not only on Gila River’s current dedication to community-based approaches but to similar evolutions in other communities.

The diabetes crisis at Gila River has roots in the nineteenth and early twentieth centuries, when the Gila River and traditional farms dried up due to upstream violation by non-Indians of laws protecting this Pima water source. Pimas became dependent on wage labor and federal commodity foods for subsistence. Genetic factors exacerbated important dietary changes occurring after World War II. Thus, while at the turn of the century there was no diabetes among the Pima,⁹² there were twenty-one cases by 1940.⁹³ It was during these four decades that diabetes began to draw national attention as a crisis among Native Americans, particularly the Pima. In the 1950s, the IHS was moved out from the inefficient and small Indian Service to the Public Health Service, and a hospital was built and staffed in Sacaton, the political center of the Gila River Indian community. Treatment was predominantly acute care owing in large part to the evolving state of etiological knowledge about diabetes. Specialized programs in prevention or diabetes screening would not exist for almost three more decades.

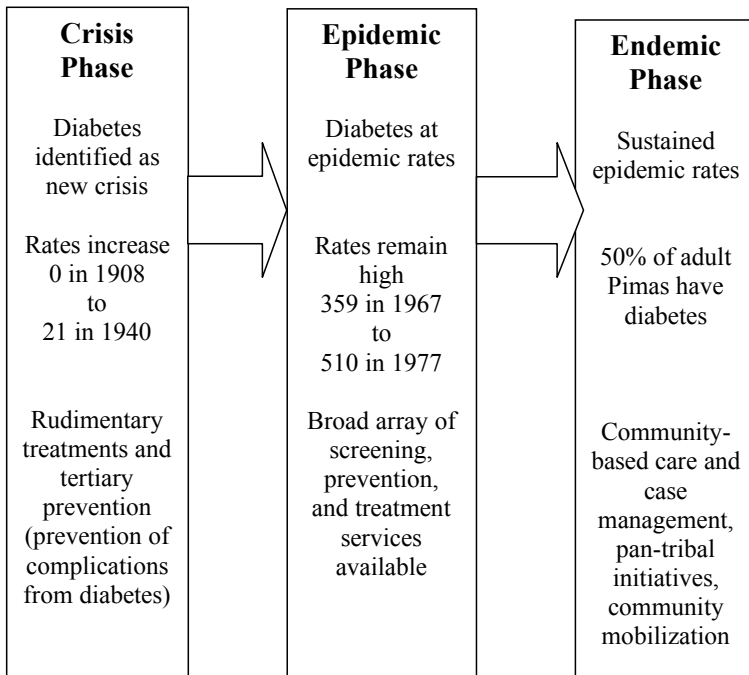
By 1967 there were 359 cases of diabetes—an epidemic—in the Pima.⁹⁴ It was in partial response to the identification of this epidemic that the NIH implemented intensive research at Gila River in the early 1960s. The Phoenix offices of the National Institutes for Diabetes, Digestive, and Kidney Disorders

produced tremendous new information on the disease, its etiology, and treatment. This work exploded the previously rudimentary understanding of disease etiology and risk factors, primarily through epidemiological, clinical, and demographic data. And this information would make possible new intervention strategies—principally, intensive prevention efforts.

By 1977, NIH researchers had documented 510 cases of diabetes in Pima Indians, a 42 percent increase since 1967.⁹⁵ Risk factors (particularly obesity) were becoming better understood, allowing treatment and prevention efforts to target risky behaviors (primary prevention), but disease rates were clearly epidemic. Gila River was one of only five communities nationwide to receive a model program for diabetes prevention, education, and treatment, opening in 1979.

The relative stability at epidemic rates of disease indicates an impending if not current state of diabetes endemicity at Gila River. We are certainly familiar with risk factors and behaviors contributing to Pima rates of the disease, including genetic factors. However, it remains to be seen whether intervention focus will remain on the risky behaviors of individual patients or patient groups, or whether the focus will change to the structural influences supporting the disease rates (see table 2). The increasing attention given to community participation models is evidence that structural and community-wide factors are getting more attention. Acute care aimed at tertiary (and even secondary) prevention will increasingly be seen as inadequate, while primary prevention and community-wide transformation comes of age.

Table 2
Evolution of Pima Diabetes Interventions



Defining the Community. The tendency to define the tribal community by its reservation borders is common. That tendency is sometimes informed by restrictions on federal funds, as are restrictions about to whom services are available (for example, federally recognized versus unrecognized tribes and enrolled versus nonenrolled tribal members). These are potentially impenetrable barriers. But even within the reservation, important differences exist between groups. The Gila River Indian Reservation is divided into seven districts, each with its own characteristics, resources, and social capital. Over the course of many years, but particularly in the past three years, efforts have been made by the tribal council to decentralize diabetes services. This is being accomplished now by a new diabetes center and administrative structure. Its beautiful new facility was recently built not in district 3, where almost all of the tribal offices are housed, but in the distant district 6. Indeed, new housing, a new pool and recreation center, and other tribal facilities are being built in districts 6 and 7, the westernmost parts of the reservation, as a way to recognize and make services accessible to more members of the community. Also contributing to the decentralization of tribal services are plans for home visits to become a central feature of future diabetes intakes, if not care and case management. By moving services not only into new neighborhoods but also into homes, diabetes care would become much more aware of its communities, if not automatically more responsive to them. Ideally, diabetes services will—similar to the various members of the tribal council who reflect the priorities and characteristics of their respective district constituencies—become tailored to smaller communities within the reservation. Services to members in remote, farming districts 2 or 4, for example, will be substantially different from those for members living in the tribal seat and within walking distance of a clinic in district 3.

Involvement of Community Members. The Gila River Indian Community was a site for the very first model programs in diabetes, implemented in 1979 by the Department of Health and Human Services to address this chronic health crisis. Since then, diabetes services have kept up with the increasing demands for monitoring, coordination of care, and treatment demanded by the ADA certification process. At the individual level members are offered a variety of programs, treatment, and prevention services. This aspect of “participation” has been criticized at Gila River for its failure to reach community members outside of the clinic or hospital. The social and economic exigencies (for example, lack of transportation to distant clinics and lack of child care) that keep many Pimas from participating more fully in biomedical approaches to diabetes prevention have been neglected until recent years. With efforts to continue decentralization of services from the hospital and clinic out into neighborhoods, improvements in individual level participation are expected.

Gila River has also had a long history of participation drives at the community level. CHWs have been on staff in the Public Health Department for more than a decade. All of the researchers I know, and many of the clinicians, have employed community-based methods for gathering information and garnering support for programs, such as focus groups, information

sessions at district meetings, and employment of community members on program staff. The Diabetes Prevention Project, described earlier, was so successful in these efforts that a DPP “community” was created and, years after the close of that program, continues to have meaning for many of its participants. The important transformation that is happening at Gila River now, in regard to diabetes care, is that the tribal council has begun to manage and develop its programs, taking greater responsibility for and charge over them while retaining the clinical and education expertise of many of its longtime, nontribal member employees.

Local Symbolic Systems. Clinical, public health, and education services at Gila River have long utilized both IHS and local sources for information about this “clinical population”: local perceptions and beliefs about health and illness; how Pimas communicate or tend to react to clinical encounters; what is considered proper and improper behavior at the clinic or in the presence of authority figures; and various other profiles. A few clinicians have worked in the community long enough to acquire a degree of cultural competency in working with members. There have also been a handful of researchers, including myself, who have conducted ethnographies and returned the results to the tribal council for use in health programming (for example, the cultural prominence of fry bread and chumuth [tortillas], notions about “borderline” diabetes, or the meaning of risk in a community with endemic diabetes). The efforts of community members to supply these data through ethnographic interviews or focus groups, for example, are a form of community participation. But the use of these data in health programming is equally vital to the ultimate success of community-based approaches to health care. Achieving broad participation in data collection, only to have the results ignored at the programmatic level, will lead to irrelevant programs. Participation must be transformed through the recognition and application of those local symbolic systems in new or revised treatment approaches. The insistence of the tribal council on home- and neighborhood-based care is one example of this transformation of ethnographic data—including but not limited to some of my own data demonstrating Pimas’s need and readiness for such services—into locally relevant interventions.

Sustainability and Colearning. Stabilizing many of the Gila River community’s efforts in recent years has been funding from their casinos. Now with less reliance on the variable amounts of federal funding, the tribe has invested heavily in new buildings and facilities including roads, housing, health services, a large recreation center with indoor pool, and diabetes and dialysis programs (to name a few). However, the sustainability of programs depends as much on community will as it does on funding and facilities. Building up to the transformation of diabetes services at Gila River have been sentiments in the community and tribal council that only the community—driving efforts rather than following those of researchers or clinicians—could effectively combat this disease and reduce its rates in the community. These sentiments now need to be harnessed through community activism and nourished, perhaps by some initial successes.

Diabetes prevention at Gila River thus demonstrates several of the known strengths of community participation, including advocacy on the part of tribal council members (and certainly others, including some clinicians) to tailor diabetes programs not only to this community but to subgroups within the reservation; a responsiveness of community members to invitations for involvement, witnessed not only in my own ethnographic work on diabetes but also in the Diabetes Prevention Project and other programs; evidence of distinct local interpretations of diabetes etiology and treatment and employment of these ethnographic data by the tribal health care corporation; and the roots of systemic transformation not only in the diabetes programs but throughout the tribe’s health care corporation.

Weaknesses in these efforts still abound, however, and one of the greatest barriers to change has to do with the length of time that this community has battled diabetes. And this brings me to a central consideration and the ultimate purpose of community participation at Gila River. That consideration is this: although diabetes presents a significant health burden, it has been at high prevalence for so long that public fear, which might produce demands for change, has been tempered by familiarity. Vinicor, a physician with the Division of Diabetes Translation at the Centers for Disease Control (CDC), has questioned the suspension of diabetes at such high rates in US society.⁹⁶ Diabetes, he argues, has not received the public status or recognition appropriate or necessary to produce effective prevention. In sum, despite tremendous gains in our understanding of diabetes and the development of medications to manage and curb its effects on the body, prevalence rates at Gila River remain high. Vinicor joins others in calling for increased public concern if progress is to be made in the reduction of diabetes.⁹⁷ Clearly, the time was ripe for Gila River’s recent structural transformation that now targets Pima diabetes from a community-based position. The proposed degree of change in structural and attitudinal approaches may be novel and powerful enough to temper Pima familiarity with diabetes and produce some long-term improvements.

GOALS FOR COMMUNITY PARTICIPATION IN INDIAN COUNTRY

As rates of diabetes at Gila River (and elsewhere) have stabilized at epidemic proportions, interventions have likewise changed. Community participation is a powerful but broad concept that has taken hold in an era of tribal self-determination. Greater clarity in our use of the phrase *community* might help us avoid ensnarement in the trap of linguistic politics. *Ownership* rather than *participation* more clearly indicates meaningful participation, investment, and control.⁹⁸ Whatever the phrase, participation rests on a continuum from less to more agency, from acceptance to authorship, and from compliance to appropriation. Each community will identify its own place on that continuum.

Four fundamental tenets of the community participation model for diabetes programs are now being given priority: (1) the identification of a meaningful target community; (2) the active involvement and equal membership of community members in all phases of the project including research or baseline data collection; (3) the exploration and application of locally meaningful

symbolic systems that address not only culture but also economic, historical, and other factors that bring communities together; and (4) an insistence on the management of political-economic realities facing diabetes reduction efforts, so that productive programs can be sustained and so that lessons learned in programming can be applied after program implementation.

Despite the current strengths in community participation programs, diabetes prevalence remains high. How can these programs report “success” when diabetes prevalence is high and rising in many Native American communities? The answer I propose lies in the evolution of endemic disease interventions, which initially focuses our attention away from structural issues to more proximate ones. Thus, the form of intervention is an outgrowth of the degree of crisis. Structural change can only grow up out of a broad and familiar knowledge of a disease, its risk factors, and the behavioral elements in its spread and prevalence. We have achieved this broad knowledge. Community participation must now initiate an era of structural change in tribal health care.

Structural barriers to reduced diabetes prevalence among Native Americans include poverty, unemployment, neighborhood pathways that reduce mobility and increase reliance on cars, limited educational resources, and limited nearby grocery stores with affordable high-quality foods (for example, fresh produce, whole grains, and low-fat meats). Tribal health care structures that continue to place emphasis on biomedical strategies and explanations for disease—ignoring relevant and active local concepts of diabetes, its management, and community values—form a major barrier to change within tribal planning groups. If left unquestioned, this narrow view of disease leads to continued emphasis on treatment (tertiary prevention), behavior modification (primary and secondary prevention), and other patient-focused strategies, rather than on the economic and political factors that:

- keep Native Americans underemployed and unemployed and, therefore, in poverty
- limit the ecological and natural resources of tribes (including space, water rights) upon which their growing numbers must depend for survival
- promote participation in the popular American “culture” of sedentary play (for example, television and video games) and immediate gratification (for example, fast food) through media and school-based influences
- permit Native Americans to hold multiple times the amount of morbidity and mortality of majority Anglos in the United States
- treat as underdeveloped, backward, or otherwise marginalize tribal members for participating in the linguistic, cultural, healing, and religious activities of their tribe, and to allow those to change, without the threat of their *authenticity* coming into question

I am suggesting that structural changes can challenge Pima familiarity with diabetes and therefore confront at least two hegemonic influences in Pima (and US) strategies for diabetes care. First, and evident in some of the programs discussed here, tribes are challenging the IHS and biomedical

models of acute health care based in hospitals and clinics. Increasingly, care is being taken out into communities, neighborhoods, and homes. For example, the notion of an identified, individual patient is giving way to a concept of family-focused treatment and community-wide interventions that better fit many Native American values privileging the group and family over the individual.⁹⁹ Likewise, the relationship between providers and community members is changing to promote greater cooperation and reduced power differences.¹⁰⁰ Second, tribes are challenging the political status quo, rallying under a banner of diabetes, to create pan-tribal fervor for community-wide change. Community participation is an approach to both research and action that can and should involve advocacy at the policy level. Through cooperative efforts, tribes might enact legislation that demands healthy (that is, pedestrian-friendly) neighborhoods and civic health and exercise programs; places restrictions on the advertisement and availability of “junk” and “fast” foods—especially for schoolchildren; and makes it possible for tribes to broadcast healthy and culturally appropriate images about Native Americans to combat the impact of negatives stereotypes.

Intertribal alliances calling for a net reduction in diabetes will be the major challenge in this effort. This movement would test the biomedical focus on disease treatment and individualized patient care. It would also demand national political awareness to the burden of disease on Native Americans, and the cultural, media, historic, and economic institutions that contribute to this problem. In sum, the responsibility for intervention must be placed in the hands of those most capable of success, regardless of orthodox assumptions from Western models of healing or capitalist economics.

Needed is a holistic approach that recognizes how genetic, cultural, environmental, and political-economic factors work simultaneously to produce the current crisis in diabetes. Education efforts must motivate individual change through community structures and support systems, relying on relevant local mores and norms. There is a need for intertribally relevant education material that is sensitive to the diversity of tribes. No longer are monocausal approaches viewing only diabetes risk factors and behaviors acceptable.¹⁰¹ But we must also be careful not to produce a “Native American version” of preexisting diabetes projects—mainly to avoid culture construction and nostalgia when these are not appropriate. Researchers and programmers dedicated to community participation may still overestimate their ability to create positive change and underrecognize the coercive and paternalistic influences of their own work. Certainly the idea of community participation is prone to gimmicks and we should be dissuaded from templates and checklists that offer a participatory product. But more detailed, local ethnographies that explore not simply inter- but also intratribal differences (for example, generational differences that have developed over the long-term presence of diabetes in a community) will take the public health model of community health even farther—out of the clinic and into the homes and daily lives of Native Americans.

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