

# Diagnostic Controversy: Gestational Diabetes and the Meaning of Risk for Pima Indian Women

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Gestational diabetes is the one form of this well known, chronic disease of development that disappears. After the birth of the child, the mother's glucose levels typically return to normal. As a harbinger of things to come, gestational diabetes conveys greater risk for later type 2 (previously "non-insulin dependent") diabetes in both the mother and child. Thus, pregnant women have become a central target for prevention of this disease in the entire Pima population. Based on ethnographic interviews conducted between 1999 and 2000, I discuss the negotiated meanings of risk, "borderline" diabetes, and women's personal knowledge and experiences of diabetes, particularly during the highly surveilled period of pregnancy. I also highlight the heterogeneity of professional discourse pertaining to gestational diabetes, most notably the debate surrounding its diagnosis. Significantly, women's narratives reveal the same set of questions as is raised in the professional debate. Implications for diabetes prevention and for balancing the increased surveillance of pregnant women with clinical strategies that privilege their experience and perspectives are also discussed.

*Key Words:* diagnosis; prenatal testing; gestational diabetes; Pima Indians; risk

The epidemiological profile of the Gila River Indian Community, coupled with the biomedical view of pregnancy as a crucial time for diabetes prevention, make pregnancy a time rife with concern about this chronic disease for Pima (Akimel O'odham) Indians. The Pima have the highest recorded rates of type 2 diabetes in

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the world (Knowler et al. 1990). And because of the relationship of gestational diabetes mellitus (GDM) to the future health of the woman and infant, women have become the focus of intensive prevention efforts by clinicians and educators at Gila River.<sup>1</sup>

In this discussion I offer two perspectives on the Pima epidemic. The first is conceptual: the meaning of diabetes risk in a population with endemic diabetes and at risk for a sentinel but temporary form of the disease—GDM. Diabetes is a disease diagnosed late in its destructive processes, after which time the body may long have battled vascular complications. Thus, risk for disease may well be interpreted as risk for those late complications. If this is the case, and I provide ethnographic data showing that it is, then pregnant women who are susceptible to GDM may have expectations about a diagnosis that are way out of line with how they are likely to feel.

In other words, they may not have any subjective experience of the relationship between GDM and its more permanent cousin, type 2 diabetes. What, then, would be their interpretation of a diagnosis of diabetes, their understanding of risk, and their perception of the implications that one diagnosis might carry for another? I show that, for many informants, the concept of risk offers little clarity at all.

The second perspective involves the production of knowledge about GDM and the diagnostic controversy<sup>2</sup> surrounding this form of diabetes. Among diabetes specialists there is some debate about (and no small amount of research devoted to) determining the best moment at which to diagnosis GDM and how this diagnosis should be made. At the center of the controversy are concerns about macrosomia (high birth weight) and other birth outcomes as well as the potential need for different diagnostic criteria for some ethnic groups. The implications of this debate around GDM for the larger context of type 2 diabetes are significant. Most important are the relationships, real and perceived, between GDM and type 2 diabetes. Two different forms of diabetes—GDM and type 2—have decisive relationships, connections, and similarities. But for prevention to work, they must also be viewed as distinct: the latter version is made preventable by the prophetic warning of the former. One is, at the same time, a harbinger of and indistinguishable from the other.

The biomedical perspective—not homogenous itself—exists simultaneously with varying local perspectives on this disease. I therefore follow my discussion of the diagnostic controversy in

biomedicine with ethnographic data from Gila River on some of the same diagnostic points of contention. The concept of “risk” and the diagnostic process for diabetes during pregnancy have multiple meanings for Pima women undergoing prenatal care. The way women respond to GDM’s typically symptomless form sheds light on their health care seeking patterns and, ultimately, their perceptions about and reactions to diabetes screening.

## OVERVIEW OF DIABETES

Diabetes is high blood glucose resulting from the body’s inability to produce or to properly use insulin. Insulin converts sugar, starches, and other food into energy. The factors contributing to diabetes include both genetics and environment (such as obesity and lack of exercise). There are approximately 18.2 million people in the U.S. with diabetes (6.3 percent of the population). Diagnosis typically occurs through either a Fasting Plasma Glucose Test (FPG) or an Oral Glucose Tolerance Test (OGTT). The American Diabetes Association recommends the FPG because it is easier, faster, and cheaper to perform. More will be said about these tests below.

There are three major types of diabetes: type 1, which results from the body’s failure to produce any insulin; type 2, which results from insulin resistance (the improper use of insulin) plus a relative insulin deficiency; and gestational diabetes, which affects about 4 percent of U.S. women. Many subtypes of diabetes exist, as does the concept of pre-diabetes, in which blood glucose levels are higher than normal but not high enough for a diagnosis of type 2 diabetes. There are an estimated 41 million Americans with pre-diabetes, in addition to the 18.2 million with diabetes (ADA 2004). So clinicians remain concerned and vigilant over this high-risk period.

Type 2 diabetes is the form most common in the Pima, with over half of adults carrying the diagnosis. I have given a detailed profile of the Gila River Indian Community elsewhere (Smith-Morris 2004), but a useful epidemiological comparison was made by Weiss (1985), which shows Mandan, Seminole, and Pima Indians having more than 24 percent prevalence, while Dogrib and Passamaquoddy Indians have less than 10 percent. Thus, while there is a range in prevalence across different Native American groups, diabetes is a significant health concern for many tribes because of political, economic, cultural, and, in some cases, genetic factors.



GDM is glucose intolerance, with onset or first diagnosis occurring during pregnancy (ADA 2000). In GDM, glucose levels return to normal after the birth of the child. Women whose glucose remains high after pregnancy must be reclassified as having type 2 diabetes and do not retain the diagnosis of GDM. Using the 1998 criteria of the Fourth International Workshop Conference on GDM, approximately 7 percent of all pregnancies in the U.S. and between 8 percent and 9 percent of Pima Indian pregnancies are complicated by GDM (ADA 2000; Kjos and Buchanan 1999; Pettitt et al. 1996). GDM alone is not an indication for Cesarean delivery or for delivery before 38 weeks gestation, although it produces an increased likelihood for Cesarean section. Maternal morbidity associated with GDM includes hypertensive disorders (specifically preeclampsia) and increased maternal length of stay after delivery (Carr 2001). Neonatal morbidity can include high birth weight (greater than 4,000 grams), birth trauma, fetal demise, hypoglycemia, and hyperbilirubinemia (ibid.). Women with GDM also have a 17 percent to 36 percent risk of developing type 2 diabetes within five to 16 years (ibid.).

GDM is also implicated in the future diabetic health of offspring. For Native Americans, diabetes may be an "acquired characteristic" beginning in utero (Benyshek et al. 2001: 35). Benyshek et al. hypothesize two phases in the emergence of type 2 diabetes: first, a thrifty phenotype generation experiences severe famine conditions in utero and goes on to develop abnormal insulin-glucose metabolism (especially when obese) in adulthood; next, the subsequent generation(s), though *not* experiencing severe food shortage, develop hyperinsulinemia, insulin resistance, and eventually glucose intolerance in adult life *as a result of excess fuels supplied to them in utero* by glucose intolerant mothers (see also Freinkel 1980; Pettitt et al. 1988). Related studies have shown a greater transmission of diabetes from mothers than from fathers (Dorner and Mohnike 1976) and from mothers who had diabetes during pregnancy than from mothers who were not diabetic during pregnancy (Pettitt et al. 1988; Pettitt et al. 1996). Diabetes support, education, and treatment for pregnant Pima women are, therefore, a priority in the long-term goal of reducing diabetes prevalence at Gila River.

From a clinical perspective, GDM poses some unique opportunities as well as some peculiar problems. Since many pregnant women already attend regular prenatal appointments, clinicians may have better access to at-risk patients than they do to the

general population. Screening, and therefore early intervention, may be more likely for GDM than for type 2 diabetes. Also, because control of glucose during pregnancy has a protective effect on both mother and fetus, clinicians view pregnancy as a good opportunity to prevent future problems. However, the clinical difficulties in treating and managing diabetes are exacerbated during pregnancy. For example, the added weight of pregnancy may camouflage other unnecessary or inappropriate weight gain, and some symptoms of diabetes (e.g., fatigue, thirst, swelling in the extremities) may also be confused with normal symptoms of pregnancy in the Sonoran desert of the Pima reservation. But the greatest problem in GDM surrounds its diagnosis and efforts within biomedicine to demarcate its boundaries.

#### DIAGNOSTIC CONTROVERSY

GDM is a disease that powerfully demonstrates the heterogeneity of medicine. Not a "coherent whole ... [but] an amalgam of thoughts, a mixture of habits, an assemblage of techniques," biomedicine and biomedical knowledge are formed out of human acts and interaction (Berg and Mol 1998: 3). A discussion of the professional controversy over diagnosis of diabetes draws attention to its historical moment and to the research context that so drives diagnostic knowledge. On this point, Rapp (1999: 208) has provided a particularly human and sharp perspective on the "problem of stabilization and disambiguation" of scientific decisions. In her ethnography of genetic screening, Rapp explores many angles to the production of knowledge about amniocentesis and points out that, "among insiders, the acknowledgment of ambiguity, uncertainty, and stabilizing judgment calls is part of normal and normalizing cytogenic practice" (209). A similar discourse about GDM diagnosis now exists in professional circles.

Since the 1980s there has been quite a bit of disagreement within biomedicine over the diagnosis of GDM. Aspects of the controversy have included: the appropriateness of testing (Jarrett 1997), the methods by which testing should be done (Juutinen et al. 2000; Neiger and Coustan 1991b; Neilson, et al. 1991; Perucchini, et al. 1999; Pettitt 2001; Weiss et al. 1998); the cut-off values for diagnosis (Corcoy et al. 2000; Magee et al. 1993; Neiger and Coustan 1991a; Rust et al. 1996; Weiss, Sent, and Udall 1989); the costs of various methods (Bonomo et al. 1998; De Aguiar et al. 2001; Schwartz,



Ray, and Lubarsky 1999); and the need for different cut-off values for different ethnic groups (Green et al. 1990). In spite of all this research effort, the U.S. Preventive Services Task Force was unable, based on current evidence of benefits and harms of screening, to recommend for or against routine screening for gestational diabetes in the general population (USPSTF 2003). Nor could they state which approaches to screening and diagnosis are optimal.

As David Pettitt (2001: 1129) stated in 2001, "the controversy over what screening test (if any) to use for the diagnosis of GDM and how to interpret the results is unlikely to be resolved quickly." While the adoption of the 75-gram glucose load test by the American Diabetes Association (based on the endorsement of the Fourth International Workshop-Conference on GDM) has, since 1977, given clinical practice its direction and focus, the meaningfulness of the test continues to be debated. At Gila River, where the entire population is deemed at high risk for diabetes, all pregnant women are tested for GDM at the first appointment or as early as possible.

The controversy among experts reveals important characteristics of the disease and tests for it that are likewise apparent to many patients, despite the sometimes authoritative presentation of the diagnosis and its screening devices by health care providers. Central to this discussion is the professional disagreement over the place or moment at which to make a diagnosis. And feeding the debate are questions about macrosomia (high birth weight) and other negative birth outcomes as well as the meaningfulness of population averages for certain high-prevalence ethnic groups (including the Pima).

### The Diagnostic Boundary Line

The fact that a diagnostic controversy exists is evidence of the problematic boundary line between diabetic and non-diabetic. This line is drawn neatly by official American Diabetes Association (ADA) thresholds, but the long-term impact of "high normal" glucose may be quite profound (Lao and Ho 2004; Mello et al. 2003; Weiss et al. 1989), and so the boundary line is frequently questioned. In much recent research, diagnostic criteria and methods are evaluated for their ability to predict negative birth outcomes such as high birth weight (Jarrett 1997; Mello et al. 2003; Neilson et al. 1991; Rust et al. 1996; Schmidt et al. 2001), *not* for their ability to predict future diabetes in the mother and infant (as in Dabelea et al. 2000; Lindsay

et al. 2000; Pettitt et al. 1993). Speaking generally, the diagnosis of diabetes is not so much a measurement of current complications or symptoms as it is a statistically determined threshold for predicting future complications and outcomes. A patient's health status at the first diagnosable moment is quite good (though this is rarely when they're actually diagnosed); diabetes is much more often diagnosed late in the vascular destructive process. So conservatives want to push the boundary line lower in order to capture more of those at risk for complications and to catch them earlier.

### Population Averages and High-risk Ethnic Groups

Given that diabetes diagnostic criteria are strongly reflective of statistical associations (regarding later complications), it is appropriate to note the differences between ethnic groups with respect to diabetes rates and complications. It is with these differences in mind that some researchers are calling for different diagnostic thresholds for different ethnic groups. Though it falls dangerously close to the slippery slope of racism in diagnosis, this recommendation has some merit. If the diagnostic threshold itself is already determined by statistical forecasting, then it seems appropriate to offer revised statistical forecasting for relevant, significant subpopulations. To insist that each subgroup (including ethnic groups like the Pima Indians) be treated using comparisons against a global (or national) norm is not only unnecessary but also unreasonable and unethical. Whether or not those revised diagnostic thresholds are made "official" by the ADA or other endorsements, I leave to those bodies to decide. But, at Gila River, decisions that respond to their greater-than-population-average risk for diabetes, including earlier testing for GDM and even a new (local) diagnostic category of "pre-GDM" (which I discuss later), are already being made.

The points of this professional debate are mirrored in women's negotiations and narratives of GDM at Gila River. And it is to this ethnographic work that I now turn for further discussion of the interactional nature of diabetes knowledge.

### SITUATING A STUDY OF GDM: ANTHROPOLOGIES OF PREGNANCY

Pregnant women are arguably the healthiest people to undergo frequent and invasive biomedical monitoring. This occurs, in part,



due to a growing intolerance in industrialized societies for *any* maternal morbidity, an epidemiological achievement of the last century attributable in large part to biomedical knowledge and technologies. However, as feminist literatures point out, biomedical monitoring and tests aimed at assessing potential risks create risk-focused environments in which competing hegemonic and interpersonal messages must co-exist (Abel and Browner 1998; Morsy 1993; O'Neil and Kaufert 1995; Terry 1989). In this space professionals as well as family and friends feel a moral obligation to the fetus as a separately identified patient from the mother (see, for example, Browner and Press 1997; Casper 1998). Further, numerous pioneers in feminist anthropology address how surveillance disproportionately affects hegemonically "weak" or non-dominant groups, such as poor and/or indigenous women. A large body of ethnographic literature explores women's power in decision making as it relates to that of biomedical practitioners, society, and the fetus. In this literature, such as the edited volumes on reproduction by Ginsburg and Rapp (1995) as well as by Davis-Floyd and Sargent (1997), reproduction is viewed as "a microcosm of broader trends" in technologization, medicalization, and control of natural, human processes (Davis-Floyd and Sargent 1997: 6).<sup>3</sup>

Ninety-eight percent of all births in the U.S. occur in hospitals. However, birthing practices do not dictate the degree or form of participation in biomedical surveillance and treatment during the prenatal period (Browner and Press 1997). While both emotional and informational needs can be met through prenatal care, biomedical information is not accepted uncritically: the occasional absence of professional consensus around some of that information, the timing of its receipt, and women's ability to meaningfully and feasibly incorporate that information into their lives and perceptions of self all influence participation in prenatal care (*ibid.*).

Despite ambivalence about prenatal care, women want reassurance that they are doing everything possible to ensure a healthy pregnancy (Browner and Press 1997: 127). The potential consequences for women who do not fill the role of a good (i.e., compliant, "low-risk") patient extend beyond the confines of the clinical encounter. As additional diagnostic tests are made available, women are morally and socially required to submit to them, to avoid the risks they define, and to respond in specific manners to their results. Women who do not subscribe to this standard risk are labeled "bad mothers" or "bad patients" and are otherwise

punished through various social mechanisms, ranging from shame to legal action against their autonomy and personal freedom (Terry 1989; Whiteford 1996).

Risk data have, therefore, gained a remarkably powerful role in the policing of pregnant bodies. Yet, as we know, the ability of professionals and patients to understand risk data is limited by serious omissions or misrepresentations in its collection, preparation, and presentation (Frankenberg 1995; Freudenburg 1988). For example, in the United States, many disease data are reported only in terms of transmission mode, "race," and sex; there is inadequate consideration of such complicating factors as socioeconomic class and of the limited choice of ethnic categories on census questionnaires (c.f. Krieger and Fee 1994: 20). Similarly, behavioral and demographic characteristics fail to account for structural and cultural factors that influence the trends in disease demographics. Risk is influenced by power dynamics that transcend ethnicity, age, and other factors typically identified in risk research. In the case of diabetes, risk focuses our attention upon blood glucose levels in relative disregard for the lived experience of diabetes across demographic, intra-ethnic, and interpretive differences (Rock 2003).

Lisa Handwerker (1994: 672), whose work among poor pregnant women reveals ways in which medical risk statistics are interpreted by different social actors, argues that "recent judicial decisions in the areas of risk provide numerous examples of faulty scientific analysis by courts untrained to deal with the intricacies of risk assessment." Women run the *risk* of imprisonment if culturally sanctioned expectations for proper management of risk during pregnancy are violated (see also Paltrow 1990; Terry 1989). The cases of pregnant Charleston women who went to the public hospital for care exemplify the legal and physical power that care givers can have over pregnant women. According to the Institute for Criminal Justice Ethics, these women were selectively tested for drugs. Women with positive test results were turned over to the police, handcuffed, and jailed "until they can make bail" (Paltrow 1990: 1).

Screening tests for symptomless, or *pre-symptomatic*, disease—including tests to screen for gestational diabetes, the focus of this research—are the hallmark of epidemiological risk achievements. The ability to identify disease or its precursors before any bodily symptoms are present is an important advantage in biomedicine and is largely attributable to the population-based research that epidemiologists conduct on disease events. Through epidemiology,



characteristics of disease and of diseased populations both before and after disease onset are identified. This creates an ability to identify, prevent, and provide early treatment for disease. Also, a type of *post-disease* state, or "remission" state, can be identified through screenings when symptoms are under medical control but risk continues. In the case of breast cancer, for example, removal of cysts that may have been pre-cancerous yields a breast without such threatening cysts, but the patient must continue to undergo monitoring for future cyst development and, often, repeat surgeries (see Gifford 1986). When the boundary between a healthy-but-at-risk and diseased state become blurred, patients can consider fibrocystic breast disease and breast cancer to be different forms of the same disease.

In the case of diabetes and pregnancy, Pima women might easily consider gestational diabetes and type 2 diabetes to be the same disease: simply, diabetes. But these two forms of diabetes have important differences. Type 2 diabetes is a diagnosis that is never removed, though glucose can be reduced to normal levels. GDM is a diagnosis that is temporary, though it leaves the body(ies) worse off than their non-GDM counterparts. The birth of the baby and subsequent disappearance of GDM seem to indicate good health. In fact, the infant may be overweight, hypoglycemic, and at higher risk for diabetes; the mother may also be recovering from Cesarean section delivery (major surgery with associated risks such as infection) and also be at higher risk for developing type 2 diabetes. Testing for GDM has become a standard practice for all pregnant women, not just for Pima women, but it is through these pre- and post-disease windows that risk data expand the purview of biomedical knowledge and authority over pregnant Pima women's experience.

There are many reasons for an ethnographic focus on pregnant Pima women. Because of the relationship of GDM to the future health of a woman and infant, responsibility for the future diabetic health of the entire community can be laid on pregnant women. GDM has become the risk focus excusing increased surveillance of pregnant women's lives in the name of future generations. However, GDM is generally asymptomatic. The few symptoms that might be present can easily be confused with symptoms related to any pregnancy in the Sonoran Desert of Arizona (e.g., fatigue, excessive thirst, and swelling in the lower extremities). The lack of symptoms indicative of diabetes not only creates

a technology-bound diagnosis but also exacerbates the competition between professional, authoritative knowledge and women's lay, experiential knowledge—two types of knowledge that can never be completely disentangled (Abel and Browner 1998:316). Where Pima women experience a symptomless pregnancy, biomedical surveillance provides evidence of disease or its imminence. And while women exert some autonomy or agency in rejecting biomedical prenatal care, authority remains with biomedical knowledge at Pima births. Almost 100 percent of Pima births occur in hospitals and approximately 28 percent of these are by Cesarean section (Smith-Morris 2004a).

#### METHOD

The ethnographic fieldwork began on the Gila River Indian Reservation in 1997. The sampling process was aimed at discovering reasons why women had declined or never attended diabetes education, thus targeting women who had never enrolled in the Diabetes Education Center (DEC), a department within the tribal hospital. Because of this sampling approach, women's talk about health care was typically generalized to all the tribal hospital services or to prenatal care; only very rarely were there specific references to the DEC. Interviews were held in settings away from the hospital and clinics.

Ethnographic methods included ongoing interviews with key informants and pregnant women, attendance with several pregnant women at prenatal appointments, and participant observation in various community social and health-related settings. Following approval by the Gila River Community Council, one intensive (full-time) ethnographic period occurred between August 1999 and June 2000, although participant observation and informal discussions occurred periodically in the two years preceding and five years since that time. Interview questions addressed Pima health knowledge, women's understanding of diabetes, and women's health care seeking behaviors.

Interviews began with general questions about health and illness, signs and symptoms of illness, women's experiences with illness and healing, and personal definitions and opinions about various health topics. General questions were also posed regarding how and from whom women received their ideas about health and



illness. These questions required some childhood recall as well as the ability to elaborate on current social and professional networks to which the women had access in order to gain information or treatment for illness. The second major set of questions introduced the topic of diabetes. Women were asked to elaborate on disease etiology, diagnosis, co-morbid conditions, prevention, education, social meaning, and treatment. Great care was taken to use culturally relevant, non-jargonistic terms so as to encourage women's openness and reflection.

Women were recruited in both formal and informal situations. Formal recruitment was conducted in the Hu Hu Kam Memorial Hospital's prenatal clinic; the Sacaton Women, Infants, and Children (WIC) office; the Gila Crossing prenatal clinic; the Gila Crossing WIC office; and at DEC education classes. Participant observation occurred in diabetes education classes, public health clinic offices and waiting rooms during prenatal visits, public health field clinics, outpatient health clinics, the annual Mulcha-tha (foot race) festival, several holiday parades and parties throughout the years, health walks and exercise events put on by the Fitness Center and Hu Hu Kam Memorial Hospital, cooking classes, family memorials and birthday parties, crystal and Avon parties, and countless meals and social visits with community members.

Sixty-three participants, ranging in age from 18 to 67, completed formal interviews, the majority being conducted in women's homes (on the reservation). Twenty-seven of these participants were pregnant and gave multiple interviews over the course of their pregnancy; this represents 14 percent of the estimated number of women who were pregnant in this community during the 10-month period. Of these, 13 reported having a diagnosis of type 2 diabetes and two more reported having GDM. An additional person reported having "borderline" diabetes, which is a term I discuss later. Ethnographic interviews were recorded, transcribed, and analyzed for thematic content.

In analyzing the data I used both quantitative and interpretive methods in order to examine the etiologic and attitudinal themes among Pima women concerning diabetes and pregnancy. I conducted inductive and *in vivo* coding of transcribed interviews (Bernard 2002) in order to determine key terms, repeated concepts in health belief or attitudes, and patterns in health care seeking behavior and expressions pertaining to biomedical care or diabetes. In general, I considered concepts reiterated by at least 10 participants to be

thematic. This quantitative summary helped direct a narrative analysis aimed at discovering patterns in the forms of expression across all Pima informants. I performed further text analysis in order to develop interpretive stances and, of course, in order to identify the exemplary, or characteristic, narratives quoted here.

The two crucial questions addressed by my ethnographic research are: (1) how do women interpret diagnostic tests for diabetes during pregnancy? and (2) how do these interpretations influence their ideas about what diabetes is and whether it will affect them?

## RESULTS

### Diagnosis as a Work in Progress

Controversy over the diagnosis of GDM, and the meaning of that diagnosis for future type 2 diabetes, is not limited to experts on the subject. Pregnant Pima women, like many women across the United States, question the relevance of a GDM diagnosis. It is unclear to many women, since *this* diabetes (GDM) is going to "go away" after pregnancy, whether it is something to be concerned about. When I asked Mary<sup>4</sup> whether she had diabetes, she responded in a way common among participants.

CMS: Are you diabetic?

Mary: No. Not that I know of. I don't know—they're still trying to [figure it out] ... They said I am but I don't know. I have to go do some more tests ... I didn't know I had diabetes when I was pregnant like with [my first child]. Too, I was—they were saying that I had diabetes too ... but after they told me I didn't have it.

Mary was diagnosed with GDM during a previous pregnancy, but being told after childbirth that her blood sugar level was normal, she concluded the original diagnosis was incorrect. In other words, she did not differentiate between GDM and type 2 diabetes, which she viewed as a permanent and debilitating disease. Rather than question the permanence of a diabetes diagnosis, Mary and many Pima women reasoned that an original but cancelled diagnosis (actually a diagnosis of GDM) had been based on some error.

The very high rates of diabetes in this community might also influence women to think that type 2 diabetes is inevitable. Women say that, while type 2 diabetes may be in some ways or for some



period avoidable, not even the most vigilant and active lifestyle can guarantee its avoidance.

CMS: Do you think that you will eventually get "outright" diabetes?

Sarah: When I get older.

CMS: Do you think that there's any way to avoid it?

Sarah: Um—I wish I could say it would take care [of it]—that [with] diet and exercise, [it would] be taken of care but I don't know.

Another woman summarized what many participants felt:

Laura: I think it . . . can be avoided for a while but I think eventually it crops up.

David Kozak has characterized the Pima reaction to decades of increasing prevalence of type 2 diabetes as an attitude of "surrender" to diabetes (Kozak 1997). This reaction is neither apathy nor futility but, rather, a collective response to years of increasing prevalence of diabetes at Gila River despite tremendous financial and clinical investment. Pregnant women's talk about GDM incorporates much of this more general, community-wide reaction to the epidemic; yet they also grappled with the "fickle" blood glucose readings of GDM. Diabetes educators should recognize that pregnant women are, therefore, not necessarily lacking information (a deficit model) but are "making sense" (Lang 1989) of a disease that, although it comes and goes, inevitably comes back to stay.

CMS: How do you think that gestational diabetes works? I mean, why is it that you can get it when you're pregnant and then it just goes away?

Kelly: You know what, that part of it I could never figure out to be honest with you because I can catch it. I mean I had it like with my first daughter at 28 weeks, my second daughter at 27 weeks, but with this pregnancy I had it at 7 to 8 weeks and that part of it I just don't understand. I could never, because afterwards I'm fine. After the deliveries and the six weeks [check-up] or you know [when they] do the glucose testing, yet I'm fine . . . I mean its like, ok, you know you do these two hours [the two-hour test], you do the one hour [test], you do a three hour [test], ok your sugars are up and then its like ok now, *now* I'm classified GCI [gestational carbohydrate intolerance]<sup>5</sup> . . . And then [I] do them again six months later and I'm classified gestational diabetes. I'm like, "Wait a minute!" you know? So what comes next? It's just basically, that's all I have to say is what comes next?

It is, in large part, the goal of diabetes education to align women's understandings of diabetes with biomedical concepts

and priorities. At Gila River diabetes education is provided in both group and individual formats through the DEC and covers six topics: nutrition for diabetes management; fitness and safe exercise; the psychosocial aspects of having diabetes; the different forms of diabetes (including pre-, type 1, type 2, and gestational diabetes); monitoring, which includes fetal kick counts, self-blood-glucose monitoring, and post-delivery diabetes control; and complications for mother and baby resulting from high blood glucose. An outcome study of women enrolled in diabetes education between the years 1994 and 2001 indicates a positive relationship between education and glucose control (Smith-Morris 2004a). In particular, the relationship between maternal education with regard to complications and subsequent blood glucose control for the years between 1994 and 1997 was statistically significant.<sup>6</sup>

However, few pregnant women have completed these diabetes education classes. This is because few Pima women are referred to classes before they have received a diagnosis of either GDM or type 2 diabetes. Consequently, education geared toward informing the screening process is tardy. Pre-conceptual counseling is the best way to manage perceptual conflicts in young, pregnant women (e.g., Charron-Prochownik 2000). Indeed, an education campaign aimed at *all* young adult Pima is one of the recommendations I discuss later. Women who *do* complete these classes seem to adopt biomedical explanations for the disease, which I confirmed through participant observation at these classes and with participants in the months following the class. For example, several female elders who attended the classes together (classes held at one of the tribe's casinos) became quite conversant in the methods for controlling blood sugar and the benefits of exercise.

But women do not, of course, accept biomedical knowledge uncritically. When I met with those female elders socially on two occasions after classes had been completed, they continued to discuss their dietary habits and exercise in biomedically informed ways. However, the degree to which this knowledge changed their behaviors is unknown; we did, after all, have frybread and beans for lunch both times. These women, already friends, used their shared experience in diabetes education classes to develop new "metaphors of sociality" (Ferzacca 2004:58), replacing bread fried in lard with bread fried in vegetable oil; serving fruit rather than cookies for dessert; making minor, acceptable substitutions in what



constitutes "a good meal" so as not to disrupt the greater goal of that meal, "the mediation of social relationships" (56).

Women's understandings of diabetes screenings are informed as much by previous (social, dietary) experience as by formal education. Information relayed by health care providers during the prenatal appointment is probably what is most influential with regard to pregnant women's perception and interpretation of the tests. Prenatal care providers are, therefore, in the best position to stress the importance of a diagnosis that "goes away" after childbirth (GDM) and to challenge assumptions about the inevitability of a (type 2) diagnosis. But these are difficult tasks to assign physicians already frantic to avoid major prenatal complications like fetal stress and emergency Cesarians. Indeed, these negotiations are challenging even for professional diabetes educators. Despite the seeming fickleness of this disease—that is, the fluctuating glucose readings both within and across pregnancies—GDM demands the same behavioral changes as does type 2 diabetes. Pregnancy, while it might provide added incentive, only makes more difficult the changes necessary to prevent or manage any form of diabetes.

### The Meaning of Risk

An individual's sense of vulnerability to disease is informed not only by professional information but also by lay and popular information, personal experience, and intuition about the likelihood of developing disease in a given context, time, and circumstance (see, for example, O'Neil and Kaufert 1995; Pearce 1993). Comparative risks and optimism also factor into a person's decisions about seeking health care (van der Pligt 1998). Thus, "taking care" of oneself involves more than avoiding "risky" behaviors. Florence expressed her sense of risk for diabetes in this way: "I think it all depends on your body, on yourself, on your own thinking. That [you're more likely to get it if] you're gonna be down and out or all negative."

Local interpretations of risk information are especially important in communities with endemic disease and long-standing prevention programs. It is for these long-standing problems that communities have the opportunity to develop large, collective banks of memory and experience that may or may not support biomedical accounts of the disease. For example, a low-risk pregnancy among the Pima is an increasingly rare occurrence. The rise in diabetes

prevalence coupled with the falling age of initial diagnosis means that young Pima women are considered closer in years to a diagnosis of type 2 diabetes than ever before. However, a person's sense of themselves and confidence in their knowledge and abilities influences their health care choices. After their first child, many ( $n = 9$  out of the 10 multigravida) pregnant women I interviewed were more willing to skip prenatal appointments based on how they were feeling. They expressed greater knowledge of pregnancy and what their bodies were going through, and a greater confidence that they would know if something were wrong. Therefore, symptomless gestational diabetes might easily go undiagnosed, as would any symptomless concern, because women are skipping appointments. Patricia said she normally attends appointments at the reservation hospital but that she hasn't gone much during her current pregnancy because, as she explained, "I think I know what's going on with me."

Risk also generates semantic disagreement, if not "outright" disagreement, over the nature of diabetes. This problem revealed itself in conversations about women's understandings of risk. In response to the question "What do you think it means to be 'at risk' for diabetes?" many women used the term "borderline" to distinguish a boundary area between pre-but-non-diabetic and diabetic.

Maureen: I don't know because... you know people that had been told they were a borderline candidate—here, you know, because... I've talked to different people and they have different reactions. So what does that mean, borderline? Either you are or you aren't!

CMS: What do you think it means to be at risk for diabetes?

Priscilla: That they were borderline.

CMS: What do you think it means to be at risk for diabetes?

Denise: Just, is that like another term for borderline?

Borderline is a term eschewed by most clinicians I know at Gila River. But it is commonly used by Pima women because, despite the authoritative presentation of the diabetes diagnosis in its pre-, GDM, and type 2 forms, diabetes still seems to have a vague and shifting boundary. Sarah's words (below) also reveal how the term "borderline" is used by Pima women to negotiate and understand the various forms of diabetes, particularly gestational diabetes and pre-diabetes. Although she says she was diagnosed



with some form of diabetes four years ago, the fact that the term "borderline" was used leaves her uncertain as to whether she has the disease or not.

Sarah: [I think I'll get it] when I get older [though I don't have it now] ... About four years ago I was diagnosed with diabetes. I have borderline diabetes. [But] someone told me, you either are or you're not, there is no borderline.

Although the terms "risk" and "borderline" are used by different speakers to help explain or understand diabetes, they have contested meanings. Since diabetes is diagnosed with the use of a numerical scale indicating a blood glucose level—if your reading is 126 or higher on an FPG test, then you have diabetes; if it is not, then you don't—then patients often describe numbers close to the diagnostic cut-off as "borderline." However, these blood, glucose numbers fluctuate. So a reading one day might be well within diabetic range, while the next day it may be normal. Indeed, this fluctuation is a major consideration in the diagnostic controversy among diabetes experts. Acknowledging these fluctuations, experts grapple with determining the appropriate fixed point at which to incur the diagnosis. Finally, some Pima who are tested over a period of time show a progressive rise in their glucose readings, furthering the cultural meaningfulness of the *linear* progress and the idea of a "borderline diabetic."

Significantly, many Pima, despite decades of prevention and education efforts in the community, still conceptualize diabetes in terms of its complications:

CMS: In your own words, what do you think diabetes is?

Eileen: Like when you drink too much sugar. And you don't drink enough water and stuff.

CMS: And so then what does it do to you?

Eileen: You have to get on dialysis.

Laura: I have it in my family. My parents got it. My dad went on dialysis... He did home peritoneal, home dialysis... And the trucks would come and deliver all his supplies. They gave him all this equipment... His body started shutting down and he got on dialysis and then he had I guess an ulcer or something... I guess they found out that he was getting [an infection] under his foot. He had, I don't remember what it was. So they sent him to Tucson and they amputated his, up to his, up to his knee. So then he had to get a prosthesis. And, you know, he couldn't ever, he never gained the strength to get back.

Catherine: There's one lady I knew, she had a big old [infection]... She was a diabetic. She was scared that they were gonna have to amputate her leg.

John: My mother was, she was blind by the time she was 50. She was a double amputee.

To these Pima risk for diabetes means a risk for complications like blindness, dialysis, and amputation. In reality, these are late-stage complications, and it is possible for people with diabetes to avoid them entirely. But if these images are prominent in pregnant women's perceptions of the disease, then how do they make sense of a positive diagnosis for GDM? Certainly, the concept of a "borderline" into and out of which they can travel, especially during pregnancy, is a helpful one.

#### DISCUSSION

To discuss these ethnographic findings, I return to the controversial boundary line between a diabetic and non-diabetic diagnosis. In ethnographic research, Pima women's words reflected an understanding of the GDM diagnosis as a work-in-progress rather than as a clear and final diagnosis. Although biomedical definitions strictly contradict this understanding, GDM is by all counts a temporary form of the disease. Women whose glucose remains high after pregnancy must be *re-classified* as type 2 and do not retain the diagnosis of GDM. The diagnosis of GDM might, therefore, eventually be seen as more clear, but certainly not final.

The first question addressed by this research concerns women's interpretation of diagnostic tests for diabetes during pregnancy. In interviews and in less formal settings, Pima women expressed a good understanding of most prenatal tests, including such activities as fetal kick counts, electronic fetal monitoring (stress tests), and urine analyses for iron and other trace elements. The screening for gestational diabetes, however, has some complicated characteristics that result in more creative interpretations; namely, a positive screening for gestational diabetes may well be followed after birth by normal blood glucose readings. Both physicians and diabetes educators know and are careful to share information about this trait of GDM (i.e., that women may expect to see their glucose return to normal); however, this does not mean that women have returned to their pre-GDM state of risk for developing type 2 diabetes.



she was 50, diabetic since her 30s. Before, [when] you had to boil the needles; that's how long she'd been a diabetic.

Laura: The amputations and diabetes, yeah, and the dialysis. Yeah, dialysis. Some [would] rather die then go on it . . . And then they just want to die and they give up. They just give up.

Caroline: My best friend's grandmother, I was real close to her, she died because of her diabetes. She had to take insulin shots. She took them every day and she got one blister on her foot and they amputated and amputated until the whole leg was gone. Then they were going to amputate the next one, and that's when she gave up and just died.

Complications are the most visible aspect of diabetes and are the stuff from which communal ideas about the disease are made up. Every Pima has a memory of these complications through her/his experiences with family members. These visibly distressing events—amputation, thrice weekly dialysis, blindness—loom large in the attitudes of non- and pre-diabetic Pima toward undergoing tests. If these complications are viewed as the characteristic manifestation of diabetes, then pregnant women may well be surprised to learn they have any form of it. Likewise, when they are healthy and feeling good, Pima may conceptualize diabetes as a remote possibility and act accordingly.

## CONCLUSION AND RECOMMENDATIONS

Is a GDM diagnosis clear and reliable? Or does a GDM diagnosis contribute to prenatal stress in ways that would actually *discourage* women from following up on diabetes referrals, as was found by Persily (1996)? As I have discussed elsewhere (Smith-Morris 2004), the issues facing this population are complex while the stakes—that is, the links between GDM and subsequent diabetes in mother and child—are high. Pima women's utilization of prenatal diabetes education is contingent upon their interpretation of the diagnostic process that, for GDM, seems to contradict subsequent normal blood glucose levels. This research reveals that women's interpretations of GDM are heavily influenced by the peculiar aspects of the disease.

In short, women have identified and grapple with the *same* conceptual problems of GDM as do diabetes professionals.

At least two potential improvements in diabetes care and education can be harnessed to facilitate these negotiations with meaning

One might reasonably ask:

Biomedical explanations (where consensus exists):

*What's the difference between gestational diabetes and "regular" diabetes?*

Diabetes is defined as having multiple forms, though the end-result is the same in each form: high blood glucose.

*How can it be diabetes if I don't feel bad?*

Most visible, and thus foremost in the mental image of the Pima, are the complications of diabetes, including blindness, amputation, and the need for dialysis.

*How can it be diabetes if it goes away?*

The high blood glucose of GDM disappears after birth. If high blood glucose persists, then the woman must be reclassified as having type 2 diabetes.

*If my test numbers are normal, how can I be diabetic?*

Diagnosis of diabetes involves a numerical threshold that, once crossed (or crossed twice, depending on the test), permanently connotes the diagnosis. Later normal glucose levels, regardless of their duration, do not remove the diagnosis. *Nor do they* warrant any kind of "in remission" status.

in balanced and effective ways. First, privileging women's experiences in the diagnostic and educational dialogue will not only improve communication but will also ultimately foster better compliance with diabetes management plans. Elongated conversations between provider and patient *allow* the provider a voice in the patient's translation of biomedical information into personally meaningful concepts. The longer and more deeply providers involve themselves in that process of translation, the more likely it will be for key biomedical concepts (e.g., weight loss, prenatal control of glucose) to "take hold" in women's lives.

But the moment of diagnosis is a late start for diabetes education. Alice told me she was not referred to diabetes education until her blood glucose reached life-threatening levels.<sup>7</sup>

Alice: When I took that diabetes [test] again, I didn't take diabetic prevention. I took diabetic education after my sugar went to 900. Up to 900! And then I ended up on insulin. Then they gave me the diabetic education class and I told them, I told them, they should've been given to me when I [was] first diagnosed with diabetes.



Some, of course, attend appointments but make few or no behavioral changes for diabetes prevention and management. Some skip the classes altogether. One physician at Gila River is offering an alternative: group appointments, during which lengthy, open-ended discussions are more feasible than they are during the traditional appointment. Her new approach is, by all reports, both effective and very popular. This format would be a useful one for prenatal care, during which diabetes education and awareness is so important.

A continuing goal is to identify thematic discrepancies between biomedical information presented in prenatal appointments or diabetes classes and what women perceive. This research addresses these discrepancies for the concepts of "risk" and "borderline" diabetes, but there are other elements in diabetes education that seem vulnerable to cultural reinterpretation, such as the accuracy and reliability of finger-stick glucose readings and, particularly for the Pima, what constitutes "exercise," "swelling," or "excessive thirst."

Michielutte (1994) and others (e.g., Ferzacca 1990; Joe 1994; Lang 1990; Olson 1999; Rock 2003) are useful resources, in terms of both content and methodology, for these types of questions. Much also rests on providers' ability to encourage women's enrollment in, completion of, and behavioral responses to diabetes education. The most effective strategy may be pre-conceptual services, including education and case management that would make diabetes lifestyle changes more attainable for Pima women.

The second improvement to be made in conjunction with these one-to-one strategies involves the strengthening of community-based efforts at Gila River. In the interest of space, I now briefly list the most important of these (a fuller discussion may be found in Smith-Morris 2004; and Smith-Morris n.d.b):

1. A population-based approach, which recognizes the high-risk status of this ethnic group *without* losing sight of the differences among Pima in their risk behaviors, resources, and readiness for prevention is fundamental.
2. Diabetes education campaigns must be invigorated and expanded to target *all* Pima, and especially all pregnant women, not just those with diagnosable forms of diabetes or pre-diabetes. Delaying education until after diagnostic confirmation of diabetes or pre-diabetic conditions is reckless.
3. Popular formats, such as the group education format and one provider's group appointments, should be used more widely, and resources should be employed to expand upon those good ideas.

4. Field nurses who spend time in patients' homes are also popular and should be used as a clinical model for these rural, dispersed populations. These nurses develop a close relationship with their patients and encourage two-way communication about diabetes, thereby acknowledging the negotiated aspects of knowledge production around this disease.
5. Youth should be a target of prevention education, particularly before they become sexually active.

A diabetic pregnancy is profoundly dangerous to a fetus *in the first several weeks of gestation*. This is weeks before the first diabetes screening is usually conducted. As mentioned earlier, the intrauterine environment may have as much impact as does genetics on the fetus's (eventual) development of diabetes. One influence is environmental, the other genetic, but both significantly affect the development of the metabolic system in humans. So Pima must recognize their ability to prevent the future generations' diabetes in the earliest stages of pregnancy. To the credit of the community and many dedicated professionals at Gila River, there is a strong school-based initiative for diabetes education. But there is a gap in education for older teens and 20-something adults: precisely the age groups starting families.

It produces in me no small ambivalence to draw attention to the experiences and interpretations of pregnant Pima women. Because of their roles—as pregnant women, as mothers, as family cooks, and as grocery shoppers—women are at the bull's-eye for diabetes prevention efforts. But technologies have "potentials that are at once both emancipatory and socially controlling" (Rapp 1999: 155). While we may understand the genetic, political, economic, and cultural influences on diabetes among the Pima (Smith-Morris 2004), the impact of the intrauterine environment connects, inextricably, the Pima mother's behaviors and decisions with the future health of all Pima. The temptation, therefore, grows to police pregnant Pima women for their contribution to intrauterine diabetes transmission and, thus, to the epidemic.

A counter-balance to this slippery slope must exist in the privileging of women's interpretations and experience of pregnancy. It is not simply logistical barriers that prevent women from attending and participating in prenatal care and diabetes education (which *have* shown to improve both prenatal health and glucose control). It is also women's interpretations of the diagnostic process that affect their readiness for and reactions to educational messages. This ethnography demonstrates the ability of Pima women to



question the same vagaries of the GDM diagnostic process as are questioned by professionals. Their interpretations of risk insist on the inclusion of experiential information, as we have learned is true of so many populations speaking through medical ethnographies. Processes of knowledge production *can* be acknowledged and productively harnessed in clinical encounters. To some extent, at Gila River this is already being done in group appointments with physicians, group education classes, and the work of field nurses. These formats for education and treatment will prove their worth in the form of better attendance, adherence to treatment plans, verbal involvement of patients in plan development, and, ultimately, reduced blood glucose levels. Through these mechanisms, diagnostic controversy and the negotiated meaning of diabetes risk are harnessed as the very mechanisms by which diabetes can be prevented.

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#### NOTES

1. In comparison to voluminous clinical research, the ethnographic work on health in this area has been sporadic (e.g., Dobyms 1989; Hackenberg 1955; Hackenberg 1979; Kozak 1997; Meister 1989; Kuller 1993; Ritenbaugh 1974; Russell 1908; Underhill 1940; Weaver 1972).
2. Since the ADA diagnostic guidelines are firm until revised, in any given clinical situation there is little room for disagreement over a diagnosis. If there is disagreement (e.g., over ambiguous or erroneous test results), then these are not the subject of my conversation. I use the term "diagnostic controversy" to refer to the professional debate rather than to controversy attending any individual moment of diagnosis. I choose the term "controversy" rather than "uncertainty"

- or "disagreement" in order to emphasize the fragmentation of the medical community on this topic as well as the socially constructed nature of diagnostic medical knowledge.
3. Another view of women's reproductive health comes from the social and cultural analysis of the body (e.g., Martin 1990, 1987; Lock 1998).
  4. All names are culturally appropriate pseudonyms.
  5. GCI refers to gestational carbohydrate intolerance, a version of diabetes recognized at Gila River as pre-gestational diabetes. This diagnostic form is not part of the ADA definitions of diabetes, but it helps clinicians identify the highest-risk pregnant Pima women for treatment and education during pregnancy at the earliest possible moment. This display of creative license in diagnosis is not only emblematic of the fluidity of diabetes diagnostics generally but is also a noteworthy indication of the importance to clinicians and patients at Gila River of preventing GDM.
  6. This relationship had a p-value of .042. Whether the educational materials, the experience of the classes, the concern over traumatic complications, or other factors were decisive in this relationship is not yet known. The remaining five education topics in the DEC curriculum also showed moderate relationships to maternal blood glucose control through Pearson correlations. Overall, the statistical analysis (of education completion to maternal glucose control) only explains about 32 percent of the variation in women's prenatal blood glucose (i.e.,  $R^2 = .32$ ), which is one of the reasons for identifying non-DEC patients for the ethnography.
  7. A blood glucose reading of 900 is very rare and typically puts a person into a coma. I have, however, heard several anecdotal cases of readings this high at Gila River.

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