Psychosocial Obstacles to Treatment of Diabetes: A Mexican-American Community in the Salinas Valley

By

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INTRODUCTION

This work is in response to my frustration with the relationship problems between health professionals and their patients. During my last year as an undergraduate student of nutrition science, I volunteered at a clinic in the Sacramento Valley of California. The client population were predominantly agricultural field workers, mostly Spanish-speaking, many migrating yearly from Mexico. I had many opportunities to observe the dynamics of the family practice medicine in this rural setting.

With the exception of the clerical and support staff who were local residents and "bicultural/bilingual", the clinicians -- especially the physicians and several nurse practitioners -- had noticeable communication difficulties with their patients. Despite the help of translators, there was a palpable tension in many clinic encounters. Although this touched all aspects of care, the problem was especially disturbing with respect to diseases requiring continued "medical management": tuberculosis, hypertension, diabetes.

Especially notable were the frequency of clinical appointments addressing diabetes in this predominantly Mexican population. I recall one interaction between one family and the dietitian who was fluent in Spanish. *Abuelita* (grandmother) had been diagnosed with diabetes some months earlier, but was resistant to make dietary changes needed to lose weight -- some fifty pounds

recommended. Seven family members from three generations were gathered around her, listening intently to the dietitian's petitions (in Spanish) to decrease the number of tortillas down from the six taken with each meal. I'll never forget their looks -- part skepticism, part exhaustion -- as they were told that they should all make dietary changes both for "their own good" and in support of *Abuelita's* needs. If I had to compose a caption to that scene, I would imagine the family saying "Hah! Just one more thing which you tell us we 'must do'. We are tired of the problems you tell us that we have!". But they sat silently, agreeing with the proposed changes, nodding, leaving with printed dietary material.

I remember standing in the corner and wondering, " What do they think about this affliction, this diabetes? Do they know why clinicians think its important? Do they agree that it is important? Why don't we ask their opinions? negotiate the plan?" As I saw that scenario repeated time and time again, I became disillusioned, a feeling compounded as I heard clinicians whisper about "those non-compliant" (Mexican implied) patients.

After completing a degree in nutrition and working for community programs in that context for several years, I entered medical school with the goal of being a "family" or "general" practitioner in an underserved community. But this change in direction was made with proverbial mixed feelings: how could I resist the frustrations, the cynicism which I

saw in clinicians working for poor, medically-underserved communities? Who do I think I am that I could be any different in practicing so-called "cross-cultural" medicine?

These are secret anxieties which I experience as I move along the trajectory of American medical education. During this tenure, I have had the opportunity to address these earlier questions in a more formalized manner through this study. What began as personal interest in "clinical communication" has evolved into a study of the social, cultural and psychological factors which frame the experience of affliction. It attempts to capture the perspectives and "roles" of clinicians, of patients, and of the institutions in which they interact to address illness.

In approaching the primary care setting, I found that pertinent factors could be explored in greater depth when addressed to a specific medical problem. Since diabetes has been designated by medical institutions (researchers, organizations, journals) as a significant health problem for Latino populations in America, that affliction became the focus of this inquiry. Diabetes is especially fitting for consideration of the psychosocial features of illness since it is medically defined as a "chronic" disease requiring extended medical care and patient vigilance.

While health professionals have numerous forums for discussing "Diabetes in Hispanics" through professional journals and conferences, the views of those most affected

by the problem -- diabetics and their families in the community -- remain unknown. Indeed, the *emic* views of lay people (non-health professionals) are rarely solicited by health and medical researchers. This omission is an extension of the typical medical/clinical interaction, the unidirectional flow of information as I observed in the *Abuelita* story above. Commonly, solutions in the form of public health programs are designed externally and "piloted" upon "target" communities. Though patient or community representatives may be approached to advise in "community outreach development", their involvement is often nominal or token, their influence too late to affect substantive changes. In other scenarios, community leaders chosen by outside agencies to be involved in initial community planning may not adequately represent the majority opinion of a highly diverse constituency. Furthermore, a preliminary review of the literature in epidemiology, applied anthropology and "diabetology" reveals that few published studies have evaluated psychosocial features of diabetes as it experienced in the Latino communities. These are some of the ideas which informed the direction and emphasis of this work.

Specific Goals

The study presented has been guided by the following objectives:

1. To conduct a community-based study of diabetes in a semi-rural Mexican-American community of California, using ethnographic methods.
2. To present case histories which demonstrate how diabetes fits into the lives of people in the study community: their feelings, beliefs and opinions expressed in their own words.
3. To explore how diabetes is experienced by diabetic patients of the community from within the differing contexts -- a Salinas clinic, in their home, and in the Mexican *barrio*.
4. To explore the different therapies recognized and used in the community from amongst both medical and traditional *remedios caseros*.
5. To discuss the role of psychosocial factors -- political, economic, class-related, institutional and cultural -- as obstacles and motivators to treatment of diabetes for such patients.
6. To assess the awareness and impressions of diabetes in the general (non-diabetic) Mexican-American community, and discuss its influence on the illness experience.

Organization of the Presentation

The first chapter, "Medical Approaches to Diabetes", discusses the professional paradigms of this disease believed to be more prevalent in Latino populations. Medical definitions of diabetes, its long-term complications and treatments will be discussed, as well as that oft used notion of patient "compliance".

In the second chapter, "Previous Studies of Diabetes in *La Raza* Community", I will review the current research efforts of epidemiologists, social scientists and clinicians as well as the interventions of public health institutions to deal with this affliction. Although the scope of the discussion will include diabetes in several Latino and Native American populations, emphasis is on Mexican and Mexican-American groups.

A short review of the application of social scientific analysis to health problems will follow in Chapter 3 with emphasis on the elements of established approaches and theories which have been applied to this study. In Chapter 4, "The Research Setting", I will attempt to describe a picture of the town of Salinas, its ethnic communities and issues as well as a brief historical and demographic overview. Chapter 5, "Methods of Study" discusses the approach to data collection for both the case study and survey subsets of the Mexican-American population.

In Chapter 6, "Presentation and Analysis of Case Studies", I will incorporate some representative social case

histories of community diabetics listing those major themes which emerged from an ethnographic analysis. This chapter gets at the heart of the diabetic problem as I viewed it in Salinas, 1986. In Chapter 7,"Diabetes Awareness in the Non-Afflicted", I present information from the survey of the non-diabetic population. I will present an integrated picture of diabetes as it is experienced by the afflicted and corroborated by information from the non-afflicted.

Finally, in Chapter 8 I will discuss ideas for community-based approaches to the "problem" of diabetes, many which have evolved from the suggestions and ideas of community members.

Footnotes follow at the end of each chapter.

Chapter 1: MEDICAL APPROACHES TO DIABETES

Before defining the problem of diabetes in the Mexican-American population, a short discussion of biomedical models of diabetes mellitus will be presented.

Medical Definitions of Diabetes, the Disease

Although there are up to eight medical classifications of diabetes mellitus, only three of these are common: insulin-dependent diabetes mellitus (IDDM or Type 1 or juvenile-onset), non-insulin-dependent diabetes mellitus (NIDDM or Type 2 or adult-onset) and gestational diabetes mellitus. Ninety-five percent of Mexican-Americans diagnosed with diabetes mellitus have the non-insulin-dependent diabetes (NIDDM). (Beyond this discussion, all references to "diabetes" will pertain to NIDDM unless otherwise specified. Diabetes insipidus is so named for its similar symptoms as diabetes mellitus, namely, profuse urination and insatiable thirst. DI is caused by a pituitary dysfunction at the brain and is relatively uncommon compared to diabetes mellitus.

In all types of diabetes, the common defect is hyperglycemia or high blood glucose which remains elevated even in the "fasted" state. Glucose is the elemental carbohydrate component in the blood and is chemically similar to sugar. Since the days of the Greek physicians, diabetes was viewed as merely

a problem of sugar metabolism and that avoidance of sugar the logical remedy. However, studies in the last ten years have revealed that metabolism of all nutrients is impaired, and that even dietary control cannot guarantee complications in some individuals.

IDDM is usually diagnosed in childhood or early adulthood with an acute onset of the "classic" symptoms. The individual becomes entirely dependent on injected exogenous insulin for a lifetime. The current medical hypothesis for IDDM suggests that "viral infection initiates an autoimmune response in which the (insulin-producing) cells are destroyed" (Cahill & Ardy,1986); the coxsackie B (mumps) virus is implicated. Although there is a genetic component to IDDM, no direct familial pattern is seen.

As the name implies, gestational diabetes is hyperglycemia or "impaired glucose tolerance" which first appears in pregnancy. The mechanism may be similar to that of NIDDM, yet the women may return to normal glucose levels upon delivery. There is concern for the development of the fetus since newborn babies of diabetic mothers are oversized with disproportionate fat, a condition known as macrosomia. There is a higher rate of gestational diabetes in populations with NIDDM, hence, in Mexican-American women.

Non-insulin-dependent diabetes (NIDDM) is the result of metabolic changes which are complicated and incompletely understood, and it is this type of diabetes which is found in high prevalence amongst Latino populations. According to the medical model, a genetic predisposition to NIDDM is required,

though its expression is highly dependent on environment. It is believed that age and obesity are the strongest determinants.

The mechanism of NIDDM is under continued medical study and debate. The current model is that the cells in the body, (liver, muscles, fat) which normally respond to insulin to "receive" or absorb glucose, become resistant to its action. Researchers hypothesize that in the genetically "predisposed" individual when cells enlarge (as in obesity) the shape of the protein cell receptor for insulin is changed making it unresponsive to circulating insulin, so-called "insulin resistance". Thus, glucose cannot enter the cells which literally "starve in the midst of plenty". The progression or extent of this metabolic defect explains the spectrum of conditions medically-defined: from occult insulin resistance to "impaired glucose intolerance" to frank NIDDM.

According to the medical model, chronic exposure to elevated glucose imposes structural changes in tissues and contribute to "long term" complications of diabetes. Alterations occur in both the blood vessels and nerves, leading to circulatory and sensory problems: accelerated atherosclerosis and attendant cardiovascular risks; retinal and visual defects; kidney impairment leading to end-stage renal failure; neurosensory changes in the limbs. People with diabetes are more vulnerable to spread of bacterial infections as well as fungal skin conditions; many women experience chronic vaginal infections.

Medical Treatment of Diabetes.

According to medical models, there is no cure for diabetes, so that the therapeutic aim is "control" of blood glucose levels. This is believed to be as important to prevent long-term complications as to relieve immediate symptoms.

Diet therapy has traditionally been the "cornerstone" to management for all types of diabetes. For patients using insulin, meals must be coordinated with the pattern of insulin injection and absorption. But for the majority of those with NIDDM, a weight-reducing diet low in fat and "sugared" foods is recommended. Only recently has there been disagreement about the sanctity of the diabetic diet. In a critique of diet therapy by Wood and Bierman in the New England Journal of Medicine (1986) they argue:

> Kelly West . . . suggested that much of our effort at dietary counseling for these patients was "ineffective and wasteful" and he urged the development of more effective approaches. . . No evidence has yet been presented or published to demonstrate that the clinical course of diabetes is improved by these dietary manipulations.

Reviewing the myriad of diet fashions recommended for diabetics over the years -- "low-protein", "high fiber", "complex carbohydrate" etc. -- the authors continue:

> The basic approach to patients with (NIDDM) who are usually overweight is to encourage caloric restriction. . . . "by preventing obesity, it is possible that the incidence of NIDDM be reduced by up to 50%.". . . Nevertheless. . . studies have proved that few people actually lose much of their excess weight. More hope is generated by other reports pointing to short-term benefits of moderate weight loss (about 15 pounds) in older patients with NIDDM. Perhaps such a limited loss will be more easily achieved and sustained.

This debate is important to this study since weight loss of fifty pounds or more is frequently the physician's therapeutic goal with many Mexican-American diabetic adults, an aim which becomes the negative focus of clinic encounters. In spite of these nutritional controversies, diet is still considered the most important focus and special programs for Mexican-American groups are being developed. (See Chapter 2.)

Oral hypoglycemic pills are used in conjunction with diet for many adults with less severe diabetes -- that is, those with moderately elevated blood glucose. Oral hypoglycemics such as chlorpropramide (trade name "Diabinase") are suited to NIDDM because these agents are believed to increase cell receptor sensitivity to insulin.

Insulin injection therapy for diabetes exposes the "fine line" between IDDM and NIDDM. While all IDDM patients require insulin for life, those with severe hyperglycemia of NIDDM who are unresponsive to diet or pills also use insulin. However, the application may be transient. Weight loss or other "life changes" (reduced stress, increased activity, etc.) can eliminate the insulin requirement.

Most medical practitioners have some general knowledge of diabetes rates expected in the "general population" and would correctly estimate a prevalence of 2 to 3 percent worldwide, with American prevalence of 4 percent. However, the picture changes greatly when considering specific groups. The biomedical community now recognizes increased rates in low-income communities, especially in people of color ,Blacks, Native

Americans and Latinos. Indeed, between 1964 and 1973 the greatest documented increase in diabetes in America was in non-whites: some 150% increase (Bernal, 1984).

"Stress" and Diabetes

Among physicians there is anecdotal awareness that stressful life events are associated with onset of diabetes in those people genetically predisposed. Additionally, "diabetic control" is known to be more difficult during periods of change and emotional turmoil. (Bernal, 1984). To date, no epidemiologic studies have confirmed the association between "stress" and the onset of diabetes. One case of transient diabetes in the literature associates diabetes with immigration (Hong,1973). In another study,the role of "acculturation" implicated in a study of hypertension. (Bernal, 1984). However, opponents of these theories claim that stress is difficult to "operationalize" for the purposes of study. Most medical professionals therefore consider emotional stress less important in the etiology of NIDDM than the measurable factors genetics, age and obesity. It was, in fact, this alleged difficulty of operationally evaluation "stress" in illness which piqued my interest in ethnographically approaching the issues of diabetes in the Mexican-American community.

Medical Views of "Compliance"

Fundamental to the biomedical paradigm is a specific model for physician-patient interaction. This model views the patient as the passive recipient of medical advice that is determined through "scientific" evaluation of the ailment. It is assumed that the physician assessment and recommendation is value-free and objective so that any "rational" patient is expected to dutifully "comply with medical advice". (And these quoted terms are commonly used amongst physicians.) Acknowledging the pervasive influence of the medical paradigm for "compliance" on clinician attitude and behavior is central to the analysis of the case histories presented in this study.

A Critique of "Compliance".

There is much concern over patient "non-compliance" amongst medical practitioners, especially with respect to treatment of chronic illnesses such as hypertension and diabetes. Numerous studies in medical journals address this "problem", yet, as Stimson points out, the research is framed in terms of defining the prototypical "non-compliant" patient (similar to techniques used in criminology):

> The research problem has been conceived as one of conformity and its opposite deviancy. The task is to find out how many deviate, and how they may be identified. (Stimson, 1974)

By extending this perspective to population studies, both medical and social researchers attempt to discover why certain subgroups, such as Latinos, are more non-compliant to diabetes treatment than the general population (at least, that is the

collective perspective -- more in Chapter 2). Rarely are research questions posed from the point of view of the patient: "why should patients comply with doctors' instructions?". Nor does the medical paradigm consider the rationality of a patient following the more meaningful, contextualized advice of family and friends over the technical council of a "stranger". An alternative to the traditional medical view stated here by Stimson, sees the patient as:

> a decision-making individual living in a culture [and social setting] from which he is receiving information about health and illness. The patient is continually open to new information about his illness . . from friends and others.

Specific features of the medical view of diabetes contributes to patient confusion about the disease. First, the unique aspect of the biomedical model of disease in general, which applies to diabetes in particular, is that medical diagnosis is based on quantification, in this case, blood glucose levels. In the U.S. numerical criteria for diagnosis were revised by the National Diabetes Data Group in 1980 (Schuman and Spratt, 1980) and distinguish between various etiologies and degrees of glucose impairment: "frank diabetes", "oral glucose intolerance", "gestational diabetes",etc. This diagnostic approach can intensify the schism between the patient's illness (experience of affliction) and disease (the medical designation of disease; these are the Kleinman definitions described further in Chapter 3). One individual may "experience" the illness, yet technically may not be diabetic. Conversely, and this is more common, a symptomless individual may be medically diagnosed with diabetes

or, even more abstractly, "impaired glucose tolerance", a "pre-diabetic" condition.

Secondly, though different types of diabetes are distinguished by different causes, when symptomatic all forms elicit the same "classic" symptoms: excessive thirst and urination, weakness and dizziness, unexplained weight loss and, in extreme situations, stupor and life-threatening coma. This ambiguity leads to confusion in patient understanding of the affliction and hence to her perception of need for therapy. Third, while the biggest problems for the afflicted individual may be the immediate symptoms of NIDDM as well as the treatment regime prescribed, the physician is often more concerned about the "long-term complications" of diabetes. The priority differences between diabetic patients and physicians contributes to conflict over patient "compliance" which is of overriding concern to health professionals.

Because medical treatment of diabetes requires that the individual make fundamental lifestyle changes, "diabetic management" becomes a focus for conflict and disagreement between nearly all clinicians and patients. Yet, as I will further demonstrate, this conflict becomes more complicated within the context of cross-cultural dynamics.

Chapter 2: PREVIOUS STUDIES OF DIABETES IN LA RAZA COMMUNITY

Epidemiological Research.

In the early part of the eighties, as morbidity statistics described previously neglected groups in America, a higher prevelance of non-insulin-dependent diabetes mellitus prevalence was revealed in "Hispanic"1 populations. The widespread nature of the problem was verified through the nationally-sponsored Hispanic Health and Nutrition Examination Survey (HHANES) of 1982 thorugh 1984.. The bulk of this evidence, however, has come through studies in Texas which have also investigated high cardiovascular deaths in Mexican-American populations.

An early investigation of diabetes in Mexican-Americans of Laredo, Texas by Stern et.al (1981) reported a three- to fivefold greater prevalence of diabetes as compared to the U.S. Public Health Service estimates for the general population. Surprised by the prevalence of a disease thought to be well-studied and characterized, epidemiologists realized that the natural history of diabetes in this "minority" group of 7.5 million was unknown. The potential for extensive study was apparent and has been dominated by two Texas research teams who have asked: is this prevalence related to "a genetic predisposition of Hispanics to diabetes, to sociocultural factors or both?" (Hanis, et.al.,1983).

Principle among several Texan investigations is the San Antonio Heart Study, a "comprehensive epidemiological investigation of NIDDM and cardiovascular risk factors in

Mexican-Americans" conducted from October 1979 through June 1982. (Hazuda,et.al., 1986) The San Antonio Heart Study (SAHS) has been extensively cited in professional journals ranging from physical anthropology to internal medicine, and has supplied most of the epidemiologic description of NIDDM in Mexican-Americans applied to clinical care and public health programs. Likewise, the Diabetes Alert Study has been simultaneously conducted in Starr County, Texas at the Mexican border. This latter study responded to statistics which indicated that Texas' highest "diabetes-specific" mortality rates (by county) -- some 52 of 1000 total deaths -- occur in the lower Rio Grande Valley, where 97% of the population is Mexican. These figures contrast sharply to rates of 2 to 4 deaths per thousand in predominantly Anglo counties. (Hanis, et.al.,1983).

The discussion which follows will review the work of the San Antonio Heart Study. By comparing White and Mexican-American adults in three different "income" neighborhoods, researchers have hypothesized on the influence of sex, Native American genetic admixture, socioeconomic status, acculturation and "behavioral variables" on diabetes prevalence. Table 2-1 summarizes the salient findings of their papers.

The medical paradigm of NIDDM holds that obesity is THE most important "triggering" factor in the onset of NIDDM. When SAHS researchers compared Anglo- and Mexican-Americans of equal "fatness"*2* , the latter group had two to four times more diabetes in all neighborhoods (in men and women, respectively). They reasoned that there must be operational factors in

Table 2-1

Summary of Published Results:
San Antonio Heart Study

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1. Presence of Diabetes vs. Ethnicity as Mexican-American

Obesity controlled. Found two to four times prevalence of diabetes in M-A versus Anglos for men and women respectively.

Hypotheses suggested: 1) "Westernized" diet 2) Genetic predisposition via Native American admixture. 3) Diet of high fat/high carbohydrate

Stern, et.al., 1983

2. Genetic Admixture Native American vs. Prevalence of Diabetes by Neighborhood

Pooled men and women. Native American admixture "measured" by skin color reflectance.

Increased NA admixture (skin color darker) in "barrio" proportional to increased diabetes (14.5%)

Decreased NA admixture (skin color lighter) in "suburbs" proportional to decreased diabetes (5.0%)

Gardner, et.al.,1984

3. Sex vs. Prevalence of Diabetes Cardiovascular risk factors

Found diabetes and CV risk factors distributed differently in MA communities according to sex.

Concluded sociocultural factors more important than socioeconomic factors in DM distribution.

Stern, et.al.,1984

Table 2-1 (cont'd)

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4. Behavioral Variables vs. Fat Patterning on Body HDL and LDL cholesterol levels

Behavioral variables measured include caloric intake, cigaret and alcohol use and exercise habits.

Haffner, et.al, 1986

5. Level of Circulating Insulin vs. Ethnicity (MA or AA)

Controlled for Body Mass Index, regional fat distribution and blood glucose levels.

Found higher levels of circulating insulin in MA versus AA cohorts.

Suggest hyperinsulinemia and cell receptor "resistance" to insulin actions as mechanism for NIDDM in Mexican-Americans.

Haffner, et.al.,1986

addition to obesity and concluded that the most important is Native American or, more specifically, *indigenous genetic admixture*. (Gardner, et.al.,1984) This follows the currently popular model among physical anthropologists, geneticists and physicians, James Neel's "thrifty genotype" hypothesis. Neel, a physical anthropologist, suggests that a diabetogenic gene -- which "offered better storage and protracted metabolism -- was of selective advantage in indigenous "hunter-gatherer" peoples (e.g. of Africa, the Americas and Pacific Islanders); that is, they were better able to withstand their "feast or famine" existence (Stein, 1985) But, Neel argues, with the "westernization" of diet in these groups that accompanied their "development", diabetes rates in people of color have exploded. Indeed, diabetes has taken its place with cardiovascular disease and cancer among the so-called "diseases of civilization". However, Neel's analysis disregards the influence of social, political and historical events during "development" on indigenous peoples which parallelled the dietary changes. Thus, it is believed that NIDDM in Mexicans relates to Native American admixture.

It is well-established, for example, that 48% of adults of the Pima tribe in Oaklahoma have diagnosed NIDDM. [Though beyond the scope of this discussion, interesting work by Kelly West on the "discovery" of diabetes in Native Americans parallels its historical emergence to the internal exile of native people to "reservations" where refined diets were dictated according to the supplies rationed by Whites. See References on West.]

The highly structured and quantified analysis of the San Antonio Heart Study in the journals masks a number of questionable assumptions. This is of concern considering the wide influence and application of their results. For example, NIDDM rates for low-, middle- and high-income San Antonio neighborhoods were found to be 14.5%, 10% and 5% respectively. The "skin color reflectance" measurements (which measure darkness of skin and are used as an indicator of the amount of indigenous genotype) shows a reciprocal stepwise increase of Native American genotype from suburb to barrio. (Gardner, 1984).

> The association of genetic admixture with NIDDM rates suggests that much of the epidemic of NIDDM in Mexican-Americans is confined to that part of the population with a substantial native American heritage. (Ibid.)

An alternative interpretation of these data suggests that the observed neighborhood trend in diabetes is related not to the indigenous genotype but also to psychosocial and economic issues of poverty which are similarly experienced by darkly-pigmented people: Pima Indians, Mexican-Americans and others. Yet such an explanation is not discussed by the researchers. Furthermore, Stern et.al (1984) state:

> . . .there is a "twofold difference in diabetes prevalence between the barrio and the suburbs in men compared to a fourfold difference in women. .

and conclude from this observed gender difference in distribution of diabetes that cultural attributes of the Mexican tradition are involved:

> These results suggest that cultural factors exert a stronger influence on diabetes and cardiovascular risk factors in Mexican-Americans than do purely socioeconomic factors. (Ibid.)

However, these "cultural factors" are never clearly defined by the authors. They do not consider that gender differences in socioeconomic variables (such as education, income) are seen in nearly all ethnic minority groups living in Western society and affect the different distribution of affliction betweem the sexes.

Descriptive factors about the San Antonio participants such as income, educational level, alcohol consumption, exercise habits and so-called "acculturation" parameters are distilled into three numerical indices. As a result, the complex relationships and important contexts between these descriptive factors for diabetics are masked in the process of "factoring", "adjusting" and "rounding off". Further, the application and meaning of the three numerical indices is not sufficiently addressed for my interpretation. Yet this clarification is necessary to interpretation of SAHS data: indices for sociocultural, behavioral and acculturative factors are correlated to physiological and anthopometric (body measurement) data for diabetics (blood glucose, weight,body fat). [See Stern,1984; Haffner, et.al.,1986; Hazuda, et.al.,1985) From these statistical correlations, broad generalizations about the cause of diabetes in Mexican-Americans are generated, often to the exclusion of self-reported and phenomenological considerations.

Three studies were found which considered diabetes in Mexico, and of these, two were headed by British teams. Diagnosed diabetes has been accelerating in Mexico since the 1940's. According to Guadalajaran physician Dr. Javier Garcia de Alba G., NIDDM among Mexican citizens is not clearly related to obesity -- that is, the disease is seen in many lean individuals (Garcia de Alba, 1985). Probably the most common assumption of medical researchers in America is the contribution of "traditional Mexican diet" in etiology of diabetes. One problem here is the vague definition of "traditional diet". This passage from Paisey et.al (1984) shows how sociopolitical conditions in Mexico has altered to the so-called "traditional diet":

> For the past 20 years the Mexican government has pursued a policy of food subsidies to ensure that maize tortillas, beans, eggs, vegetable oil and wheat bread are freely available. . . This policy, together with traditional patterns of nutrition, has resulted in the usual diabetic individual's diet consisting of 46.5% of calories from carbohydrate with a high polyunsaturated to saturated fat ratio. (Paisey,et.al.,1984)

Here then, policy influenced food availability and culturally-preferred selections in Mexico and, indirectly affected diabetes rates. This resembles the situation of the Oaklahoman Native Americans groups described by Kelley and the South Dakotan Sioux chronicled by Lang (1985). In both groups, the rise in diabetes can be historically associated with political domination which spawned rationing of more refined foods in reservations.

The San Antonio Heart Study and, to a lesser degree the Diabetes Alert Study, inform most of the conventional wisdom on

diabetes available to the American medical and public health professional communities, information which is popularly transmitted and accepted. Yet questions of social, political and historical elements of diabetes in Mexican-Americans are not considered in analysis of this affliction. There appears to be an inherent bias in the presentation of SAHS, one which is limited by an research aproach that consistently and systematically de-emphasizes the importance of psychosocial and socioeconomic factors and their distribution along racial lines in both America and Mexico. Moreover, in a number of publications the authors attribute increased diabetes in Mexican-Americans to Native American genotype, ethnic Mexican traditions, and the lack of "acculturation" to American values and lifestyles. It is ironic that the SAHS research attributes "acculturation" to American culture is somehow "protective" for diabetes (e.g. health club memberships they say) , when the disease is also deemed a "disease of civilization" for indigenous peoples.

Some Clinician Views

With the issuing of the *Comer Bien* diet program throughout 1986, a series of health professional conferences entitled "Diabetes in the Hispanic Patient" were presented throughout the state, and sponsored by the California Diabetes Control Program. The frequency and refractoriness of the diabetes problem in many Mexican-American communities throughout the state was emphasized. Rodolfo Chavez-Pardo, medical director at the San Ysidro Health Center near the California-Mexico border, reported

that during January through June 1985, 6.5% of patient visits involved diabetes mellitus as a primary diagnosis. Throughout his years of medical practice to Mexican and Chicano patients, Chavez-Pardo believes that a lack of "cultural" sensitivity on the part of predominantly Anglo providers accounts for the reported in treatment. This implies that "sensitivity-training" of non-Latino health professionals and recritment of more Latino clinicians would help address non-compliance in this community. He believes other contributing factors include that:

> (1) Hispanic patients do not have a clear concept that it is the amount of blood glucose which is abnormal in diabetes, not its mere presence.
>
> (2) There is extended belief among the Latino population that diabetes is a curable disease and that folk remedies are very effective in controlling and curing the disease.
>
> (3) Traditionally, not only diabetics, but most Hispanic patients have a very passive attitude regarding their diseases, and put a lot of emphasis on the external intervention of a healer to change their fate. Most consider that there is little the patient can do to modify the course of an illness.
>
> (4) Treatment modalities from most to least preferred include oral agents, dietary modification, increased physical activity, and insulin.
>
> (5) Hispanic patients believe that the physician is the "leader" of the health care team and what other associated personnel (such as dietitians) do is less important.
>
> (6) There is a basic difference in patient-physician relationships in American and Hispanic cultures. Here, the interaction is more "business-like" whereas in Mexico it is important for there to be a meaningful human interaction.
>
> (Chavez-Pardo, 1986)

Chavez-Pardo claims that these factors emphasize the uniqueness of diabetes in the Mexican-American population based on cultural differences rooted in ethnic traditions from Mexico. (This will be further discussed in Cahpter 6.) Beatriz Beliz, a Health Educator in southern California, adds that Anglo professionals aren't familiar with the thought processes behind the actions of Mexican-American diabetics and so label them "ignorant", "lazy" and "non-compliant".

The reflections of these two experienced clinicians express the views held by many public health activists about obstacles to treatment of diabetes in the Mexican-American community. In general, many clinicians, public health researchers and medical anthropologists believe that clashes of cultural "explanatory models" between clinicians and patients lead to poor diabetes care: patient health beliefs and "misconceptions" which are rooted in Mexican ethnic tradition, clinician approaches which arise out of either cultural insensitivity on the part of Anglo health care system or professionalism or both.

A review of the literature in epidemiology, applied anthropology or diabetes education shows that few published studies have ethnographically evaluated psychosocial features of diabetes as it is experienced in the Mexican-American community. Similarly, diabetes has long been recognized in the Native American (including Eskimo) populations, but only recently have thorough ethnographic accounts of diabetes been available for these group. (Lang, 1985; Hagey, 1984)

However, in progress is an "ethnographic", clinic-based study of Mexican-American diabetics in the low-income *barrio* of San Antonio, conducted by Urdaneta and Thompson. The researchers found that "in discussions with health care professionals, it is reported that Mexican-Americans are highly noncompliant to treatment regimens." Yet, they state, no published research shows this group to be any more or less successful in management of this disease than any other group. In an unpublished report of their preliminary results, they state that:

> The question of compliance/non-compliance cannot be ignored and the research team suggests that one possible explanation for low compliance rates could be that available education materials and programs are not specifically designed for Mexican-American diabetics. The available instructional materials and programs for diabetics are generally not sensitive to the specific needs of the Mexican-American diabetic population. Logically, it follows that a person cannot comply if there is no information, or if there is none available in terms that can be understood.
>
> (Urdaneta & Thompson,1985)

Simultaneous work in California addresses this issue.

Public Health Actions

According to the California Department of Health Services Diabetes Control Program, the specific needs of Mexican-American diabetics includes bicultural and bilingual adaptations of therapeutic diets, cooking instructions and exercise plans. In September 1985, this agency unveiled *Comer Bien para Vivir Mejor* (Eat Well to Live Better), a program of "skills-oriented nutrition counseling for Mexican-American (NIDDM) diabetic patients", a

project partially underwritten by the Public Health Service and the California Beef Council. Responding to the absence of Spanish language diabetes education materials, *Comer Bien* is a comprehensive package designed primarily for use and dispense by registered dietitians. The American Dietetics Association Exchange Diet usually perscribed for diabetics by physicians is translated in terms of "traditional Mexican foods".3 The creators of this program cite recent, though still controversial, nutrition research which advocates a "high complex-carbohydrate" (whole grains, usually high fiber) diet for optimal diabetic "control". Though Mexican-American diabetics have typically been urged by physicians and dietitians to avoid a corn and bean-based diet, *Comer Bien* encourages these traditional foods, and structures the therapeutic plans around them. as the High Fiber Hispanic (or HFH) diet. In the accompanying Professional Guide, it states:

> When asked what foods they commonly eat, most Hispanic people would reply,"We eat beans, rice and tortillas." The High-Fiber Hispanic Plan was developed to incorporate this view of the way foods are grouped into a system resembling the ADA exchange system.
>
> It is more effective to teach that a serving of beans represents a "beans" exchange than that a serving of beans equals both a "bread" and a "meat" exchange. Similarly, placing tortillas, rice and cereals each in their own groups is an easier concept to explain than having them all in the "bread" group. In this way, the HFH plan makes the exhange system concept as practical as possible for Hispanic patients.
>
> (Hall, et.al, 1985)

In recognition of illiteracy in the "target" population, the materials incorporate pictures and symbols believed to be culturally meaningful, for example a large cooking spoon described as a "traditional utensil" represents one serving size unit. The program includes exercise and cooking intructions: guides for walking and stretching; how-to's on cooking frijoles without lard or fat.

According to the creators, the plan is optimally presented to a newly-diagnosed diabetic patient through a series of four instructional sessions with a registered dietitian, in the usual clinical style. Classically, the physician making the diagnosisof diabetes refers that patient to a dietitian for "follow-up" nutritional counseling. Nutritional counseling sessions are arranged through separate appointments and require that the patient make additional trips to the facility to receive these services.

Although the *Comer Bien* program addresses the paucity of bilingual-bicultural health education materials, its creators allude to other obstacles in treatment of diabetes. Indeed, structural factors appear to have prevented an accurrate field assessment of *Comer Bien*:

> . . . the educational kit was field tested in a variety of rural and urban practice settings. The field test of the guide revealed a very high degree of professional acceptance and an enthusiastic response to the materials; very few substantive changes were indicated. The main limitation of the field test was structural; that is, in most clinical settings serving Hispanics, missed appointments are a frequent problem. Therefore, only a handful of

> patients completed the four-session series within the field testing period which prohibited a complete evaluation of client outcomes. [Emphasis added.](Foerster, 1985)

Despite professional satisfaction with the appropriateness of *Comer Bien* for the clinical setting, more significant obstacles to treatment of diabetes prevail and prevent availability of this program to community members. *Comer Bien* approaches the problem of diabetes primarily within the context and style of clinical encounters and medical assumptions: it is individualized, encourages patient behavioral change, maintains the stylized professional roles of clinicians and patients. A *Comer Bien* approach will be useful to some identified diabetic patients in the Mexican-American community: the most capable and educated. But taking an individualized, clinic-based approach obscures social, class and economic etiologies of the diabetes and of "non-compliance" in low-income communities.

Diabetes in other Groups in the Raza Community

In addition to Mexican populations, Puerto Ricans have higher reported rates of diabetes than the non-Latino populations. Bernal (1984) cites that diabetes prevalence in the island territory is about 7%. Like Mexican-Americans, Puerto Ricans are believed to be more non-compliant to medical treatment and Bernal's doctoral disseratation assessed the specific determinants of that phenomenon. Bernal's study of Puerto Ricans in Hartford, Connecticut reports wide variations in "compliance" behavior in these urban Puerto Ricans, dependent

by numerous factors such as age, length of diabetes, access to material resources, English fluency, cultural health beliefs. Thus three numerical/statistical indices used to predict the likelihood of "compliance" were developed. While still within the context of the medical paradigms of diabetes care, Bernal's study suggests that similar issues with diabetes are present in a very different Latino community. Again, the genetics versus environment question is appropriate.

In his often-cited editorial in the American Journal of Public Health (1980), "Identifying 'Hispanic' Populations", David Hayes-Bautista questions the classifications of Latino communities in public health research which is used to direct policy. He suggests that the historical myopia and lack of understanding of Latino populations by epidemiological researchers introduces biases into studies. Hayes-Bautista's criticisms hold important implications in the study of NIDDM in Latino groups.

He suggests that many health studies determine "Hispanic" ethnicity based on Spanish-surname, or self-designation of "Spanish orgin" from among Mexican-American, CHicano, Mexican, Cuban, Spanish, Central American, and "other Spanish". However, these umbrella classifications lump together as "Hispanic" people with predominantly Caucasian Spanish heritage to those with entirely indigenous "Indian" or Raza ancestry and every combination in-between, so-called *Mestizo*. Not only is distinction between the Caucasian and Indigenous/Raza groups important for consideration of diabetes risk -- for it is

believed to be indigenous genotype associated with predisposition -- but is also necessary to understand the very different social, cultural and political forces on these two groups in all American countries:

> One important point must be noted here: it was a disadvantage [in early days of California] only to be labeled Mexican; to be labeled a Spaniard carried no social stigma. As McWilliams pointed out, there is a reason for this: Mexicans were Indians, dark, non-white, and considered uncivilized; Spanish were white, "civilized", and European. In fact, until the past decade, the highest compliment an Anglo could pay a Mexican or Chicano was to call him or her "Spanish" thereby conferring an honorary and temporary whiteness. (Hayes-Bautista,1980)

He continues:

> The terms currently in vogue --"Hispanic" and "Spanish orgin" -- are both misleading, stereotypical and (one hates to use this trite term in the 1980s, but it is still true) racist. Spain is a European country and its inhabitants are white people of European stock. No Spaniard has ever suffered undue discrimination, either in Latin America or in the United States. Raza, be they Chicanos, Mexicans, Puerto Ricans, etc., have not been denied access to social benefits because they might have had a distant Spahish ancester: discrimination has been suffered because Raza are of Indian descent. Indeed, in Mexicao as in all Latin America, the Spanish themselves discriminated against the Indians and the indian-descended *mestizo*. (Ibid.)

For this reason, the discussions which follow will employ the classifications of two Raza or Latino groups: Mexican and Mexican-American. Further consideration of this topic is taken up in the chapter on Methods.

Summary

A "clinic-centered" view of diabetes underestimates the central influences of social, political, class and economic conditions -- so-called structural factors -- in the determining the reactions and roles of both Mexican-American communitiy members and of health professionals in dealing with illness. Other researchers have approached the study of diabetes with the assumption that people's cultural influences, such as those defined by ethnic or national affiliation, are constant. My approach assumes that people's cultural habits react and change as a result of social conditions under which they live. Psychological responses of the individual patients and clinicians as well as institutions (agencies, clinics, hospitals) to their perceived social, political and class "roles" define the psychosocial aspects of affliction. I have asked:

> Are the obstacle to treatment of diabetes in the Mexican-American community a result of deeply-embedded cultural values or psychosocial factors resulting from living conditions?

I found that the only way to unravel these complicated questions and to assess the experience of diabetes in the Mexican-American community of Salinas, California required using ethnographic methods of participant observation, getting involved in the community, home and clinic settings.

1. The term "Hispanic", an operationally and methodologically confusing label, lumps groups ranging from the purely Caucasian-Spanish to the indigenous people of the Americas. Nevertheless, the term has "stuck" in much of the literature addressing diabetes in Raza groups. Its use will be discussed in a later chapter.

2. Fatness is assessed using calibrated skin calipers to measure subskapular, biceps and triceps subcutaneous fat, which are then distilled to a singular number, a "fatness index" if you will. (Stern,et.al.,1983)

3. The American Dietetics Association Exchange Diet for Diabetics has been around for some forty years. All foods are organized by food group exhanges and portion size, and each diabetic person is assigned a certain number of each food exchange per day, e.g. two bread exchanges, five fruit exchanges etc. The classic limitation of these diets has been their inappropriateness for other than the "middle American diet".

Chapter 3: APPLYING SOCIAL SCIENCE TO HEALTH PROBLEMS

Sociological analyses of health problems and medical systems are not new, but the focus has broadened from descriptions of "exotic" medical systems in "developing" countries and toward critical consideration of biomedical institutions of the industrialized societies. Thirty years ago, the typical medical anthropological study catalogued rituals of traditional "folk" illnesses and healing techniques in traditional societies as a means of defining cultural traits, or of romanticizing the inherent "goodness" of folk medicine. More recently, critical anthropological and sociological studies consider the role of illness and of healing processes -- particularly within Western biomedical model -- in the maintenance of social, class and economic structures. The work of Parsons on illness as social deviance (and as sociogenic) and of Goffman on stigmatizing illness are examples of this trend (Parsons,1972; Goffman,1963).

Amongst public health and medical professionals, however, the work of Arthur Kleinman is perhaps the best known and most frequently cited in works of so-called applied medical anthropology. As a physician-psychiatrist with a masters in anthropology and extensive field work experience in China, Kleinman advocates the utility of "clinical social science" and patient "explanatory models".

Integral to these concepts is his distinction between *disease* and *illness*.

> Contemporary medical practice has become increasingly discordant with lay expectation. Modern physicians diagnose and treat *diseases* (abnormalities in the structure and function of body organs and systems) whereas patients suffer *illnesses* (experiences of disvalued changes in states of being and in social function; the human experience of sickness). Illness and disease so defined do not stand in one-to-one relation. (Kleinman *et.al.*, 1978)

Thus, Kleinman *et.al.* propose that biomedical clinicians would better convey their medical information as well as increase patient "compliance" by inquiring about the patient's beliefs about the illness. Kleinman believes that within the clinical interview, these five to ten basic questions can elicit the patient's Explanatory Model:

> All of this can be accomplished systematically and quickly by training clinicians to elicit the patient's model with a few simple,direct questions. . . [1] What do you think has caused your problem? [2] Why do you think it started when it did? [3] What do you think your sickness does to you? [4] How severe is your sickness? Will it have a short of a long course? [5] What kind of treatment do you think you should receive?

Indeed, these questions try to get to the heart of the patient's meaning of disease, and form the basis of the EMIC interview schedule developed by Weiss (see Chapter 5). However, this approach assumes that patients are able to articulate the complex web of symbols and emotions of their illness. By relying on information elicited in the strange, exotic setting of the clinic, Kleinman presumes that

responses will be "true" to the patient's experience. For example, in a journal article addressed to physicians, Kleinman advocates that:

> Training modern health professionals to treat both disease and illness routinely and to uncover discrepant views of clinical reality will result in measurable improvement in management and compliance, patient satisfaction and treatment outcomes. (Ibid.)

Critics of Kleinman's "clinical social science" suggest that elicitation and use of a patient EMs in the clinical setting borders on coercive. Fellow psychiatrist Michael Taussig argues:

> Like so much of the humanistic reform-mongering propounded in recent times, in which a concern with the natives' point of view comes to the fore, there lurks the danger that the experts will avail themselves of that knowledge only to make the science of human management all the more powerful and coercive. For indeed there will be irreconcilable conflicts of interest and these will be "negotiated" by those who hold the upper hand, albeit in terms of a language and a practice which denies such manipulation and the existence of unequal control. (Taussig,1980)

I find Kleinman's Explanatory Model method limited because of the great assumption that patients do and think as they say. The EM model implies that a clinical basis for intervention is most desirable. In spite of these limitations, I believe that Kleinman's EM questions can be useful as a means of asking introductory questions in the community, and it is in this manner that I ultimately applied Kleinman's work (see Chapter 5).

Kleinman's "clinical social science" has spawned a generation of surveys, questionnaires and interventions created by health professionals and social scientists to elicit patient EMs as a way to address better "compliance". These are especially common in public health and nursing journals and are presented as "health belief models" and "health knowledge scales" that address general beliefs or specific diseases, including diabetes (the "Diabetes Patient Knowledge" test in Hess and Davis (1983); the "Diabetes Knowledge Scales" in Dunn,et.al.(1984); and other scales in Harris and Linn (1985) and Becker and Janz (1985). One drawback I find common to all of these instruments is the assumption that patients "believe in" the medical model of disease.

Susan Sontag, in her revered monogram Illness as Metaphor, posits that symptoms and signs of disease have not only concrete, material meaning but something else as well. Scheper-Hughes and Lock (1986) summarize her thesis:

> . . . (signs and symptoms of sickness) assume an "other", a "double" -- an ephemeral and spiritual second reality expressed in the cultural images, metaphors and collective representations that gather around particularly dreaded and moral wounds and diseases. These metaphors -- often wildly extravagant -- represent uniquely human ways of coming to grips with suffering and death (including one's own) and to invest meanings in events that otherwise threaten to be absurd in their indifference, their randomness. The rub is that the (metaphor), the cultural images and representations of the "master" diseases of our time -- cancer, heart disease, schizophrenia, AIDS [diabetes?] -- are more ugly than sublime, more degrading than elevating, more exploitative than consoling.

Though Sontag decries the danger of metaphorization of illness, Taussig,in interpreting a disabling illness in one woman, believes metaphors get at the meaning of affliction which is lost through medical-clinical practices:

> This case study illustrates that in denying the human relations embodied in signs, symptoms and therapy, we mystify those relations and also reproduce a political ideology in the guise of a science of physical things. This I call *reification*. . . . . .In this way our objectivity as presented in medicine represents basic cultural axioms and modulates the contradictions inherent to our culture and view of objectivity.

Likewise, in their overview of critical medical anthropology, Scheper-Hughes and Lock (1986) argue:

> that the most "truthful" way of regarding illness is one that pierces the hidden meanings, the metaphors of illness, the messages in the bottle through which patients, and society at large, express their horror, their repugnance (and their protest) at suffering, illness and decay.

And later:

> As patients, all of us, we can be open and responsive to the hidden language of pain and protest. . .or we can silence it, cut it off by relegating our complaints to the ever expanding domains of medicine. . . .Once safely medicalized, however, the social issues are short-circuited, and the desperate message in the bottle is lost.
>
> In short, we wish to stress that while illness symptoms are biological entities, they are also coded metaphors that speak to the contradictory aspects of social life, expressing feelings, sentiments, and ideas that must be otherwise kept hidden. (Scheper-Hughes and Lock, 1986).

This then is the body of dialogue in critical medical anthropology which formed the theoretical preparation for field work and subsequent analysis of case histories of

diabetes in people of the East Salinas Mexican-American community. With respect to the various perspectives with which ethnographic "data" can be collected and analyzed -- that is, with depth and complexity, or superficially, quantitatively -- Geertz's discussion of "thick" versus "thin" data supports my decision to emphasize the often-convoluted, fully contextualized case histories of diabetics in this study:

> And it is in understanding what ethnography is, or more exactly *what doing ethnography is*, that a start can be made toward grasping what anthropological analysis amounts to as a form of knowledge. This , it must immediately be said, is not a matter of methods. . . it is not these things, techniques and received procedures, that define the enterprise. What defines it is the kind of intellectual effort it is: an elaborate venture in . . . "thick description".(Geertz, 1973)

He adds that focusing on collection of discrete observations and description is misleading because "it leads to a view of anthropological research as rather more of an observational and rather less of an interpretive activity than it really is". (Ibid.) Thus, the presentation of material in this study of diabetes tries to capture the essence of "thick description" and interpretation as Geertz envisions the ethnographic process.

Dr. Lotte Marcus, director of the Cross-cultural program at Natividad Medical Center (and my field supervisor) agrees that there has been some confusion as to what is "cross-cultural" work. Referring to the historical collection of cultural diseases and treatment -- the *susto*

of Mexico, the newborn "chill" disease in Laotians and the like -- as collection of anthropological "fact", Marcus states:

> All these "facts" however, -- all this conscientiously collected glossary of cultural checklists and do-or-don't background sheets may not really attune us to the complicated risks of an actual cross cultural encounter which, in the experiencing, may be far more dense, contextually bewildering and implicitly challenging to our hitherto unexamined value system. . . So "cross-cultural" means first of all, if it means anything, an exchange that goes two ways. Not us learning about "them" -- but learning about "us" in the very act of learning about "them". (Marcus,1986)

She adds that encounters which are too often labeled "cross cultural" are also "cross contextual"; in the case of one person's illness:

> He was, simultaneously an economic statistic, a political symbol, a cultural casualty, a psychosocial exhibit, a bureaucratic victim. (Ibid.)

Thus, consideration of the multiple contexts of illness is a central objective of this consideration of diabetes.

In addition to these academic discussions which apply sociological interpretations to health problems, what might be described as the "social activist" sector take a slightly different approach to illness and its social significance. Paulo Freire, a Brazilian scholar of education, developed the notion of *conscientization* (critical awareness) which David Warner and others working in developing countries are applying to health problems. In David Warner' book with

Bill Bower, "Helping Health Workers Learn" (1979), Freire's work is summarized:

> Conscientization is an open-ended learning process carried out through "group dialogue". A group of persons comes together to discuss and try to solve problems they have in common. . . .There is no "expert" who has the answers and whose job it is to pass his knowledge on to others. Instead, the persons in the group search for better understanding of the problems they face together.

Integral to this approach to health and other social issues is the notion of *participatory research* in which the members of the community of interest (e.g. the adults of the East Salinas Mexican-American community) work with "outsiders" to address identified concerns (e.g. the problem of diabetes). This approach was used by Freire to address illiteracy and unemployment in impoverished rural Brazilian villages, by Werner to create a self-sustaining health program in rural Mexico and by other nutritionists and primary care planners in Guatamala, Indonesia and other countries.

In terms of the implication to this study, the Freirian model for community "problem-solving" exemplifies the attitude which I attempted to bring to this field work, one which is antithetical to the professionalism in industrialized societies: that the community members are equal partners in this process of information-gathering and discussion of the designated problem, as much teachers to outsiders as recipients of outside perspectives on the issue. (The specific processes will be further discussed in the last chapter, "Ideas for Change".)

Moreover, the Freirian model describes the kinds of reflections I faced about my role and motivations as I faced field work in the East Salinas community. Calling myself a "participant" observer seemed to me a misrepresentation. It was clear enough that, at least initially, I had no other role in the community than to visit people and listen about diabetes -- I now see that this was appreciated but initially I felt guilty that I didn't "teach" or "bring" something. As my relationships grew with several of the people who became my "informants", as I was invited for repeat visits, meals, bowling, etc., my role expanded and I became chauffeur, sounding board, and resource for questions about the health care bureaucracy. Not only did I feel more comfortable in the exchange of "services" for information, but my expanding roles game me additional opportunities to observe how people cope with their diabetes in difference circumstances and contexts.

Chapter 4: THE RESEARCH SETTING

The Salinas Valley is a 100-mile stretch of prime agricultural land nestled between two mountainous coastal ranges in Central California. The City of Salinas is the northernmost point of the valley, as well as a main commercial center, and is situated approximately 100 miles south of San Francisco, and ten miles west of Monterey Bay. Though a quaint and provincial town, Salinas is known internationally as the home and fictional source for writer John Steinbeck and nationally as the center where Cesar Chavez and the United Farm Workers (UFW) union gathered political momentum during the early seventies.

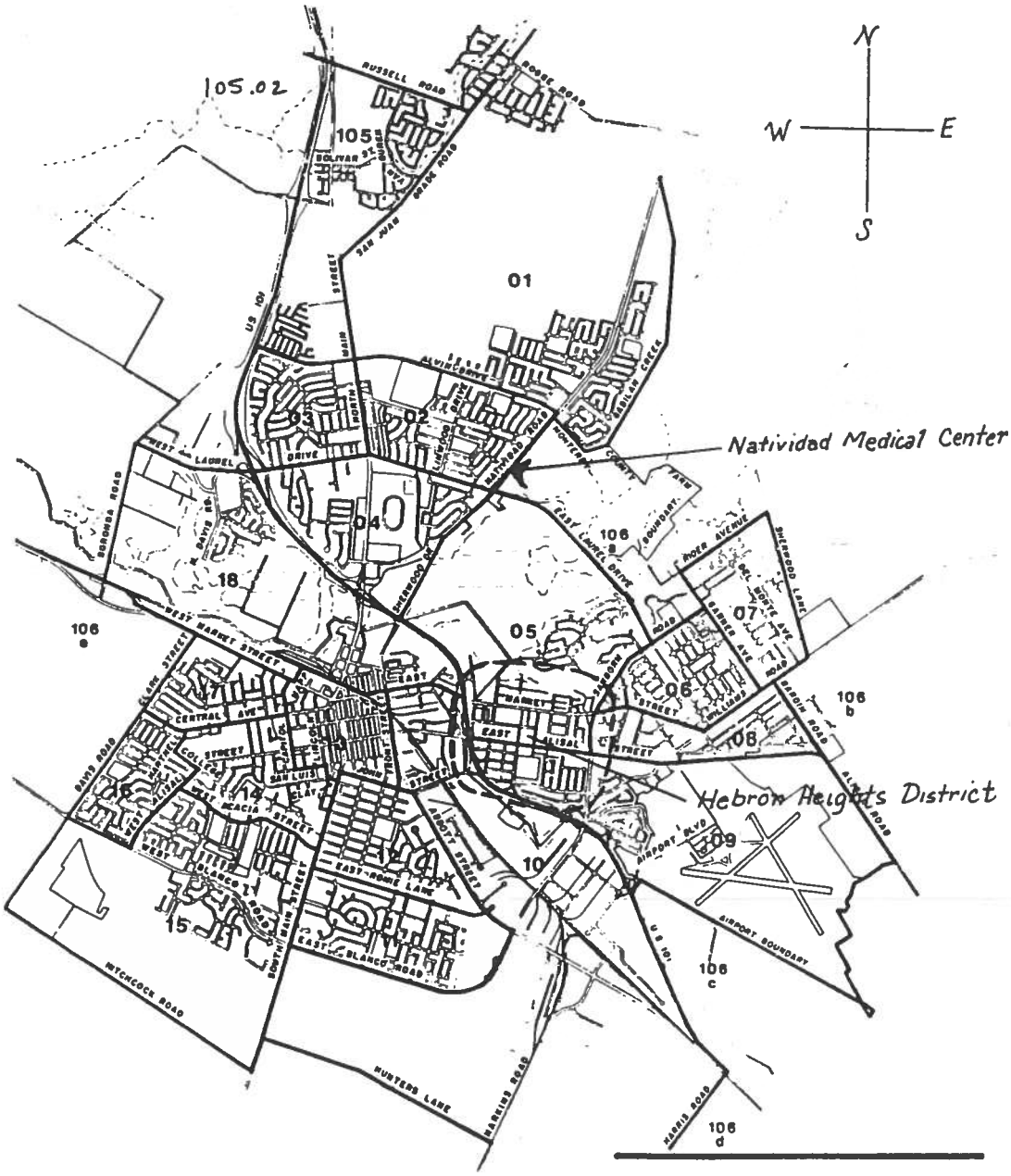
In the eighties, Salinas remains a town of contrasts and contradictions. Bisected by Highway 101, a main traffic artery between San Francisco and Los Angeles, Salinas is composed of neighborhoods and districts which are distinct in ethnic and economic composition. Census statistics from 1980 puts the proportion of "Spanish origin" residents at 38 percent (probably an underestimate). While the northern and western districts are predominantly Caucasian and middle-class, the Central and East Salinas neighborhoods are Mexican and Mexican-American, generally lower/working class. Census statistics correlate districts with "high Spanish origin" with family poverty: greater then 19% of families live below poverty level in four districts (City of Salinas, 1986).

Banks, post offices, stores and medical facilities cater to their respective cultural clientele in Salinas; while Northwestern

FIGURE 4-1

43A

Census Tract Map



Salinas is the economic and social center for agricultural landowners and professionals, so East Salinas is the hub of "the community" of seasonal and migrant workers. Although the mainstream media touts the annual Salinas Rodeo as a major civic event with parades, city-sponsored celebrations and the like, only a handful of Latino residents are seen at these festivities. It is possible to live one's entire life in one sector and have no need or desire to venture to "the other side".

Although Mexican-American residents live in numerous central and eastern districts of Salinas, the Hebron Heights area bordering Market and East Alisal Streets embodies the stereotypical *barrio*: bungalows house multiple families across many generations; family-run restaurants; men and youth wearing straw hats -- unemployed perhaps -- "hanging out" on street corners and porches; clinics for "head and back pain" and temples for Jehovah's witness' offer somatic and spiritual relief. As one resident commented to a man I was with, "The only blonde men we see around here are policemen or they're dead."

An important feature of community bonding is the weekly Market located at the Drive-In movie theater. With foods, medicinal herbs, clothes and audio tapes from Mexico displayed under the blue plastic tarps of makeshift booths, the smells, flavors, sounds and comforts of the Southern homeland can be experienced within the city limits of Salinas.

Because of the availability of work for unskilled and skilled agricultural laborers, the Salinas valley has supported a large population of migrant and seasonal workers from Mexico since the 1930s. Of the 18,000 or more agricultural workers employed in the peak summer harvests for lettuce, strawberries and artichokes, only 3000 of these are "migrant", while the remainder reside in the area all year (Marcus & Barnett,1986). (According to State of California criteria, a worker is considered "migrant" if she/he does not return to the principle residence that day.) Yet these California Employment Development labor statistics are questionable since it is well-known that "illegal aliens" -- many now from Central American countries -- are discounted in official surveys, and probably are as high as three to ten thousand illegals.

While the stereotypical Salinas Valley laborer -- the stooped-over, leathered-skinned man -- may still be seen, more women and youth are joining the labor force in the fields, canneries and frozen packaging plants. But many work less than 40 hours a week,are underemployed and "lay-offs" are a common complaint during the summer of 1986. The summer of this study marked the second year of a bitter cannery strike in neighboring Watsonville. Some Salinas residents, many unemployed and desperate, were bused in as strike-breakers. Riots broke out as strikers opposed the use of "scabs" from their own Raza community, an eerie sign of the extent of economic desperation for these groups in the 1980s.

The East Salinas-Hebron Heights Mexican-American population is a heterogeneous mixture of American-born ethnic Mexicans spanning several generations to recently arrived Mexican nationals. Likewise, there are wide variations in "acculturation" to American lifestyle. I spoke with native Mexicans who consider themselves middle-class economic refugees, and who comment disdainfully, though perhaps perceptively, about the lower-class Mexican-Americans in the community: *Son ni de aqui, ni de aca* , "They are neither from here, nor from there". Conversely, several from the "lower class" group complain bitterly that government social programs cater to the Mexican migrants while the U.S.-born citizens -- the Chicanos -- are not eligible for assistance. Thus, undercurrents of conflict remain in the Latino community despite the public vision of solidarity in East Salinas.

Salinas has a history of contrasting political interests. For example, throughout the late 1960s and early 70s, Salinas City Council and School Board meetings were the forum for wider social debate concerning civil rights for ethnic minorities. The United Farm Workers union enjoyed wide support in East Salinas and gave credibility to a number of grass-roots activities in the community at that time. A unique English program, "English On Wheels", originated and flourished in Salinas. Students were taught language skills in the context of life situations -- negotiating rent, getting work, bartering for a car -- that are typically intimidating to those without language facility. Creative techniques were used: videotapes using puppets and masks; "role-playing" enactments of video tapes for language

learning. Yet the success in empowering workers through language was perhaps too much for the Salinas City Council and others: with language proficiency came the ability for people to speak out at town forums, to strike and effectively protest their living and working conditions. By the late seventies, the innovative programs were "diffused" into the school district bureaucracy; lack of space was cited for contract abrogation with the School District. The students went on strike; Dr. Marcus resigned. Currently, English classes for adults are under the direction and control of that institution and are run in the traditional didactic manner.

In speaking with twenty-year veterans of the East Salinas community, elements of intrigue and scandal inevitably emerge. In addition to external pressures, factions within the community contributed to the depolitization from the 70s to the 80s. Accusations and stories of embezzlement, infidelity and power-mongering on the part of community leaders are exchanged among those who remember. And these tensions have contributed in part to the transient success of collective activism in Salinas. Former activists complain that their grass-roots efforts were co-opted by government-sponsored programs which imported Whites to work on community "development".

So while technocrats and industrialists from the San Francisco and Los Angeles areas are migrating to Salinas in the eighties seeking the economic refuge of a rural area (see Figure 4-2), access to material resources is becoming more difficult for those in the Mexican-American community than fifteen years ago.

FIGURE 4 - 2

47A

"COME TO SALINAS FOR THE LETTUCE"

Len Perham, *Vice-President*
Integrated Device Technology

GOOD FOR GROWING

Salinas has long been known as one of the great agricultural centers of the world, but now it's more than that. It's a dynamic new center for growing technological companies. Cabot, Cabot & Forbes Salinas Airport Business Center has proven that your company can harvest economic benefits without sacrificing business advantages.

LETTUCE ECONOMIZE

In Salinas, your company's need for quality space is not compromised by affordability. *"By locating in Salinas at CC&F's Airport Business Center, we are within striking distance of Silicon Valley, but have been able to enjoy the reasonable land prices at an optimum location."*
John Conklin, *President*
Magnetic Circuit Elements

CULTIVATE THE LABOR FORCE

One-hundred and twenty thousand widely skilled individuals live within thirty minutes of the Salinas Airport Business Center. *"The available work force in Monterey County was an important factor in our decision to select Salinas as an operational site."*
D. John Carey, *President*
Integrated Device Technology

COUNTRY LIFESTYLE

Your most important asset, your employees, will enjoy a relaxed, affordable, quality lifestyle only 19 miles away from the Monterey Peninsula, one of the most beautiful living environments in the world. *"The availability and affordability of housing in Salinas was a significant factor in favor of our decision to locate here."*
Personnel Spokesman
Electronic Data Systems

MAKE A HEAD TO HEAD COMPARISON

Contrast the overcrowded, overpriced Silicon Valley with the open space and rental economies of Salinas. *"Certainly the attractive lifestyle available to all our employees living in Monterey County was an added plus to the fundamental economic business reasons that led us to make this move to the Salinas Airport Business Center."*
Len Perham, *Vice-President*
Integrated Device Technology

REAP THE REWARDS

The Salinas region provides for a less costly foundation on which to build your future.

When you take a look at the advantages, your company can be Silicon Valley close but a lot of lettuce ahead with a move to Cabot, Cabot & Forbes Salinas Airport Business Center. **For more information call Bill Diaz at (415) 424-8886.**

Political organization is rare as families in order to keep ahead of debts and lay-offs, and to send children to technical schools. Many of the best and brightest youth leave permanently. This then is a picture of a community in which diabetes is becoming a widespread and recognized affliction.

Chapter 5: METHODS OF STUDY

CASE STUDIES of DIABETICS

Intensive study was conducted for twelve weeks from May through August of 1986.

The Study Population

The field work setting was the Hebron Heights and East Salinas communities in Salinas, California. (Map, Fig.4-1) Although not all participants reside within the lines of these census districts, the shared experiences of work, housing and family among Mexican and Chicano people in the area constitute a network which transcends boundaries.

In order to legitimize my work in the community, I based myself at Natividad Medical Center, one of thirty-nine remaining of the sixty-two original government-sponsored county facilities in California. NMC serves both MediCal (MediCaid) and designated Medically-Indigent Adults (MIAs) and is staffed by medical residents and instructors participating in the Family Medicine program affiliated with the University of California, San Francisco. NMC has young physicians-in-training who are considered to be the best and the brightest, and the educational component allows for innovative programs at the facility.

Included in the Family Medicine curriculum is a Behavioral Sciences teaching which has more recently included a "cross-cultural medicine" curriculum appropriate to this ethnically and culturally diverse community. I was housed under the auspices of this latter program, and supervised by Lotte Marcus,Ph.D.,

Lecturer in Family and Community Medicine and Director of the Cross-Cultural Curriculum. (In fact, this study will will become part of NMC's Cross-cultural curriculum and may be distributed among the four Family Medicine programs affiliated with UCSF.)

According to the data gleaned from an informal review of medical records at Natividad Medical Center,nearly 80% of their family practice clinic population reside within the zip code districts of Hebron Heights, a part of East Salinas (Marcus & Barnett,1986). A number of residents of these districts have medical insurance coverage; they are more apt to see private family physicians who work at Salinas Memorial Hospital located in West Salinas, a predominantly White neighborhood. But once a head of household becomes disabled (for example with diabetes), unemployed, and uninsured, the family is forced to seek MediCal services at the Natividad. Though its not explicitly stated, members of the East Salinas community are sensitive to the two-tiered structure of health services in Salinas: services for the middle and working classes versus those for the poor, the unemployed and medically-indigent at Natividad. Even though the Natividad clinics are operated by a young, capable, enthusiastic group of medical residents and attending physicians5 affiliated with a large university, and despite the fact that 90% of the clinical staff is Spanish-speaking, patients come to the "county hospital" with a mixture of gratitude and disdain, of need and denial of that need.

The continued care of diabetic adults at NMC is primarily coordinated at two locations. The Diabetes clinic is a weekly, four-to-five hour service directed by one internist as well as up to four residents or medical students. Patients arrive at nine o'clock in the morning to queue up for a blood glucose test before they eat. At this time, they also confirm an afternoon appointment. Patients either return later, or (quite frequently) remain in the waiting room throughout the day. In the latter case, people become well-acquainted over the course of many visits such that casual friendships form amongst the patients. though none seem to develop beyond the context of the hospital setting.

The Family Practice Clinic (FPC) is the second area of diabetic care at NMC. Whereas in the Diabetic clinic, patients may see a variety of clinicians over time, in the FPC, each patient is consistently seen by the same resident, as per the family medicine model. Appointments are more tightly scheduled and the wait is shorter.

Choice of Case Studies

It was at these two clinical sites then that I met many of the informants for this study. My approach to patients was generally well-received because so many were bored by sitting there all day and eager to talk. In addition I became well-acquainted with one woman named Consuela through Dr. Lotte Marcus; Consuela in turn introduced me to three other informants through her community network whom I later interviewed1. (see page 62).

Thus, seventeen adults with diabetes were originally selected as informants for case study. Of these, all but one woman received public medical services at Natividad Medical Center. For nine of the diabetic adults (five women, four men), I observed and audio recorded their clinic conversations with physicians and I conducted a two-hour follow-up interview in their homes. Owing to logistic complications, four of those remaining cases were interviewed in the home only. In the course of being around the clinic, I heard about the reputation of one woman, Esperanza,(whose story appears on page 106). I never had the opportunity to formally observe or interview her, but her situation was such a powerful, if discouraging, example of the obstacles to treatment of diabetes that it is included in this discussion. The names of the case studies which I will be discussing here are: Consuela, Rosita, Mariana, Berto, Mary, Santina, and Esperanza.

The method of introduction and informed consent to participate was approved by the Committee for the Protection of Human Subjects at the University of California, Berkeley [See Appendix B for the complete protocol]. Each diabetic patient was informed that this study was an effort to better understand people's experiences with diabetes and was told:

> Although I know about what doctors think about the causes and problems of having diabetes, I would like to learn about what the people think.

People were informed that participation involved two phases: (1) observing and audio recording2 their clinic visit; (2) conducting a follow-up interview at the home on another date. Consent was given verbally and, where appropriate, participants signed a NMC "release" form for audio recording as per requirements of the Monterey County.2 The sampling of diabetic adults eligible for case study was dependent on convenience and feasibility given the time and resources of this study. Yet,based on my conversations with Dr. Ted Rose, Chief of Medicine at Natividad Medical Center, with whom I discussed the cases, I believe they were highly representative of the population served by NMC.

Home Interviews of Diabetics

Prior to field work, I considered a number of tested interview schedules as models but I found each inadequate for my purpose in this study. Linn with Harris (1985) developed a Diabetes Health Belief Scale for middle aged diabetic men which can only be answered within the context of the biomedical model. Bernal's interview schedule for Puerto Rican diabetics emphasizes objective assessment of skills and knowledge needed for medical "self-management" of the disease (Bernal, 1984). Although these sections were not appropriate, open-ended questions about personal history with diabetes, and about social and demographic factors were adopted from Bernal's protocol. As I mentioned in Chapter 3, Mitchell Weiss, a colleague of Arthur Kleinman, created the Explanatory Model Interview for Classification (EMIC), which he calls "open-ended probes to elicit explanatory models

and patterns of help seeking." Developed for use at a general clinic in rural India, the EMIC was closest to the spirit of my interviews, namely inviting the patient to share on her personal views and experiences about diabetes. A sample of EMIC includes:

> 1. What do you think has caused your problem?
> 2. Why do you think this illness started when it did?
> 3. What does this illness do to you?
> 4. How does your illness affect your family?

Early on in my field work, I began the interviews with these types of questions, but I discovered problems with "sticking to the protocol". First, by depending on interview responses alone, I would be assuming that individuals' reactions and behavior as stated in the context of the interview are consistent with behavior, i.e. that people state what they mean instead of discovering what they mean by observing the actions.

Secondly, I found in the first several encounters with my diabetic informants that in spite of using the EMIC questions, the responses were necessarily free-flowing and anarchistic, and the interview had to follow. My lead-in questions would inevitably unlock an unyielding flow of richly contextualized stories in every case. Although my original proposal was to collect peoples Explanatory Models for diabetes, I found that the heart of the problem was embedded within the complex histories. In fact, I discovered diabetes to be a larger and more complex picture than what could be obtained through following protocols.

I therefore decided to do a thematic interpretive analysis based on the issues which arose in the case histories.

As I will try to show in Chapter 6, the significant themes of the affliction of diabetes are embedded in these personal histories, these *novelas* -- what we would call "soap operas". I propose that it is there that one must search for the essential clues to the metaphors and symbols of diabetes, as it was shown to me by those afflicted in the Salinas community. So, for the case histories, in addition to using the EMIC questions above as introductory probes, I recorded extensive field notes which were later organized for content and thematic analysis.

Each individual case was given an identification number to insure anonymity in all written and recorded material. After audio recording of the clinician and patient clinical interaction, the conversation was transcribed and all identifying features removed, i.e. the case histories which follow in Chapter 6 have been given pseudonyms. The notes (and transcripts) for each case were maintained in individual folders which were kept in a locked office. In the discussion of Chapter 6, I have presented exerpts of dialogues between doctors and patients as a means of showing that the medical interview itself becomes part of a larger power struggle.

DIABETES AWARENESS SURVEY of NON-DIABETICS

I also assessed the level of concern about diabetes in families residing in a migrant field camp (in rural Chular, 15 miles south of Salinas). In June of 1986, a pilot survey was conducted on waiting to be seen at an evening clinic3. Basic questions about awareness and concern with diabetes were elicited. I found that there was low interest in diabetes as compared to concern about infectious and childhood diseases in this migrant camps, and I decided that at this time the Diabetes Awareness Survey might be more appropriate for use with the stable, seasonal worker group in town. Therefore, the survey was conducted at one of the four housing cooperatives run by Community Housing Improvement Systems and Planning Association, Inc, (CHISPA).

CHISPA, a non-profit organization, coordinates cooperative housing which was originally organized by the farm workers union and other local groups during the seventies. Four sites currently operate, each catering to a slightly different subgroup: the elderly, the working families, single men, etc. Strict income criteria are used to select residents and continued activism in the community is expected. Thus, residents of CHISPA differ from others in Hebron Heights in significant respects, for example, they are more consistently employed, have more "in tact" nuclear families that other neighborhoods in Hebron Heights. On the other hand, a higher percentage of CHISPA residents are from Mexico, as opposed to largely American-born Mexicans in greater East Salinas. (This points

again to the heterogeneity of the Mexican-American community.) If traditional Mexican beliefs are an important factor in attitudes about diabetes and obstacles to its treatment as is suggested in previous studies, I believed that these elements would be more apparent in the CHISPA cohort responses. Balancing these pros and cons, I concluded that the CHISPA group would give a representation of beliefs in a Mexican group in transition with American culture. Additionally, CHISPA residents are prospective NMC patients such that their attitudes and concerns about diabetes are of interest to family practitioners.

Designing the Survey Instrument

After two months of conducting the case studies, I noticed common features amongst the diabetics with respect to the onset of their disease. I began to wonder whether a prototype story of a "typical" diabetic would also be recognizable to a non-diabetic in the community? *El cuento de Juana*, or "The Story of Juana",is the fictitious story of a Mexican-American woman whose experience of diabetes is intertwined with a tale of family problems and worries. The English version appears in Figure 5-1 and the Spanish in Appendix A.

The story form was used as a more interesting and culturally-acceptable "method of introduction" to our inquiries. The survey instrument was read and corrected for appropriateness of language and style by Dr. Lotte Matcus as well as my "key" informant, Consuela. Additional corrections to

Figure 5-1: SURVEY PROTOCOL FOR
NON-DIABETICS

(English version)

PART I. THE STORY OF JUANA

I'm going to tell you a short history of one woman. Afterwards, I will ask you to give me your opinion about this woman's problem. There are no wrong answers, since I am only interested in your opinions:

"Juana lives in King City with her husband. Many years ago they married in Texas, where Juana was born. In the early days, they followed the work in the fields and Juana gave Pedro five healthy children. They traveled everywhere in a gib truck. Then later settled down in King City so that their children could go to school. Juana worked in a cannery and Pedro worked as a foreman in the fields. THe two always worked long hours every day. But, they were very happy and proud and on their aniversary, Pedro gave Juana a parrot which always sits on her shoulders. The parrot alsways says funny things, and their children and grandchildren knew that all was well in the family when the parrot chattered.

"When Juana was thirty-nine years old, she hurt her back in the cannery by carrying heavy boxes, and she had to quide her work. Then Juana, who was always a strong woman, began to gain weight. She worried a lot because she couldn't work and because Pedro worked even longer hours then to earn enough money. And shortly after her forty-third birthday, Juana began to be very thirsty all the time. Eventhough she was tired, she couldn't sleep because she had to back and forth to the bathroom about eight times each night. Juana was becomming more forgetful and irritable. Her legs and arms hurt more and more. Her problems continues many months and Juana thought, 'This must be old age, nothing more!' But her parrot remained very calm and quite, a sign which the family noticed.

"But one morning, while she was cooking breakfast for Pedro, Juana fell. Her vision was very blurry and her mouth so dry from thirst that it seemed full of cotton. The parrot -- for the first time ever -- flew to Pedro's side, as he ran to find Juana lying on the floor. But Pedro had faith, because the parrot continued to sing very softly as it settled on Juana's shoulders."

Questions about the story:

1. Have you heard of a person with this health problem like Juana's? Does her problem seem familiar?

Code: Yes = 2, Maybe = 1, No = 0

2. Do you know or have you known anybody with this problem?

Code: If yes, what relationship to you?
Myself = 4 Friend = 2
Relative = 3 Acquiaintance = 1

No = 0

3. What is the name of this problem or illness?

Code: Diabetes or "sugar in the blood" = 1
"I don't know" or incorrect name = 0

4. Do you have any other ideas about the story?(open-ended)

PART II. ABOUT DIABETES

Now, I am going to ask you other questions about you opinion of an illness that many people in the Salinas community have:

5. Have you heard of an illness called "diabetes" or "sugar in the blood"?

Code: Yes, I think so = 1
No, I am sure not = 0 (Go to Part III)

6a. Do you have diabetes or do you know people with diabetes?
Code: If yes, what relationship to you?
Myself = 4 Friend = 2
Relative = 3 Acquaintances = 1

No = 0

6b. How many people do you know with diabetes? _____

Other comments? (open-ended)

7. If diabetes is familiar to you, do you know what it is , or what happens with a person with diabetes? (open-ended)

8. For people with diabetes, what happens to them? What is their emotional reaction? (open-ended)

9a. Do you know any home remedies for diabetes?

Code: Yes = 1 No = 0

9b. If yes, what are they?

Nopales (prickly-pear) _____Tea *savila* _____
Tea *ruda* _____ *Betabel* _____ Tea *governadora* _____
Pit of avacado _____
Others: _____

9c. It "yes" above, from whom did you learn about these home remedies?

10. Is there a cure for diabetes?

Code: Yes = 1 No = 0

11. Do you know the medical treatments for diabetes?

Code: Yes = 1 No = 0

What are they? (open-ended)

12. Do you think that the medical treatments help more, less or are no different from the home remedies for diabetes?

Code: More = 3 Less = 2 No different = 1
I don't know = 0

13a. Have you heard ot the "shot" or "insulin" as a treatment for diabetes?

Code: Yes = 1 No = 0

13b. Do you think that there are risks with this treatment or is it safe? What are the risks? (open-ended)

14. Which from this list are the three most important factors as a cause of diabetes?

Drinking too much liquor _____
"Nerves"/*Nervios* _____
Obesity/ Too much weight _____
Too much work _____
To ear too much grease/fat _____
sugar _____

Other causes?

15. For each group below, which has greater risk or diabetes (or "more" diabetes)?

a. Men _____ Women _____No difference _____

b. Older people _____ Young people _____ No diff _____

c. Fat people ___ Slim people _____ No diff. _____

d. Mexicans ___ Americans _____ No differnce _____

PART III. DEMOGRAPHIC FACTORS

Age _____ Sex _____

Married/ Widow/ Single/ Divorced

Religion_____

Education - Level completed: _____

Location: _____

First language - Spanish _____ English _____

English ability - "As well as Spanish" = 3
"More or less well" = 2
"Not very well" = 1
"No English" = 0

Location of birth _____

Present employment _____

Time in U.S. _____ In Salinas _____

How often do you return to Mexico _____

When was the last time you returned to Mexico _____

language style were suggested by Carmelo and Blanca Monarrez who conducted the survey. I had learned that people in the community exchange information casually and on a daily basis using stories. Thus, after one reading of the story by the interviewer, people were asked about their familiarity with and their ability to identity Juana's unnamed problem. In the second part of the survey, specific questions addressed awareness and familiarity with diabetes. (See English version of survey in Figure 5-2)4.

Conducting the Survey.

Carmelo and Blanca Monarrez, two new residents of the CHISPA community, were hired to implement the Diabetes Awareness Survey. Both are natives of Mexico who attended school there and have resided in both countries throughout their adult lives. I trained to conduct the survey by having them observe my administration of the protocol during three occasions and by supervising them for the first five which they conducted. That they were relatively new residents to CHISPA, that they were not medical professionals (therefore non-threatening) and that they were able to pick up local linguistic styles and cues in their recordings made them an ideal pair to conduct the survey.

The CHISPA community was prospectively informed of the survey using a method of the experienced community "pollster", Consuela. Each family was visited door-to-door and given a flyer containing information about the survey. It was billed as a "survey about health" since the first section of questions (*El*

cuento de Juana) required there be no prior suggestion of diabetes. Whenever possible, appointments were made for administering the questionnaire at a convenient time, a practice strongly recommended by the community informants. Perhaps as a result of these preparatory efforts, surveys were completed for 85 of the 86 households approached.

The survey administrators initially read *El Cuento de Juana* and asked specific questions addressing the story before going on to specifically question about diabetes. In the case where an answer was categorical -- for example, a yes/no situation -- responses were recorded using previously-devised numerical codes. For example, when a person indicates his relationship to a diabetic person, the response was marked as: self = 4, relative = 3, friend = 2 and so forth (see survey). In other questions, open-ended responses were expected and original statements were recorded verbatim in Spanish and later transcribed *verbatim verbatim* to retain original impressions of respondents. Conformity in recording was assured since the couple conducted the surveys together for nearly all households.

All responses to open-ended questions were transcribed according to question topic, and each response was indicated by the age and sex of respondent. For the "coded" questions, I conducted a statistical analysis using the Frequency and Crosstabulation programs of the CRUNCH interactive statistical package version 3.1 (CRUNCH Software Corp, Oakland,CA.).

1. Consuela proved an inexhaustable resource for "finding diabetics" (i.e. " On Pearl St. I can 'get' you fifteen"). She introduced me to one woman, Rosita, as well as Rosita's sister, Angela. Having announced my work to her students at the English class -- a sort of "Call Laura, she help you with all about health problems" I think -- I received four calls from Spanish-speaking women asking about *nervios*. Given my time limitations, I only followed up on the case of Senora Martin, who receives thrice weekly dialysis at NMC due to advanced diabetic kidney disease.

2. As part of the Cross cultural curriculum development by Dr. Lotte Marcus, audio recording of physician-patient conversations was used as a means of identifying areas of miscommunication.

3. As part of an outreach project for resident physicians at NMC, a series of evening medical clinics were organized with people at a camp in Chular. I assisted one physician and the "cross-cultural" supervisor at one such event in July. Casually observing the sparse living conditions, and the profound health problems in the group (microencephaly, congestive heart failure, dermatologic problems from exposure to pesticides), I wasn't surprised that diabetes is not amongst the urgent concerns of this group.

4. Especially useful was an survey by Mendelsohn which assessed beliefs about cancer in French and Indionesian students. He developed questions to rank respondents' opinions about the causes and treatments of that disease, and these had useful application in this study. (Mendelsohn, 1986) Demographic information was collected in the manner of Dewey (1984) in order to tabulate responses according to characteristics such as age, sex, language facility, birthplace (U.S. or Mexico) and the like.

Chapter 6: DISCUSSION AND ANALYSIS OF CASE STUDIES

What follows is a descriptive study of how diabetes fits into the lives of people in the Mexican-American community of Salinas. I will discuss the roles of social, economic, cultural and psychological factors in treatment of diabetes. As reviewed above, researchers more commonly attribute "non-compliance" to medical treatment in Mexican and other Latino groups to elements of traditional cultural beliefs. I have asked, "are the obstacles to treatment of diabetes in this study population predominantly cultural or predominantly psychosocial in nature?" I will try to demonstrate that cultural values and traits are constantly undergoing change, always in transition and respond to social conditions.

I will discuss six whose histories are representative of the four major themes found in the majority of cases: powerlessness; strained relationships with the "helping" institutions; emotional responses of diabetics; symbolism of dietary restriction. Other themes include the persistent problem-solving style of crisis orientation among diabetes and the responses of physicians to these patients.

Throughout discussions with the adult diabetics who were followed as case studies, a recurrent theme was the issue of powerless and control: to paraphrase many, "I try to do it (control my diabetes) but I can't do it. Further analysis of the

case studies revealed that factors in people's lives and histories contribute to self-definitions of powerlessness.

Powerlessness is the perception that one is unable, not unwilling, to make changes in one's life and environment. Powerlessness is closely related to the notion of "control" and "locus of control", features central to medical models of diabetes treatment. For most of the case studies, diabetes is considered another issue in their lives which they cannot control. Diabetes becomes for them a metaphor for the powerlessness which typifies life in a community with limited access to material resources, educational and economic opportunities.

One of the most poignant examples of self-defined powerlessness is the story of Rosita Garcia and her family. Not only does she see and act as the most powerless member of her family, but her husband and children act less powerfully within their community. They express frustration that much of their lives is determined by outside forces. Their story is not an uncommon one in this study community:

I met Rosita through the women's network -- the women who can recite names and addresses from memory as well as how many kids so-and-so has and (in a whisper) who her husband has been seen with. Because Rosita had no phone -- it had been disconnected because her unruly teenage daughter had run up bills above their means -- I visited her with Consuela, who is the cornerstone of the women's network. Rosita and Consuela

have been friends for twenty-five years, and, they frequently talk about the days when they were workers in the fields and their would-be husbands would take them to dances. They describe their relationship as closer than sisters.

Rosita's house is in central Salinas, an area of small but neatly kept bungalows. The Garcia home is notably different: the wooden steps buckle under slight weight, the paint cracks under sun; around the lawn sit plastic gallon milk containers filled with water; they say, to keep the local dogs from defecating on the grass (but I never find out how this was supposed to work.)

A big boy answers the door, Rosita's youngest, immense at thirteen years. For her two teenage children, Rosita buys clothes at rummage sales, not only because its cheaper but also to find "oversized" pants. I enter the home which is dark and small. On the dark wood-paneled walls are pictures of the eleven Garcia children at various ages, and trinkets of the Catholic faith: a large tapestry of the Last Supper, crucifixes and statues of Jesus and Mary. These surround the color TV like a festooned alter which is topped by a late model VCR.

But the activity is in the kitchen, the hub of the Garcia home. There I met Rosita, her sixteen year old daughter Marga and other female cousins, granddaughters -- I'm not sure of the all the relationships, but their were six women "hanging out". Four were not more than twenty years; two of the girls were pregnant. Rosita was cooking and I learn that she is famous in her community for frijoles and mole. Among this crowd of

women-- all over 200 pounds each-- I feel dwarfed, and the strangeness of my presence here is more conspicuous. Then Rosie, Consuela and I retire to the dining room for our visit.

Rosita is fifty-six, and has lived in the Salinas valley since 1946. Born in Texas in the thirties, she was raised in the bed of a pick-up truck, her family migrating for field work as a Mexican version of the "Grapes of Wrath". And similar to those fictitious characters, Rosita never attended school and cannot read nor write in Spanish or English.

Like many of our later conversations, this one began with Rosita and Consuela reminiscing on the early days. Rosita had known the father of Consuela's seven children years ago in the fields. The subject usually meanders to children and problems.

> R: You know I wish we had known about the Pill you know because you know we didn't know. I wouldn't have had so many, would you?
>
> C: NO! (Laughing) But we didn't know nothin'. WE let our uh-husbands take care of everything. But now you know they know better but they don't. . .
>
> R: Yeah, they don't listen. . .

. . and they gesture to the pregnant ones in the kitchen. I ask about the Catholic Church stance on birth control, and the pragmatic Rosita replies, "Well, God didn't mean for children to come into the world when you can't care for them!"

Through Consuela, Rosita knows that my interest is in diabetes, and she turns the conversation to what she calls her two lifelong problems: "being overweight" and "falling asleep all the time." Her (diabetic) father tells her now that keeping her fat as a child was part of the family pride: "*Mira que gordita,*

que bonita -- Look at the little fat girl, how lovely!", the people would say. But now says Rosita, "I'm tired of being overweight all my life."

Although Rosita reports that her father, mother and two sisters were diabetic, her own five-year history of disease began without dramatic symptoms.

> I did't know, I was feelin kind of weakand dizzy but then the doctors checked me and said I have the diabetes, but I feel that all the time you know: weak dizzy sometimes. The diabetes pills I've been taking five years or more. But like I say, I dunno, I still feel the same all the time.

It does not take Rosita long to get to the heart of the problem:

> When I get nervous I eat a lot. That's when I feel fat and I think that's when my sugar is up. My doctor said I feel like this because of my weight. And I told him "I want you to give me something. . . to want not to eat." But that's when he send me to the dietitian and she give me this.

Rosita handed me the American Dietetics Association exchange diet for diabetics, a regime I found so complicated that it contributed to my flight from the nutrition profession. To the illiterate Rosita, this printed diet is as mystical as any other written work. And the diet, she says, bears no resemblance to the food-style in their house. Life at the Garcia home revolves around eating, and this is Rosita's responsibility. When her husband works, she rises at 4 A.M. to make his lunch. She drinks coffee (2 to 3 cups) then and eats part of what she has prepared -- usually two tacos at this time. Then Rosita

returns to bed until she rises to prepare the kids breakfast: eggs, oatmeal, toast, etc.

> Its hard because my kids like to eat a lot. My kids have to eat meat everyday, but I get tired of making it all the time. My husband wants oxtails. They're full of fat! But when I tried to stop buying them, he gets mad. He yells, "You make them!"

So Rosita's own adaptation of a diabetes diet consists of moderate changes: she has reduced from six to one tortilla at each meal; she has soup and coffee and tortillas at lunch. But for dinner, its the decision of the family -- usually meat. Certainly, there is a conflict with respect to food choices: using all of the animal fat for cooking saves money, but is contrary to the weight loss and diabetic plans.

Rosita is a veteran of numerous English as a Second Language (ESL) courses which she never passed. Last year, she enrolled in the library-sponsored Adult Literacy Program and has a home teacher, since she cannot travel to classes -- they have no money for car insurance and unlike her husband and kids, Rosita is frightened to drive illegally. She is learning the formation of letters and basics of reading. "I want to learn to read recipes that tell me how not to use fat, things not too fat." I showed her the new state-sponsored *Comer Bien* diabetic diets which are in Spanish with accompanying pictures, because if anyone, she was the "perfect candidate", the "model target" of this program and I wanted her opinion. As I explained how the program worked and showed her the colorful materials, I quickly saw that Rosita was not impressed. What is difficult for her is not just the concrete recognition of words, but the ability

to abstract, a skill that comes through formal education. The processes of mixing and matching food groups, substituting nutrient types, the very heart of American diabetic diet management requires abstraction which is foreign to Rosita. So without education, the task of following therapeutic diets is difficult and discouraging for Rosita and for others I met in the community. With respect to following dietary prescriptions for diabetes, Rosita feels powerless because of her responsibility to feed the family as they desire, her need to save money by re-using flavorful meat fats, and her inability to read or incorporate therapeutic diets.

In addition to these, Rosita is burdened by family stresses which bring a nervousness she only knows to calm through sleeping and eating. She has "many problems" which make her nervous. Her "husband" works six months of the year as a field worker. Though also a diabetic, he drinks heavily, she says. It is an issue for them which she treats gingerly:

> See like my husband drinks, and I don't want to ask him (to do anything).See he drinks Saturday night and on Sunday sometimes he get up early to start drinking . . . When he drinks too much he start cussin' talkin things that don't make sense. That's when we get mad, he start talkin over and over. Like I said I get too nervous. I don't know when I've been so nervous.

On my subsequent visits, I uncovered more and more of the tension involved in Rosita's marriage. In fact, she considered me somewhat of a buffer between herself and her husband, and thought maybe I could break their impasse (again an issue of powerlessness). "Maybe you can talk to him later on. I told him

that you wanted to talk to him about diabetes and tell him to take his pills!" Apparently Rosita thought she could speak through me to Ricardo (and a similar scenario occurred with daughter Marga, too), that I, an outsider, had some power greater than her own to mediate her home life. I met Ricardo briefly once and he spoke only in Spanish, keeping his head down and deferentially speaking through Rosita until I replied in Spanish. A seasonal worker, he has built a stable career as a "contract laborer": working for one agricultural company from April through October, and collecting unemployment for the balance of the year. Ricardo is lean and strong, tanned and is rarely seen without his workboots and straw hat. Rosita says that except for the drinking and cussing at them, he's pretty good, since he brings nearly all the money home to pay the bills, unlike the men other men she knows of. "Sure, he goes drinks but mostly its around home."

We got a better sense of Ricardo at a later gathering at the Garcia home -- a "going-away" party for me (as usual, Consuela plans, Rosita cooks). The event ran from three o'clock onwards with a constant stream of people, many of whom I had never met. It was a three-ring circus and, my field supervisor, Dr.Lotte Marcus, who knew many of these folks from her years of working in the community during the seventies, wrote her impressions about it shortly afterwards:

> The one working man in that group was Mr. Garcia: swarthy, dark, dirty from having just worked in the fields, with the usual formal apologies for being dirty. While we eat, he calls and Rosita brings him his belt into the shower. Just off from work, he's holding a beer can already half-drunk and this

> continues for the time I am there -- til 6:30. A good-looking man, with some sparse English, He's feverishly drunk , gentle drunk. Rosita is embarrassed by it, but hides it behind the passive-aggressive nature of the fat person. But in this group, he is the victim. Working six months a year at ACME packing company, he lives six months on unemployment, In his drunk, he mumbles about how they are going to let him go. The managers complain now about every box that is not well-packed:what in effect he is saying that he has no one to complain to about his grievances, except, as he says, *esa* pointing to his beer, which he calls *la chingada1. His monologue becomes a stream of truths he would not dare say without alcohol,* but the women cover them up: there is no way now of knowing whether there will be other work; the work is dirty and grimy; he has diabetes but when the pills stop, he won't take any and he asks his wife to show me the bottles -- $60 and they always buy half for $35. He continues: there is no insurance to pay for the pills; doctors just take your money and do nothing. He also feels that when he takes the pills he gets "hot" for *la vieja* [his "old lady"] who gets embarrassed and says for her its just the opposite. Consuela deflects the embarrassing truths be saying *chiles* make you hot for love and everybody dissolves with laughter. She has saved the day by covering up.

Ricardo, we see, has his own issue of powerlessness with respect to the world out there: the employers, the doctors, even the alcohol. At least he can be in control of Rosita, of his family life, except,that is, their sexual relations. During an earlier lunch date I had with Rosita, she asked if I could tell her a reason for her decreased desire for Ricardo: "could the diabetes cause me to not want him? 'Cause that's what I told him." Holding back on the medical explanations for impotence in diabetic men (rarely is a corollary in women discussed), I waited for more explanation from Rosita.

> I just don't want to be with him when he gets drunk. And then he gets even madder and asks me if I'm seeing another man. I say "an old lady like me?? Of

> course not! Its just that I don't like you to drink and cuss.!"

But I think Rosita answered her own question with her own insights as to why she feels hopeless, why she has no leverage with her husband, why her sleepiness and overweight and diabetes continue:

> It hurts me if things go bad, Even if I don't want to think about it, its just there. I can't do nothing about it. I try but I can't help it. Like I tell my kids, I know all the people (in the barrio) have problems, but I think they have more power or something. Because I see them working, I see them doing things. But for me, I can hardly do nothing. I get real nervous, and like my body...

Rosita worries about daughter Marga -- sixteen, a grade-school dropout and unemployed -- who is also out of her control. If Rosita crosses her, Marga threatens to run away. And Rosita can't bear to have any more children "in trouble". During the summer, two grandchildren -- ages 9 months and 4 years -- moved into the Garcia home because another one of Rosita's daughters was convicted for drug possession and sales. An older son is in jail, but Rosita can't -- or doesn't want to -- remember where or why.

While in Salinas, I became privy to some of the women's gossip, their insights about each other. Within the established sisterhood most of the talk was constructive and caring, rarely malicious. For example, Consuela likes Ricardo but thinks Rosita should challenge his authority, as Consuela herself and many other women have done with their men often at the expense of the relationship, in order to go to school, or get jobs or

whatever. But I think Rosita's hesitance is understandable given her few skills and her lack of self-confidence. What's more, Rosita later confided to me that she and Ricardo never married. She had been married with babies when her first husband left her; Rosita met the handsome Ricardo who was willing to take her as his woman, but on his terms. They went on to have eleven children , but she fears that Ricardo could leave her cleanly, at any time and this keeps her from leaving the house much to visit friends, or from taking the cooking jobs which would relieve their financial burdens. So much of her life feels beyond her control to her.

To medically control diabetes, Rosita would first need to take control of the chain of contributory elements in her life: diet - illiteracy - husband /family - (his) alcohol - employment - income. But to make these changes requires material and educational resources to which Rosita has never had access, as well as major changes in family dynamics. Why, she might wonder, should she make these efforts to control a condition which makes her only "weak dizzy sometimes" (and recall that she experienced few symptoms at first)? It follows then, that diabetes, which, she is told by clinicians "she can and must control", becomes a somatic metaphor for all of her powerlessness, a diagnosis of powerlessness given by the medical system.2

Though fourteen years her junior and living in East Salinas, Mariana Luna shares many of Rosita's dilemmas and similar issues of powerlessness and defeat.

Mariana came up to me as I was sitting in the waiting room of the Natividad Diabetes clinic with another diabetic gentleman. "I'm a new diabetic" she said with a sigh. I made arrangements to meet Mariana at her next appointment. But she didn't show up for that one, or the next or the next. After tracking her down for ten weeks, I found that she had missed four clinic visits as well as three dietitian's appointments over the course of six months.

It wasn't until I visited Mariana in her home that I was able to understand why she feels time taken for clinic visits is a luxury. As I entered the Luna home, I was swarmed by little children --she has five at home between 14 years and 19 months. Mariana yells for me to come over to her at the pilot seat of her home, the sewing machine. This is Mariana's favorite spot -- sewing is her "outlet": "I get nervous so I go to the machine." Mariana is developing a little business of selling her home-sewn, quilted picture frame covers to friends.

Mariana is forty-two and from Brawley, California, near the Mexican border. She went to school through 8th grade but stopped going because migrating from the Imperial Valley to Stockton to Fresno meant changing schools a lot and "too much pressure", she says. She married at 18: "I was 110 pounds then, can you believe it? I'm 220 now".

As she sits cutting a pattern, she tells me the story of diabetes, balancing sewing pins between her lips.

> It began about seven or eight months after my youngest. I was drinking water all day long like I couldn't get enough. I was having itching downthere [meaning her vagina], and real hot behind my neck. Real dizzy like I was gonna pass out. My husband says "its cause your overweight." But there has to be something else.
>
> So one day I was at Longs and the lady at the table was sticking people you know and testing the blood. At first I thought no way, but my friend Teresa talked me into it. They said my sugar was real high, like 349 or something? And they tol me to go to the doctor, but I was going out of town the next day so I came here. They told me to come here that night and then they gave me another test. It was 300 -and - something.So they told me to come back Sunday and do it over but I was going to leave Sunday afternoon. I came in the morning and it was still high. So they gave me a prescription to take one [pill] everyday. So I left for Brawley and then I got real sick over there.

Because Mariana had her first diabetes diagnosis in the chaotic setting of the emergency room, and because she was leaving town the next day, she says she's never really gotten an medical explanation of the diabetes or its treatment from a clinician. She adds that in the clinic, there's no time. She knew a little something about the disease because her stepfather and her brother-in-law have it too.

> I didn't know all that much until I started askin' questions. I already asked some other people you know how do they feel and they told me real hot all the time back here [behind neck] and infections down there. (My brother-in-law) said that they used to drink and stuff like that and it wasn't good for them and that's why got the diabetes cause of drinking. [The doctors] told me its because I'm overweight. But then I don't know. I have no idea where it comes from or what it do to you if you don't take care of yourself or nothin'. I mean I hear from other people

> that you can get blind, you can have a stroke and stuff like that. . . Especially now that my head aches and my chest hurts a lot, I get kind of worried.

Like many of the other East Salinas residents with diabetes, Mariana gets a lot of her health information through talking with friends, and hearing about the experiences of others. About people at work, Mariana told me in hushed tones:

> You know I lost two friends there. They started going to Weight Watchers but then *de repento* both of them got sick and died of cancer. So I decided, heck ! I'm not losing weightbecause whatever was in there came out more because they lost weight. What if I lose weight I might get a stroke for sure.

Mariana's prescribed treatments are the hypoglycemic pills and a weight loss diet for diabetics. But based on the experience of her friends, Mariana believes weight loss (and by implication, dieting and food restriction) is an indication of weakness, something which might bring on disease rather than prevent it, a view quite different from the medical model. These community experiences in part inform her decision to avoid the medically-prescribed diet, though financial problems come into play as well.

> I'm not following it too good right now, cause I have to buy certain things and I can't afford them. I have to use what I have. And I'm on a real low income right now. . . .It's just that you have to have certain things to eat and sometimes I just don't have those things. You've got to have meat, some kind of meat, some kind of fish, and sometime I just don't have that.

It appears that Mariana misunderstood the diabetic Exchange Diet list to mean that one must choose from each of the groups. For example, that substituting less expensive beans for meats is okay was not clear to Mariana even after her session with the

nutritionist. But because Mariana didn't find the information useful or applicable to the context of her life, she didn't return to subsequent sessions, she was, as they say in medical terms, "lost to follow-up".

As for the money problems, Mariana says that started back four years ago. Her husband was a mechanic for Toyota, and since Mariana was also working at Simplot cannery, they had a healthy income. But he injured his back which has since required two operations. He's never returned to work and he stays around the house -- sort of a shadowy figure because, she says, he gets too nervous around the kids. Says Mariana:

> I applied for Aid (AFDC) and I figured that if I go to work and if I don't make my hours, and since the union went down on us -- so instead of making $7.27 they went down to $6.22 -- so you know I have to work every day 'cause it will be up to me to pay all the bills, rent, everything. So I figured if I stay home for awhile until he gets back on his feet, I know I'm gonna have income every two weeks. . because of the Aid. Every two weeks we'll get a check and at least every two weeks I could pay my rent and pay my utilities and do whatever I have left I can manage, you know, with the rest. But . . . if I go to work, I have to be there everyday: I can't miss! Then the way my headaches have been hurting all the time? I can't afford to miss a day! With Welfare, we only have $50 less a week, so its not too bad.

For Mariana, dealing with the problem of diabetes complicates a vicious cycle in which she is victim: she can't work because of the head and neck aches; with her husband's disability and lower union wage rates, its not worth her while. She can't exercise she says because of her foot pain *en los huesos* (bones). But all of the pains are intensified by her

worries, her sense of responsibility for the finances that are worse because she can't work.

Even though Mariana knew I was interested in diabetes, through our conversation it was clear that diabetes and its treatment is relatively unimportant to her in comparison to other more pressing issues. The thirst, the infections, the hotness which interfere with her sewing -- these she tolerates in comparison to the stress of her financial burdens. But "with the way its been going", her concern with diabetes is outweighed by the structural barriers in her life: her husband, the kids, the union, the employers, the bill collectors -- all of these form the external loci of control which ultimately affect Mariana's decision-making about care of her diabetes. Living on limited material resources, its a matter of priority management, as Mariana described in her discussion of taking welfare. Other problems will continue to be more important than diabetes, that is, until a medical crisis demands attention. Though somewhat more skilled than Rosita, Mariana feels she has few options ("So you know I have to work 'cause its up to me to pay the bills. . . but") Again, issues of powerlessness underlie Mariana's inability to attend to her diabetes care.

Given that powerlessness is an important factor in wellness in diabetes, is it a result of predominantly cultural or social phenomena? In most aspects of her life Mariana does not have the attributes of traditional Mexican lifestyle which I saw in other women: she views herself as the "breadwinner"; she claims to be the chief disciplinarian; her diet consists of predominantly

"American" foods, she is highly acculturated to American media, fashions, etc. Therefore, it seems more likely that her self-perceptions of powerlessness are related to having fewer opportunities and options as well as limited access to material resources as a Chicana or Mexican-American in this country.

Rosita internalizes the struggles which her family experiences in the community. Mariana perseveres in the face of economic difficulty. In both cases, I have tried to show that diabetes becomes for the people of this Mexican-American community a metaphor for all situations which seem beyond their control. But for Consuela, diabetes is a metaphor for her personal campaign to overcome powerlessness both personally and in her community. Unfortunately, all to often Consuela "wins the battle, but loses the war". She struggles to find a "steady life", makes some headway, but is inevitably pulled back into some life crisis. I propose that she may be representative of many other women in the community trying to break free from constricting situations.

Thus, Consuela's life is epic. Indeed, Consuela sees it as her duty to the community to share her story. Her case represents one woman's struggle against the self-perception of powerlessness, and of the ways in which external social and class factors have beaten her down for years, have imposed controls so powerful that her fight is ultimately ineffective. What is unique about Consuela is that despite the cyclic crises -- each one bigger than the last -- she survives. Not,

however, without great cost to own health and to that of her family. For Consuela, diabetes is less a metaphor for powerlessness than a symbol of her life struggle against it: she's outlived the fatal predictions of doctors by five years. Still ambulatory with 325 pounds on her five-foot-three-inch frame, Consuela is a visual reminder to clinicians of an individual's ability to "fight the physiological odds" in spite of poor compliance to medical advice. In Consuela's view, diabetes is just another thing she must fight for, like everything else in her life.

Dr. Lotte Marcus, who developed the unique and controversial English on Wheels language program in Salinas during the early seventies, had hired Consuela as a community liaison, and the two worked together for seven years. Thus, I was able to receive Consuela's confidence as an extension of the trust and mutual respect which has united these women over the years.

Consuela was born in Mexico in September of 1934. I know little of her early years, but her family moved to Tuscon, Arizona; at thirteen she first enrolled in school. Attending school in various locations, Consuela finished grade five at age eighteen. She describes that most of her life then was involved with the community of agricultural field workers and there she met her husband. Consuela says Carlos was part of her field team, but since they weren't allowed to talk during work, their courtship developed by passing notes to each other. By the

third note, the two decided to wed, a hastiness which she regrets now saying, "we should have lived together like kids these days".

To know Consuela is to be disarmed by her wit, her bawdiness and her barbed but gentle charm which is common in the community. Says Dr.Marcus, "What Consuela is capable of -- and its not a small gift -- is an incredible theatrical performance. She rises to the occasion of an occasion." Consuela pulls out these talents when describing her husband and the early years of marriage and family life to which she attributes "all (her) problems". For example, she says that with her husband it was "'pump, pump, pump' and seven children the result"3. And while everyone is laughing (including myself), they are less likely to notice the minimum expectations and the lack of reciprocity in marriage which her words imply.

And the reality behind the tales was quite sobering. Things were not great in the marriage early on, and Consuela claims that nearly all her pregnancies were marked by "epilepsy" attacks from "*nervios*". Carlos worked in the fields and canneries as did Consuela after their youngest daughter, Alice, was born in 1960. Consuela had "a surgery to not have kids" which, she says, made her able to enjoy sexual relations for the first time in her life. But Carlos began the proverbial wanderings: gambling away their little money; entertaining women. His actions, she says, caused her by age 26 to double her weight to 250 pounds through uncontrolled and often unconscious eating, part of her self-described *nervios*. Due to Carlos'

infidelity, Consuela bravely -- quite contrary to community and cultural "norms" at that time -- left Carlos, taking the children to the San Joaquin Valley, where she worked in the fields and as a short-order cook.

Consuela reports that "epileptic attacks" and nervios were frequent at that time because she was "alone raising seven children". (The exact nature of the epilepsy is uncertain, since she describes her daughter's recent psychotic episodes similarly.) On the other hand, Consuela recalls this time as her first freedom, her first consciousness about the nature and causes of her community's struggle and explains that she took that anger toward her husband and turned it toward "the fight". "Ever since then, I have had to fight: for my family, for my money, for the schools, for this community." The way Consuela adapted to respond to conflict during this time -- and its worked many times -- was to unleash her passion, pound her fist on a few tables, approaches which have too often been exhausting and ineffective. But to Consuela the gestures themselves are the signs of power. And her collection of small victories have made her a local heroine, a woman warrior, among many silently struggling women in East Salinas. Meanwhile, her stubbornness has also prevented her from coordinating with other community groups. For example, according to Consuela and her group of women, the *Mujeres Unidas* [Women United] in the seventies, the created the original idea for low-cost, cooperative housing in Salinas, now known as CHISPA. According to Consuela and her friend Gina, "other groups" as well as the

City Council took their ideas and moved the *Mujeres* aside, and "if they hadn't stolen our ideas, we would be running CHISPA today!"

She used her shrewd social instincts both for her own survival and on behalf of the social struggle for the Mexican-American East Salinas community. In fact, she so strongly identifies the two that she can barely tell herself apart from the community. (For this reason, I needed to get interpretations of diabetes from a broad scope of individuals for as my "key" informant, Consuela painted diabetes as one of the most important community-wide tragedies when in fact she was speaking about herself.) As a door-to-door salesperson for the nationally-syndicated Stanley Home Products, Consuela was able to make commissions as she widened her recognition in the Hebron Heights area. (Having the highest sales in central California, Consuela was sent to Boston for an award.) As the Chairperson of the Title I Parents committee in 1970, Consuela was recognized by several Salinas bureaucrats as an important community representative. Still, she has not really improved her ability to organize nor argue cogently on behalf of herself and community, which is why she experiences problems in both spheres as crises.

In the early days of the United Farm Workers Union stronghold in Salinas, Consuela was "hired" (very possibly unpaid) and trained in Sacramento by a federal agency to conduct a community survey which would assess the need for Food Stamps and Aid for Families with Dependent Children (AFDC or welfare).

It was as a result of her involvement that Consuela herself applied for Welfare only to receive one of the biggest blows of her life: she was denied welfare since Carlos had secretly enrolled their family five years before. He was having the AFDC checks sent to his own post office box. It took one trial and two appeals for Consuela to get welfare while exposing Carlos. (During this bitter fight, Consuela sent two of her teenagers in search of their "fugitive" father to his hometown in Michoacan, Mexico. Again, she acts on her visceral reactions, takes direct action.)

It seems Consuela's personal difficulties and pain solidified her central role in the Salinas political movement of the 70s. Indeed, these personal trials only served to fuel her fighting spirit in community affairs. Publicly she was a community figure. Privately, she struggled to support the children with cooking and field work until 1970. Her second son, who became "retarded" after a blow to the head at age five, was a greater burden as he got older. Consuela feared that her daughters would get into "trouble". Her health was good through these times except for the vicious cycle: *ataques de nervios* and "being big" (then 270). So while Consuela's public persona was that of confidence and activism, she felt little control over the concrete realities of her day-to-day existence: there was always a boss, a supervisor, a landlord -- usually White, often male -- who, she says, punctured the dreams she had for her community. This is an irony which remains in Consuela's life today. (See the story with Ms. Smith below and Mr. Slickman in Chapter 7.)

On the other hand, in the UFW days Consuela was shrewd and pragmatic enough to align with the mostly-White, politically-progressive, middle-class activists who began to surface in her neighborhood throughout the sixties and early seventies. Always willing to strike a deal, Consuela would happily speak at City Counsel meetings or rallys and deliver her stories as needed for "the cause" . . . in exchange for a ride to the doctor, or some help with rental negotiation, or a "lead" on a job. This is not to imply that her speeches and activism was staged or contrived for it is her sincerity and belief in community action that "worked" on her listeners, the City Council or School Board. In 1970, her networking with activists led her to full-time work as Community Aide with "English on Wheels".

These were the golden days for Consuela: she had work, there were troubles at home but always some support amongst the community of activists, her co-workers at EOW. Carried by the success of the program, she learned some of the ropes of collective organization but when EOW left and the English programs became absorbed into the School District, Consuela moved from being part of the family of community activists into being an employee*4*.

Now, fifteen years later, many of the players have left, the issues are less inflammatory, people in her community -- like the rest of the country in the eighties -- focus on their personal struggle just to keep themselves employed. Consuela lives in a one-bedroom bungalow, alone since daughter Alice moved out while I was there. Her home is in the center of

Hebron Heights and a stream of young children and loitering men and dogs flows along her quiet street. Hers is a wood-paneled house where I spent a good deal of time chatting. One enters directly into the living room. I probably made the initial mistake of looking around when I first went there, for when Consuela was "training" me to do the survey, she told me,"Okay, when you go into the people's homes okay you shake their hand you know and look at them straight 'cause they don' like eh-lookin' around they think 'hey! what's the matter you don' like my place?'". Consuela's place is very homey and warm mostly because there's usually a guest or two trading stories with her. She presides on the activities from "her" chair. A sofa is adjacent and to the left there's a plastic pig: two-feet tall, painted as the image of a glamorized cartoon-like character -- I never asked the significance of the pig, but it takes up the whole surface of the coffee table (possibly a penny bank). Across the room on a bookshelf is a graduation picture of one daughter, and a pair of foot-high lead busts of President Kennedy which serve as bookends to five books. Consuela's color TV is usually tuned to American soap operas or Spanish channels. Unlike most of the homes, her living room is the hub. She keeps little food and fewer utensils in her kitchen (for Consuela never cooks for herself anymore) and in the tableless dining room is a lopsided "treadmill" for walking while watching TV (circa 1950 I believe).

It is in Consuela's home that the small group of women meet as they have done for twenty years. Consuela says she wants to return to concerted community work again. Now when

she is well enough, she and and a friend,Gina, think to rekindle *Mujeres Unidas* (see Chapter 7). Consuela refers to the "officers" of the group which formed in the seventies, says the group is still strong, but when pressed confesses that they have no meetings "because we all have to work to support ourselves." The *Mujeres* define themselves by their common roots in thee field work, the common experiences of family struggles, and the common "problem of being big". Thus, many of the *Mujeres Unidas* have diabetes. The flyers were dispensed during my going-away party, and comments Lotte Marcus:

> On the official form, she has typed up (without any names of presidents and vice-presidents though she always speaks of "treasurer",etc.) the legend reads "counseling, self-help". There is nothing political which I remember from the seventies. So the barrio group adjusts to present-day realities. "Yeah, you know", Consuela says," the Union is dead. . . ." There is no mourning for lost vision because the vision had not become hers. She gave the performance of a vision. (Marcus, 1986)

From 1973 through 74, Consuela received a scholarship to attend Weight Watchers. Going from 260 to 170 pounds, she recalls "I felt so good, so nice." With the group support and a safe place to talk about her problems (though the others attendees were not from the community) Consuela says it was easier for her to control her eating. Then one day her third son, aged 17, who was working for a tree-cutting company, had his leg severed and was allegedly hanging in the branches for more than an hour before emergency services arrived. Consuela visited the scene and recounts an immediate *ataque de nervios*

which remained with her for three months. Her son lost his leg, but recovered. This is Consuela's interpretation:

> Three days after the accident, I began a terrible thirst. I was always shaking and trembling like wino ever since I saw him up in the tree. I could only sleep maybe one or two hours a night. My eyes were open all the time; I couldn't remember nothin'. I wanted to run away to someplace.

This continued about three months until she finally went to the emergency room at Natividad and was diagnosed with diabetes. She was 40 years old. She knew a little about it because years ago she had nursed her disabled diabetic mother-in-law. Although Consuela had a private family physician up through the birth of her children (receiving insurance early on through farm workers coverage) she switched to the comprehensive services for medically-indigent adults (Medi-Cal) at this county hospital. Since 1974, she claims to see the doctor every six months, more frequently when she is has "problems". But her records show that her visits are sporadic. Consuela now uses insulin twice daily, because her early attempts at diet therapy alone were unsuccessful.

Since her diagnosis thirteen years ago, the pattern of crisis orientation to problems continues: an issue develops (Consuela's own but more often a problem of her children), she worries, the *nervios* follows, she eats uncontrollably, her diabetes "goes high", physical symptoms result. Able to care for her diabetes during peaceful times, Consuela says she loses all conscious "control" of her eating, sleeping and insulin administration pattern when a crisis develops.

I witnessed this pattern throughout the period of study. When I first arrived in Salinas, Consuela was living with her 26 year old daughter Alice, with whom she shares a reciprocally dependent and smothering relationship. Alice also cared for their 72 year old neighbor, don Jose Martinez who has lost his eyesight and leg to the ravages of diabetes. The three were inseparable, doing everything from shopping to gambling in Reno together. But throughout the summer, I noticed strains in Alice's complicity with the situation, and finally one morning I received a phone call from the nearly-hysterical Consuela:

> I just sent Alice to the emergency room in a taxi. She have an epilepsy attack after she hit her head in the casino last weekend. Yesterday I send her there six times, but they keep sendin her back. Can you go seen she okay?

What unfolded was a long tale of what the medical professionals were calling "psychotic behavior" -- oh yeah, they said, we know her in "the system" -- but which Consuela insisted was the family illness, epilepsy. Throughout the summer and fall, Consuela and Alice struggled in a battle of separation: Alice would be hospitalized, return home and, inevitably, attend to Consuela until she became wild, violent with her mother. Finally, don Jose, whose devotion to Alice runs deep, pledged to marry Alice to "get her away from that *bruja* [witch]", her mother.

For Consuela, this family crisis was more than she could bear and her health suffered. I saw her wheezing, with a chronic bronchial cough, eyes blurred from the diabetes and *nervios* which prevented her sleep and eating, she was barely able to work, and her employers began to complain (see story below). Three times

she insisted upon accompanying me during my early safari's into the community for the survey work, but Consuela couldn't walk more than one block without exhaustion. While Consuela was able to turn to her friend Lotte and to myself -- her mediators into the system -- she avoided seeing people in her community, those for whom she is usually an example of strength. So for all of her years of triumph over adversity, the physical effects of diabetes prevented her characteristic resilience against problems. Ultimately, for Consuela also, the illness diabetes became a metaphor of powerlessness and defeat.

Consuela's pattern of crisis orientation demonstrates another theme seen in and described by many of the diabetic community residents. Its an approach antithetical to the medical model of treatment which emphasizes "lifestyle" changes for long-term glucose "control" and prevention of systemic complications. Yet given the context of Consuela's life, she like many others find that crisis intervention and triage is the best they can do to forestall diabetic symptoms including coma and death.

And so it is for many women and men in the community that diabetes punctuate epic personal tales. The delivery of these stories in the *barrio* setting is animated and dramatic; they portray individuals who struggle heroically against the odds of low education, under- or unemployment and disability, mental illness, family problems with drugs or violence. It is not always stated, usually implied, that an anti-heroic figure or institution is at the root of these struggles, generally embodied as the "evil" landlord, *mayordueno* [field supervisor], teacher,

civil servant, even doctor -- all anonymous caricatures of the dominant Anglo-American society.

Another major theme is the relationship between diabetic patients and the system to which they turn for help. For many of the social and medical problems which have been described, people in the Mexican-American community of Salinas turn to the "medico-social welfare" bureaucracy of the the dominant Anglo society for solutions. Yet, these institutions also represent the oppressive society. For example, Consuela has told me many times "Everything I have I've had to fight for", against icons of the dominant culture embodied as the Salinas City Council, the School Board, her employers. Without concrete alternatives, it is to that same dominant culture that people must turn for assistance with social and medical problems caused, albeit indirectly, by that culture. When Mexican-American diabetics go to the "government-sponsored" clinic (i.e. Natividad Medical Center), they are told to control their own diabetes, even though living as minorities to the majority culture, they have seldom experienced control over economic, social and class-related issues. How do people respond to this dilemma? These deeply-rooted contradictions between patients and the "helping institutions" are played out in clinical interactions with medical professionals, often as behavior which is labeled as "non-compliant". The story of Berto provides an excellent example of one reaction to this contradiction.

When I first saw Berto in the clinic waiting room, I was unsure if he was one of the diabetic patients. Unlike the others, he wasn't that large, wasn't blind and was unusually cheery and cooperative with me and all of the clinic personnel.

Now fifty-two years old, Berto recalls how he felt about his diagnosis of diabetes fifteen years ago:

> The doctor told me that because I was holding down two jobs, my resistance had gone down. I was working for two farms as a foreman, supervising the workers. We had six kids at home. When I found out I had the diabetes, I thought the world was gonna end, especially since I can't have this and that [to eat]. I was only 37 years old. Half my life down the drain.

Berto's analysis -- that a diabetic is especially unhappy because he can't eat traditional Mexican foods -- is commonly cited in the literature, but strikes me as secondary to more fundamental conflicts. I suspect that Berto's profound sadness is caused by deeper contradictions for which medically-imposed dietary changes are merely symptomatic.

Berto describes a period when he acted as though he didn't have diabetes and continued to meet daily with his friends after work, often drinking one or two sixpacks of beer at a time. As for many men, he believes that alcohol contributed to "my sickness". (Recall also Rosita's husband.) But after a hard day of field work, it was the expected behavior. Berto hid the diabetes from his friends because, he says, it is a weakness, a shame. Despite a fluctuating sugar level, Berto worked for seven more years until a forklift accident at Frescas Farms -- a back injury -- put him out of work permanently at age 44.

Without a job and having lost compensation litigation suit due to perjury by the company's physician, Berto lost his home, and as he puts it, an important part of his family: their faith in him.

Currently, Berto and his wife live with their daughter's family in a two bedroom apartment. His wife works "off and on" in at a plant which prepares frozen produce, "but there's not enough work this year."

As for many people I met in the East Salinas Latino community, Berto has learned that a "cheery" and cooperative personality with the Anglo bureaucracy is the most effective means to move through the system which provides him with free medical care and disability compensation. In fact, a similar phenomenon is well-documented in studies of some Black-American communities, the so-called "Uncle Tom" syndrome. Its effective in fooling some clinicians into thinking they are satisfying their customers. Yet the facade does not always serve Berto well. In this clinical encounter between Berto and his diabetes clinic physician, we see that obstacles to his treatment is obscured in the clinical context:

D: You saw Dr. X last time on April 1st, and then you were taking 60 in the morning and 20 in the afternoon
B: Yes

D: What are you takin' now, same dose?
B: Ummm-hummm, I might be skippin once in a while. . .
D: Sixty in the morning and twenty in the evening,huh?
B: AhhhhhI-I might be skippin' once in a while but it it its just ah. I I I been meaning to . . take it every night. But the 60 I don't ever go, I take it I'll be truthful.
D: Okay. Yesterday did you take the 20 at night?

B: Ummmm. No.
D: How about two days ago?
B: Yes
D: You took it then. So would you say: maybe half the time? you take the shot?
B: Yeeeah Yeah
D: Okay, Your sugar is up today: its 261 and that shows you were skipping the dose.
B: Okay.
D: And you . . mmmmmm. It would be possible , well is the problem the two shots a day? You just forgot?
B: I forgot last time. But eeeeeeh [pause] Well, I guess so yeah.
D: Its possible to try and do it with one shot a day. Its not as smooth, in general and it might result in your sugar being too low in the afternoon. You do pretty well when you take your two shots a day, you really do pretty well. So would rather you continue to jus try and be more religious about it?
B: Yes yes, I think so. Uh huh Ahhhhh.
D: Its gonna be better for you like that.

Berto later told me that the doctor urged him to keep seven or eight bottles of insulin on hand as a back-up supply, and he agreed to do so knowing well he would not.

But in a later home interview with Berto, he revealed to me that his failure to take the afternoon insulin was not a matter of forgetfulness, but a strategy intended to reduce his medical expenses. His family, he says, is tired of his problems and resent not only his special dietary needs but also the expense of diabetes treatment: he claims some fifty dollars a month for the required insulin. Says Berto of his family's support:

> They go they're way and I go mine. My wife? She's fifty-fifty. It creates problems for us.

Rather than expose the financial and familial tensions i.e. the social obstacles to his treatment to the physician, Berto would rather appear forgetful, careless. (In fact, those are not uncommon stereotypes of the Latino diabetic patients whispered by some health professionals.) He believes that if he claims financial hardships to the doctor again, he will get the same response he says he received at an earlier appointment: "Well, I can't really do anything about that." Berto later stated:

> I asked him about my other problem [a chronic post-nasal drip] and he said "beats me!" What kind of a doctor is that! I used to like him but now, I think he's too busy. I'm disgusted with him.

The way Berto sees it, its the same shrugged-shoulders response which he heard about his lost compensation for the accident, and the response his wife hears about the lack of jobs this year: the usual bureaucratic rejection. What is unusual about Berto is that he continues to use the clinic system in spite of these frustrations. By contrast, when Consuela disagreed with the clinic advice, she promptly sought another physician. Why would Berto remain and appear to believe "in the system" that leaves him with seething anger?

Berto embraces the role of "non-compliant" diabetic, a form of deviant behavior in the medical system. This phenomenon is discussed by Stein (1985) in his chapter, "The Contest for Control: A Case of Diabetes Mellitus in Multiple Contexts". Stein believes that any system (family or medical or social) which convinces the individual that he is helpless and dependent supports non-compliant behavior. These are messages Berto has

heard as a Mexican in America, a farm worker, then a "victim" in an occupational accident, a disabled diabetic man. The psychotherapist Stein focuses on family systems which generate deviant behavior and believes that the medical system substitutes in that caretaker role for diabetic adults. In the case of Berto and other diabetic men in the community, I would argue that the dominant Anglo bureaucracy functions in this deviant nurturing/paternalistic role. For Berto, the medical system, embodied in the form of the diabetes clinic, symbolically merges with the social welfare system, the banking system, the agricultural industry and all of those bodies from which he has heard a familiar contradiction: "We are helping you. You cannot have this job/ this loan/ this medical treatment". Notice the similarity between the institutional messages and and Stein's description of the overprotective (and pathogenic) parent of a "non-compliant" diabetic man he studied:

> always vacillating between overprotection and neglect . . . encouraging his grandiose, out-of-control behavior by setting no limits, while later protesting their helplessness to constrain him. Inconsistently caring for him, (they) failed to teach him to care for himself. [Emphasis added]

Stein further comments upon the deviant physician-patient relationship:

> Yet, the patient did not sustain his pathology exclusively on his own. He was essentially told, "You must learn to control yourself. You will never be able to control yourself. We will even help you to be out of control or look the other way and then resent you and finally reject you. . . .

Later in the clinic transaction, Berto, in classic passive-aggressive form, flaunts his sins as a diabetic:

B: C' c'could it be that I had a few drinks Sunday?
D: Yeah, it probably didn't help
B: Cause I felt like I still got a hangover [chuckling]
D: Uh huh
B: I don't usually drink. But I had two drinks or three somethin' like that
D: Uh-huh
B: It was a special occasion.
D: Sure, well it probably didn't have that much to do with it.[higher glucose]
B: No?!
D: No.
B: But I still feel that I have the hangover
D: Well, maybe 'cause you're no used to it [both laugh]. The main problem is skipping your afternoon insulin.

Again, Stein comments:

> He complies, then rebels, then must atone. . . "You must. . . I'll try, but . . . " The result of this ambivalence is a monumental internal struggle over self-control.

When I spoke to the physician about his feelings when patients like Berto repeatedly disregard medical advice, but return in penitence, he replied (and here I'm paraphrasing):

> When I see those constantly-elevated blood glucose levels, I know they didn't follow the diet or didn't take their insulin, and they know that I know. But . . . what can I do? I give them the physical -- they expect it -- even though I know that the physical won't show me anything important [i.e. not as much information as an EKG or another test]. But we go through the motions. . . Getting frustrated is maladaptive.

But coming from an educational and professional tradition which emphasizes physician control, paternalism and dominance, chronic "non-compliance" is very wearing indeed, and produces the resentment that leads to stereotyping of the offenders, such as those remarks about Mexican-American diabetics cited by Beliz (Chapter 2).

The contradiction created when people in this community must seek assistance from the dominant culture can cause disastrous clinical encounters, as in Consuela's case.

On the day I first met Consuela in late May, she was preoccupied and "not feeling too good."

> My diabetes is getting high. It start happening when I got mad at the school supervisor. And I don't bring it out so I eat and I don't think about it. Its nervios.

> I feel like a rock -- can't move. I been gaining three pounds a week, but for three days I vomit everything up. When I eat something or when I see her, it start hurting same as when I had the gall bladder surgery.

Consuela was in a state of shock. After her years as English on Wheels, she had continued as a Community and Teacher's Aide at the Salinas Adult School, the new body of ESL. But in those eight years, a strong bureaucracy replaced the progressive founders who never minded Consuela's mispronunciations and misspellings. More than a "job", this work as "Community Aide/Teacher's Aide" is a strong part of her identity in the community: she is admired and respected by generations of students and is a cheerleader for learning English as a means of self and community enpowerment.

But two weeks prior to our meeting, Consuela received her evaluation from the district supervisor, Ms. Smith, known to be a particularly "stiff" and rather humorless bureaucrat. The evaluation cited "problem areas" which Consuela must remedy to continue her employment : lose weight (preferably 50 pounds); control her "offensive" body odor; learn to spell correctly; work on better pronunciation; attend the local junior college to achieve aforementioned language skills. Worse still, attached to the evaluation was a sheet containing the written recordings of Consuela's mispronunciation of English language. Smith had followed Consuela around one day and recorded all her grammatical mistakes -- admittedly she has many for example confusing gender pronouns. Next to these were printed the "correct English usages". Consuela was devastated and, quite

realistically, feared that the notes would be used as documentation to have her fired.

To worsen the matter, that week, Consuela's daughter Alice experienced another attack: "epileptic" according to Consuela, but the incident returned her to Day Treatment for the mentally ill (it was one of many psychotic breaks for Alice). Having been violent, Alice was put in the psychiatric ward. With "(her) nerves so bad" and her diabetes affected, Consuela was unable to mount her usual fighting spirit, yet knew no other resort. She told me, "I know I got to fight, but I just . . can't . . . now".

When she met with her old friend Lotte and myself, Consuela felt in a double bind. While her employers demanded weight loss and bodily odorlessness, Consuela claimed that the stress made her "eat and smell more". (In fact, she believed the "smell from down there" to be caused by her low-calorie diets -- a greater double bind! We later discovered that a chronic vaginal infection, common in diabetic women, was the curable cause.)

So as a result of our triage, she decided to visit the Natividad clinic both to attend to the worsened diabetes and to appeal for temporary disability, some compensated time to "work on myself". "After all these years, I gotta take care of me", she said and we supported this attitude.

The clinic transaction demonstrates several common experiences for diabetics. First is the issue of power. Consuela, the woman warrior of her community, came to the

interaction wanting support and "formal approval" or her plan to get temporary disability. Like many people, Consuela brought issues of daily living -- issues which affect diabetes "control" -- to the medical transaction. She was ready to have control, to negotiate her medical and disability options with the physician: that is, she came from a sense of powerfulness. Yet when confronted with the austerity of the clinic setting, the physician and the executive power he has to determine her "disability" options, Consuela became powerless, unable to speak coherently, recoiling against his challenge. But there were other problems. Having not seen her for six months, he couldn't remember the details of her case. And there were forty more in the waiting room just like her!

[P = staff physician; C = Consuela]
P: How's it goin'?
C: Not too good, doctor, There are a lot of things wrong
P: Not good?
C: Yeah!
P: Like what sort of things?
C: Yeah, I'm having a problem with my job. I don't know, I think they want to fire me. They want to get rid of me.
P: ooOOOOohh. Huh!
[Consuela hands him her work evaluation.]
C: So this is all about my work. And I been having a lot of uh, you know. Like I be talking to you, talking to some people and uh. . . I lost what I was talkin'. And I stay sometime for 3,4,5 minutes that I have to stop talkin again because you know like a. . a record when its ah you know not good. So everything's lost and I can't concentrate, and I thinks its because I am very nervous about a home problem with my daughter.
P: Uh hummm
C: And uh--
P: --well, what do you want me to do.
C: Okay. First, well first I want to see if they can make ma a whole 'valuation of my . . . of everything about me. Plus, I want to see, uhh well? . . .what step I can follow after that.
P: I can't -- if you want a complete physical exam you could get one of those here. I can't do it today. . . There isn't really anything I could do about this [shaking the letter].

He goes on to deny her belief that her "smell" is caused by weight loss. She responds with a litany of her physical ailments -- many new to me -- and described seeing a chiropracter for neck pain as well as an opthamologist for retina laser treatments5 in the past few weeks. In this setting, Consuela's story rambles, bears little resemblance to what she had told me before. The doctor responds accordingly:

P: I don't really understand what's goin' on here. Since I saw you in May of '85, you had gained 20 pounds from your previous visit, which was in February of '85. NOW in July of '86 which is a year later, you've gained 24 MORE pounds. You haven't lost at all, you've GAINED! And . . . you know, that. . . its just there.
C: Well, I'm tryin to see if I can dedicate most of my time of my health. But I have to support myself.
P: (softly) Sure, I understand.

After a brief physical exam, the physician left -- I think to compose himself for he appeared exasperated -- and returned with a plan of action for Consuela. Stressing the importance of her weight loss, he suggested she begin sessions anew with the hospital dietitian. As for the disability?

P: 'Kay, if you want disability, the disability people have their own doctors who examine you to determine if you're disabled. . . You're NOT disabled because of your diabetes; you may be disabled because of how much you weigh and how big you are. You very well may have some disability from that, but they will still want you to be examined by one of their doctors. . . . But I hope you realize that that's really only ONE of the complaints that the people at work have about you. There are . . one,two,three,four. . .there are FIVE! different complaints. . . I can't . .. we can't get into that. That's between you and the school. . . And just having you declared disabled isn't going to solve those problems.

I think that Consuela had come to the clinic with an expectation that the physician become her advocate in the fight against the school. But he was unsympathetic with respect to the

evaluation. She said, "He used to be okay, but now he don't care." She was humiliated and frightened for her employment future as a result of that clinical encounter. Afterward she visited a Chinese herbalist and took teas for a week which made her "sleep like a baby." It took Consuela days to be able to talk about the clinical encounter. She has not returned to that clinic since and now pays considerably more to see a private doctor.

Another theme emerging from these case histories is the aspect of physicians' response to diabetes in members of this community. I have shown two clinical interactions which, while not "typical", represent important features which were repeated in other encounters. I do not wish to paint a picture of stern, cynical and heartless clinicians at Natividad for if there are any capable and well-meaning health professionals left, they are here! Physicians at Natividad are at the front lines, patching up the wounds of those who are the casualties of our social structure: the young poor families, single often alcoholic men, field workers exposed to pesticides, the chronically mentally ill.

Rather, I believe that clinic interactions as those above which are unsatisfactory to both patient and physician reflect the present reality: medical education or "training" does not equip its ranks to address the "non-medical" affects on health. The physicians at Natividad are exceptions to this stereotype, but due to the number of patients now loaded onto public sector medicine, they too are overwhelmed. In response, most focus on

the technical "delivery" of health services, which they see as their primary function; "all other" including focusing on communication and cross-cultural issues become secondary. As one medical resident said during my presentation of the diabetic case histories at Natividad, "We know about all this but we have to be reminded."

Given that diabetes is a somatic metaphor for the loss of power and control in the life of the afflicted, it is not surprising that those diagnosed respond to the news with profound depression and hopelessness. Another major theme in this study is the characterization of a specific set of emotional responses in diabetics. Apparently, this is a widely-held view of diabetics in the East Salinas/Hebron Heights community. When asked about the mood of diabetics, survey participants said that many non-diabetic people are "depressed", "irritated", "sad" (See Chapter 7). Obviously, physiological shifts in glucose affects well-being. For example, Mariana expressed a sadness and defeat when she introduced herself to me in the Diabetes Clinic. But I think that Mary's experience represent the more common reaction of depression and denial. She reacts to a diagnosis of diabetes as one might react to the death of a loved one: denial, anger, rationalizations and explanations for its cause, self-blame. Whether she ever accepted the medical diagnosis is uncertain.

Mary is half-Mexican, half-German and has lived all her life in the agricultural community of the Salinas area. At 45 years, Mary was educated through junior college, which, she says, became a necessity when her husbands left her (she has had three). She has worked in "Meals on Wheels" and other (now defunct) federal nutrition programs as a cook. Having overcome alcohol abuse and a work-related back injury from which she has been disabled for a year, Mary feels that diabetes is "unfair", but also perhaps her "own fault". Mary is culturally American in her dress, language, diet, but she has shared many experiences of struggle with Mariana, Consuela and Rosita. I spoke with her at the clinic just a month after her initial diagnosis of diabetes.

> Yeah, its been different because it used to be from my house to my job, there eight hours, and then home. So its a whole new life now since [the illnesses]. . . Its drawing me into a whole different area: me. Y'know this is my body. Its taking me to things that I would like. I think probably too late because you know I was depressed. There's been a lot of things happening to me in my life. So here I am: sick. And I gotta do something: drop my weight and everything. But so far it s been on a talking basis. Trying to adjust myself and program myself to start doing things for me. . . .It takes a lot of time. Its hard too and hard to go through it alone. I don't know if there's any support groups for the weight. Also getting into um diabetic places where I can learn . . . to share more instead of cooking. You know maybe there's fear or something locked up but I'm moving on. Its gonna take a process. I cheated [on diabetic diet] -- How could I have done that?! You know I feel so guilty about it so then I go and sleep. I don't want to do this, this pattern: sleeping, drinking water and taking my pills. Like I said its ah it really different from how it was. But . . . I gotta like this -- ME.

Yet in the clinical interaction which followed my interview with Mary, she was never given an opportunity to express the symbolic meaning of diabetes in her life. Instead, the clinician (a medical student) encouraged Mary to get it together, return for more diet counseling ("but",she replies,"they only tell me things I already know!"), accept it. Mary interprets his medical advice in one way: "more discipline", just as with fighting her alcoholism; she responds by blaming herself for this disease which she associates with stigma:

> So all this has happened to me and I don't know its its just that it coulda been a process of things like in my life. My other sisters never had a problem like I did -- I was the only one that drank. They were the homemakers in their homes y'know with their really nice,quiet life and their husbands and everything. I was the only one that drank in my family . . . and drank really . . . a lot.

Although Mary appeased the clinician by promising to follow his medical instructions with the conviction of a reformed criminal, she never showed up to her Natividad clinic appointments again. Nor did she respond to my calls to meet with her again, effectively expressing in a passive-aggressive manner, "I don't want to have anything to do with any of you or your diabetes. Just one more thing for me to suffer." This mixture of denial with depression is not an uncommon response by community members to a diagnosis of diabetes, as corroborated by survey results in Chapter 7.

The only individual studied who was able to successfully "normalize" her formerly elevated blood glucose levels was Santina. A soft-spoken, serene, often-pious woman around fifty-five to sixty years old, Santina attributes her "excellent diabetic control" (the words of her physician) not to the efforts of her family physician at Natividad (though, she says, "they are lovely people there"), but to "the guidance of the scriptures of Jehovah."

From the outset, Santina's history begins similarly to the stories of Consuela and Rosita. However, Santina emphasizes that her family were "Spaniards from Mexico" (her grandfather held some political office in Mexico and it was from some popular dissent that his family fled to California), and highly valued education such that she completed high school. She married a field worker and worked as a cook for the agricultural crews while raising her family throughout the Salinas Valley. But through these years, her husband became involved with women and drinking, struggles which plagued her health because she "had not yet found Jehovah". When at age 50 she found the Scriptures and the Mexican-American congregation of Jehovah's Witnesses who became her "spiritual brothers and sisters", Santina found the strength to leave her husband who was "fed up with my Bible reading". Santina is also estranged from her three adult children who have also found her new lifestyle alienating. It was Santina's "spiritual friends" who suspected her symptoms of diabetes before she went to the clinic and suggested a regime of diet and home remedies, including *nopales* (prickly pear) which

she follows carefully. Although Santina originally used oral hypoglycemic medication, she is now able to "control" her blood glucose entirely through diet.

I asked Santina how she was able to rationalize leaving her family for a solitary life in which she collects social security disability and teaches Bible classes to others in her housing project. "Why, it wasn't my choice at all! It was Jehovah's!" So, in order to make more healthful lifestyle changes, Santina called upon the support of a Higher Authority as well as her congregation. She feels strongly that others in the Mexican-American community who struggle with family and health problems are responsible for their own plight since they are simply "not listening to Scriptures". Her criticisms reflect as well a broader conflict of Catholicism versus Jehovah's Witness doctrine raging in many Mexican-American communities. What is important to take from the case of Santina however, is the key element of support in her ability to successfully "control" both her life problems and diabetes. Could the process of enpowerment through group support in the Church be applied to the broader East Salinas Raza community through more secular contexts?

Of the sixteen adults with diabetics, the only individual who was able to take "control" of her medical treatment of diabetes was Esperanza, a woman from a neighboring county referred to the Monterey County facility because of her intransigence to medical treatment in her home county. Of all

the patients who were routinely annoying to clinicians, Esperanza skillfully triggered the most frustration, repulsion and anger.

I was called into an examining room by a medical student who was at a impasse with Esperanza, who was speaking only Spanish, even through it was clear that she understood the English spoken around her. Esperanza had brought her Disability application forms, but the medical staff refused to sign them citing her very high blood glucose as proof of blatant "non-compliance". She admitted to eating candies at night during work because at the cannery she was unable to take breaks, but "I could stop if I wanted". She complained that the insulin schedule was incompatible with her work schedule -- so the doctors need to change it! What's more, said Esperanza, she couldn't come for an appointment next week because it conflicted with the narrow window of time she had to apply for the next seasonal job. Of course, if they'd kindly give her the disability approval then she wouldn't have to worry about that job.

Esperanze was playing hardball, challenging the authority of the clinicians in manners which they found unorthodox and intolerable. Stein (1986) says of these archetypal patients:

> (She) is a kind of modern Till Eulenspiegel6 whose merry -- and deadly -- pranks violate what we strive to uphold and indulge what we struggle to repress. . . Unofficially admired and feared, envied and applauded, (she) acts out all reversals of civility. (She) is everyone's badness. (She) is the universal cultural anti(heroine).

Yet no one really wanted to talk with her and messages were shuttled via intermediaries, including me. I think the attitude

was essentially "if we give in on this one (granting disability), then they'll all come asking for it", a trend which they say has passed through the clinic in waves. She left without the disability granted and with a new supply of insulin, but I think Esperanza was the victor in the interaction.

I arranged to make the transcounty trip to esperanza's residence. We made an appointment and she called back to check if she would need "Medi-Cal stickers" [a form of reimbursement] for our talk (I said no). But when I arrived at the appointed hour, her daughter peeked through the half-open doorway: her mother was out, she said, and besides her diabetes was better now thank you, good-bye. Yet I saw esperanza peering from the back room. Despite my explanations that I wanted to hear her story, to be an advocate if I could help, they wanted no part of it. The next week at the hospital, I learned that Esperanza's daughter called to complain that the hospital had sent a "spy"; Esperanza would never return to Natividad again. And when I worked through my remorse at this misunderstanding and turn of events, I realized that her reaction was not to my visit but in response to a long history of mistrust in dealing with people or institutions who represent the dominant Anglo-American culture. Though a "loss" for the medical system, Esperanza remained in power of her diabetes treatment, and will likely move to another level of therapeutic resort on her own terms, but will not decrease her social distance to the medical system.

Turning now to sociocultural factors which have been suggested in diabetes treatment in Mexican-American populations, how much does resistance to medically-suggested dietary changes affect diabetes treatment? Recall from Chapter 1 that therapeutic diets formerly discouraged traditional Mexican diets for their high calorie- and high-fat content. However, the *Comer Bien* program (see Chapter 2) incorporates traditional Mexican foods into diabetic food plans on the belief that maintenance to traditional ways will help Mexican-American diabetics "comply" to treatment.

Through participant observation and informal dietary assessment of the case study diabetics, the results of this study have shown that many people in the Salinas community do not eat an exclusively Mexican diet, and the range of "traditionality" is great as a result of rapid acculturation. For example, Rosita's diet incorporates many traditional foods, while Consuela (since she has been living alone) reports a relatively low proportion of these. Although Mariana uses low-cost foods, she is also concerned about convenience and sometimes serves "whatever the kids will eat" which, according to Mariana is more often than not American convenience foods such as frozen fried chicken and canned spaghetti. Mary, who has been a cook, boasts of the variety of Italian, French and other specialties of "her kitchen" which she regretted to give up due to her diabetes, adding:

> One of our family traditions (Fourth of July) is a Bar-be-que and I have my sisters in Salinas and we all get together and my son came over. Everyone gets together and sits around and watches TV. And I couldn't eat! You know they had baked potatoes and corn and chips. I cheated on the corn and so that's one reason why me sugar is high [today].

These reports are consistent with work done by Dr. Kathryn Dewey, nutritionist at the University of California, Davis; she reports that diets of working Mexican migrant families is under considerable transition to American foods, especially with the consumer influences of their rapidly-acculturating children. Similarly, I found that the twelve diabetics studied ate a variety of foods, and do not eat the Mexican diet as health professionals might stereotypically believe.

So what about comments by Berto that "I used to eat a lot of Mexican foods. . . but then I had to follow their diet and in order to stay on their diet I couldn't eat Mexican foods. The dietitian said that the Mexican foods wouldn't be as good." He speaks about imposed dietary changes as a loss of personal autonomy. For example, Berto claims that his wife and daughter have taken to putting a bowl of "forbidden" candy on the coffee table, ostensibly for the children but Berto laughs, "I wonder if they're trying to torture me. Its funny but I never liked candy before, but now I want it." Similarly, Mariana tells of her relationship with sweets:

> In the middle of the night I want something sweet so bad, I uh crave sweets bad. Not all the time, I crave. . . sometimes. Then I found a little what's that? a "kiss" candy bar? (chuckles) and I went and ate it cause I couldn't stand it, I wanted an ice cream or candy or something.

This issue is the fourth major theme which I observed among diabetics: the meaning of dietary restriction. Certainly food choice is a very personal issue -- perhaps one of the few choices which people in the community feel they can make for themselves. In addition, sharing traditional foods strengthens community pride and being known, as Rosita is, for her cooking skills is one of the few honors of community life still bonding people together in spite of the encroaching influences of dominant Anglo culture. The notion that diabetes treatment implies dietary restriction of satisfying and culturally-meaningful foods appears as an intolerable imposition on civil rights by medical professionals, a demand on patients that goes a bit too far, is too personal. Although prior to a diagnosis of diabetes, traditional Mexican foods might not have been important to those more-acculturated members of the Salinas community, the realization that diet also will fall under the "control" and influence of medical professionals (therefore, the dominant culture) contributes to perceptions of powerlessness. Therefore the way to feel more powerful and in control consciously or unconsciously, is to ignore dietary changes, to be "non-compliant".

One of the only features of traditional Mexican culture which is intertwined with diabetes is the maintenance of assigned of gender roles. This phenomenon in numerous Latin cultures has been called *machismo;* the notion that the division

of labor and responsibility is accorded to each sex. The male dominates over family decisions, employment and collection of material resources, while the female is responsible for child-bearing and care, domestic chores and harmony. Ultimately though, the male is the unopposed authority in the family. *Machismo* is not exclusive to Latino cultures, and may be a feature in numerous communities in which access to material resources is threatened. Certainly this would explain why elements of *machismo* seem to be intensified in more economically impoverished Latino communities. The relationship of Rosita and Ricardo described earlier is the most extreme example of the dynamics of *machismo* found in this study.

However, the social ordering of *machismo* is changing. As in other communities of American, more women are becoming single mothers (Consuela was a pioneer). Instead of persevering through chaotic family dynamics, more women are leaving (usually alcoholically-impaired) husbands, becoming single mothers, believing they can best care for their children alone. While the Mexican-American male formerly felt powerless to support the family in the face of discrimination and economic hardships, there is a trend toward feminization of economic powerlessness, no doubt related to the documented feminization of poverty. (An exception to this trend occurred in 1987 in near-by Watsonville, where women led a nationally-publicized cannery strike which was ultimately successful.) More and more women in the community are, like Consuela and Mary, becoming single parents, taking on the responsibility far beyond the defined feminine role of

machismo. Like the wives of Juan and Berto, women are becoming principle wage earners in their families because of the disabilities of their husbands including diabetes. It appears that economic necessity is transforming the cultural tradition of *machismo* in the East Salinas community.

The traditional roles of *machismo* can also be affected by a diagnosis of diabetes in a family. Women with diabetes are told by clinicians that they must "take control" of their weight, change their diet even in the face of protests of family members. Diabetic men who become unemployed as a result of the illness, such as Berto and his friend Juan, perceive a loss of power and control in the family structure. For some, this relates to their wives becoming the principle wage earners, or to their "inability" to participate in typical male social events like beer-drinking marathons. Now nearly 53 and blind as a result of diabetic neuropathy, Juan is supported by social security compensation as well as his wife's wages. He has become the child caretaker of their younger children and grandchildren and from his little sofa-throne near the TV, Juan yells commands and oaths to the kids, like a failing monarch giving the illusion of power. Yet still other men are not able to tolerate role changes as Juan has and family break-ups may result. Women like Consuela and Santina refuse to return to relationships with men and have "violated" cultural rules for women in order, they say, to remain mentally and physically healthy.

There is a perception in the community that more women than men suffer from obesity and *nervios*. The stories of Consuela, Rosita, and Mariana underscore the association of obesity or "being big" with stressful experiences. Likewise, alcohol abuse is believed to be a bigger problem for the men. Out of six diabetic men in the case studies, Berto, Juan and Ricardo (and two other men not described here) state alcohol as the principle cause of their diabetes. In the Diabetes Awareness Survey, an equal number of respondents --13.6% -- state *nervios* and alcohol as the most important cause of diabetes. The majority of diabetic adults questioned, as well as many non-diabetics surveyed (Chapter 7), imply that these three phenomena are caused by life events which "you can't control" i.e. they are associated with self-perceptions of powerlessness. Indeed, psychologists and psychoanalysts might agree that by funneling unmet needs into eating or drinking, one is able to displace and, at least temporarily, satisfy needs, quell anger, fear, and frustrations.

However, *nervios* was only used to describe the response of women. *Nervios*, like *susto*, is documented as a traditional Mexican classification of illness, but its meaning has a slightly different flavor from community to community. The most commonly named cause of *nervios* in the Salinas community is summarized with the words of one woman: "*tener problemas y no se puede resolverlas.*" that is, "to have problems which you aren't able to solve." That obesity, alcohol abuse and "stress" (*nervios* or epilepsy) are causally-implicated in medical discussions of

diabetes suggests a link between the causal explanations of diabetes held by both physicians and community members.

In summary, what is the influence of traditional cultural beliefs as an obstacle to treatment of diabetes? As Dr. Chavez-Pardo (Chapter 2) and others have suggested, both features of the Mexican cultural tradition and the lack of understanding of cultural views by health professionals may contribute to the inability of people to "adequately care for their diabetes". Says Chavez-Pardo,

> Traditionally, not only diabetics, but most Hispanic patients have a very passive attitude regarding their diseases, and put a lot of emphasis on the external intervention of a healer to change their fate. Most consider that there is little the patient can do to modify the course of an illness.

Furthermore, Chavez-Pardo attributes the misunderstanding of medical definitions of diabetes by some Mexican-American people to traditional beliefs instead of to poor access to material resources and economic opportunities. In terms of the hypothesis that diabetes becomes a somatic metaphor for self-perceptions of powerlessness, are the observations which Chavez-Pardo posited related to cultural traditions or to social factors? (This questions raises the controversial notion of Oscar Lewis' "culture of poverty" which I discuss briefly in footnote7.)

As a summary of characteristics and circumstances of the sixteen diabetic adults studied in the Salinas Mexican-American community, I present Table 6-1 which illustrates a few of the

TABLE 6-1
OVERVIEW OF CASE STUDY PARTICIPANTS:
PERSONAL, MEDICAL AND SOCIAL ATTRIBUTES

Case#[1]	1	2	3	4	5	6	7	8	9	10	11	12	13
PERSONAL													
Sex	F	M	M	F	M	M	F	F	F	F	F	F	F
Age (yrs)	45	57	52	42	57	>60	60	52	51	65	58	56	--
Primary Lang	E	Sp	Sp/E	E/S	Sp	Sp	Sp	Sp/E	Sp	Sp	Sp/E	Sp/E	Sp/E
Marital	Ma3	Ma2	Ma	Ma	S	Ma---Ma		D	Ma2	W	Ma	Ma	W
Born	US	Mx	US	US	US	Mx	Mx	Mx	US	Mx	US	Mx	US
Educ.	12	6	9	8	3	--	0	4	0	0	12	12	
Transport Self?	+	0	+	+	0	+	0	0	0	0	+	+	0

1. Name code: 1= Mary, 2= Juan, 3=Berto, 4=Mariana, 5=Jorge, 6=Geraldo, 7= Linda, 8= Consuela, 9= Rosita, 10= Alicia, 11= Maria, 12= Santina, 13= Ramona

LEGEND: F=female; M=male; +=yes; 0=no; E=English; Sp=Spanish; S=single; D=divorced; Ma=married; US = United States; Mx = Mexico.

TABLE 6-1 (cont'd)

DIABETES STATUS[1]

Case #	1	2	3	4	5	6	7	8	9	10	11	12	13
Interv'd	+	+	+	+	+	+	+	+	+	+	+	+	+
Clinic Observatn	+	+	+	+	+	+	0	+	0	0	0	+	0
Dr's View	lst	gd	fr	gd	gd	fr	fr	pr	fr	ESRD	--	ex	pr
Other Disease	0	++	0	+	0	+	++	++	++	+++	+	++	0
Yrs DM	<1	18	15	<1	4	5?	5?	12	5	20	20	4	5
Treatment:													
Insulin	0	+	+	0	+	+	0	+	0	+	+	0	+
Pills	0	0	0	+	0	0	+	0	+	0	0	+	0
Diet	pr	gd	gd	pr	ex	pr	pr	pr	pr	gd	gd	ex	pr
Remedios Caseros	0	+/0	+/0	-	+/0	+	+	+/0	+/0	+/0	+	++	+/0
Self-stated cause DM	weight alcohol	alcohol	heredity,alcohol hard work	not sure, weight	hard work (denies alcohol)	"don't know"	"don't know"	nervios	nervios	worries	sustos, starch in diet	Mexican diet weight	weight, sweets

1. LEGEND: ex=excellent; gd=good; fr=fair; pr=poor; ESRD=end-stage renal disease
lst = "lost to follow-up"

TABLE 6-1 (cont'd)

FAMILY ISSUES[1]

CASE #	1	2	3	4	5	6	7	8	9	10	11	12	13
"Problems Worries"	0	0	+	++	0	0	0	+	++	+	+	+	++
Legal	0	0	0	0	+	0	0	0	+	+	+	0	0
Violence	+	+	0	0	0	0	0	+	?	?	+	0	0
School (truancy)	0	0	0	+	0	0	0	0	+	0	0	0	0
Alcohol/ Drugs	+	+	+	+/?	+	0	0	0	+	?	0	0	0
Mental Illness	+	0	0	0	?	0	0	+	0	+	+	0	0

1. LEGEND: ? = suspected

TABLE 6-1 (cont'd)

INTERACTION WITH SOCIAL/HEALTH AGENCIES1

CASE#	1	2	3	4	5	6	7	8	9	10	11	12	13
Welfare	+	+	0	+	+	R	R	+/0	+	+	0	+	0
Disabil. (SSI)	+	+	+	0	+	0	0	0	0	+	0	+	+
MIAs	+	+	+	+	+	+	+	0	+	+	+	+	0
MediCal/ Care	+	+	+	+	+	+	+	+	+	+	0	+	0
Health Services:													
priorDM	Pv	Pv	Pv	Pv	Pv	Pv	Pv	Pv/Pb	Pb	IMSS	Pv	Pv	Pv
current	Pb	Pb	Pb	Pb	Pb	Pb	Pb	Pb/Pv	Pb	Pb	Pv	Pb	Pb

1. LEGEND: Welfare = includes AFDC, Unemployment, General Assistance; MIAs = California State definition for "medically-indigent adults", i.e. without sufficient private and public insurance support; Pv = medical care by physician in private practice; Pb = Medical care delivered through government-supported institutions (county hospitals, public health clinics, etc); IMSS = Mexican public health service.

numerous "external societal factors" which impinge upon those with diabetes. Almost every diabetic individual and family considered has experienced unemployment or family problems (violence, school truancy, mental illness, substance abuse). Many diabetics have little formal education and are currently dependent on supplemental income and medical care sponsored by government agencies of the dominant culture. Labor unions which brought hope and solidarity to the Mexican-American community throughout the sixties and seventies are dwindling in power and influence. I would argue that for members of the East Salinas Mexican-American community social conditions such as these are so overwhelming that elements of "traditional Mexican culture" do not have an opportunity to flourish, only as a counter-measure against inevitable Americanization. The influence of traditional beliefs on treatment to diabetes is not applicable or, if at all, only marginally so, influenced by a distant and constantly receding past. I feel that the words of Dr. Braulio Montalvo (which I found courtesy of Dr. Marcus) summarize my interpretation of the "culture" versus "social inequity" issue based on my experience in East Salinas:

> The danger of the interest in ethnicity is that it can distract us from the ways that poverty and social or economic circumstances -- or short-sighted policy makers -- can smash and trample peoples' lives. That is not pretty; but "ethnicity" often is. (Montalvo,1986)

1. In Spanish, an oath of profanity describing sexual intercourse, Here literally, he says "the _____ed one."

2. A postscript to Rosita's story: At the time of this writing, I haven't seen Rosita for three months, but Consuela has kept me up on her events. In March, Rosita's older daughters pooled their money to send their mother on a month-long trip to Texas to visit her aunt. I didn't receive an update on the matter until the morning of my presentation on diabetes at Natividad. I had invited Consuela and Rosita to share their views on diabetes with the medical residents and physicians. But early that morning, I received a phone call from Consuela:

> Have you heard? Rosita had a heart attack and was in the hospital last week for five days. But she'll be at the presentation today!

In fact, Rosita did not attend, and has returned for ten days more. At the time of this writing, I have been unable to reach the Garcia family and neither has Consuela. They have no phone.

3. Excerpted from Lotte Marcus' "field notes" after my going-away party at Rosita's house.

4. The information is based not only on personal interviews with Consuela and other informants who were there, but also of my observations of films and video tapes which document the civic history of Salinas (and EOW) during those turbulent times.

5. The treatment for advanced diabetic retinopathy, a complication of chronic diabetes.

6. A German folk character.

7. Based on his study of a rural Mexican village, Lewis was the first to suggest that:

> the poor, by virtue of their exclusion from the mainstream of the societies in which they live, develop a way of life all their own, one that is qualitatively different from that of the middle-class societies. . . The pressure of coping with everyday survival leads to a present-time orientation; the lack of opportunity, to low aspirations; exclusion from the political process, to feelings of powerlessness and fatalism; disparagement of the poor on the part of society at large, to feelings of inferiority; the inability of men to provide adequately for their families, to mother-centered households; unrelenting poverty, to passivity and a sense of resignation. (Steinberg, 1981)

In this study, some of these observations have been suggested with respect to diabetes. Yet the interpretation of Lewis' theory, and of our observations here, are of concern. Similar observations have been used by conservatives to rationalize non-intervention in poverty. In his chapter "The Culture of Poverty Reconsidered", Steinberg objects to the extrapolation of Lewis' theory to imply that the "culture of poverty" is transmitted generationally, and therefore, self-perpetuating in a community. In retraction of his earlier work, Lewis wrote:

> The crucial question from both the scientific and the political point of view is: How much weight is to be given to the internal, self-perpetuating factors in the subculture of poverty as compared to the external societal factors? My own position is that in the long run the self-perpetuating factors are relatively minor and unimportant compared to the basic structures of the larger society. (Lewis quoted in Steinberg, 1981).

It is ironic and perhaps not coincidental that diabetes, a disease medically treated through "control", should be a problem in this population, many of whom have been unable to control "external societal factors". Steinberg summarizes issues which I have tried to illustrate in this paper:

> There is intellectual perversity in the tendency to use the cultural responses of the poor as "explanations" of why they are poor. Generally speaking, groups do not get ahead or lag behind on the basis of their cultural values. Rather, they are born into a given station in life and adopt values that are consonant with their circumstances and their life chances. To the extent that lower-class ethnics seem to live according to a different set of values, this is primarily a cultural manifestation of their being trapped in poverty. In the final analysis, the culture-of-poverty thesis . . . is nothing more than an intellectual smoke screen for our society's unwillingness or inability to wipe out unemployment and poverty. (Ibid.)

Chapter 7: DIABETES AWARENESS IN THE NON-AFFLICTED

The statistical figures which I will discuss below are presented in tabular form at the end of the chapter(pp131-145).

DESCRIPTION OF THE SURVEY POPULATION

The survey of non-diabetics residing in the CHISPA residences primarily during afternoon and evening hours. This timing predisposes the data to greater representation from those who describe themselves as "homemakers" (*ama de casa*). It was not surprising then that of the 85 respondents, 63 (74.1%) are women while 22 (25.9%) are men.

The ages of survey respondents ranged from 18 to 69 years, but the mean and median ages are 36.4 and 35.0 years, respectively. The age distribution by sex shows that the majority of male respondents were within 31 to 35 years (40.9% of men); the ages of women respondents clustered within 31 to 40 year range (41.2%). I find this age distribution of non-diabetic survey participants interesting since, according to medical models, these years represent the "early middle age" period associated with the onset of diabetes in Raza populations.

Seventy-one (83.5%) respondents were born (and usually raised through early childhood) in Mexico, but this high proportion is skewed somewhat by the experience of the men. That is, all of the male respondents are from Mexico while this was the case for 39 (77.8%) of the women. Several Mexican towns and states were highly represented as birthplaces for CHISPA residents: Guanajuato, Jalisco (including Guadalajara), Michoacan

and Mexicali. This supports what has been previously reported in the literature on immigrating populations from Mexico: Raza living in American neighborhoods tend to originate from common locations in the homeland.

Education

For the total population, the mean level completed was grade seven. (There is some discrepancy introduced in comparing the Mexican and American school systems but it is not significant for the purposes of this study.) There was a wide variation of formal educational experiences in the respondents ranging from no school to completion of two years beyond high school. The majority of men had either a fourth or sixth grade education (each with 22.7% of men) while 4.5% of men never attended school. Although 7.9% of the women are without any formal education, a higher percentage of women than men completed at or above high school level (14.3% of women). This may reflect the educational experience of the sub-group of younger, American-born women.

Employment

The majority of respondents described themselves as the *ama de casa* (the "homemaker" or "soul of the home") or *campesino* ("field worker"), reflecting the dominant female and male roles in the CHISPA group. Of women, 59.7% self-reported *ama de casa* while 57.1% of men claim to work in the fields. One man claimed to be disabled (from diabetes) and two unemployed, however, no women described themselves in these categories. I believe that this feature of a high percentage of employed families

constitutes a major distinction between those living in CHISPA versus other areas of East Salinas.

English Language

A second feature of this CHISPA groups which may differ from other East Salinas residents is their facility with the English language. Most respondents described themselves into one of two groups: speaking English "as well as Spanish" (37.6%), or "not very well" (32.9%). Based on my interaction with community members, however, I believe there is an underestimation of English language ability in these responses. Nearly one-fifth of respondents report that they speak no English at all.

RESPONSES TO *EL CUENTO DE JUANA*

Participants were read the story of Juana which described the experience of one woman with diabetes. About half were "familiar" with her problem (48.3%). Although six people (7.1%) personally identified with Juana's issues -- most of them women who recognized her situation as similar to their own -- the majority of respondents recognized as the problem of a relative (25 or 29.4%) and or a friend (10 or 11.8%). However, 44 respondents (51.7%) knew no one with Juana's problem. These proportions remain when responses of men and women are considered separately.

When asked to name Juana's problem, 51 or 60% responded with "diabetes" or "*azucar en la sangre*" ("sugar in the blood"). Thirty-four (40.0%) could not name the problem correctly.

Proportionately more men than women were able to name Juana's problem. I had expected the opposite, however, since in "traditional" Mexican families women are the caretakers of family illness.

We invited participants to comment on *El Cuento de Juana* and received a range of elaborations which are listed on the following page. A number of women said they identified personally with Juana's situation, but more to her problematic situation in general rather than the diabetes symptoms specifically. The troubling family situation, Juana's inability to work and the difficult lives of workers received the most comments by survey respondents. Physical symptoms alone do not seem to be the central focus of the CHISPA participants who listened to Juana's story.

QUESTIONS ABOUT DIABETES

One hundred percent of the survey respondents "had heard" of the illness diabetes, and 69 (81.2%) knew at least one person afflicted. Fifty-five percent of survey participants have diabetic relatives, while 17.7% and 3.5% are familiar with the disease through friends and acquaintances, respectively. These proportions are similar for men and women. Of the 85 survey participants, 4.7% (three women and one man) are medically-diagnosed diabetics. It is interesting that two more women (making a total of six respondents) personally identified with Juana's "problem" based on the contextualized story, though they

Other ideas about the story?

En el trabajo tenia una amiga que tomaba mucha agua y sentia mucha sed y se adelgazo' mucho. Tomo pastillas para adelgazar y murio el ano pasado. Se fue' a Mexico porque aqui no la atendian.

At work, I had a friend who drank a lot of water and was thirsty a lot and got very thin. She took pills to get thin and died last year. She went to Mexico because they didn't take care of her here.

(Woman, 35 yrs)

Por tanta familia se sentia debil y por su peso. Y nos tratamos porque los doctores cobran mucho y no tenemos dinero. Yo tengo los mismo sintomas de Juana, pero no le ido con el doctor. Me hace dano comer chocolates.

Because of too large of a family she felt weak , and because of her weight. And we treat ourselves because the doctors charge a lot and we have no money. I have the same symptoms as Juana, but I haven't gone to the doctor. Its not good for me to eat chocolates.

(Woman,38 yrs)

Me siento muy cansada y la vista irritada y tengo dolores de hueso en la piernas y me da mucho sueno y voy mucho al bano. No he ido con el doctor.

I feel very tired and I have blurred vision and pains in the bones of my legs and this makes me sleep a lot. And I go to the bathroom a lot [urinate]. I haven't gone to the doctor

(Woman, 40 yrs)

A Juana le dio diabetes porque no fue con el doctor a tiempo, y tambien se preocupaba mucho porque no podia trabajar.

Juana got diabetes because she didn't go to the doctor soon enough, and also because she worried a lot because she couldn't work.

(Man, 60 yrs)

A Juana tal vez le dio la diabetes porque se preocupaba mucho porque no tenian un lugar fijo para vivir. Yo ya he sentido esa situacion.

Perhaps Juana got diabetes because she worried a lot because she didn't have a secure place to live. I have felt this situation.

(Woman, 37 yrs)

Pues que sufria mucho como todos los que trabajan en el campo.

Well, its that she suffered a lot like all those who work in the fields.

(Woman, 32 yrs)

Los que trabajamos en canerias, empaques y campos sufrimos mucho porque ganamos poco y no comemos bien ni a nuestras horas.

Those of us who work in canneries, frozen food packaging plants and fields suffer a lot because we make so little and don't eat well, nor at our usual times.

(Woman, 48 yrs)

Tal vez Juana se puso nerviosa y triste porque no le ayudaba a su esposa a trabajar, porque muchos esposos las abandonan cuando no trabajan.

Perhaps Juana became nervous and sad because she didn't help her husband work, because many husbands leave their wives when they don't work.

(Woman, 43 yrs)

are not technically diagnosed diabetics at the time of the survey.

Of the respondents acquainted with diabetes, 51 (60.0%) know from one to three people with the affliction, 16.5% (14) know four to six and 4.7% (4 and all of them diabetics) know more than six people with the disease.

When asked if they have ideas about "what happens to a person with diabetes", 62 or 73.0% of participants responded affirmatively. The list of responses generated (p.138) shows that respondents have access to medical information about diabetes, but tend to emphasize certain symptoms or interpret complications of the disease differently than physicians. The most frequent occurrence mentioned 23 times (37.1%) was "blurred vision" or "blindness", while "much thirst" was cited 17 times (27.4%). Mentioned nine times each were "tiredness", "much hunger", "need to change diet" and "pains in the body". These then were the most frequently mentioned symptoms of diabetes listed by non-diabetics. They are quite accurate although medical models might classify these phenomenon differently (for example, "blindness" would be considered a complication not a symptom of disease).

The responses of participants generated a long list of symptoms, signs and effects which demonstrate a wide range of diabetes awareness in this group (listed on page 138). It is interesting that those effects or complications of diabetes which physicians believe are the most compelling reason to control the disease appear less frequently in the CHISPA list,

e.g. "coma", "heart effects" and "kidney effects". Five people mentioned that one "can die" and one mentioned that diabetics become "angry". Further analysis of these data which I plan to undertake at a later date might relate the degree of "closeness" to diabetes with the type and accuracy of description given. Perhaps more interesting than the tabulated responses are the participants' comments about diabetes; a selection of typical responses appear on the following pages (125 A,B).

Participants were then asked how a person with diabetes reacts to the disease, how they feel (p.139). Forty-three were able to respond to this inquiry with a broad list of descriptions. Twelve respondents (27.9%) described diabetics as *corajudos*, that is "angry" or "stubborn". Other responses included "sad", "irritable", "nervous", "want to be alone" and "lose desire to live". In general, from the responses painted by the survey respondents -- many who live with and know diabetics in the community one can begin to see a shared community picture of diabetes which considers the emotional as well as physical toll of the disease equally. In general, most medical texts do not mention, much less emphasize, the types of emotional reactions which accompany diabetes as the survey respondents volunteer. The comments listed on page 125C exemplify this point.

The last set of questions were designed to distinguish between the beliefs about diabetes held by non-diabetic community members and those of physicians. Based on my own little knowledge of the disease prior to medical training and

Comments about diabetes:

Mi esposo no esta en tratamiento ni lleva dieta. El esta a la buena de Dios. El orina mucho y se ha desmayado dos veces, y no va con el doctor porque no cree en ellos, porque piensa que los perjudican en lugar de curarlos.

My husband isn't using treatment nor following a diet. He is at the grace of God. He urinates a lot and has fainted two times, and he doesn't go to the doctor because he doesn't believe in them, because he thinks they harm instead of cure you.

(Woman, 48 yrs)

Pierden la vista y peso. Eso es lo que me dicen mis amigos. Tambien toman mucha agua.

They lost their vision and weight. This is what my friends tell me. Also they drink a lot of water.

(Man, 33 yrs)

Pierden la vista, no se pueden cortar porque no cicatrizan, tienen que llevar dieta. Sienten comezones en la vagina.

They lose vision, and can't cut themselves because they don't heal well, and have to follow a diet. They feel itching in the vagina.

(Woman,59 yrs)

Sufrimos mucho porque tenemos una dieta permanente y tenemos mareos.

We suffer a lot because we have to follow a diet permanently and we have dizziness and nausea.

(Woman, 47 yrs)

Mi papa dormia mucho y tubo dos comas diabeticos y sentia los ojos muy irritados. Y mi mama come mucho dulce y tambien se ha desmayado y uno de mis amigos ya perdio' la vista. Mi papa ya murio en Mexico y mi mama vive en Mexico. Yo pienso que tambien tengo diabetes. Tengo los mismo sintomas pero no he ido con el doctor.

My father slept a lot and had two diabetic comas and his eyes were always very irritated. And my mother ate a lot of sweets and also had fainted, and one of my friends has already lost her vision. My father already died in Mexico, where my mother lives. I think I have diabetes also. s I have the same symptoms but I haven't gone to the doctor.

(Woman,40 yrs)

Se sube el azucar en la sangre. No puede comer pan, ni sodas -- inada! Bajan de peso. Va a doctor y le dice que tiene que comer una dieta balancia. Unos murieron del corazon, otras de ancianidad, pero no murio' de diabetes.

The sugar in the blood rises. You can't eat [sweet] bread nor sodas -- nothing! They lose weight. They go to the doctor and they tell you to eat a balanced diet. Some die from a heart problem, others from old age, but no one dies from diabetes.

(Woman, 33 yrs)

Se enojada... todo se le enojado. Le molesta ser acerca de mucha gente.

They are angry -- always annoyed. It bothers them to be around many people.

(Woman, 37 yrs)

Comments:

Uno de mis amigos cambia mucho de allegre a triste hasta que murio, y el otro que tiene mas dinero se atiende y con dinero la penas son menos.

One of my friends changed a lot form happy to sad until he died, and the other who had more money took care of it; with money the pains are lessened.

(Woman, 59 yrs)

Era duro para aceptar. Con hombres ya no functionaria igual. El era como criatura, muy exigente. El ahora es mas acerca a Dios. Siempre hay problemas en una familia grande como diez. Los hijos y hijas va a sufrir.

It is hard to accept. With men they will not funciton equally. He [her husband] was like an animal, very excitable. He is now closer to God. There are always problems with a big family of ten. The boys and the girls are going to suffer.

(Woman, 37 yrs)

Yo me altero mucho y no puedo controlarme y mi familia sufre por eso.

I've changed a lot and I can't control myself and my family suffers because of this.

(Woman, 47 yrs)

Muchos al darse cuenta que tienen esta enfermedad se asustan y no la aceptan y se ponen muy irritables. Se aislan y se diprimen mucho y pierdan la iniciative y ganas de vivir.

Many people when they realize that they have this disease are frightened and don't accept it and become very irritated. They isolate themselves and feel depressed a lot and lose initiative and desire to live.

(Man, 40 yrs)

that of my family and peers, I expected that a population of predominantly non-diabetics would be unable to elaborate on specific features of the disease, but I was wrong.

The table of page 140 shows the response to the question, "What do you think causes diabetes?" in which respondents were asked to rank from a list of seven options. By far, "too much sugar" was deemed the number one cause and the most frequent response overall. "Heredity" was ranked second as the number one cause of diabetes, but in overall frequency ranked below other responses such as "too much grease", "too much liquor", "obesity" and "nervios". Although most physicians would cite obesity as the number one cause of diabetes, it ranked nearly equally with "nervios" in this survey. Other causes were volunteered by respondents such as *sustos* ("surprises" but also the name of a folk illness), "to have many problems", "too much work" and "angers" (see page 140). So these stated causes of diabetes suggested by participants imply that the community members have a more "holistic" view of the causes of diabetes, even more than entertained in medical discussions.

In trying to assess what people think about relative risk of diabetes, survey participants were asked whether one group or another has greater risk of developing diabetes. These results appear on page 141-2. The majority of the total survey population, at 52.9%, responded that there is no difference in risk between men and women, and this held true for the responses in male and female subgroups. Respondents also concurred that there was no significant difference for diabetes

between the old and the young. However, a majority at 61.9% believe that "heavy" people are at greater risk than "slim" people. Interestingly, there was a split at 45.9% each between those who believe that Mexicans are at greater risk than Americans and those that believe there is no difference between the two groups.

Through discussions with diabetic informants (case studies), I learned about a number of *remedios caseros* or home remedies for diabetes reportedly used in some Latino communities (p.143). It became clear to me that in spite of the frequent and romantic mention of *remedios caseros* by East Salinas diabetics, none employed them regularly (Table 6-1). Nonetheless, I was curious about the breadth of this "folk knowledge" in the CHISPA population. Forty-nine (57.6%) of the survey respondents knew about *remedios caseros* for diabetes, and generated a list of twenty-six remedies. Of the 49, 37 people (75.5%) named *nopales* (prickly-pear cactus) as effective in controlling diabetes when eaten raw, cooked or as juice. [Indeed, research in Mexico focused on the hypoglycemic effects of *nopales* as documented in Fernandez-Harp (year unknown).] *Te savila* was mentioned by 30 of the 49 (61.2%). That nopales and te savila are the most frequently cited remedies is consistent with the frequency I heard amongst the diabetics interviewed. A complete list of the *remedios caseros* listed appears on page 143.

Although the depth of knowledge and devotion to *remedios caseros* varies widely in this community, I found that with

respect to this disease, diabetics and non-diabetics alike believe medical remedies are more efficacious. When asked directly whether medical or non-medical (*remedios caseros*) interventions are more effective, 50 (58.8%) responded that medical interventions help more. Although inquiry about *remedios caseros* is important in terms of maintaining cultural identity in the community and is of academic interest to social scientists, it appears from this study that *remedios* do not contribute to reasons why medical prescriptions for diabetic management are not followed in this population.

In fact, the responses to some of the CHISPA survey indicate that the non-diabetic population hold views about diabetic management influenced by both medical and popular models. A majority of 55 (64.7%) respondents claim that there is no cure for diabetes, a view shared by medical professionals. 51 (60.0%) claim to know the medical treatment for diabetes and the range of their responses is listed on page 144. A majority of 64 (75.3%) respondents have heard of insulin and this was of particular interest since references in the literature and amongst public health activists suggest that many Latinos believe insulin to be injurious (p.145). Of 42 responding to this issue, 14 (33.4%) believe insulin is "safe", 21 (50.0%) say "there are risks", and the remaining 7 (16.7%) "don't know". Some risks volunteered by respondents include "overdose", developing risk of "drug addiction", "loss of sight", "heart attack" and that "all excess is bad".

SUMMARY

The CHISPA survey of diabetes awareness in non-diabetics reveals a population that has pre-conceived notions about diabetes, some but not all agreeing with the medical model for this disease. In general, people seem to have formulated a view of diabetes that is a blend of personal experience with the afflicted, of information transmitted through community networks and of a "trickle down" of medical knowledge. There are some similarities between the views of respondents and most physicians. It appears that community members -- many who will become diabetic patients in the future -- come to the medical encounter with specific, and in some cases, sophisticated notions about diabetes. Rather than speaking to the patient as a "blank slate" on which to transmit medical knowledge, physicians might do well to elicit the views of diabetes held by patients and, wherever possible, their families as a tool in enhancing communication.

I believe that the significance of these preliminary results are great. These figures far surpassed my expectation of the diabetes "awareness" in the East Salinas population. Not only were half of the participants able to identify the disease based on a non-medical description, but over eighty percent are acquainted with the effects of the disease in people's lives. These preliminary results suggest the CHISPA (and East Salinas) residents are familiar with the disease and are likely to have a well-formulated impression of diabetes based on what they hear from and observe in relatives, friends and acquaintances.

In addition, the emotional toll of the disease on the afflicted are grimly described by respondents. For many, it was difficult to separately describe the physical from the emotional features of the disease, once again reminding us that patients see illness as a whole process. At the onset of the survey, I thought that finding specific knowledge of diabetes in a non-afflicted population would be like finding the proverbial needle in the haystack. But, the survey results demonstrate the widespread awareness of the disease in this "high risk" Latino population and the potentially great influence of non-afflicted family and friends on the outcome for the diabetic.

DIABETES AWARENESS SURVEY

CHISPA / Las Casas de Madeira
July - August 1986
Salinas, CA.

Households surveyed	86
Surveys completed	85

Part I. Description of the Survey Population

Sex

Females	74.1% (63)
Males	25.9% (22)

Ages

Total Population

Range	18 - 69 years
Median	36.4 years
Mode	35 years

	Age Groups	% in Age Groups	
Males	31 to 35 yrs	40.9	59.1
	36 to 40	18.2	
Females	26 to 30	17.5	
	31 to 35	20.6	58.7
	36 to 40	20.6	

Education

Total Population

Mean Level Completed	7.2 yrs
Median Level completed	6 yrs

Level Completed	No. persons (%)
> 12	9 (10.8)
GED	2 (2.4)
11 - 12	9 (10.8)
9 - 10	10 (12.0)
7 - 8	10 (12.0)
5 - 6	22 (26.5)
≤ 4	15 (18.0)
0	6 (7.2)

Range of Grade Levels Completed According to Sex (% of Total Sex)

	Highest	Lowest
Men	22.7% Level 4	4.5% No School
	22.7% Level 6	4.5% Level 3
Women	20.6% Level 6	7.9% No School
	14.3% Level 12	4.8% Level 1
		4.8% Level 2

Birthplace

	U.S. % (no.)	Mexico % (no.)	Other % (no.)
Total	15.3 (13)	83.5 (17)	1.2 (1)
Females	20.6 (13)	77.8 (49)	1.6 (1)
Males	0	100 (22)	0

English Language Ability

Codes	**3***	**2**	**1**	**0**
Total (no.)	32	9	28	16
(%)	(37.6)	(10.5)	(32.9)	(18.8)
Females(no.)	25	5	22	11
Males (no.)	7	4	6	5

Codes: 3 = *Casi como espanol* (Almost like Spanish")
2 = *Mas o menos bien*(More or less well")
1 = *No muy bien* ("Not very well")
0 = *Nada de ingles* ("No English")

Employment

	No.	(%)
Ama de casa	36	(42.4)
Campos/Campesino	23	(27.1)
Empaque/Canneria	9	(10.6)
Janitor	2	
Disabled	4	
No empleo	2	
Other *	6	

*One response for each: ayudante de maestro. floreria, correctional officer, truck driver, cafe`, health department.

Highly Represented Employment
By Sex

Men		Women	
Campos	57.1%	Ama de Casa	59.7%
Empaque	9.5%	Campos	21.0%
Disabled	14.3%	Empaque	11.0%

Part II. El Cuento de Juana (The story of Juana)

Do you know or have you known a person with this problem?

	YES	NO
	No. (%)	No (%)
Total Population	41 (48)	44 (52)
Females	30 (48)	33 (52)
Males	11 (50)	11 (50)

If yes, who?

	Self	Relative	Friend	No One
	No (%)	No (%)	No (%)	No (%)
Total Populn	6 (14.6)	25 (60.9)	10 (24.4)	44 (51.7)
Females	5 (16.6)	19 (63.3)	6 (20.0)	33 (52.4)
Males	1 (9.1)	6 (54.5)	4 (36.4)	11 (50.0)

Do you know the name of this problem or illness?

	Diabetes/Azucar	Don't know
	No. (%)	No. (%)
Total Populn	51 (60.0)	34 (40.0)
Females	37 (58.7)	26 (41.3)
Males	14 (63.6)	8 (36.4)

Part III. About Diabetes

Have you heard of an illness called "diabetes " or "azucar en la sangre?"

Yes	100%

Do you have diabetes or do you know people with diabetes?

	YES	NO
	No. (%)	No. (%)
Total Populatn	69 (81.2)	16 (18.8)
Females	51 (80.9)	12 (19.0)
Males	18 (81.8)	4 (18.2)

If yes, who?

	Self	Relative	Friend	Acquaint.
		No. (%)		
Total Populatn	4 (4.7)	47 (55.3)	15 (17.6)	3 (3.5)
Females	3 (4.8)	35 (55.5)	11 (17.5)	2 (3.2)
Males	1 (4.5)	12 (54.5)	4 (18.2)	1 (4.5)

Do you know what this illness is, or what happens to a person with diabetes?

	YES	NO
	No. (%)	No. (%)
Total Popuin	62 (73.0)	23 (27.0)

Sx/Signs	Frequency (%)
La vista oscura/Ciego	23 (37.1)
Mucha sed	17 (27.4)
Cansancio/debilidad	9 (14.5)
Mucho hambre	9 (")
Se cambia dieta	9 (")
Dolores del cuerpo (piedras, brazos)	9 (")
Se baja peso	8 (12.9)
Dolores de cabeza	7 (11.3)
Orinar mucho	7 (11.3)
Desmayado	6
Alta presion	6
Hierdas no cicatrizan	5
Azucar se sube	5
Puede morir	5
Cuerpo no produce insulina	4
Afecta el corazon	3
Embollos	2
Coma	2
Mareada	2
Paralisis	2
Engordar	2

Others - one response each:

"ataques", perder apetito, deprimido, nervios, no puede dormir, temblores, perder oido, sufrimiento, comezones en vagina, infecciones, afecta la riñon, se enojada.

What happens to a person with diabetes? What is their reaction? How do they feel?

N = 43 responding

Response	Response	Frequency Stated
Corajudos	Angry/Stubborn	12
Tristes	Sad	7
Irritables	Irritable	7
Nerviosos	Nervous	6
Debil/Palido	Weak/Pale	5
Se cambia	They change	5
Deprimidos	Depressed	4
Enojados	Angry	3
No acepta la enfermedad	Don't accept the illness	3

Others - one response each:

Perder ganas de vivir	Lose desire to live
Mas quieto	Quieter
Quiere estar solos	Want to be alone
Estericos	Hysterical
Amargados	Embittered
Exigentes	Demanding

What do you think causes diabetes?

	Frequency by Rank				
	*1	*2	*3	*>4	Total
Azucar	20	17	16	9	**62**
Grasa	4	14	16	6	**40**
Demasiado Licor	11	13	6	8	**38**
Obesidad/Gordura	10	11	10	7	**38**
Nervios	10	8	8	10	**36**
Herediteo	18	5	7	4	**34**
Sopresas/Sustos					**9**
Tener muchos problemas					**7**
Demasiado Trabajo					**5**
Corajes					**4**

Otras:
Comer demasiado en general, No comer a nuestras horas, Cholesterol, Tomar sodas, Mala nutricion cuando chico.

Opinion of Relative Risk for Developing Diabetes

Do men or women have more risk of diabetes?

	Men No. (%)	Women No. (%)	No Difference No. (%)
Total Popuin	10 (11.8)	30 (35.3)	45 (52.9)
Males	3 (13.6)	4 (18.8)	15 (68.2)
Females	7 (11.1)	15 (68.2)	30 (47.6)

Do the old or young have higher risk?

	Old No. (%)	Young No. (%)	No Difference No. (%)
Total Popuin	33 (33.9)	8 (9.5)	43 (51.2)
Males	10 (45.5)	2 (9.1)	10 (45.5)
Females	23 (37.1)	16 (9.7)	33 (53.2)

Do "heavy" or "slim" people have higher risk?

	Heavy No. (%)	Slim No. (%)	No Difference No. (%)
Total Popuin	52 (61.9)	3 (3.6)	29 (34.5)
Males	10 (47.6)	0	11 (52.4)
Females	42 (66.7)	3 (4.8)	18 (28.5)

Do Mexican or do American people have higher risk?

	Mexican No. (%)	American No. (%)	No Difference No. (%)
Total Popuin.	39 (45.9)	7 (8.2)	39 (45.9)
Males	12 (54.5)	0	10 (45.5)
Females	27 (42.9)	7 (11.1)	29 (46.0)

Do you know if there are home remedies for diabetes?

	YES	NO
	No. (%)	No. (%)
Total Popuin.	49 (57.6)	36 (42.3)
Females	37 (58.7)	26 (41.3)
Males	12 (54.5)	10 (45.5)

Remedy named	**Frequency**
Nopales	37
Te savila	30
Yerba del manzo	5
Te ruda	4
Hueso de aguacate	3
Te governadora	4
Te diabetina	2
Te doncella	2
Others	18 *

*One response for each: Te malabar, cascara del mezquite, Alcachofa, betabel, ajo y limon, te de lagrima de San Pedro, comer muchos verduras, fennel seeds, calabazas, hierva del sapo, la jaimaica, hojas de Tepozan, vivora seca, te de la arnica, dieta de puras plantas, marrubio, meloncello, vine de planta frijole.

Is there a cure for diabetes?

	YES	NO
	No. (%)	No. (%)
Total Popuin.	29 (34.1)	55 (64.7)
Females	23 (36.5)	39 (61.9)
Males	6 (27.3)	16 (72.7)

Do you know the medical treatment for diabetes?

	YES	NO
	No. (%)	No. (%)
Total Popuin.	51 (60.0)	34 (40.0)
Females	32	31
Males	9	13

Treatment	**Frequency of Response**
Insulin	27
Diet	13
Insulin + Diet	4
Pastillas	3
Sacarina	2
Insulin + Pastillas	1
Insulin + Pastillas + Diet	1

Have you heard of insulin or "the shot"?

	YES	NO
	No. (%)	No. (%)
Total Populn.	64 (75.3)	21 (24.7)
Females	48 (76.2)	13 (20.6)
Males	16 (72.7)	8 (36.3)

Do you believe that insulin is safe or are there risks?

N = 42 responding

Frequency of Response

	SAFE	RISKS	DON'T KNOW
Total Populn.	14	21	7
Females	12	12	7
Males	2	9	0

Risk stated	**Frequency**
Sobre dosis = Overdose	6
Droga/ Drug Addiction	6
Perde la vista = Lose vision	3
Ataque de corazon= Heart attack	2
"Todo exceso es malo" = "All excess is bad"	2
Others	4*

* One response each: Cancer, "Todo la medicina tiene riesgos", Se perden dientes, "Habio oido es peligroso".

Chapter 8: IDEAS FOR CHANGE IN THE COMMUNITY

The dialogue generated through the collection of case histories of diabetics in the East Salinas community revealed networks of support amongst community members. For in spite of the structural barriers that prevent regular meeting times and locations, that obstruct follow-through on proposed community projects -- no transportation, no telephone, no money to put to collective efforts -- the foundations of trust and understanding essential to collective action remain intact, though fragile.

Some bonds form out of alliances amongst subgroups with common experiences: the working men, young mothers in the CHISPA residences, Consuela's peers in *Mujeres Unidas*. And as was described earlier, historical rivalries between some of these groups has prevented community-wide union of interests in the past (recall Consuela's resentment of the CHISPA organizers). Secondly, many residents have grown accustomed to the disturbing pattern of government-sponsored community development programs which are managed by highly educated Latinos often imported to the community by Anglo policy-makers at the state level. Thirdly, as Consuela and Gina have commented about past *Mujeres Unidas* frustration, "We [women] have lots of ideas but we have to work to support ourselves and don't get a chance to work for the community too!"

In conducting the survey, we found that numerous respondents in the CHISPA residents, as well as members of the migrant camp we visited, were interested in learning more about

ways that they can manage medical problems in their homes. People are uncertain about how and when to attend to an ailment at home, when to visit a medical facility, how to interact with the medical bureaucracy in general. In short, people want to acquire a health and medical literacy so that they might use the available medical services more effectively. Yet these needs fall outside of traditional parameters of medical practice. If this process is to be truly "cross-cultural" then clinicians also might consider innovative ways of interacting with this community.

My discussions with a number of the women of Consuela's *Mujeres Unidas* revealed that they are interested in, as some said, "support". Consuela and Rosita speak of having of a place where they and women like them -- "women who are single and raising kids and are big too" -- can meet to talk out their concerns, learn (they say) about diabetes and talk about how hard it is to lose weight. When I responded that "the literature" says such group therapy is unpopular in Latino communities, one woman responded, "Well, maybe twenty years ago and maybe with some of the younger ones from Mexico, but now we see it helps.", again a reminder that culture is always in transition. The priority for the *Mujeres* is in community-based organization and autonomy in the development of such a project. Certainly during my months in Salinas I have witnessed their ability to relentless maintain autonomy. It is this kind of self-determination which Freire and Werner call *conscientization.*

In my hope to return some of that which I have learned from the people of the East Salinas community, I plan to continue working for them as a liaison, letter-writer, consultant -- in short in any role needed to assist with their own community action. But this is a stance which is antithetical to the paternalism and action orientation of traditional biomedical and public health education. It requires getting out of the offices and clinics and into the homes and work places, actions which few clinicians consider. As Therese Drummond (1975) says of her application of the Freirian model to nutrition education:

> . . .instead of coming from the top down with a paternalistic social action, [it] becomes an action starting with the people, growing out among them -- real growth rather than propaganda, management, or manipulation.

In spite of my "ideals", I have discovered that in the Salinas *barrio*, people are tired, must work hard and long hours, must see results of collective action before they risk investing time and energy. I began considering ideas for change with those who I knew, the enthusiastic though small and somewhat physically-disabled group, *Mujeres Unidas*, who might provide the necessary spark and example.

At this writing, I have already become involved with the *Mujeres Unidas* effort to organize for community change. Consistent with the ethnographic process, I'd like to describe a short case history in the *Mujeres Unidas* search for a direction for organization.:

At the time of my going-away party of which Dr. Lotte Marcus so eloquently wrote (Chapter 5), Consuela and Gina showed

up with spiral notebooks and brief-cases overflowing with *Mujeres Unidas* paraphernalia. For they saw that eating event not only as a social occasion, but as a showcase of their group's rebirth.

> But as we eat - a la Luis Bunuel - and as another sister-in-law walks in (Consuela's husbands's sister) the real scene reveals: we are in a nest of walking wounded -- Consuela: her wellness state has been documented by Laura, so has Mr and Mrs Garcia's; the neighbor's diabetes is in a well-advanced state and now the sister-in-law asks whether we at the hospital could teach her to give shots: six in her family also have diabetes. Consuela "claims" on Pearl St. she can "get" another fifteen! . . . In my ten years in Salinas I was not aware of diabetes as such an issue: which only goes to show that what you look for (I was looking at language) is what you see. But that's exactly what Consuela manages to do: 15 years ago Consuela's *Mujeres Unidas* -- always just a hand-handful of *barrio* women -- were doing their *Dia de Manana* talk (for the children); then with English on Wheels, she began the "education talk" (and did actually get her kids through Hartnell [Junior College] an enormous achievement); and now, with Laura's arrival, it's health and diet. . . *Mujeres Unidas* gives Consuela her respectability -- as a woman without a man; as the woman warrior, the woman survivor. She talks about Carmen who was supposed to come here and talk about grants [she never showed up]; she wants to talk to me about, "yeah, you know. . . psaicoloschi" and she talks about a discount *Mujeres Unidas* gets either for the bus, or at the hotel in Lake Tahoe or Reno where they go and gamble. (Marcus, 1986)

I got a call from Consuela three months ago, "Carmen meet a man who writes grants for $300,000 or more and he wants to help us!" Carmen, a Chicana woman who operates a bus travel service between Salinas and the Reno casinos, introduced Consuela, Gina and myself to Mr. Slickman. Tall, White, grey-haired and grey-suited, a chain smoker, Mr. Slickman listened and smoked as Consuela and Gina poured out their visions of *Mujeres*

Unidas as an "umbrella group". Denied this hope of opportunity for so long, they could almost taste the money which Mr. Slickman promised and were giddy with enthusiasm: they proposed a food bank, a cooperative funeral project, a shelter for the homeless ("that's the thing now"), and of course the diabetes and health outreach.

But I could see Slickman was floored. He had not expected their passion, their spontaneity. He could not believe they were without the accoutrements of organization in the usual sense -- phones, checks, a Board of Directors -- and failed to see their cohesiveness. For he could not face who they really were: older women, uneducated, not polished, no pretenses, with very big financial needs. He sat there jotting a few notes, puffing on his cigaret in feigned sincerity, giving "assignments" for each of us (I was to write up a preliminary health proposal and I did so, dutifully). But I knew that he wasn't interested, would never follow-through. It took three months of meetings arranged and postponed, promises made and broken by Carmen and Slickman before Consuela and Gina terminated the alliance. Says the bitter Consuela again disappointed, "I'm going over to their office and taking all our papers 'cause I don't want them to steal our ideas!" And the disappointment has made them cautious about proposed alliances with a Natividad-affiliated health education council. Says Consuela, "The man called me and wanted me to meet with them in the hospital office. But I say, if you so interested in the community, then you come here and see

it! He don't want to see our homes and our problems but he have to." 1

I struggle to find my role with the *Mujeres*, fight against urges to "organize" my vision of a viable project in their sphere, suppress feeling of guilt that I'm not "doing" more for them [latent paternalism?]. Yet, the experience of ethnographically unraveling diabetes in East Salinas has left me with insights which I hope can guide my trajectory not only in the diabetes issues but along medicine. These are summarized here by Andreas Fuglesang, a devotee of Freire (quoted in Drummond's 1975 article), with wording altered to suit our setting:

> To help people to become conscious of their potential as creative beings, to make them see that they can control their environment and themselves in a better way, is the task of the field worker, whatever (her) professional starting point. . . The essence of [community outreach] is not to try to change people, but to create such new opportunities. Then, people will change themselves.
>
> In the development of consciousness nobody is the teacher. The teacher is just one of the group. The group is teaching itself. It cannot be an objective to transfer knowledge and values from a group in society which is powerful to groups which are less powerful. It is the dialogue between groups which can bring society forward and it is the dialogue which is the tutor in the circle.

1. Although diabetes and obesity are the current primary focuses of the *Mujeres*, it will be by their design and decision that health outreach will evolve. We are currently discussing the notion of training women to be community health workers, identified educators and resources in East Salinas in a fashion similar to David Werner model at Project Piaxtla,in Sinaloa, Mexico.

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APPENDIX A: SURVEY PROTOCOL FOR NON-DIABETICS

(Spanish version)

PARTE I. EL CUENTO DE JUANA

Voy a contarle a Ud. la historia corta de una mujer. Despues de contarla, voy a preguntarle a darme su opinion de lo que es la problema de esta mujer. No hay repuestos incorrectos, solo estoy interesado en sus opiniones:

Juana vive en King City con su esposo. Hace muchos anos que se casaron en Texas, donde nacio' Juana. Al principio, seguiran el trabajo en los campos y Juana le dio' a Pedro cinco hijos muy saludables. Viajaban por todos lados en una gran < troca >. Entonces, se establecieron en King City, asi sus ninos podrian asistir la escuela. Juana trabajaba en un canneria y Pedro trabajaba como un < foreman > en los campos. Los dos siempre trabajaban muchas horas cada dia. Pero, eran muy felizes y orgullosos y en su aniversario, Pedro le dio' a Juana un pajaro, que siempre se sentaba en los hombros de Juana. El pajaro siempre decia cosas muy divertidas, y sus hijos y sus nietos sabian que todo estaba bien en la familia cuando hablaba el pajaro.

Cuando Juana tenia trienta y nueve anos, se dano su espalda por llevar demasiadas cajas en la canneria, y tuvo que acabarse de su trabajo. Entonces Juana, que siempre era una mujer fuerte, se subio de peso. Se preocupaba mucho por no poner trabajar y que Pedro trabajaba aun mas horas para ganar bastante dinero. Y despues de sus cumpleanos cuarenta y tres, Juana empezo' a sentir mucha sed. Nunca podia parar su sed aunque bebia como cuatro botellas largas de "Coke" o agua cada dia. Aunque estaba cansada, no podia dormir a causa de que iba al ba$o ochos veces cada noche. Juana estaba mas olvidadiza y irritable. Sus piernas y brazos le dolia mas y mas. Se continuaba sus problemas muchas meses y pensaba Juana, < eso es la ancianidad, nada mas! >. Y su pajaro se quedaba mucha mas tranquilo y quieto, un sig$o que noticia su familia.

Pero una manana, mientras cocinaba el desayuno de Pedro, Juana de cayo . Su vision estaba muy oscura y su boca tan seca de sed que parecio' lleno de algodon. El pajaro, por el primer vez, volo' al lado de Pedro, quien corrio' a Juana a buscarla en el suelo. Pero Pedro tuvo fe, porque continuaba a cantar muy suavamente el pajaro, mientras se sento en los hombros de Juana.

Preguntas sobre el cuento:

1. Habia oido Ud. de una persona con la problema de salud como suya? Parece familiar su problem?

Si = 2, Quizas = 1, No = 0

2. Le conoce o le habia conocido a Ud. una persona con esta problema?

Si si, como relacionado? Si mismo = 4
Relativo = 1
Amigo = 2
Conocidos = 1

No = 0

3. Que es el nombre de esta problema o enfermedad?

Diabetes o azucar en la sangre = 1
No sabe o nombre incorrecto = 0

4. Otras ideas sobre el cuento?

PARTE II. SOBRE LA DIABETES

Ahora, voy a preguntarle a Ud. otras preguntas sobre su opinion de una enfermedad que tiene muchas personas en la comunidad aqui en Salinas:

5. Habia oido Ud. de una enfermedad se llama < diabetes > o < azucar en la sangre >?

Si/Creo que si = 1
No /Seguro que no = 0 (Va al parte III)

6a. Tiene Ud. la diabetes o les concoce personas con las diabetes?

Si si --- si mismo = 4 No = 0
relativo = 3
amigo = 2
conocidos = 1

6b. Cuantas personas? _____

Otras ideas? _____

7. Si esta familiar la diabetes, sabe Ud. lo que es esta enfermedad, o que pasa con una persona con la diabetes?

8. Para las personas con la diabetes, que paso con la diabetes? Cual fue su reaccion emocional?

9a. Sabe Ud. si hay remedios caseros para la diabetes?

Si = 1 No = 0

9b. Si si, cuales son?

Nopales _____ Te savila_____ Te ruda_____
Te yerba del manzo _____ Betabel _____
Gobernadora _____ Hueso del aguacata _____
Otras:_____

9c. Si si' arriba, de quien aprendio Ud. estos remedios?

10. Es una enfermedad que cree Ud. tiene cura la diabetes?

Si = 1 No = 0

11. Sabe Ud. del tratamientos medicos para la diabetes?

Si =1 No = 0

Cuales son?_____

12. Cree Ud. que los tratamientos medicos les ayudan mas, menos o no hay diferencia entre los remedios caseros para la diabetes?

Mas = 3 Menos = 2 No diferencia = 1
No se = 0

13a. Habia oido del "shot" or la insulina para tratar la diabetes?

Si = 1 No = 0

13b. Cree Ud. que hay riesgos con esto tratamiento o es segura? Cuales son los riesgos?

14. Cuales son los tres factores importante que le causa la diabetes, de esta lista?

Tomar demasiado liquor _____ Los nervios _____
La herencia _____ Demasiado trabajo _____
Obesidad/Demasiado peso _____
Comer demasiado de grasa _____
de azucar _____

Otras cosas?_____

15. Por cado grupo, cual tiene mas diabetes (o mas riesgo de la diabetes)?

a. Hombres _____Mujeres _____ No diferencia _____

b. Los ancianos _____ Los jovenes _____ No diferen. _____

c. Gente gordo _____ Gente delgado _____ No diferen._____

d. Mexicanos _____ Americanos _____ No diferencia _____

PARTE III. FACTORES DEMOGRAFICOS

Edad _____Sexo _____

Casado/Viudo/Soltero/Divorciado

Relicion _____

Educacion - La nivel que termino: _____
Donde : _____

La lengua nativa - espanol _____ ingles _____

Abilidad en ingles - Casi como espanol = 3
Mas o menos bien = 2
No muy bien = 1
Nada de ingles = 0

Tiempo en EUA _____ En Salinas _____

(Cuantos veces regrese a Mexico? _____
(Cuanto tiempo hace que regrese a Mexico?_____

Locacion del nacimiento _____

Trabajo _____

APPENDIX B: DOCUMENTATION OF APPROVAL BY THE COMMITTEE for the PROTECTION OF HUMAN SUBJECTS

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SUMMARY

The Mexican population in California is at greater risk for development of non-insulin-dependent diabetes mellitus (Type II or NIDDM) than the general population. In California, the 1980 age-adjusted deaths attributed to diabetes were 23.4 per 1000 in Mexicans versus 11.41 for non-Mexicans. In a comparative study in which Mexican and white groups were controlled for obesity, Mexicans had a two-to four-fold greater prevalence of NIDDM. At a recent conference there was a call for a comprehensive study to document the factors which lead to clinical problems in diabetes care for Mexicans. The goal of this descriptive study is to answer the question: how is the biomedical syndrome known as diabetes mellitus identified and understood within the indigenous or traditional health care system of a Mexican community in California?

SURVEY POPULATION / SUBJECTS

The study population are members of the Mexican community who reside in the northern Salinas valley of California, including both migrant and seasonal agricultural workers. While migrant workers travel from distant locations to secure work during the peak-season and live in residential centers or camps, seasonal workers may live year-round in the Salinas area, such as in the Heburn Heights barrio. People who formerly depended on agricultural work but have now diversified in the community will also be important for case study because they might explain their experience of combining traditional Mexican beliefs about diabetes with health care in the biomedical American system they encounter. All of these groups are predominantly Mexican and many, especially the migrant families, live in communities insulated from American culture. This population is suitable for this study because they hail from rural areas of Mexico where they have had less contact with Western biomedical practices. The general Mexican population in California is diverse: from migrants to third-generation American citizens. Yet they share a core system of health beliefs and behaviors despite acculturation. The agriculturally-based communities in the Salinas valley provides the best representation of Mexican cultural health care systems.

PROCEDURES

Fieldwork is organized into two phases, and each will involve a different subgroup of the larger Mexican community in the Salinas valley.

Exploratory phase: June 15 - July 13, 1986. The ethnographic component of fieldwork involves in-depth case study of three to five diabetics who are Mexican. Some are known to staff of the Family Practice clinic at Natividad Medical Center (NMC) in Salinas. Introduction to prospective participants will be directly through the NMC staff. Alternatively, leaders and organizers of community groups (English as Second Language, United Farm Workers, Catholic Relief Services, Migrant Child Education) will recommend appropriate individuals who might feel comfortable with in-depth interviewing . All potential participants will be given information about the study and will give oral informed consent before study begins (Appendix A). This phase of fieldwork will be conducted in the clinics, the homes participants and at community events in order to observe how people with diabetes can function and interact with their family and friends. Fieldnotes will be taken.

During in-depth interviews audio tapes will be used to record lengthy conversations. Tapes and notes will be kept in a locked case in an NMC office and destroyed at the end of the study.

The object of in-depth interviewing and observation of the diabetic person through his or her daily activities is to understand the full experience of having NIDDM, from the point of view of a member of the Mexican community. Questions will be based on those from instruments used in previous studies in medical anthropology and nutrition (Appendix B). The general areas of survey include: 1. Grouping diseases/ organizing symptoms 2. General health beliefs 3. Diabetes beliefs 4. Nutrition / Dietary information 5.Demographic and social assessment. Representative samples of the types of questions used are included in Appendix C. By using a variety of questions in the case study interviews, a condensed interview format will be developed for use in the second phase of fieldwork.

Community interviewing phase: July 14 - August 17, 1986. Based on the information gathered in case studies, a structured protocol will be used to interview at least 50 adults (over 18 years) who reside at residential centers for agricultural workers, as well as in the Heburn Heights barrio in Salinas. Access to these groups will be made through "camp managers" and leaders of community organizations (mentioned above) who are currently being contacted about this study. Introduction of the investigators and description of the study will first be given to prospective participants at large community meetings. Next, families will be greeted door-to-door and invited to participate in the structured interview. This method of approach has been used successfully in published nutritional studies of migrant communities. Oral informed consent will preceed interviewing.

The interview responses will be recorded on printed forms. Each camp, residential center, or neighborhood block will be given fictitious names. Each house will be identified by number and each adult interviewed within will be distinguished by a letter (e.g. Willow camp, house 52, person B). No identifiers will be used in collection of data. Interviews will be conducted in homes and appointments will be arranged for the time most convenient to the family members. The interviews will not exceed 60 minutes. If at any time, the participant is uncomfortable or inconvenienced by the interview, it will be terminated immediately.

BENEFITS

In clinical practice, there are numerous cross-cultural conflicts which hinder delivery of medical services to Mexican groups in California, in spite of available bilingual services. A model of the health care belief system for NIDDM as it is experienced by a member of this community will be described. The results of this study will be presented as an ethnographic and ecological description of diabetes in one Mexican community which will be available for education of health professionals who work with similar populations. It is hoped that this information will contribute to development of more appropriate treatment plans for NIDDM in this group, as well as a re-examination of health education programs currently in use.

RISKS

The Mexican population in the Salinas valley must be considered a vulnerable group. Sixty percent of all patients seen at NMC are from Mexico and thirty percent speak only Spanish. Because of language and cultural barriers, many are uncomfortable functioning within American institutions, such as the health care facilities. Some may feel threatened when confronted with American student investigators. On the other hand, comfortable and friendly interaction with Americans may alleviate some of these fears. One concern with this study is that participants may view the investigators as people in "positions of authority", such as representatives of the Immigration and Naturalization Service. Some may believe that their participation is required in order to receive health services available in the Salinas area. The informed consent is designed to prevent this confusion. Since the investigators will be introduced to the community through known and trusted community leaders, and since our style will be informal, though systematic, we believe that participants will feel no threat.

The nature of the information disclosed in the interviews is neither potentially dangerous nor damaging. It is personal insofar as beliefs and opinions are elicited, though anonymously. The most sensitive information is collection of certain demographic information, specifically annual income estimates. This question will be posed in terms of general ranges of values, and is necessary to the study in order to document the hardship of buying expensive medications which are routinely prescribed to diabetics in this community by medical professionals. Other potentially sensitive information included in the demographic section will be asked near the end of the interview.

INFORMED CONSENT

Oral informed consent is most appropriate to this community and will insure anonymity. Statements will be recited by the investigators at the beginning of the first interview session with each prospective participant. Two different statements will be used for the different groups studied in the exploratory (case study) versus the community interviewing phase because the procedures for the two groups vary slightly (see Appendices A and B). In the case of the second group, the informed consent statement does not explicitly mention NIDDM because we want to discover the participants' classification of this disease in the context of their personal health belief system. Mentioning the disease might artificially place it in the minds of respondents early on in the structured interview, distorting our analysis. Consent will be exchanged in English or Spanish according to the preference of the participant.

INSTRUMENTS

Representative samples of questions used in the exploratory/case study phase of fieldwork are included in Appendix C. These give a flavor of the information that will be obtained through the interviews. Because the objective of this phase is to determine topics of relevance in the analysis of diabetes, the interviews will begin with open-ended questions that will illluminate aspects of inquiry not previously considered by the investigators. The final format used in the community interviews will be based on the results of case studies in this exploratory phase. A copy of this format, to be

used in the second phase of fieldwork, will be forwarded to the CPHS as soon as it is completed, approximately July 1, 1986.

INVESTIGATORS / SPONSORS

The principle investigator, Laura Jones, is a medical student in the UC Berkeley-UC San Francisco Joint Medical Program. This fieldwork will contribute to completion of thesis requirement for a Masters in Health and Medical Sciences. She participated in community interviewing and nutritional studies of migrant workers during undergraduate work at UC Davis. Maria de los Angeles Osegura, an alumnus of UCB in the Department of Anthropology, will assist with all areas of fieldwork in Salinas. Members of her family were migrant farmworkers from Mexico and she is involved with health care delivery to this community. Both investigators speak Spanish, and Osegura is a native speaker.

Faculty sponsors for this work include Linda C. Jackson, Ph.D., Department of Anthropology, Katherine Brown, Ph.D., Department of Health and Medical Sciences, and Norman Kretchmer, M.D., Ph.D., Department of Nutritional Sciences. At Natividad Medical Center in Salinas, Dr. Lotte Marcus, Ph.D., Director of Cross-Cultural Medicine, will serve as fieldwork advisor. Drs. Brown, Jackson and Marcus are medical anthropologists who have considerable experience with fieldstudies.

As faculty sponsor of this student's research, I accept a shared responsibility to assure compliance with campus policies and guidelines on the protection of human subjects, including my responsiblity for appropriate monitoring of the student's research progress and activities, and timely reports to the Human Subjects Committee of material changes in direction or circumstances relating to the use of human subjects.

Student Investigator:
Laura B. Jones
Department of Health & Medical Sciences
U.C. Berkeley
642-5479

Laura B Jones

Faculty Sponsor:
Katherine Brown, Ph.D.
Department of Health & Medical Sciences
U.C. Berkeley
642-5479

Katherine H. Brown

11 April 1986

APPENDIX A

(ENG)

UNIVERSITY OF CALIFORNIA, BERKELEY

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HEALTH AND MEDICAL SCIENCES PROGRAM

ROOM 106 T-7
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ORAL CONSENT TO PARTICIPATE IN A STUDY

Good afternoon.

I am a medical student in the University of California. This summer I am living in Salinas and am studying what people think about their health. _____(Name of contact person___ told me that you would be interested in talking about this. Your participation would help me with my studies.

I hope to learn how you feel about diabetes. To do this, I want to speak with you for a little while today in the clinic, and arrange an appointment to visit with you in your home. I would like to speak with you about the history of you and your family, and also the history of your diabetes. For example, what are your thoughts about the cause of your diabetes? and, how do you maintain your health with diabetes? I am interested in your way of life, and if diabetes is a problem for you. If there are any questions that you would not like to answer, you do not have to respond. It would help me to record your voice so that I can take notes on paper of our conversation later on, but this is voluntary. All of the information which we discuss is confidential, and we will not use your name in any notes.

I have studied the problem of diabetes in the Spanish-speaking community for two years. I hope that the information from this study will improve the medical services available to the people of the Salinas valley. I have the support of community groups, such as _____(names of supportive groups)_____, and of the clinic at Natividad Medical Center in conducting this study. But, if you do not wish to participate in this study, your decision will not change the services that you receive at the clinic.

You may give me your oral consent now, or you may think more about it. I will be in contact with you in a few days. Thank your very much for your time.

Laura Jones
Medical Student
Care of : Natividad Medical Center
Salinas, CA.
(408) 757-0200

APPENDIX A
(SPA)

UNIVERSITY OF CALIFORNIA, BERKELEY

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CONSENTIMIENTO ORAL DE PARTICIPAR EN RECURSO

Buenos tardes.

Soy una estudiante de medicina en la Universidad de California. Estoy viviendo en Salinas este verano y estoy estudiando lo que piensan la gente sobre su salubridad. __(Nombre de la informante)____ me informó que usted sería una persona interesada en hablar sobre esto. Su participación me ayudarían en mis estudios.

Deseo aprender como se siente Ud. sobre diabetes («betes»). Para hacer eso, quiero hablar con Ud. por un rato hoy en la clinica, y arreglar una cita para visitar con Ud. en su casa. Quiero hablar con Ud. sobre su historia personal y de su familia, y tambien la historia de su diabetes. Por ejemplo, ¿Que son sus pensamientos de la causa de su diabetes? Y, ¿como mantener su salud con diabetes? Estoy interesada en su manera de vida y si diabetes es un problema para Ud. Si hay alguna pregunta que no desea contestar, no tiene que responder. Me ayudaría a recordar su voz para hacer notas en papel mas tarde, pero es voluntario. Toda la información es confidencial y no usamos su nombre en las notas.

Había estudiado las problemas de diabetes en la comunidad de habla hispana por dos años. Deseo que la información de este estudio improbará los servicios medicales para la gente del valle de Salinas. Tengo el apoyo de los grupos communidades como _____(nombres de los grupos)_____, y de la Clinica del Centro de Medicina Natividad,para hacer esto. Si no quiere participar en este estudio, no cambiará los servicios de la clinica que Ud. recibe.

Puede Ud. dar su consentimiento oral ahora, o puede pensar mas en esto. Yo estaré en contacto con Ud. en unas pocas dias. Muchas gracias por su tiempo.

Laura Jones
Estudiante de Medicina
Cuidado de: Centro del la Medicina Natividad
Salinas, CA.
(408) 757-0200

MONTEREY COUNTY

NATIVIDAD MEDICAL CENTER
(408) 757-0200 - P O BOX 1611, 1330 NATIVIDAD ROAD, SALINAS, CALIFORNIA 93902
RAY K. BOLINGER
ADMINISTRATOR

LAURA JONES, Medical Student

CONSENT TO PHOTOGRAPH/AUDIO-TAPE INTERVIEW DATE_____ HOUR_____

The undersigned hereby authorizes the above-named hospital and the physician to photograph or permit other persons to photograph the patient or tape the patient while under the care of the above hospital, and agrees that the negatives or prints or audio-tapes prepared from such photographs may be used for such purposed and in such manner as may be deemed necessary, except the following:

_____

_____

Witness_____ Signed_____

CONSENTIMIENTO PARA FOTOGRAFIA/PARA GRABAR ENTERVISTA FECHA_____ HORA_____

El abajo firmado por esto authoriza el hospital nombrado arriba y el medico para tomar una fotografia o permite otras personas para tomar una fotografia o usar una grabadora del paciente nombrado arriba durante el cuidado del hospital nombrado arriba, y estoy de acuerdo que los negativos o los impresos preparados de tal fotografia o cintas de grabador pueden ser usados para el proposito de ensenar alguna cosa por medio de la practicia de familia o en una manera que sea juicio con exclusion de lo siguiente:

_____

_____

Testigo_____ Firma_____

BERKELEY: COMMITTEE FOR PROTECTION
OF HUMAN SUBJECTS
(642-7461)

June 20, 1986

MS. LAURA JONES
Health & Medical Sciences Program

Re: 'Health Beliefs of a Mexican Community in California: Diabetes Mellitus as a Model' - Graduate Research

Based on receipt of your oral statements responsive to the Committee's concerns, the referenced project has been approved in full.

The number assigned this project remains as 86-4-65. Please refer to this number in all future correspondence concerning this project. The expiration date of this approval is April 24, 1987. Approximately six weeks prior to the expiration date, a Continuation/Renewal Form will be sent to you. Please fill out the form, per its instructions, and return with any attachments, i.e., subject information/consent materials. If the project has been completed, please sign and return the form to this office.

With respect to the Committee's approval of your use of human subjects, any significant changes or untoward events must be brought promptly to the Committee's attention.

Should you have any questions regarding this matter, please call the CPHS office at the A&E Building.

Thomasine Kushner

Thomasine Kushner, Ph.D.
Executive Officer

TK:fk

cc: Dr. K. Brown
Director H. Sadler

BERKELEY: COMMITTEE FOR PROTECTION
OF HUMAN SUBJECTS
(642-7461)

May 1, 1987

MS. LAURA JONES
Health & Medical Sciences Program

Re: "Health Beliefs of Mexican Community in California: Diabetes Mellitus as a Model" - Continuation of Graduate Research (Funded by Smith Klein Beckman Medical Perspectives Scholarship)

The referenced project was reviewed and granted continuation approval by the Committee for Protection of Human Subjects on Friday, April 24, 1987. Approval was also granted for your use of Dr. Lotte Marcus' transcription of patient/doctor interactions.

This approval is with the understanding that your subject information and consent procedures, as approved previously by the Committee will continue to be observed during the coming year.

The number assigned this project is 87-4-61. Please refer to this number in all future correspondence concerning this project. The expiration date of this approval is April 23, 1988. Approximately six weeks prior to the expiration date, a Continuation/Renewal Request form will be sent to you. If the project is to continue, please fill out the form, per its instructions, and return to this office. If the project has been completed, please sign and return the form to the Committee.

With respect to the Committee's approval of your use of human subjects, any significant changes or untoward events must be brought promptly to the Committee's attention.

Should you have any questions regarding this matter, please call the CPHS staff at the A&E Building.

Walter J. Freeman

Walter J. Freeman, Professor
Chairman, CPHS

cc: Dr. Katherine H. Brown
Director Harrison Sadler
Dr. Lotte Marcus
Natividad Medical Center