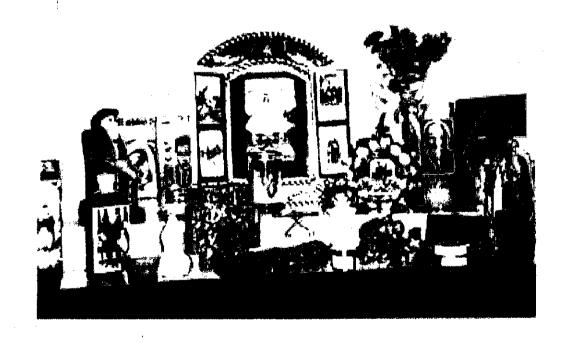
Understanding Mexican American Cultural Beliefs And Traditional Healing Practices: A Guide for Genetic Service Providers on the U.S - Mexico Border



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UNDERSTANDING MEXICAN AMERICAN CULTURAL BELIEFS AND TRADITIONAL HEALING PRACTICES:

A Guide for Genetic Service Providers on the U.S./Mexico Border

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I. INTRODUCTION

The racial and ethnic composition of the population of the United States is undergoing significant change. In contrast to the European roots that predominated among earlier settlers, by the middle of the twenty-first century the average U.S. resident, as defined by census statistics, will trace his or her roots to Africa, Asia, the Pacific Islands, Spanish-speaking or Arab countries.¹

The ongoing demographic shift is one compelling reason for genetic service providers to become knowledgeable and culturally sensitive to the alternative methods of healing practiced by people whose roots are in non-European cultures.¹ While use of "alternative" medicine is prevalent in the United States, 72 percent of persons who are receiving some form of alternative therapy do not inform their physicians of this practice.^{2, 3}

Cultural awareness in biomedicine offers the possibility for greater understanding between people seeking care and health care providers. Increased sensitivity can facilitate positive interactions with the health care delivery system and optimal health outcomes for patients served, resulting in increased patient and provider satisfaction.⁴

Hispanics are the fastest growing minority population in the U.S.^{5,6} Most Hispanics live in the southwestern states: Arizona, California, New Mexico, and Texas.⁷ Because Mexican Americans represent the vast majority of people served in the target communities along the U.S./Mexico Border⁸, the information in this guide is necessarily focused on Mexican and Mexican American culture. It was developed as part of a project entitled, "Reducing Barriers to the Provision of Genetic Services in South Texas" that was extended to incorporate findings from West Texas, Arizona, California, and New Mexico. Between 1999-2001, ethnographic interviews were conducted with a total of 40 medically indigent Mexican American clients, 45 traditional healers, and 43 genetic services providers in 14 study sites, primarily along the U.S./Mexico border. Information from these extensive interviews, as well as the literature, is incorporated into the material provided here.

The challenges of health care in this new millennium will require contributions from many perspectives to meet the needs of the people in this country. This guide is offered in the hope that it will lead to greater understanding of our cultural differences and commonalities, as we work together to meet the challenges that lie ahead.

"....As patients, we are more than lonely, isolated flecks of matter; we are members of families, communities, and cultures. As this awareness finds its way into hospitals, operating rooms, clinics, and doctors' offices, perhaps it will spread further, as well. Healing begins with caring..."

II. USING THE GUIDE

Understanding Mexican American Cultural Beliefs and Traditional Healing Practices: A Guide for Genetic Service Providers on the U.S./Mexico Border was developed as an aid to help genetic service providers better understand their client populations and reduce barriers to the provision of genetic services. For health care providers with little experience caring for Mexican Americans, this guide is intended as a thorough orientation. Health care providers with experience caring for Mexican Americans may find their assumptions challenged as well as their understanding affirmed.

The guide has eight main sections:

- (1) Who are the Mexican Americans? provides information on demographic factors, socioeconomic factors, health, and ethnic origins.
- (2) Cultural Values/Beliefs and Their Relationship to Health Behaviors addresses major components of culture that shape health behaviors.
- (3) What is Curanderismo? describes traditional healing (curanderismo), its origins and practice.
- (4) Mexican American Folk Beliefs Regarding Genetic and Other Conditions describes beliefs and practices regarding causation and prevention of genetic conditions and birth defects, compares perspectives on specific conditions, and describes other cultural beliefs regarding health and illness.
- (5) Client Perceptions of Genetic Services and Barriers to Care provides a detailed explanation of the study methodology, describes the perceptions of genetic services among medically indigent Mexican American clients, and identifies barriers to care.
- (6) Cultural Competence and Genetic Practice provides definitions, rationale for cultural and linguistic competence at individual and system levels, and measures for developing cultural competence.
- (7) Tool Kit contains resources for these sections.
- (8) Supplement section provides elaboration on population sources, religion, *curanderismo*, and a compendium of herbal medicines for more detail.
 - Key points are bulleted in boxes for easy reference.

Supporting information for key points is provided in bold lettering.

A bibliography is provided and arranged by chapter. In preparing this guide, there are instances

✓ Suggestions for working with Mexican Americans in the health care environment are checked in boxes with bold borders.

in which certain words may be used interchangeably. For example, the terms "patient" and "client" are used interchangeably, reflecting choices of this project's authors, as well as the choices of published authors whose works are referenced. This also holds true for the use of the terms "folk" and "traditional," and for ethnic labels.

III. WHO ARE THE MEXICAN AMERICANS?

This section includes information on demographics, socioeconomic and health status indicators, population sources, assimilation and ethnic labels. This information is included here as background for genetic service providers on the nuances of the Mexican American client population.

Demographics and Socioeconomic Indicators

As a group, Mexican Americans:

- Comprise approximately one fourth of the population in the states bordering Mexico.
- Are younger and have twice the birth rate of non-Hispanics.
- Have less formal education than non-Hispanics.
- Work in lower paying jobs with little or no health care benefits or are unemployed.
- Experience a wide range of economic disadvantages in housing, employment, and education.
- Experience disproportionate levels of poverty.

Hispanics are the second largest and fastest growing minority population in the U.S. ^{1,2} Most Hispanics live in southwestern states: Arizona, California, New Mexico, and Texas. ³ According to the U.S. Census 2000, the majority of Hispanics in each of these states listed Mexican as Hispanic type in the census survey. ⁴

State	Total Population	%Hispanic Population	% Hispanic Type: Mexican
Arizona	5,130,632	25.3	82.2
California	33,871,648	32.4	77.1
New Mexico	1,819,046	42.1	43.1
Texas	20,851,820	32	76

The population share is larger in smaller metropolitan areas and cities along the border where Mexican Americans comprise as much as 94 percent of the population. ⁴ The growth in the number of Mexican Americans has been attributed to the high percentage of young couples and a birth rate that is twice that for non-Hispanics. ⁵ It is these factors that underlie the growth in this population, not, according to popular myth, an influx of illegal immigrants.

Mexican Americans are the youngest of Latino groups, with 39 percent under the age of 18 compared to 24 percent of non-Hispanic whites. They are also less educated than non-Hispanics. In 1996, the proportion of Mexican Americans 25 years and over with high school diplomas was 47 percent, compared with 86 percent for non-Hispanic whites and 75 percent for African Americans. Because of youth, lower levels of education and immigration status, most Mexican Americans work in lower-paying jobs with little or no health care benefits, or they are unemployed. ⁶

Mexican Americans experience a wide range of economic disadvantages in the U.S. in housing, employment and education. Approximately 26 percent of all Mexican American families in The University of Texas Health Science Center at San Antonio/Department of Pediatrics

1992 lived in poverty, compared to 9 percent of Anglo families. In 1999, poverty rates and number of poor declined for every racial and ethnic group including Hispanics. Nevertheless, there remains a wide discrepancy in poverty rates between white, non-Hispanics (7.7 percent), overall U.S. poverty rate (11.8 percent), and Hispanics (22.8 percent).

For the most part, Mexican American households derive their income from working-class occupations, with 78 percent of employed Mexican American men and women working in lower blue-collar, service, lower white collar, and agricultural labor. Only slightly more than 12 percent occupy managerial and professional positions in comparison with 29 percent of Anglos.

Health Status Indicators

As a group, Mexican Americans:

- Experience health problems at rates disproportionate to their numbers in the general population.
- Have children at greater risk for poor health, increased morbidity, and underutilization of health services.
- Are among those least likely to have health insurance and/or to receive preventive care.
- Have lower rates of low-birthweight births and infant mortality.

Latinos, including Mexican Americans, experience major health problems at rates disproportionate to their numbers in the general population.² They are at increased risk for certain medical conditions including diabetes, hypertension, tuberculosis, human immunodeficiency virus infection, abuse of alcohol, cirrhosis, specific cancers and violent deaths.¹⁰ Diabetes, the seventh leading cause of death in the U.S., is two to three times more common in Mexican Americans than in non-Hispanic whites.¹¹ Mexican Americans are more likely than non-Hispanic whites to die of work-related injuries, AIDS and homicide.¹²

Latino children are at greater risk for poor health, increased morbidity, and underutilization of health services. Their illnesses are not treated as early, and secondary complications are more frequent (when compared with the general population). Mexican Americans are among those Latino populations least likely to have health insurance and/or to receive routine preventive care. 15

In terms of health status, it is important to note that the health of a population undergoing assimilation and acculturation declines significantly between first and third generations. For example, first-generation Mexican American women have a healthier nutrient intake than second-generation Mexican American women or white non-Hispanic women of childbearing age. Mexican Americans have lower rates of low-birthweight births and infant mortality than the general population despite underutilization of prenatal care services, younger ages at childbearing, and generally lower socioeconomic conditions. Although Mexican American women born in Mexico are at greater risk of not receiving prenatal care, they tend to have lower rates of low-birthweights compared to U.S. born Mexican American women.

Although not well understood, there is "something about traditional Hispanic culture that has a positive effect on health." Research studies have found that foreign-born Hispanic Americans have lower death rates, on average, than those born in the U.S. But even those born in the U.S. are less likely than non-Hispanics to die of cancer, heart disease and stroke, the three leading causes of death for Americans. Reasons cited for lower death rates may have to do with lifestyle factors such as a supportive family structure and low rate of infant mortality. More research is needed to understand the genetic and sociocultural factors influencing both positive and negative health indices of the diverse Mexican American populations.

Population Sources

While social scientists may refer to Mexican Americans as a single group, they are, in fact, extremely heterogeneous. Ethnic heterogeneity is compounded by level of education, socioeconomic status, generation, time spent in the United States, degree of affinity to traditional Mexican culture and proximity to homeland.²³

At least five sources have contributed collectively to the Mexican American population including Native North Americans, Spanish colonists, West Africans, elite Mexicans, and agricultural laborers. 24, 25, 26, 27, 28, 29

Descendants of agricultural laborers, as well as recent Mexican immigrant laborers, comprise the largest portion of the Mexican American population along the Mexico/U.S.border. There is a continuous flow of

Mexican Americans are an extremely heterogeneous group.

documented and undocumented laborers who retain strong cultural and linguistic ties to their country of origin which has several hundred indigenous cultures of its own. Descendants of agricultural laborers and recent immigrants comprise the client population which this manual seeks to address in reducing barriers to genetic services. (See Supplement for historical background of population sources and discussion of the Colonias, housing developments along the 2,000-mile U.S./Mexico border that lack adequate infrastructure where many of the descendents of these agricultural laborers as well as recent immigrants reside).

Ethnic Labels

No consensus has been reached as to what to call the Spanish origin and/or Spanish surnamed populations of the southwestern United States. Field experience reveals that Mexican Americans prefer and use several different terms of address, usually based on context. For example, a person might prefer "Latino" or "Hispanic" when dealing with large organizations, "Mejicano" with family³¹ and American of Mexican descent when wanting to emphasize allegiance to the United States (i.e. U.S. Armed Forces veteran of Mexican descent).³²

Frequently used ethnic terms include:

- Mejicano preferred by many members of the barrio (Mexican American neighborhood);
- Mexican American ranks a close second to Mejicanos in preference;
- Chicano preferred by a small segment of individuals, particularly those involved in social and political movements;

- American of Mexican Descent preferred by those who wish to express their allegiance to the United States;³²
- Hispanic a term coined by the U.S. Census Bureau for 1970 census; criticized by some for emphasizing Spain over indigenous cultures³¹; an ethnic identifier used in New Mexico and parts of Arizona by people who trace their descent to the first Spanish settlers of the region (i.e. Juan Oñate) and who consider this identifier a point of honor³³
- Latino derived from Latinoamérica, the Spanish term for the American continent south of the Rio Grande River; considered by some to be a standard generic term for individuals residing in the U.S. whose heritage is Latin American³⁴; a person from one of the Americas whose first language is Spanish.

Assimilation and Acculturation

- Mexican Americans have a bicultural adaptation to U.S. society.
- Many Mexican American families are a blend of U.S. citizens, legal immigrants, and undocumented immigrants.
- The closer to the U.S./Mexico border, the stronger the border bicultural identity.
- See maps at http://www.borderhealth.gov/maps/Usmxbdr3.gif/maps.html

Assimilation is a process by which immigrants relinquish their cultural and linguistic heritage in acquisition of a new identity. Acculturation, often mistakenly used interchangeably with assimilation, is a more limited term that refers to the process by which members of one group adopt the culture of another, which changes the identity of the original group to a certain extent. Once thought of as a one-way process, more recent conceptualizations include impact of both groups on each other.³¹

The unique acculturation experiences of Mexican American families produces a bicultural adaptation to U.S. society. Family functioning in the bicultural home reflects a more Mexican orientation, and activities outside the home and community reflect a more Euroamerican orientation. This extends to language, where bilingual Mexican Americans often use Spanish for informal, in-group, familial and personal interactions, and use English for communicating with outsiders. As previously referenced in the discussion on health status indicators, assimilation and acculturation are important covariates of health behavior and health outcomes for later generation Mexican Americans.

Immigration issues and proximity to the border strongly affect the acculturation process. Between 1986 and 1992, 2.3 million people from Mexico became permanent U.S. residents.³⁷ The U.S. government also grants citizenship through birth and marriage. Thus, Mexican American families may include U.S. citizens, legal, and undocumented immigrants.³¹

Historically, the relationships and networks among families have not been distributed in the same manner throughout the border region. The closer to the border, the stronger the probability that a border bicultural identity will emerge. There are "border balanced" households that balance source of income from the United States with social residency in Mexico. It is not uncommon for children to attend elementary and secondary schools in the United States while their parents reside in a Mexican borderland town or city. Intermarriage with U.S.-born Mexicans also results from such households.

- ✓ Knowledge of a person's choice of ethnic identifier may provide insight into the degree of acculturation, political perspective, and level of familiarity in the context of a particular situation.
- Be aware that assimilation and acculturation are important covariates of health behavior and health outcomes for later generation Mexican Americans. Young, second and third generation Mexican Americans may experience declines in health status through acculturation. They need help reclaiming beneficial aspects of traditional culture.

IV. CULTURAL BELIEFS/VALUES AND THEIR RELATIONSHIP TO HEALTH BEHAVIORS

Diversity within the Mexican American population makes it difficult to generalize about cultural attributes and their effects on beliefs and behaviors. Many of today's fourth, fifth and sixth generation Mexican Americans have assimilated into the general Anglo population but may maintain certain Mexican cultural attributes selectively. More recent immigrants retain strong linguistic and cultural ties to Mexico.¹

With an appreciation for this diversity and an understanding that this material is intended for genetic service providers caring for the medically indigent Mexican American population in the Southwest, this section offers information on the following primary cultural beliefs and values:

- Familismo
- Familismo and Children
- Familismo and Pregnancy/Prenatal Issues
- Gender Issues
- Fatalismo (Fatalism)
- Respeto (Respect)
- Personalismo (Personalism)
- Health and Illness
- Religion
- Language and Communication
- Time Orientation

Each section begins with key points, followed by supporting text, and ends with suggestions genetic service providers can use in providing care to Mexican American clients.

A detailed discussion of the study methodology for the ethnographic data referenced in this section is found in Section VII. Client Perceptions of Genetic Services and Barriers to Care.

Ultimately, the client and client's family are the best sources of information concerning where along a continuum of cultural expectations a client falls.

FAMILISMO

- Family is the primary social unit and source of support for individuals.
- Familismo emphasizes interdependence over dependence, affiliation over individualism, and cooperation over confrontation. ² This is the guiding framework of collective orientation that supports family and community life.
- The family is the first place people turn to for help and the most important source of emotional and physical support for family members who become ill. 3,4,5
- Family issues greatly influence the patient's interaction in the genetic evaluation process.

Familismo is a characteristic of Mexican American families that emanates from the value that the family, not the individual, is the most important identifying unit and source of support for Mexican Americans.^{6,7}

For Mexican Americans, la familia (family) refers not only to a group of people, but to what family stands for (e.g. a way of life). Some researchers believe familismo, the perceived strength of family bonds and sense of loyalty to family, is the most important value embedded in Mexican American culture. Contrary to assimilation perspective, studies have shown that regardless of class, Mexican extended families in the United States become more extensive and stronger with generational advancement, acculturation, and socioeconomic mobility.

Mexican Americans tend to cast wider boundaries than Anglos to include more distantly related and fictive kin, including non-blood relatives such as the ahijado (godchild), compadre, comadre, padrino and madrina - a ritualistic kinship system known as compadrazgo. Hijos de crianza (non-biological children who are or have been primarily reared in a client family) are also part of the extended family network. An extended family member does not necessarily need to be part of the patient's household to wield influence. The system of compadrazgo, which ensures a Catholic upbringing for a child in the event of his/her parents' death, contributes to a unique view of adoption among Latinos. Adoptions outside the extended family are rare since the expectation is that the grandmother, aunt, older sister, or godmother take over the role of deceased parents.

Friends and kin often provide a safety net and substantial aid in time of crisis, as well as in "normal" times (the daily activities that constitute the life cycle). Exchanges occur in a variety of forms: labor services, access to information, and material assistance.

Latino families, like all other families, are not static; they are typically in transition, so it is difficult to define the normative Latino family. Providers need to recognize that factors such as class, geographical region, and acculturation state may contribute to more or less traditional behaviors in that there is intergenerational diversity in family structures and values. 11,12,13

Decision-making about health matters is a family affair not left to the ill individual. ¹⁴ Efforts directed at the individual patient and not the family system tend to result in lack of support, and even sabotage, of treatment recommended. The patient's extended family network system can enhance or obstruct care. ¹⁵ In the majority of ethnographic interviews in this study, clients cited examples of ways the extended family influenced their decisions. Regarding the care of her son, one mother explained, "His grandpa, I asked him, because you know, it is a family thing. His dad. I talked to his uncle, I will talk to his aunt, I will talk to the family, immediate family is what counts. Their decisions are important to me…" Another stated, "Well, supposedly I'm supposed to make a decision already for the medication, but I'm still not satisfied, because my family is real involved with N. [the child], too. I have to discuss it with my family and then her nutritionist."

Family issues greatly influence the patient's interaction in the genetic evaluation process. Whether intact or estranged, past and current status in family relationships can often "make or break" the genetics evaluation. Accuracy of the historian's information and access to family medical records are key targets in family history-taking. Equally important are the degree of influence the family has on the patient's decision-making process ¹⁶ and the need to respect a patient's need to consult family members.²

Although the family is the mainstay of support, there is a large network of community organizations that provide support targeted to Hispanic families. Providers should be familiar with these groups in their communities and refer as appropriate.²

When a baby is born with a genetic condition, it is still sometimes the case that a new mother is informed of her baby's condition when she is alone. Three clients in the study reported that this situation had happened to them. As one client explained, "I was told by the doctor, 'She's not going to make it, she's got fluid on the brain and she's just not going to make it.' They had no bedside manners and they didn't even wait for my husband to get there to tell me."

This practice violates familismo and makes a lasting negative impression on the families.¹⁷ Prior studies indicate that these negative impressions become experiential barriers to care. Mexican American families cited health care providers' negative attitudes as a barrier to future care.^{18,19}

FAMILISMO

- ✓ Providers should assess specific family traditions and history (i.e. Is this a female-headed household? Are there divergent religious practices within the family?).
- Keep in mind that decision-making about health matters is a family affair. When a Mexican American patient does not agree immediately to comply with a specific treatment, it does not necessarily mean the individual lacks motivation, interest or understanding. It is likely that the patient wants to confer with other family members <u>first</u> to get their advice.
- ✓ Although competent adult patients have the right to make autonomous decisions, families greatly influence the patient's decision-making process. During genetic evaluation, providers should try to understand how influential the family is (including what the family will think if the patient makes an "unpopular" decision) and which members hold power. ¹6
- ✓ Providers should consider the extended family network in the individual patient's care and evaluation of the patient's progress.
- ✓ Ensure that supportive family members are present when news of a baby's genetic condition is given.
- Refer Hispanic families to community organizations and support groups that can serve their needs (e.g. have bilingual and/or bicultural personnel and programs).

FAMILISMO AND CHILDREN

- Children are highly desired and valued.⁴
- Love for their children can be a major force in changing poor health habits among their adult caretakers.²⁰
- There is considerable permissiveness with children, especially children with disabilities.
- Children born with major disorders are often viewed as a gift from God.

Latinos consider children an essential part of the family. The loss of a child, or even a pregnancy, represents a loss of expectations and hope of the future.²

In Latino cultures, children validate a marriage. Parents tend to be very nurturing toward their children.²¹ The strong sense of love and care for children among Hispanics has been shown to be a major force in changing poor health habits among their adult caretakers.²⁰

Traditionally, children are taught to respect their elders and to be polite. They are not usually included in adult conversations and are expected to be quiet, reserved and well-behaved in front of strangers.⁵ This teaching is expected to result in a child who is bien educado or well brought up.²¹

Parents foster a great sense of interdependence and responsibility in children which often extends throughout a person's lifetime. Children are immersed within an extended family network and internalize a strong set of social expectations. This socialization may result in a different set of goals and learning processes than that of the dominant culture. Hispanic mothers often prefer the children's father (or household male authority) to provide discipline. This is more the case for adolescents and, again, dependent on the family structure. 22

There is considerable permissiveness with children, and especially children with disabilities.²² Children born with major disorders are often viewed as a gift from God. This belief is expressed by families who say they will accept "lo que Dios me mande" (whatever God sends me) and assume responsibility for care. As one of the geneticists interviewed for this project explained, "Hispanic families seem to manage the care by themselves and do a beautiful job. They are much more of the philosophy that this is the way God sent me the child."

Disabilities may also be viewed as punishment or having supernatural causes. ^{10, 21,22} Some families may pamper their children with disabilities as a "pobrecito" (poor little one) instead of setting reasonable expectations. Several cases of "pobrecito" were identified in the ethnographies for this study. For example, parents would indulge their children who had spina bifida, providing them anything they wanted to eat. This practice had the unfortunate consequence of creating obesity and other health problems in their children. As one client who frequented a clinic with her two affected children reported, "Here in the clinic, every once in a while we come across a child with a disability, and the kid is tearing around and doing all kinds of stuff. You think the mom would do something about it but no, they just let them because supposedly, they have special needs…" These ideas are explored further under sections dealing

with fatalismo, health and illness, and Mexican American folk beliefs regarding genetic conditions. See also the "Guidelines for Serving People with Disabilities" in the Tool Kit.

Babies born in the United States automatically become U.S. citizens but also have Mexican citizenship which allows them to inherit property and rights of Mexicans. Thus, these babies are seen as a legal bridge to the U.S.²³ In trying to secure a better future for their children, families cross the border daily to take them to U.S. schools to learn English and have exposure to U.S. culture.

Familismo and Children

- ✓ Keep in mind that families may not respond immediately to recommendations for teaching self-sufficiency skills to a child with a disability.
- Developmental goals for the child may have to be addressed in alternative models that enable the family to realize the need for learning self-sufficiency. For example, a primary caretaker who sees that weight control is vital to self-sufficiency of a child with spina bifida can help influence other family members who treat the child as "pobrecito" (poor little one).
- ✓ When counseling for death, miscarriage, or pregnancy termination, providers must consider the influence of culture on the expression of grief and the ability to handle particular situations.²

FAMILISMO AND PREGNANCY/PRENATAL ISSUES

- Pregnancy is considered a natural process that does not warrant high levels of medical intervention.
- Pregnancy is regarded as an important family event. The pregnant woman receives extensive physical and emotional support from immediate and extended family members.⁴
- Aspects of traditional culture, such as less reliance on sophisticated technology, may be antithetical to prenatal diagnostic testing.²⁴
- There are subtle influences on Mexican American women's prenatal diagnosis decisionmaking that are more complex than the assumed cultural norms.²⁵
- For some Mexican American women, prenatal diagnostic testing is as much a cause of doubt and anxiety as it is a source of reassurance.²⁵

Pregnancy is considered a natural process and does not have a connotation that warrants immediate or high levels of medical intervention.¹ For example, in Texas, approximately one-third of Mexican Americans clients do not seek prenatal care in their first trimester (compared with 13% of whites and 26% of blacks). Yet, even, with later access to prenatal care, low birth weight prevalence and infant mortality are comparable to rates for whites and half the rates for blacks.²⁶

Special care is taken to ensure health of the baby during pregnancy and beyond. The pregnant woman receives extensive physical and emotional support from immediate and extended family members. The father of the infant is generally living in the home. Older more experienced women in the family serve as role models to teach and advise younger women about pregnancy and to help with child care. Health care providers should be aware that although this is a definite cultural model, it may not be attained, particularly for young, isolated, newly arrived women.²⁷

Lesser acculturation has been associated with a greater likelihood to refuse MSAFP testing. There may be aspects of traditional Latina culture that are antithetical to accepting prenatal diagnosis.²⁴ For example, there is less reliance on sophisticated technology. For Spanish-speaking Latina women, MSAFP testing does not seem to have relevance to their pregnancies.²⁴

In a study of the amniocentesis decisions of Mexican-origin women and their partners, who were offered amniocentesis after receiving a positive AFP result, 60 percent of the women accepted and 40 percent declined amniocentesis. This refusal rate is significantly higher than in most

other U.S. populations. Those who accepted were more likely to indicate that physicians' recommendations were an important factor in their decision. Those who refused were more skeptical about the accuracy and value of scientific information and reported a higher degree of discomfort with technology, machines, and needles. Neither women's nor men's religious backgrounds and practices were associated with their amniocentesis decision.²⁵

Some of the most important factors affecting amniocentesis decision-making were women's understanding of risks of amniocentesis, their fear of birth defects, their faith in medicine, and their relationships with their doctors. Religion, machismo, and attitudes toward abortion were far from being the deciding factors. Their prime concerns were to do what was best to ensure a healthy pregnancy and to resolve uncertainty, which led women to opposite decisions on amniocentesis.²⁵ It should be noted that this research was conducted among women and their male partners enrolled in California's state-administered program for prenatal diagnosis. It did not include the estimated 25 percent of women who declined AFP testing in the program.

A common misunderstanding among Mexican American women who accept amniocentesis is the assumption that only one of their options, acceptance of the procedure, is sanctioned by medical science. Among the most powerful reasons for considering amniocentesis is the desire to maintain good relations with the medical staff, who ultimately help them through childbirth, and the wish to avoid being thought ignorant.²⁵ The cultural values of *simpatia* and *respeto* (discussed later under the subheading *Respeto*) may predispose women to agree to whatever their medical staff recommends and may not represent fully informed, autonomous choice.

Originally, clients of prenatal diagnosis were white women of higher socioeconomic status. They were at risk because of advanced maternal age and embraced testing in search of reassurance. However, for some Mexican American women, the offer of prenatal diagnosis confers the "burden of unwanted decision-making." The AFP test and the offer of amniocentesis are as much as cause of doubt and anxiety as a source of reassurance.²⁵

Some clients indicate a preference that genetic counseling end as soon as they have declined an offer of amniocentesis. However, in practice, genetic counselors continue through their protocols, often asking clients several more times if they are sure that they do not want the procedure. This type of counseling sometimes heightens a client's ambivalence and can lead to a protracted period of indecision.²⁵

In this project study, several of the prenatal clients interviewed at their first visit had little understanding of the purpose of their referral or the availability and purpose of genetic services. One client couple had experienced four spontaneous abortions and a stillbirth before being referred for genetic services. The husband expressed frustration at not being referred earlier and expressed at length the need to make people aware of genetic services. Another parent of a child receiving genetic services reported, "I think that there are a lot of people who don't realize what a genetic clinic could do for their children. I wasn't aware of the services."

Familismo and Pregnancy/Prenatal Issues

- ✓ Providers should be sensitive to the subtle influences on Mexican American women's prenatal diagnosis decision-making and not assume that a client's culture automatically determine their behaviors.²⁵
- ✓ Patients should be fully informed of the implications of prenatal diagnostic testing.
- Providers should be sensitive to the ways in which Mexican American clients' prenatal diagnosis decisions can and do fall prey to misunderstandings, exaggerated fears, and a misplaced concern about good relationships with medical staff.²⁵
- Providers should assess the social support system of the pregnant Hispanic client and not assume that the extended family is readily available to provide assistance during pregnancy or the perinatal period.
- Anticipatory guidance should be provided by genetic service providers and other physicians to patients referred for prenatal or pediatric genetic services; See the "Questions You May Have for Your Genetic Specialist" in the Tool Kit.
- ✓ Anticipatory guidance can assist client families in evaluating their ability to care for a child with a genetic disorder. Patient education materials and support groups are available through resources such as the March of Dimes and the Genetic Alliance¹⁶. Check the listing of national organizations in the Tool Kit.

GENDER ISSUES

- There are two forms of *machismo*. False *machismo*, created by a loss of dignity and respect, leads the Mexican American man to put down women and even to brutalize them. True cultural *machismo*, however, is defined by a father's love of family and his role as protector and supporter.²⁸
- In the realm of pregnancy and prenatal testing issues, the man's role may be regarded as one of supportive helper rather than controlling a woman's reproductive behavior. 25
- The overtly submissive role of some Mexican American women is often modified in practice by *marianismo* which emphasizes the covert power and centrality of the mother.^{5,29}
- Acculturation, participation in the work force, and access to education are changing the traditional gender roles and relationship in Mexican American families. 30,31
- Modesty (*pudor*) is an important value to Mexican Americans. Consulting a health care provider of opposite gender can be embarrassing for patients, especially if it involves discussing sexual matters. ^{22,32}

Machismo or male qualities of dominance have been described by some as a cultural reason why Hispanic men attempt to prove their masculinity through substance abuse, use of prostitutes, and refusal to use condoms.^{33, 34} In this perspective, men have "complete freedom to drink, fight and carry on extramarital relationships at will." This machismo is "created by a loss of dignity and respect, thus generating a false machismo which leads him (the Mexican man) to put down women and even to brutalize them...True cultural machismo, however, is defined by a father's love of family as he struggles to prevent the racist, ethnocentric, exploitive, and suppressive forces that not only endanger him but destroy the family itself." In this form, machismo conveys the image of the male as leader and protector of his family.

In the realm of pregnancy and prenatal testing issues, however, the man's role may be regarded as one of supportive helper rather than controlling a woman's reproductive behavior. This view is consistent with the "separate spheres" model in Hispanic societies that considers women responsible for family matters and men responsible for public and economic activities.²⁵

Marianismo emphasizes the covert power and centrality of the mother. The term conveys admiration for motherhood as it is named for the Virgin Mary, spiritual mother of the Catholic religion. The overtly submissive role of some Mexican American women is often modified in practice by marianismo. Marianismo and the positive expression of machismo can be viewed as culturally complementary and mutually reinforcing.

Hispanic relationships, particularly those among people in the lower class, are hierarchical in nature, although this is changing. Status and authority are accorded by virtue of age, experience and gender, with males holding the highest status. In traditional Mexican American families, the husband is the authority in the family.⁵ The father makes the decisions while the

mother runs the home.² Cultural insiders also describe the role played by the mother in making important family decisions.³⁵ In addition, acculturation, participation in the work force, and access to education are changing the traditional gender roles and relationship in Mexican American families. Among the caretakers of children with genetic conditions who were interviewed, several fathers had taken on the role of bringing their children for services and were very involved in their ongoing care. Couples arranged their work schedules to better manage their children's health care needs.

Another reality is that female-headed families are part of the picture for Mexican Americans and other Hispanics, as is the case for other families in America.^{13, 36} Acculturation, participation in the workforce, and access to education are changing gender roles in Mexican American families.^{30,31}

Pudor (modesty) is important to Mexican Americans. For a patient, consulting a medical practitioner can be embarrassing, especially discussing sexual matters with a provider of the opposite gender. Individuals may refuse parts of a physical examination or treatment if it threatens their modesty. Women may be reluctant to undertake patient care at home if it means they must touch a male's genitalia, even if the male is their own son (this is true after puberty). It should also be noted that for recent immigrants and unacculturated women, questions about extramarital sex and the use of alcohol and drugs are considered a personal affront. For Mexican and Mexican American women along the border, using a partera (midwife) for delivery is a cultural preference that protects this modesty.

Gender Issues

- ✓ Identify whether gender of client and provider is an issue in communicating with and caring for the client.
- ✓ Where prenatal testing is involved, assess how the woman and her partner feel about their roles and responsibilities toward the unborn child. This awareness will provide insight into blame or guilt issues that may arise in genetic testing and evaluation.
- Consider the positive expression of machismo, which requires men to take responsibility for their families and protect them, in patient-provider interactions.
- ✓ Consider the power of marianismo in working with client families.
- ✓ Incorporate ways to preserve modesty in care. For example, a patient's body should be covered as much as possible during physical examinations.²
- ✓ Be aware that genetic conditions affecting genitalia may be extremely difficult for families to discuss.

FATALISMO (Fatalism)

- Fatalismo, the belief in destiny, is reinforced by a strong adherence to a worldview that God is omnipresent and controls or mediates everything.
- Fatalismo may also be an outgrowth of class dimension where people who are poor and minimally educated have a limited sense of options. 19,37
- Integration of the ideas of *Dios mediante* y si *Dios quiere* (if God wills) and "Help yourself and God will help you" links *fatalismo* to active self-participation.

Fatalismo is a cultural value expressed by the belief that if something were meant to be-if it were destined-it would come about. This belief has been reinforced by the strong adherence to religion. Often Hispanics will add the phrase si Dios quiere (if God wills) to the end of statements referring to expectations or desires. The fatalistic expression que sera sera (what will be, will be), taken to the extreme may encourage relinquishment of responsibility. Taking the approach that "God helps those who help themselves" links this value with active selfparticipation.⁵ An integration of si Dios quiere and self-responsibility may be a fuller interpretation of fatalism..."Ayudate que Dios te ayudara... Help yourself and God will help you." Although client caretakers interviewed for this project often expressed the belief that their child's condition was "God's will," this did not translate into passive inaction or fatalism that has often been attributed to this expression. In fact, client caretakers of children with genetic conditions were persistent in trying to obtain and coordinate their children's complex care despite fragmented methods of service delivery and other barriers. This determination is captured in the comments of the client caretaker who said, "I mean, soon as we started taking him to rehab, we did everything to stimulate him. Everything the doctors did there, I brought home: little towel, sand paper, anything to make him stimulated, anything. We got him a walker. We did exercises of the legs to build up his muscles. We did everything. I was not about to have a "vegetable". I knew this kid had potential... Now, my "vegetable" is a Special Olympic gold medal winner..."

Some researchers argue that the belief in fatalism among Latinos is an allegation without substantiation, but others feel it is a common cultural attribute and appears to foster acceptance of disabilities rather than "shopping" for cures. ^{22, 38} Fatalism may be more specifically an outgrowth of class differences. Persons who are poor and minimally educated may have a limited sense of options. ^{21, 37} They often have an external locus of control and tend to function with a sense that there are things outside their ability to control, as they have indeed experienced.

FATALISMO (FATALISM)

- ✓ Find out how the patient perceives his or her ability to manage health. Ask the client/family if they feel there is nothing that can be done about a problem or if it is God's will.
- ✓ Explore outcomes and provide anticipatory counseling, especially with clients who have strong fatalistic beliefs.
- ✓ Consider using the concept which incorporates an acceptance of God's will with self-responsibility in action... "With God's help, anything can be accomplished," in working with patients who have expressed their belief in God's will.

RESPETO (RESPECT)

- Respeto signifies attention to proper behavior and indicates an expression of deference.⁴
- Patients, particularly women or those from lower socioeconomic groups, may expect a paternalistic relationship with their genetic service provider.³⁹
- If a patient does not agree with a prescribed regimen, it is doubtful he or she will comply. However, out of respect, a patient is not likely to voice disagreement but may simply not return for care. 5
- Older, more traditional Hispanics may feel uncomfortable with giving a person in authority much direct eye contact as it is perceived to be disrespectful.⁵
- Formality is viewed as a sign of respect. This translates into the importance of properly addressing patients.⁵
- A patient's name is an important part of both his or her culture as well as identity.⁵

Respeto refers to a quality of self which must be presented in all interpersonal relationships. It signifies attention to proper and moral behavior and indicates an expression of deference to the person one addresses. Deferential behavior is determined on the basis of gender, social position, economic status, and position of authority.⁴

Respect for authority influences the Mexican American patient's interaction with his or her health care providers. Genetic service providers should recognize that patients, particularly women or those from lower socioeconomic groups, may expect a paternalistic relationship in that they want the physician to tell them what to do rather than ask questions. In one study, 32 percent of Mexican American prenatal genetic clients said they would have liked their counselors to be more directive, or at least more explicit about their own opinion of the value of fetal diagnostic technologies. They also looked for nonverbal cues for answers. 25

Second opinions may be seen as a decrease in trust.³⁹ If a patient does not agree with a prescribed regimen, either morally or because it is not culturally sensitive, it is doubtful he or she will comply. However, since Hispanics respect power and authority, the patient is not likely to voice disagreement but may simply not return to the provider or agency for care.⁵

Hispanics may feel uncomfortable with giving a person in authority much direct eye contact as it is perceived to be disrespectful to that individual's authority. 5 Patients may demonstrate their respect for the provider by looking down when they are spoken to, a practice which should not be interpreted as being evasive or dishonest. 2,40 Avoidance of eye contact, a very old tradition, is not likely to be noted among more acculturated individuals. 41

Formality is viewed as a sign of respect.⁵ Address all clients, except minors, as Mr. or Mrs. (Señor or Señora) and surname unless a client initially requests use of his or her first name. Over time, a patient may ask to be addressed on a more familiar basis. A patient's name is an

important part of both his or her culture as well as identity. Every attempt should be made to spell and pronounce it correctly. Do not address a client by his/her first name unless you have been given prior permission. Do not "Anglicize" a Spanish name.⁵

With older patients, adding "Don" or "Doña" before the <u>first name</u> is a sign of respect, particularly if the health care provider is signficantly younger than the patient. Hearing someone addressed as "Don" or "Doña" connotes a special elevated status, whether achieved or ascribed. A person would never refer to him/herself in this way.^{5,41} Thus, the way the mother of a child with genetic conditions refers to the older woman who accompanies her to the clinic appointment (possibly her mother or mother-in-law) provides useful insight into their relationship.

When conversing in Spanish, it is inappropriate to use the informal "tú" in conversation with someone who is referred to as "Don" or "Doña." Providers should use the formal "usted" unless they have permission to use "tú." Note, however, that the person addressed as "Don" or "Doña" has the prerogative to use the familiar "tú" or formal "usted" when conversing with the provider.⁴¹

The names Maria (for the Virgin Mary) and Guadalupe (for the Virgen de Guadalupe) are frequently given first names. Patients' names beginning with Maria or Guadalupe, should be addressed by their entire name as in Maria Patricia or Maria Elena. If only one name can be used, providers should use the second name. To do otherwise is similar to addressing the patient as Jane Doe. As a practical example, parents waiting for their child to be seen in the genetics clinic may not realize the child's name has been called if they only hear the first name, i.e. Maria. They may miss their appointment.⁴¹

Hospitality and graciousness in the home are expressed through offers of food and drink to visitors. When a health care provider makes a home visit, rejecting this offer signifies rejection of the person making the offer. When an offer is made, rather than declining, a provider could request something else that is preferred, (i.e. "You know, what I would really like is a glass of water"). Also, it is not unusual for a patient to present a health care provider with a small gift during the course of medical treatment. Non-acceptance may be interpreted as rejection.^{5,41}

RESPETO (RESPECT)

- Providers should remind themselves that being either non-directive or being an authority figure may put them in direct conflict with a client's expectations. Providers may need to explain to clients the provider's role as a facilitator in the decision making process and that the client-family makes the final decision. 16
- ✓ Elicit a client's understanding of health information by politely requesting that the patient repeat what he or she understood the provider to say.
- ✓ Keep in mind that a client's avoidance of direct eye contact may be a demonstration of respect, not evasiveness.
- ✓ Address all clients, except minors, as Mr. or Mrs. (Señor or Señora) and surname unless a client initially requests use of his or her first name. With time, a patient may ask to be addressed on a more familiar basis.
- ✓ Make every attempt to spell and pronounce clients' names correctly.
- ✓ Older clients may be addressed as Don or Doña (Mr. or Mrs.) and their first name as a sign of formality and respect (this is a VERY important point).
- During a patient encounter, it is recommended that providers begin by addressing the person they know and then extending a greeting handshake to the eldest male present say, "Who is this that I have the privilege of meeting?" and then continuing with greeting other people present in order of seniority.⁴¹
- ✓ Make every effort to accept offers of hospitality.

PERSONALISMO

- Personalismo is an orientation toward human interaction that emphasizes empathy, kindness, and sincere personal concern. 41
- A client's relationship is with the individual provider rather than the institution.⁴²
- Personalismo helps build an atmosphere of trust and can enhance self-disclosure by clients.

Personalismo (also referred to as complacencia by some) is an orientation toward human interaction. A person who is empathetic, kind, friendly, helpful, approachable and nonjudgmental in his or her actions is exhibiting personalismo.⁴¹ Mexican Americans tend to trust individuals rather than institutions because of this personalismo.^{38,42} They appreciate personal conversations to determine perception of illness.¹⁴

Personalismo can be conveyed by greeting clients and inquiring about their general well-being or family before getting to the actual business of the visit. Personalismo helps build an atmosphere of trust and intimacy, and enhances self-disclosure by clients. A hurried approach by the genetic service provider might be construed as a failure of personalismo, causing a client to not return. Whenever possible, clients should be contacted and recontacted by the same genetic counselor [or other genetic service provider]. In addition, this genetic service provider should let clients know they may phone them with specific questions or concerns.

Amabilidad (amiability) refers to a cultural need for positive, smooth interpersonal relations (also referred to as simpatia by some).⁴¹ This expectation of agreeability and pleasantness under stress can lead to the client's perception that neutral behavior on the part of providers is negative.²²

Latino families assume that the physician will take time to engage in conversation and be friendly and supportive, and may interpret absence of special interest as a lack of overall concern, or even as a prejudice against them.² On a personal level, the majority of clients interviewed for this project indicated satisfaction with their genetic service providers. Client satisfaction may be due, in part, to increased opportunities for *personalismo* in the way genetic services are provided.

However, more than half of all the clients interviewed described dissatisfaction with provider communication during the course of their care, particularly in the early stages, and most frequently with other biomedical providers who had referred them for genetic services. Issues of *personalismo* and *amabilidad* were at the core of many of these communication problems. "He came right out and said, 'Your son has birth defects from head to toe,' He could have said, this doesn't look right, or maybe we need to have this checked out. He just got right down to it, 'Your son has a webbed neck, look at him, his head is not the size of a two-year old..' And so, it is the way he went about telling me that bothered me."

The importance of culturally competent communication is further demonstrated in the example of the monolingual Spanish-speaking couple who underwent ultrasound at one of the genetics

clinics included in this study. They were aware they had been referred for a possible problem but had very little understanding about it. They reported, "This was our first experience with that type of exam [sonogram] so we were frightened...we needed to be told something positive to give us faith and strength. When she [sonographer] was performing the exam, she looked so preoccupied and pensive. We asked her what she could see. She answered that she could not say and that we would be discussing it with the geneticist...Surely she could share with us a few words. Since that time, we have been living in burning coals waiting for the doctor to tell us the bad news.." Here, the sonographer [bilingual Mexican American] shifted from using personalismo to a business-like demeanor prescribed by her position. For the couple, this unexpected and unexplained shift in communication style heightened their anxiety.

Personalismo

- ✓ The preferred interactive style of genetic service providers is that they be warm, family-oriented, and understand the values of dignity and respect.
- ✓ Personalismo can be conveyed by offering a handshake as a greeting, touching the head of a child, and inquiring about a client/family's general well-being before getting to the actual business of the visit. This preamble is crucial.
- ✓ Amabilidad can be conveyed through expressions of kindness and forethought concerning a client's needs.
- ✓ If the client/family needs to be seen more than once, it is important to have the same counselor or health provider. If a new counselor or provider will be working with the family, introduce him/her to the family.
- ✓ Ensure culturally competent communication practices that assuage client anxiety regarding procedures such as sonography.

HEALTH AND ILLNESS

- Health is the absence of pain. Illness is considered to be a state of physical discomfort and incapacitating disability.⁴⁴
- Mexican Americans use both biomedicine and traditional healing, relying on whatever they believe works.⁴¹
- Women are the initial primary health care providers for the Mexican American family.⁴⁵
- Disability may be perceived as punishment or a gift from God, as in the case of children with disabilities.^{22, 45}
- Addressing a client's perception of the problem and being culturally sensitive in care can enhance compliance and satisfaction.^{14,47}
- Family support can enhance the client's ability to continue health promoting behaviors. 14
- Hospitals are viewed as a place of last resort.³⁹
- Illegal status of one member of a family may prevent the entire family from seeking care. 48, 49

Traditional thinking among Mexican Americans is that health is the absence of pain.^{2,14} Good health means having a sturdy body, the ability to maintain a high level of normal physical activity and absence of persistent pain and discomfort.⁴⁴

Illness is considered to be a state of physical discomfort and incapacitating disability.⁴¹ Many Mexican Americans classify illness as either "natural" or "unnatural." Natural illness is thought to be caused by God's will or fate, while unnatural illness originates from evil done to one by another.^{50,51}

In response to illness, many Mexican Americans use both biomedicine and traditional healing. It appears that neither economic status, education, family size, nor primary language distinguish which persons use folk medicine and which do not. 52,53 Some researchers suggest that use of traditional healing varies with degree of acculturation to mainstream U.S. culture. 54 Those less acculturated rely more heavily on traditional practices. People are willing to use modern pharmaceuticals and other elements of biomedicine without giving up major aspects of their traditional explanations of illness. 55

Clients use whatever resources are available and that they believe will work to alleviate their health problems. They use their *malicia indigena*, a quality described as cautious and based on common sense experience, in their decision-making about health care matters. Logic from their perspective plays an important role in the acceptance or rejection of various healing modalities.⁴¹

The woman is the initial primary health care provider for the Mexican American family. Medical information is passed down from mother to daughter, and the woman must decide when an illness is beyond her ability to treat and requires outside help. Primary symptoms considered in determining the severity of an illness are incapacitating disability, pain and the appearance of blood. When attempts at home management are unsuccessful or if the woman decides outside help is needed, she usually discusses symptoms first with family and friends, then she may utilize folk healers, and finally she may consult a physician. 32

In Latino culture, disability may be defined by the function in the family and community, not by medical definition.² Disability is also sometimes perceived as a punishment from God, a special type of moral and spiritual trial or "cross to bear." Mexican Americans may regard illness as punishment for evil thoughts or deeds, or just bad luck.^{56,57} Although interpretations on cause of disabilities or birth defects for children may result from an array of influences, Mexican Americans also approach disability with an attitude of acceptance and an assumption of responsibility for the care of the family member with a disability. ⁴⁶ (See previous discussion in this section on fatalismo).

Children born with major disorders are also seen as a gift from God. The majority of clients interviewed expressed this concept. "They told me V's condition was a matter of chance. Now I feel God gave me a blessing..." "God gave me what I wanted, a child with special needs..." As one of the geneticists interviewed noted, "People who are truly spiritual have a better capacity to be accepting. Not so much fatalistic but accepting. This is a beautiful child in his or her own way, and there is a reason God sent me this child. It is a blessing, it's something positive. I had a family with a child who had Down syndrome and that child unfortunately died, and they went and adopted another child with Down syndrome. They felt that kids with Down syndrome were just something so special, and that's what I call spiritual." This quality of acceptance may affect a family's approach to care. Most genetics professionals have been trained in a Western medical model that involves physically and emotionally "fixing" as much as can be "fixed" in any encounter. However, fixing the problem may not be a priority for the Mexican American client. Providers should be aware that genetics services are but one resource for the family. 58

One theme that was repeated by families and also identified in the interviews of two geneticists was the issue of hope. As clients explained, "They tell us there is nothing to be done, that is just heart-breaking," "No one gives me hope. Only, you know, this is going to happen... You know that worse than that is going to happen. What am I going to wait for?" The geneticists reported that providers need to identify something hopeful and constructive in a family's situation that they can focus on so "they are willing to be fighters and try to manage the situation." They also emphasized the importance of explaining to clients that what they read or are told about a disorder is very often a worst case scenario and does not reflect the range of the disorder's expression or the influence of that particular family's care of the child.

Having family members present during examination (of their child) and teaching often enhances the Mexican American client's satisfaction and compliance. This is especially true when the

family member has a chronic condition. Support from the family will enhance the Hispanic client's ability to continue health-promoting behaviors. 14

Mexican American clients appear to respond more readily to directions and treatments when it is evident that the provider is incorporating cultural beliefs into the plan of care. It is also very important for the provider to pay attention to the client's perception of the ailment. If the perception of the problem is not addressed, the client will be dissatisfied and will be less likely to comply with the regimen prescribed. The need to assess patient perceptions was emphasized by several geneticists and genetic counselors during the course of the study.

Hospitalization can be a special problem for Mexican Americans. Hospitals are viewed as a place to go as a last resort or where people go to die, often because this has been the only experience many Mexican Americans have had. Consequently, there is reluctance to "let go" of a relative who is ill. Also, in Mexican American tradition, the whole family comes to the hospital to visit and stay. This tradition frequently differs from U.S. hospital visitation guidelines, which can be a source of discomfort for patients and their families.³⁹

Immigration status may greatly affect a family's interaction with biomedical health systems. The illegal status of one member of a family may prevent the entire family from seeking health care for fear of deportation of that family member. ^{48, 49} They do not drive for fear of being stopped and must rely on others for transportation. The genealogy of one client family, covering 30 members and five generations, depicts an extended family typical of those interviewed. Within the family were 13 Mexican Nationals, nine U.S. citizens, four individuals with dual Mexico/U.S. citizenship, three individuals who lost their U.S. citizenship through missing and/or unfiled records, and one person in the process of obtaining legal U.S. residency. Of these 30 family members, five adults and four children live in a four-bedroom house. Three of the adults do not speak English.

Newly-arrived immigrants find temporary places to live, and tend to change residence often as they attempt to stabilize themselves economically. Constant changes in residence make it difficult to track clients for ongoing treatment.^{48, 49}

There is a continuous back and forth flow of people, resources, services and problems between the two countries. Fifty-nine percent of the clients interviewed reported Mexico as their birthplace. Client families included members who have Mexican, U.S. or dual citizenship, individuals trying to recover original dual citizenship status, and undocumented persons. All of the clients interviewed maintained active ties with extended family in Mexico, traveling back and forth and, in several cases, living with family in Mexico for brief periods while continuing to work in the U.S. Negotiating the mundane details of existence in this setting is complicated by the duality of systems but something that the people must do everyday. As one of the clients interviewed explained, "It is not that we don't want to own our own place. It is that we don't want to get into debt because we could lose whatever we put down if our legal situation is not clear. We cannot make plans to buy anything until our legal situation is resolved."

Approximately half of the clients interviewed in this ethnographic study sought services of traditional healers at the same time that they were also under the care of genetic service providers. Clients used whatever resources they could access and believed were efficacious to alleviate their health problems. There was no reported cognitive dissonance concerning

simultaneous use of traditional folk healing and biomedical services from U.S. and/or Mexican physicians. Clients sought treatment from *curanderos* for treatment of *susto* ("soul loss" or "fright sickness"; see elaboration in Section VI.) and other folk-defined illnesses. As one client reported, "it is something that doctors do not understand." They also consulted *curanderos* for herbal remedies "to get something natural to prevent nausea during my pregnancy," in addition to using herbs for home remedies. Several parents interviewed reported on-going consultations with *curanderos* in matters concerning the care of a child with a serious genetic condition while others described taking children to see traditional healers and physicians in Mexico in search of alternative treatments, "They do special testing and new research therapies such as water therapy." (See Section V. and Section X. for elaboration on *curanderismo* and herbal medicine).

Health and Illness

- ✓ View each family as a unit to ascertain what meaning they ascribe to illness and disability. Assumptions should not be made without first getting to know the family, since so many variables contribute to views on causation and disability, particularly related to children.²¹
- ✓ Address the patient's perception of his or her ailment.⁴⁷ Be sure to ask the patient, "What do you think caused this condition?" and "In your opinion, what can be done to treat it?" "Why?" (Refer to the "Brief Assessment of a Patient" in the Tool Kit)
- ✓ Provide clients with anticipatory guidance for their genetic service visit using the "Questions You May Have for Your Genetic Specialist" (in English and Regional Spanish) found in the Tool Kit.
- ✓ Acknowledge a patient's perception of his or her ailment. This means being attuned to how the ailment is treated at home, including the use of home remedies or consulting a traditional healer.
- ✓ Frame questions about alternative practices in a positive manner to prevent putting families on the defensive, e.g. "Some of our families use *remedios caseros* (home remedies) or herbal medicines such as *manzanilla* (chamomile). Are you using any of these now?
- ✓ Negotiate integration of traditional and Western medical treatments. Many folk remedies, such as rehydration through drinking of teas, are beneficial. Allowing the patient to take his or her home remedy along with prescribed medication (as long as not contraindicated) can be a culturally relevant strategy to improve adherence to a therapeutic regimen. ^{59, 60} (See Margarita Kay's Healing with Plant in the American and Mexican West⁶¹ for phytochemical analyses of medicinal herbs).
- ✓ With symptomless illness, explain secondary complications to help improve understanding and compliance with the prescribed medical regimen.⁵
- ✓ Be aware that a family's acceptance of their child's condition might preclude the biomedical model's "fix-it" approach.
- ✓ Consider asking parents to designate certain family members to be trained along with them in special medical regimens for their children.²¹
- Facilitate arrangements for families to stay in the hospital or nearby for in-patient procedures and provide anticipatory guidance about hospital practices to families.
- ✓ Contact representative members of the client's local cultural community (e.g. minister, community center worker) for guidance regarding resources. Also check the Tool Kit for a list of national agencies and websites for information and referral.

RELIGION

- There is rich diversity in the practice of Catholicism and Folk Catholicism in Mexico and the United States.⁶²
- Mexican American's view of healing is rooted in their spirituality and faith.
- Prayers are directed to a favorite Saint or a Saint associated with a particular need.
- The importance of the Virgin Mother is a prominent feature in Mexican American Catholicism. Families may implore the Virgin Mother to intercede to cure a child's disease or disability.²¹
- A manda is a promise made in return for God's help. 2,21,63
- Milagros are objects symbolizing special needs for which people appeal for help. 41,61
- Although Mexican Americans remain predominantly Catholic many also attend Protestant churches. There is a growing influence of Protestant sects in the U.S. and Latin America.⁵
- Not all Mexican Americans are devout church attendees. 64

Nearly five hundred years of cultural melding between native beliefs and Spanish Roman Catholicism has produced a rich diversity in the practice of Catholicism and Folk Catholicism in Mexico and U.S. border states. Native beliefs and rituals were literally incorporated into Catholicism.⁶⁰

Mexican Americans' view of healing is rooted in their spirituality and faith. There is much less dichotomizing of physical and psychosocial problems than is found in the Western biomedical model.⁴¹ Health is viewed as entailing harmonious relationships in both social and spiritual realms.⁶⁵ These concepts are contrary to central assumptions of biomedicine.

Integration of spirituality and healing is clear from clients' descriptions of their experiences. Even those not actively practicing their religion make pilgrimages to shrines for healing and report that family members do so on behalf of their children with genetic conditions. They describe the importance of prayer in healing such as making appeals to Saint Jude, a popular Catholic saint who helps with hopeless causes. Clients refer to God as the primary source of healing in such ways as, "If Dios (God) wants to cure illness, he does it..." "Doctors are the tools of God."

Mexicans and Mexican Americans are devout followers. Prayers are directed to a favorite saint or a saint associated with a particular need. In South Texas and Northern Mexico, two late 19th century/early 20th century folk healers revered as folk saints are Don Pedrito Jaramillo and El Niño Fidencio Constantino. Healing in their name is still actively practiced in South

Texas.³⁸ There are also many popular Catholic saints such as San Martin de Porres (poverty) and San Judas Tadeo (impossible situations).²³ In New Mexico, Santa Rita is popular as the patron saint for copper miners as is El Santo Niño de Atocha, the patron saint of persons in need and the protector of those who have been unfairly imprisoned.

The importance of the Virgin Mother is a prominent feature in Mexican American Catholicism. It is not uncommon for a parent to implore the Virgen de Guadalupe (especially popular in Mexico) or the Virgen de San Juan del Valle (very popular in South Texas) to intercede to cure a child's disease or disability. The use of mandas (a promise or offering in return for God's intervention) is another aspect of intercession. Amandas are an especially common practice among pregnant women. A woman who has had difficulty getting pregnant or carrying a child to term may promise God to give her newborn a special Biblical name (Samuel, Elizabeth are frequently chosen).

Milagros (miracles) are small silver-like objects symbolizing special needs for which people are appealing for help (i.e. the figure of heart, eye, breast, kidney). The milagro is the petition to the saint to concede a miracle for which the person makes a promise (promesa) in return. Once the petition is granted, tokens of recognition of healing that has taken place are placed in church sanctuaries which often have a special section for just such purposes. These testimonials may be photographs of loved ones, milagros, crutches no longer needed, hospital name bracelets, braids of hair or notes. People may pin milagros onto clothing or at the bedside of a patient. San Javier de Bac near Tucson, Arizona, San Juan del Valle in South Texas, Sanctuario de Chimayo outside Santa Fe, New Mexico, and San Juan Capistrano near San Diego, California are all sacred shrines where many of these practices can be observed.

For Catholics, the days of Holy Week leading up to Easter are of utmost importance. Families do not usually socialize on Maundy Thursday (*Jueves Santo*), Good Friday (*Viernes Santo*), Saturday (*Sábado de Gloria*), or Sunday (*Domingo de Resurrección*). Providers should avoid scheduling patients during times when they are celebrating high holy days, whatever their faith preference.

Although Mexican Americans remain predominantly Catholic, it is important to recognize that many also attend Protestant churches, particularly evangelical, Spanish-language churches such as Pentecostal, Jehovah's Witnesses, Seventh Day Adventist, Baptist and Nazarene. In reality, there is a growing influence of Protestant sects, both in Latin American countries and in the U.S. 67 Of the 40 clients interviewed for this project, 25% identified themselves as belonging to Protestant denominations.

Unlike long established Catholic churches, Protestant sects court new members actively by going into the most economically deprived communities (colonias), evangelizing door-to-door and making use of other strategies of community organization. Division of faith within families and communities could become an important source of conflict for Mexican Americans in the future.

Another point is that although Mexican Americans tend to be devoted in their religious practices, not all Mexican Americans are deeply religious. This is particularly true of acculturating youth, who may not place as strong a value on religion as their elders.⁶⁴

Religion

Suggestions for Genetic Service Providers:

- ✓ If a Mexican American client indicates feelings of guilt or shame, as may be experienced with a child's diagnosis of a genetic condition, ask about the extent of religious affiliation. Many times a priest or other clergy can help reduce feelings of guilt or anxiety substantially.⁵
- Show respect for, and even encourage as appropriate, religious practices of patients and their families. For example, providers should allow families to bring and use religious objects in a patient's hospital room. Families may wish to place the fuente con agua (a glass or bowl of water) under the patient's bed, say a rosary, or pin milagros, laminated plastic cards depicting a favorite saint and prayer, and medallas (medals) to the patient's bedside.
- ✓ Ascertain specific family religious preferences and do not assume all members, nuclear and extended, are of a single faith.
- ✓ Ask the client/family if a spiritual/religious leader or healer has been consulted.
- ✓ Keep in mind that many Mexican American clients emphasize spirituality and faith
 in their view of healing and appreciate acknowledgment of this value in the context
 of their care.

LANGUAGE AND COMMUNICATION

- Use of Spanish language is an affirmation of ethnic identity as well as primary means of family communication.²¹
- Bilingual Mexican Americans commonly use Spanish for informal, familial interactions and English for communicating with others.⁶⁹
- For people who are Spanish-language dominant, speaking in Spanish enables greater expression of feelings.⁵
- Not all Spanish-speaking persons are literate in written form.
- If providers lack proficiency in the patient's language, they should use interpreters.⁷¹
- Mexican Americans are very sensitive to interpersonal relations and may pick up on nonverbal communication cues.^{2, 21}
- Physical proximity between Hispanics is approximately half that required by Anglo-Americans.³⁸

Many Mexican Americans value the Spanish language not only as a primary means of family communication but also as affirmation of ethnic identity. However, second and third generation Mexican Americans, who are more likely to learn English in school and through television, may have little or no knowledge of Spanish. For all Latin American groups in the United States, the degree of fluency in Spanish will vary, especially with acculturation rates.²¹

Bilingual Mexican Americans commonly use Spanish for informal, familial interactions and English for communicating with outsiders. ⁶⁹ Awareness of this tendency to shift from one language to the other can prevent misunderstanding that switching to Spanish is a way to hide information. This practice is often just tied to linguistic preferences and habits of speech. ²¹

Speaking in Spanish enables monolingual and bilingual Hispanics with Spanish-dominant language fluency to express their feelings and emotions more honestly. It allows for a significantly greater level of comfort in self-disclosure for Hispanics. During ethnographic interviews for this project, even clients with English-language skills preferred to respond to questions in Spanish.

Not all Spanish-speaking persons are literate in written form. Mexican Americans experience illiteracy not only in English, but also often in Spanish. Although fluent in Spanish, many Mexican Americans have no formal education to support reading and writing, and/or the Spanish they know has been learned phonetically and seldom seen or reinforced in written form. Sensitivity to low literacy among clients requires simplification of paperwork and methods of acquiring information that do not embarrass clients.

Of the 40 clients interviewed for this project, 29 were monolingual Spanish-speaking. Language barriers and use of cryptic medical terminology were identified as two of the most significant challenges to providing and receiving genetic services. The functional illiteracy in English and Spanish among clients, including a lack of understanding of basic human biology and other concepts, compounded the communication difficulties experienced between clients and their genetic service providers. Standard medical Spanish or English terminology was seldom understood by the majority of these clients. The comments of one of the geneticists (bilingual) encapsulate the challenge of discussing genetics with these clients, "One of my most dreaded moments is trying to explain chromosomes to someone with a second grade education who doesn't even know what a cell is..."

If providers lack proficiency in the patient's language, they should use interpreters, who know the appropriate medical nomenclature, can translate from one language to another, and are also trained in cultural sensitivity in the context of service delivery.⁷¹

Issues of linguistic competency for genetic service providers and the use of interpreters are discussed at length in Section VIII. Cultural Competence and Genetic Practice.

If a patient is Spanish-speaking, providers should use any knowledge they have of the language to communicate. Any sincere attempt at using Spanish is greatly appreciated by patients and will help facilitate a more trusting environment. Once trust (confianza) has been established, Hispanics will be more informal, characterized by warm, intense interactions (personalismo).

Latino persons, including Mexican Americans, are very sensitive to interpersonal relations and may pick up on nonverbal communication cues as a way to assess their interaction with others, particularly in relation to an authority figure. A provider's affect or body language can convey to a client or family a view of the provider as caring and respectful or someone who disrespects their style of living. ^{5,21}

Another nonverbal issue of which to be aware is that physical proximity between Hispanics is approximately half that required by Anglo-Americans in face-to-face interactions.³⁸ Hispanics also tend to be physically expressive, often gesturing with their hands and face as they speak. Many traditional healers greet their clients with a hug and handshake.⁴¹

Language and Communication

Suggestions for Genetic Service Providers:

- ✓ Do not assume that a family or parent is literate in English or Spanish. Assess this carefully so that patient education materials are used appropriately.²¹
- ✓ Provide genetics education materials in basic regional Spanish and English and use simple anatomical charts and other visuals for those who cannot read.
- ✓ Visual aids may be helpful in explaining genetic concepts² but avoid explanations that are overly technical.
- ✓ Avoid embarrassing low literacy clients by using simplified paperwork and methods
 of acquiring and/or providing information.

 ⁴⁸
- ✓ Providers who lack proficiency in the patient's language should use interpreters. Refer to Section VIII. Cultural Competence and Genetic Practice for information on use of interpreters and improving linguistic competency.
- ✓ Determine if the agencies to whom clients are referred have bilingual services appropriate to the needs of the family.
- Be aware that a patient may perceive added distance between her/himself and the provider as signaling detachment.² Chairs should be closer together in patient-provider encounters to avoid a sense of distance and alienation.³⁸
- Refer also to the previous section on *Personalismo*.

TIME ORIENTATION

- Some Mexican Americans have a present-time orientation.⁴
- Promptness is based on relationships, and finishing an important conversation with a family member or friend is more important than being on time.
- Frequent crises of poverty (e.g. unreliable transportation) and other issues of managing daily existence influence patients' ability to get to appointments on time.⁴¹

Keeping in mind that the following construct is a generalization, it has been stated that many Mexican Americans have a different orientation to time than that of dominant American culture.⁵

Punctuality is not highly valued in Mexican American culture. Promptness is based on relationships, and finishing an important conversation with a family member or friend is more important than being on time.⁷² The unpredictability of a day in clinic can mean that although patients make their appointments on time, they end up waiting anyway. This reality reinforces lack of punctuality. The majority of the clients interviewed for this project expressed their gratitude for having only minimal waiting periods.

It is also a fact that patients frequently have other issues, such as unexpected and frequent crises of poverty (e.g. unreliable transportation) that influence time of arrival for appointments. When patients understand the expectations, they adapt to schedules and often use extraordinary means to meet expectations.⁴¹

Present-time orientation may work against health promotion and disease prevention.⁴³ Clients may not understand acute versus chronic illness and may find it difficult to adhere to long-term plans.⁴

Suggestions for Genetic Service Providers:

- ✓ Asking about the reasons for tardiness rather than assuming cause, is the best approach to understanding any problems associated with keeping appointments.
- ✓ Use of personal phone calls or mail reminders can help clients keep appointments (if telephones are still working and families have not relocated).
- ✓ If a client arrives late for appointments consistently, consider setting subsequent appointments 15-30 minutes earlier than the expected time of arrival as a way of working within the patient's time orientation.
- ✓ Use the present-time orientation positively by focusing on risks at a particular stage of care as, for example, in prenatal care.⁷³

V. WHAT IS CURANDERISMO?

- Curanderismo is the traditional healing system of Hispanics, including Mexicans and Mexican Americans.
- It remains a resource for healing among Mexicans and Mexican Americans.
- The strengths of *curanderos* are their use of the family as a natural support system, willingness to spend time and provide non-threatening counsel, availability in border communities for people regardless of their documentation, and reinforcement of cultural identification.¹

This section provides an overview of *curanderismo* and a discussion of traditional healers and their practices. From the ethnographies of clients interviewed for this project, it is clear that *curanderismo* remains a resource for healing among Mexicans and Mexican Americans, including clients seeking genetic services. Supplemental information on *curanderismo* and traditional healers, and lists of medicinal herbs, and herbal medicine resources can be found in the Supplement section.

Definitions

Curanderismo is the traditional healing system of Hispanic Americans -- including Mexicans, Mexican Americans, Central Americans, South Americans and people of the Hispanic republics of the Antilles.² The word curanderismo is derived from the Spanish verb curar, which means "to heal." Traditional healing can be defined broadly as a set of beliefs and practices derived from ethnic and historical traditions that have as their goal the amelioration or cure of physical, psychological and spiritual problems.³

Traditional healing is practiced within families using home remedies (remedios caseros). It can also be practiced informally with families and neighbors by individuals not recognized by the community as folk healers or by a specialized practitioner, a curandera (female) or curandero (male) who is identified as such by the community.^{4,5}

Curanderismo places strong emphasis on the social, psychological, and spiritual factors contributing to illness and poor health.⁵ There is much less dichotomizing of physical and psychosocial problems than is found in the Western biomedical model. Folk concepts of etiology do not distinguish between psychic, spiritual and somatic disorders; rather, these forms of illness are included in a theory of causation that combines naturalistic with magical and religious elements.⁶

In curanderismo, illnesses are natural or supernatural. Natural illnesses have natural causes such as improper function of the body and infections. These illnesses are usually treated with herbs. Supernatural illnesses are caused by negative influences such as harms (daños) placed on the person by an enemy or by envy (envidia), coveting the person's relationships, job, emotional health and/or material possessions. Sometimes, however, what seems like a natural illness, such as diabetes mellitus, is determined to have supernatural causes. In perceptions of

curanderismo, biomedical physicians cannot cure a supernatural illness since it is outside their realm of understanding.⁶

While beliefs in metaphysical aspects of *curanderismo* cut across socioeconomic lines, most individuals relying on traditional healers have lower socioeconomic status, less education and exhibit lower levels of acculturation.^{8,9,10,11}

Influences on Curanderismo

Major historical influences have shaped the beliefs and practices of *curanderismo* used by Mexican Americans in the Southwest.⁵

From the Judeo-Christian influences, curanderos explain that their healing abilities are a gift (don) from God, and that they heal through God's power and the patient's belief in God.⁵

From Greek humoral doctrine comes the concept that the healthy body is in a state of equilibrium in terms of "hot" and "cold." Illness results from disequilibrium after exposure, internally or externally, to excessive heat or cold.⁵

From Arabic medicine comes the idea that the brain is a transmitter of energy. This idea is manifested when the *curandera* directs her psychic energy at the patient's diseased organ. It is also manifested when someone transmits too much energy to another weaker person and makes him or her ill.¹¹

Medieval and later European witchcraft held that supernatural forces can be controlled by humans themselves, rather than these supernatural forces having their undisputed control over humans.⁴

Extensive knowledge of medicinal herbs existed among indigenous peoples of the Americas, as is the case with most human societies. Maya, Inca, and Aztec civilizations all had herbal traditions with a profound understanding of local medicinal plants. 12,13,14,15

Another pervasive theme from indigenous people is the importance of balance and harmony in maintaining health. ^{6, 16} There are also widespread ideas about magical and emotional causation of illness among indigenous people. These ideas play a significant role in illness theory, particularly the ideas of soul loss occasioned by fright, spirit intrusion, object intrusion and breach of taboo. ^{17,18} Aztec medicine was holistic. It involved use of divination for cause of illness, prayer, rituals and empirically validated herbal remedies. ¹⁹ Indigenous culture also links health with natural forces such as the land, sea, moon, and stars. ²⁰

Between 1500 and 1870 A.D., millions of Africans were enslaved and taken to the New World, bringing their spiritual beliefs and medical practices. Some of these beliefs and practices were incorporated into *curanderismo*. The Afro-Cuban system, *Santería*, involves various rituals and therapeutic practices that blend Catholic saints and African orichas (similar to saints) from southwestern Nigeria in West Africa. It has not only survived acculturation but has expanded its influence in the U.S. 22

Modern beliefs about spiritualism and psychic phenomena have influenced curanderismo. Spiritualist beliefs derive from communications believed to emanate from spirits of the dead.²³ Allen Kardec, a French physician of the late 19th century, popularized ideas of spiritual trance possession and communicating with the spirits of departed loved ones.²² His ideas are responsible for the rapid growth of "spiritual temples" in Mexican American communities.⁵ There are also the spiritualist movements of two folk saints, Don Pedrito Jaramillo from Falfurrias in South Texas, and El Niño Fidencio Constantino from Northern Mexico.²⁴

Curanderos have incorporated scientific concepts into their work, such as the germ theory, contagion and psychology. Depending on their exposure to biomedicine, some are familiar with parasites and use medical equipment such as thermometers and sphygmomanometers.^{5, 21}

Curanderismo is neither obsolete nor static. Just as other health care delivery systems change to meet new needs, to utilize new knowledge, or cope with new environmental conditions, curanderismo is changing.^{5,21} From the ethnographic interviews in this study, it is apparent that what is emerging in both the Southwest and Mexico is a blend of traditional curanderismo practices with non-biomedical healing modalities from other cultures perceived as most effective.

The interest in alternative healing modalities is not the exclusive domain of traditional healers. There are international efforts underway to explore the efficacy of alternative medicine through rigorous clinical trials. Some physicians in the United States and in Mexico are investigating and, in some cases, adopting alternative treatments, particularly herbal medicines. Under the auspices of the National Institutes of Health's National Center for Complementary and Alternative Medicine, there are hundreds of funded studies throughout the US, including the Southwest. Both California and Arizona have clinical trial sites. For example, the University of Arizona, Department of Pediatrics, Health Science Center, Tucson is conducting clinical trials on treatment of functional abdominal pain in children using guided imagery and chamomile tea (manzanilla) as therapeutic modalities.²⁵

Over 90 percent of the client informants in the study knew about *curanderos* and *parteras*, with more than half using their services while also availing themselves of genetic services. Clients sought *curanderos* for treatment of folk-defined illnesses such as *susto* ("soul loss" or "fright sickness") and treatment of their children's genetic conditions. *Curanderismo* continues to thrive as a resource that is community-based, does not require documentation or means testing, and provides services within the context of the culture, usually at little or no cost.

Traditional Healers

Many curanderos have knowledge of two or more specialty areas and use techniques from these areas. Consequently, while defining specializations is useful in describing practices within the folk-healing system, it is artificial in that there are no such clear distinctions.

A number of different types of professional *curanderos* exist, and they are distinguished from one another and among themselves primarily by their predominant curing technique or combination of techniques.⁵

Curanderos have been referenced as a specialty although it is acknowledged that other specialties are also called curanderos by the public. According to some researchers ⁵, a curandero sees at least five patients per day, believes s/he has a special gift (don) for healing and makes use of the theoretical knowledge of curanderismo. Traditionally, they have not charged for their work but accept donations of money or other materials. The curandero total has been described as a healer who employs four levels of medicine: education, body work, medicine, and sacred tools. ²¹ Education involves teaching patients to take responsibility for their health and how to breathe, rest, hydrate and eat properly. ²¹ Body work involves the laying on of hands such as massage or simply touching with compassion. ²¹ Medicine includes plants, animal products, minerals, and proper handling of medicines. Tools are objects such as the branches used for performing a barrida (ritual sweeping) and limpia (spiritual cleansing), fuente con agua (open glass or bowl of water), feathers, crystals, and even medical instruments such as a stethoscope. ²¹,

Theoretical knowledge of *curanderismo* is defined in terms of three levels: material, spiritual and mental.⁵ The material level involves use of objects and rituals and is the most extensively practiced and widely reported.^{5,21} Objects and rituals are seen as effective in healing since, according to one prevailing theory, all persons, animals and certain objects can emit or absorb vibrating energy.⁵ This energy can be negative or positive. Illness is a concentration of negative forces in a person's body. These forces, depending on their origin, can affect a person mentally, physically or socially. The *curandero* uses objects and rituals at the material level to make a diagnosis and effect treatment by altering or correcting the patient's energy.^{5,21,27}

Objects, mainly those which are commonly available and familiar to the people seeking help, include herbs, spices, fruits, nuts, animals and animal products (e.g. eggs), flowers and religious symbols (e.g. crucifix, pictures of saints, incense, oils, specially prepared waters and candles). These materials are believed to have the ability to remove negative influences or sickness²⁵ and are often arranged on an altar, either stationary or portable (called a *retablo*).

The materials found on the altars of healers in New Mexico and Arizona show a much greater use of Native American artifacts such as sage bundles and eagle feathers with ornate beadwork handles. Different types of feathers are used for different healing rituals. They are have special significance to the healer and are treated with great care, wrapped individually and carried in a hand-tooled leather case. Several of the healers interviewed in the extension study discussed rediscovering the healing modalities from their Native American ancestry, ranging from Toltecs to Ojibwas. One of the healers explained that the Sundance ritual is still being practiced in New Mexico and El Paso in West Texas. Women are now allowed to take part in this ritual for giving thanks to the Gods for granting special requests. The ritual involves fasting, dancing, and at times, dramatic self-mortification such as piercing. In addition, healers in New Mexico and Arizona also reported experimenting with newer healing modalities such as craniosacral therapy, described as non-invasive palpation of cranial bones to encourage the body's self-healing capabilities.

Rituals such as saying prayers, burning of copal and aromatic herbs, or using special rites in preparing herbal treatments are an essential part of the healer's work. One of the major ritual practices is the barrida. ^{5,21,27} A barrida is a ritual sweeping of a patient. Using bundles of herbs (rosemary, rue, and sweet basil are often included), the curandera ritualistically sweeps the client while reciting prayers and anointing with prepared waters and oils. A barrida is done to

accomplish a *limpia*, or spiritual cleansing. Ritual cleansing transfers the problem from the patient to the object, gives strength and comfort to the patient's spiritual being, and protects against the continued effect of negative vibrations.^{5,21} At the conclusion of the *barrida* and *limpia*, objects used in these rituals are often burned to destroy negative energy that the cleansing objects have absorbed.⁵

At the spiritual level, the *curandero* serves as a medium to communicate with the spiritual world. Practice at this level rests on the soul concept. The soul is the life and personality force of a human being. ^{5, 21}

The mental level is the least commonly practiced and the one considered most dangerous to both the healer and the patient.⁵ To cure, the *curandero* either dominates the patient mentally to eliminate social and psychological problems or channels mental vibrations at the affected part of the patient's body.⁵ Few *curanderos* feel comfortable and adept with healing at the mental level. They relate it to spirits of the dark (*obscuridad*) and magic used in sorcery and witchcraft.²⁸ The sicker the patient, the more precautions the healer must use to protect against the negative forces assailing the client.^{21,28}

Parteras are midwives, usually women in their 30s or older, who are themselves mothers and/or grandmothers.²⁸ Poverty-level incomes are not the only reason many women along the U.S./ Mexico border make use of their services.⁵ It is also a cultural preference. Parteras are women and protect the modesty (pudor) of the patient, a strongly held value. Patients and parteras share the same language and culture. Use of the partera is a family tradition. Parteras learn their skills from their mothers. Referrals are word-of-mouth and repeat patients.⁵ Patients typically bring a relative (husband, mother, sister or mother-in-law) on the first visit. Mexican nationals also use parteras.^{21,28} In Mexico, most births still occur in the home. Two-thirds of the population has no medical insurance.²⁹ As a consequence, parteras do most of the deliveries. The Mexican government reluctantly acknowledges and supports the licensing of these midwives. (See Supplement for elaboration on discussion of midwifery).

Herbolarios and yerberos are herbalists. The herbolario uses all parts of the plant or tree. The yerbero uses leaves of medicinal plants. Herbal medicine is a mainstay of curanderismo with knowledge of herbs typically handed down through the family. Although herbal medicine is used by a number of different types of professional curanderos, the herbolarios indicate that they specialize in use of herbal medicine. In rural areas, it is common for people, not just traditional healers, to cultivate a small plot of herbs. For those herbs which cannot be cultivated or collected, there are also botánicas, yerberias, and candle shops. These shops, readily identifiable in the local yellow pages under herbal and/or candle shops, sell herbs (fresh and dried), candles, and other supplies. Lists of commonly used medicinal herbs, roots, and teas can be found in the Supplement section.

Active dissemination of information on the use of herbal medicines among Hispanics continues ranging from publications such as Folklorist Eliseo Torres' Green Medicine: Traditional Mexican-American Herbal Remedies²⁹ to the formal training of folk healers and biomedical providers. For example, the Universidad Autónoma del Estado de Morelos (University of Morelos, Mexico) offers a continuing education course, "Diplomado en Plantas Medicinales Y Medicina Tradicional de Mexico," to folk healers and biomedical providers. The Mexican government has recognized the efficacy of some traditional remedies and is actively supporting ways to make them readily accessible and at low cost. They are using this strategy to address the

health care needs of a large portion of the population that cannot afford or access biomedical care.²⁹ The widespread use of medicinal herbs is found in Germany, France, Japan, China, much of Latin America, and many other countries.²⁸

Sobadores treat muscle aches and pains, sprains, and tenseness.⁵ Although many do not have formal training, they adhere to set procedures in treatment. They perform a masaje (massage) for treatment of pain, headaches or nervous tension. Another treatment, the sobadita, is for a specific muscle problem like sprained ankle. Craniosacral therapy (previously mentioned as a non-invasive palpation of cranial bones to encourage the body's self-healing capabilities) was identified as being used among the folk healers in New Mexico and West Texas but was not reported by the healers interviewed in South Texas.²⁸ Hueseros, those who set bones and dealt with muscle sprains, no longer exist as a group in along the border (replaced, in part, by chiropractors). However, where chiropractors are few, sobadores have taken over some of the hueseros' functions. In the interior of Mexico, these differences do not prevail.²⁸

Espiritistas and espiritualistas are "spiritists" or clairvoyants. 5, 21, 28 Although espiritistas and espiritualistas are considered two separate specialties, there is disagreement in the definitions among those familiar with these individuals, those who were self-identified as such and in the literature. Whatever the case, it is correct to say that their practice is primarily on the spiritual and mental level. There are fewer of these individuals and they are more difficult to access. Before healing, they go into a trance and become conduits for spirits of the light (espíritus de la luz) which direct them in ways to heal clients. 5, 28

Riferas are card-readers.⁵ Other healers, particularly curanderos, also read cards usually as an adjunct to their other work.²⁸ The cards used may be the Tarot, a 40-card deck from Mexico, and the more highly esteemed Spanish deck.^{5,28} Card readers make specific predictions about health, home, and social conditions. They console clients and discuss past occurrences. In New Mexico, healers referred to card-readers as señoras, a way of giving social status to these individuals which is similar to using the term "doña".

Rayistas and Graniceros are individuals who have survived being hit by lightning or hail and are believed to be imbued with special healing power and energy.²⁸

Terapeúta corporal bioenergética (bioenergetic corporal therapist) or TCBs can be thought of as modern curanderos. These folk healers are incorporating Eastern and Western medical practices, as well as indigenous practices. They use herbal medicine, massage, acupuncture, auricle therapy (acupuncture on the ear), urinotherapy (using patient's own urine to treat a variety of problems), reflexology (massage and acupressure on soles of feet), temescali, sphygmomanometer, stethoscope (to check blood pressure), magnets, and passing copper rods over marked channels of acupuncture to free the flow of energy through the body. TCBs are concerned with helping an individual "vent all that energy pent up in his body which produces physical problems." A prevailing belief is that good health exists when there is harmony between the emotional, spiritual, and physical realms of an individual. The TCB tries to assess sources of a client's disequilibrium. To treat the physical problems alone, typically the biomedical approach, is only a partial and temporary solution that does not address the root of the problem. TCBs are taught that for many clients, particularly those who work in the home, there may be a need to "unload" (desembuchar) pent up anxieties. In order to facilitate this catharsis, TCBs are explicitly taught to greet and embrace each client warmly and spend about

an hour interacting with the client. Thus, the *personalismo* and *amabilidad* of the TCB are part of the treatment.²⁸

Temascaleros - Persons who use the temascali, a recently revived Aztec practice involving a medicinal sweat bath (in Nahuati, the language of Aztecs, te=rock; mas=steam; cali=house) for treating health problems such as infertility, allergies, respiratory problems, rheumatism, asthma, and for postpartum healing.²⁸ In the extension study, several of the folk healers interviewed discussed the use of the temascal. The rituals described are similar and rich in spiritual symbolism. However, the Native American temescal is designed to be portable.

Suggestions for Genetic Service Providers:

- ✓ Be aware that some clients may be using the services of a *curandero/a* at the same time they are receiving genetic services.
- ✓ Frame questions about alternative practices in a positive manner to prevent putting families on the defensive, e.g. "Some of our families use *remedios caseros* (home remedies) or herbal medicines such as *manzanilla* (chamomile). Are you using any of these now?
- ✓ Be aware of common folk-defined illnesses and associated healing practices (See Section VI. Mexican American Folk Beliefs Common Folk-defined Illness)
- ✓ When possible, negotiate integration of traditional and Western medical treatments. Many folk remedies, such as rehydration through drinking of teas, are beneficial. Learn more about phytochemical analyses of herbal remedies through resources referenced in Section X. Supplement Compendium of Herbal Medicines.

VI. MEXICAN AMERICAN FOLK BELIEFS REGARDING GENETIC CONDITIONS AND COMMON FOLK-DEFINED ILLNESSES

In this section, beliefs about causes and preventive measures for genetic conditions and birth defects, and condition-specific perspectives among clients, traditional healers, and genetic service providers are presented. In addition, eight other common folk-defined illnesses and their associated health practices are also discussed.

Information is based on extensive ethnographic interviews of 40 medically indigent Mexican and Mexican American clients in genetic service clinics, 43 genetic service providers, and 45 traditional healers in Arizona, California, New Mexico, and Texas, as well as from the literature. (See Section VII. Client Perceptions of Genetic Services and Barriers to Care for an elaboration on study methodology). A review of this section offers genetic service providers a deeper understanding of the folk beliefs that may influence utilization of genetic services.

Causes of Genetic Conditions and Birth Defects

- Clients attribute multiple causes, both natural and supernatural, to their child's genetic condition.
- Chance and God's will are predominant ideas in clients' explanations of causation.
- For curanderos and parteras, heredity/"gene problems" and lifestyle are two primary explanations of causation. Each curandero's viewpoint may encompass several ideas, biomedical and traditional, simultaneously.
- Clients and curanderos consider fathers as having far more influence on birth outcomes than in the biomedical viewpoint.

Mexican American genetic service clients interviewed for this study attributed their children's genetic conditions and birth defects to multiple causes, both natural and supernatural. Chance and God's will were predominant ideas in explanation of causation. "My son's Down syndrome was due to pure chance...there was nothing we could have done...God planned this situation..." Along with the idea of God's will was the idea that there is a divine reason for having a child with a birth defect. When asked, many Mexican American families described something positive about having a child with a genetic condition such as strengthening family bonds.

Clients also attributed heredity (e.g. "bad genes"), environmental toxins, emotional problems such as depression, baby's lack of oxygen at birth, lack of prenatal care and prenatal vitamins, pregnancy complications, falling or physical injury to the abdomen, baby's father's use of alcohol and other drugs and not taking care of his general health, teratogenic agents (e.g. tranquilizers), use of abortifacients (specifically yerba de la vibora and oregano), susto (fright), lunar eclipse, intercourse during menstruation, and punishment from God as causes of genetic conditions or birth defects.

For curanderos and parteras, heredity/"gene problems" and lifestyle were the two primary explanations of causation. Lifestyle-related causes cited were alcohol and drug abuse, poor nutrition, and sexually transmitted diseases. Each curandero's viewpoint could encompass several ideas, biomedical and traditional, simultaneously. For example, heredity, alcohol abuse, and a lunar eclipse were included in the same explanation. Social pressures, lunar eclipse, fear, mal puesto (hex), thinking about having a child with a birth defect, lack of oxygen at birth, illness such as diabetes, being older, use of abortifacients, and environmental toxins were also causes. A Yaqui healer who was interviewed also explained that if a woman is frightened by an animal during her pregnancy, this can affect the baby's health. This same attribution of causality has also been reported by the Tohono O'Odham.¹

For clients and *curanderos*, fathers are considered to have far more to contribute to birth outcomes than in the biomedical viewpoint. For example, a woman considering marriage should ascertain if her husband-to-be is a heavy drinker or heavy smoker, if he has syphilis, and if he is promiscuous.

Prevention of Genetic Conditions and Birth Defects

- Clients and traditional healers emphasize healthy lifestyle habits such as avoiding alcohol and drugs, not smoking, and good nutrition as preventive measures.
- Clients and traditional healers perceive that having good relationships with family, community, and in the workplace during pregnancy are preventive measures.
- Some clients referenced prenatal care and taking vitamins, including folic acid, as preventive measures. Few traditional healers are aware of the use of folic acid.
- Clients' ideas of prevention demonstrate integration of spirituality and healing.

Genetic service clients most frequently listed avoidance of alcohol and drugs (especially for the father), prenatal care and vitamins, including folic acid, not smoking, avoiding stress during pregnancy, "God and doctors," "God and parteras," "Doctors, God, and family," genetic counseling, and using birth control as preventive measures.

Among curanderos, awareness of folic acid is minimal and vitamins were understood primarily as a source for iron and in one case, vitamin B12. Good nutrition, including plenty of fruits and vegetables, was viewed as more effective than vitamins. Overall, healthy lifestyle habits and healthy relationships (e.g. good relationships with family, community and in the workplace) were perceived as having the biggest influence on preventing genetic disorders and birth defects. This perception realistically reflects the particular circumstances of the people served (limited resources and consequent inability to afford vitamins, medications). Other methods of prevention referenced include adequate rest, that both parents stay healthy, being aware of family history of genetic conditions and avoiding problems, wearing a metal item such as a pin or key to prevent cleft palate caused by lunar eclipse and abstaining from intercourse during a particular day of each month (calculated a specific way).

As with other traditional healers, parteras reported healthy lifestyles as having the greatest effect on preventing genetic disorders and birth defects. Avoiding alcohol, drugs and extramarital sex and having good nutrition were the predominant methods of prevention. Good nutrition was described as including plenty of fresh fruits, vegetables, and herbal medicine teas for nausea. Also, meat was to be avoided (because of the perception that toxins are injected or fed to animals in the feedlots). Pre pregnancy preparation by eating well and avoiding toxins (alcohol, drugs, chemicals) was also an important concept. Some parteras were aware of the use of folic acid for neural tube defect prevention through exposure to public health interventions and/or their midwifery training. Prenatal care and education were also considered preventive measures though less frequently.

Suggestions for Genetic Service Providers:

- ✓ Be aware that alternative explanations of causality may influence a client's understanding and acceptance of genetic information.
- ✓ Providers should maximize opportunities to support good relationships within family, community, and workplace during pregnancy that are perceived as preventive measures.
- Providers should reinforce healthy lifestyle messages and work to promote awareness of folic acid.
- ✓ Young, second and third generation Mexican Americans may experience declines in health status through acculturation. They need help reclaiming beneficial aspects of traditional culture.

The following section represents the perspectives of traditional healers, clients, and genetic service providers interviewed for this study. The specific conditions listed were ones for which the children of the client caretakers interviewed were receiving genetic services. Thus, this table is not intended as an exhaustive list of genetic conditions. The primary difference between the causes reported by clients in the original study in South Texas and the expansion study along the U.S./Mexico border was the greater number of references to teratogenic agents and environmental toxicities among clients in the expansion study.

Condition-specific Perspectives - Explanations of Causality and Treatment

Condition (in biomedical terms)	Traditional Healer	Client	Genetic Providers
Fetal alcohol syndrome	Alcohol use during pregnancy can cause birth defects; both parents should abstain	Alcohol use during pregnancy can cause birth defects; both parents should abstain	Alcohol use during pregnancy can cause FAS/E; it is a lifelong condition; pregnant women should abstain.

Condition (in biomedical terms)	Traditional Healer	Client	Genetic Providers
Mental retardation; Down syndrome	Due to a missing gene; due to an extra chromosome of the father; errors in DNA	Due to pure chance; God's will; told that it was genetic but is doubtful since no one else in family is affected; Family does not perceive a problem; cause unknown to family; teratogenic agents	Many children with severe mental retardation have genetic disorders. Chromosomal abnormalities are common, with Down syndrome and Fragile X making up the majority of cases; may also be associated with use of alcohol, drugs and environmental exposure.
Spina Bifida and other NTDs	Venereal disease/infectious genes passed down through generations;	Marital stress and late diagnosis of maternal diabetes; Agent Orange; will use curandero if helps; taking child to cathedral for healing; mother-in-law makes pilgrimage to shrine of San Juan del Valle in San Juan, Texas; falling down and hitting stomach; use of abortifacients; insecticides, fertilizer; relatives attributed spina bifida to eclipse and God's punishment; anencephaly caused by environmental pollution; when clients use biomedical terms such as anencephaly, these have usually been learned in the course of their care; otherwise, common, graphic terms are used to describe a condition, e.g. water on the brain, deformado; nacio malito (little one born sickly)	NTDs involve incomplete development of the brain, spinal cord, and/or protective coverings for these organs. NTDs occur when the neural tube fails to close in the embryo. Most common NTDs are anencephaly, encephalocele, and spina bifida. Babies with anencephaly are born with underdeveloped brains and incomplete skulls. Anencephaly results in miscarriage, stillbirth or a newborn who dies within a few days or weeks. Spina bifida accounts for over half of all NTDs. It occurs when the neural tube does not completely close leaving an opening in the spine. It can range from a mild defect to a serious condition, involving paralysis, loss of feeling, infection, loss of bladder and bowel control.

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Condition (in	Traditional Healer	Client	Genetic Providers
biomedical terms)	·		÷
Macrocephaly	Massage the head so that it doesn't grow; infectious genes passed down through generations	Sotos syndrome was possibly caused by fright (susto) from being in a car accident, lack of oxygen because baby was born by C-section; or caused by chance (not inheritance)	Most commonly caused by increased intracranial pressure with hydrocephalus. Found in genetic syndromes such as Sotos syndrome or NF-1.
Cleft Lip and Palate	Lunar eclipse; Due to infection or infestation; do not mix dirty clothes from children in the other	Lunar eclipse; pregnant women can protect against effects of eclipse by wearing a metal object (such as a	Conditions which occur early in pregnancy when tissues that usually form the lip or roof of mouth fail to
	laundry; pregnant women can protect against effects of eclipse by wearing a metal object (such as a key) pinned to outer garments	key) pinned to outer garments.	Cleft lip is an opening in the upper lip between mouth and nose. Cleft palate is an
			opening in the roof of the mouth. Type and severity of clefts vary. Sometimes clefts can be found in families
			who have clefts in other family members. Some clefts can be linked to certain syndromes. Treatment involves
			team of medical specialists including surgeon, orthodontist, speech and language therapist, ENT surgeon and pediatrician. Multivitamins can reduce facial clefting.

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Condition (in biomedical terms)	Traditional Healer	Client	Genetic Providers
Seizures	If a patient has seizures, boil a small slice of dehydrated umbilical cord to treat (this was perceived as effective on a child when medication was not); faith can heal; do whatever works; Epilepsy requires a long period of treatment, therefore it is difficult for folk healers to treat	Runs in the family; evoked by strong negative or positive emotional experiences (e.g. receiving news of sudden death of a loved one); vitamin deficiency; eating uncooked pork that has a worm that scars the brain; parents make mandas or pledges, "If my son doesn't have seizures, I pledge to pay for a celebratory mass"; teratogenic agent (tranquilizers taken during pregnancy)	A temporary disruption of normal brain wave pattern. Causes are organic brain injury, metabolic disturbances, fever, infections, poisons or toxins or other unknown reasons.
Advanced Maternal Age	Older mothers more often have children with birth defects; refer women with advanced maternal age and high risk pregnancy to biomedical health providers (a practice influenced by licensure requirements of documented midwives): For other types of curanderos, the concept of AMA does not exist	Not considered an issue	Risk for having a child with a chromosome abnormality increases with mother's age
Muscular dystrophy	No specific explanation ascertained	Teratogenic agent (hormone injections received in Mexico to prevent pregnancy); Rh incompatability	Genetic service providers counseled client caretaker (father) that hormone injections and Rh incompatability were not the causes of the child's condition; Many neuromuscular disorders are a result of genetic mutations that affect the proteins in nerve and muscle cells. The loss of or abnormalities in these proteins cause genetic neuromuscular disorders.

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COMMON FOLK-DEFINED ILLNESSES

- A culture-bound syndrome is a folk-defined illness treated within the context of a particular culture.²
- Some of the Mexican American culture-bound syndromes can be linked to recognized physiological conditions and cannot be analyzed solely on the basis of sociocultural factors. They may also represent different labels for serious medical conditions (e.g. caida de la mollera).
- Culture-bound syndromes are useful screening labels for patients with high disease loads (susto) or are harmless in and of themselves but their folk treatment may have significant medical consequences.²
- Patients rely heavily on use of home remedies, particularly herbal medicine, for the treatment of folk-defined illnesses.
- Patients may use medications and supplies, such as needles, from other countries or from previous treatments that could be inappropriate or dangerous.

This section addresses eight common syndromes and their associated health practices.

- 1) Caida de la mollera ("fallen fontanelle"). This is a condition that can occur in any infant until the anterior fontanelle closes. The traditional belief is that this disorder arises from removing the nipple too abruptly from the infant's mouth, bouncing or dropping the infant, letting the baby fall to the floor, tossing the baby in the air too hard, or bumping the baby's head. Symptoms include depressed anterior fontanelle, diarrhea, listlessness, restlessness, an inability to suck or grasp a nipple firmly with the mouth, changed suckling sounds and, occasionally, fever. Treatments include inserting a finger in the child's mouth and pushing up on the palate, holding the baby upside down over a pan of tepid water so that the tips of his hair touch the water, slapping the soles of his feet, and applying a poultice made of fresh soap shavings, eggs or warm salted olive oil to the depressed area of the infant's head. Biomedicine attributes this condition to severe dehydration, with treatment involving carefully balanced intravenous fluids to correct fluid and electrolyte imbalance.
- 2) Susto ("soul loss" or "fright sickness"). The traditional belief is that this condition is due to a sudden frightening, upsetting or stressful experience such as a car accident, seeing someone being harmed, receiving sudden news of the death of a loved one, or being chased by a dog.^{2,4} It can affect people of all ages. The experience is thought to dislodge a person's spirit from the body.² Symptoms include languor, listlessness, anorexia, daytime drowsiness, nighttime insomnia, jumping at sounds, irritability, diarrhea, and depression.^{2,4} Susto pasado is a severe form of the chronic illness, exaggerated or persistent, and is considered potentially fatal.⁶ A common pattern of folk treatment is to try a barrida (ritual sweeping) and limpia (spiritual cleansing and reconsecration) followed by soothing herbal teas.^{7,8}

Methods of treatment suggest that *susto* has more than just psychological significance.² People who are *asustado* (victims of *susto*) have a significantly higher disease load, have diseases that are more serious than the overall patient population, and have a significantly higher mortality rate.⁹ Further, herbal teas have bioactive compounds and their use has potentially significant physiologic consequences.¹⁰ The extensive use of sugar water as a treatment provides some support for a hypothesis that *susto* is linked to stress and hypoglycemia.¹¹

Like susto, espanto is a form of spirit loss, but it is much more severe.^{6,7} Susto takes place when the person is in possession of his or her spirit, and although the spirit may temporarily leave the body due to fright, the spirit is believed to be nearby and can be returned to the body easily.^{5,6} Espanto usually occurs when a person is sleeping. Since at this time the spirit may leave the body to wander during dreams, it may not be nearby to return to the body.^{6,7}

3) Empacho ("bolus of food lodged somewhere in the digestive tract"). According to ethnographic research, individuals of any age can be affected, but infants, children, adolescents, and women in the immediate postpartum period are at highest risk for this condition. The traditional belief is that empacho is due to a bolus of food that has become stuck to the abdominal lining. Metaphorically, curanderos also use the term empacho to describe any kind of blocks to the emotional or energy body. Eating improperly cooked foods or certain foods at the wrong time, eating while emotionally upset, swallowing chewing gum, swallowing saliva during teething (instead of drooling), and eating foods one does not like are all thought to be causes. Major symptoms include marked bloating of the stomach or "stuffiness" of stomach or intestines, constipation, indigestion, diarrhea, vomiting, and lethargy. It is diagnosed by feeling for abdominal distention, a large lump in the stomach, and bundles of knots in the calves of the legs. 13, 14

The most common treatments are gentle abdominal massages with olive oil to dislodge the bolus, and ingestion of herbal teas such as manzanilla (chamomile) or yerba buena (spearmint) and other substances to break up the blockage. Laxatives, upset stomach remedies, and teaspoons of olive oil are also given. Another treatment is to roll the person on his or her stomach, pinch the skin on the lower back and pull on it until it "pops." The popping sound is taken to mean that the blockage has been dislodged. Supposedly rolling an egg on the patient's stomach while reciting prayers evokes an energy that opens the intestines. Of concern is the use of greta (lead oxide) and azarcón (lead tetroxide) to treat empacho. Traditionally used by Mexicans and Mexican Americans as laxatives, these lead compounds are highly toxic to children and have caused numerous cases of lead poisoning in the Southwest. Mothers should be encouraged by health care providers to use massage and teas to treat empacho and educated to discourage use of lead compounds.

4) Mal de ojo ("evil eye"). This is an illness thought to be <u>inadvertently</u> caused by unusual strength in the gaze of certain persons (especially those with dark, piercing eyes such as the actor, Omar Sharif). Strong eyes are said to heat up a child's blood. There is a belief that a person projects something of himself when he admires another. If the person receiving the admiration can't handle it, illness results. Mal de ojo can happen to anyone, but pregnant women and children are considered most vulnerable. Symptoms associated with this disorder include fretfulness, general malaise, weeping, headaches, high fever, aches, and pains similar to those of colic. Animals and objects are also thought to be harmed by mal de ojo. For example, an admired vase might be cracked, chipped or damaged. To guard against mal de ojo, the

admirer must touch the person being admired.^{4,6} Genetic service providers should find a natural, friendly and discrete way to hold or touch any Hispanic children they gaze upon and admire. Children may wear an ojo de venado (deer's eye), a large seed pod threaded on a red yarn bracelet, to protect against mal de ojo.¹⁵

- 5) Bilis (rage). Bilis is thought to be caused by excess secretion of bile that floods the person's body when suffering from chronic rage. The condition is said to cause digestive problems and toxicity of the body. A curandero cures bilis by relaxing the patient with massage, barrida and limpia, gentle, positive counseling, and prescribing soothing herbal teas and baths.
- 6) Mal aire (bad air). The traditional belief is that this disease can be caused by prolonged exposure to the night air. ¹² Children are considered especially susceptible. Mal aire causes cold symptoms, earaches, facial paralysis, and neuralgia. ^{6, 12} One of the traditional ways to avoid the illness is to swaddle young children tightly in blankets before taking them out at night. This practice has been explained as more a metaphor for protection than a health rule. ¹² Other methods of protection involve avoiding drafts and covering the nose and mouth with a handkerchief against the cool night air as when coming out of church, theater or heavily attended social gathering. ⁸
- 7) Mal puesto (a hex or curse). There are people (and not just Mexican Americans) who believe that their misfortune is the result of a hex or curse.^{6, 12} Such people may be vulnerable to charlatans or impersonators of curanderismo. ¹² One of the study informants is a curandera and psychiatric nurse who does not believe in mal puesto but addresses it with clients seeking aid. She advises her clients to "take responsibility for your health and the health of your family...God is much more powerful than any person or 'witch'..Put your energy into the development of your soul and spirit. If your spirit is healthy, no harm can penetrate your soul." ¹²
- 8) Mala suerte or salado (bad luck). In curanderismo, there is a belief that the energies and expectations put into life have a direct effect on what happens to people. 12 When a person interprets events as bad luck, he/she creates a vibration which, mirrored in the environment, reflects back on the person, and bad luck takes on a life of its own. Treatment involves use of the barrida and limpia (ritual cleansing) and pláticas (heart-to-heart talks). 12

Other practices that genetic service providers should be aware of include:

Remedios caseros (home remedies). Providers should be aware that patients rely heavily on use of home remedies, particularly herbal medicine.²⁰ Over-the-counter medicines such as acetominophen and various types of vapor rubs are also used frequently.²¹

Imported pharmaceutical products. Patients may use medications imported from other countries or from previous treatments that could be inappropriate or dangerous. ¹⁵ Cafergot is a treatment for migraines and adrisal is a treatment for premenstrual syndrome. ⁸ Although neither of these pharmaceutical products is available in the U.S., people ask family and friends who travel to countries where they are available to bring them back. Most medications, such as antibiotics, are available without a prescription in Mexico and at 40-45 percent lower cost. ⁸ Some medications dispensed in Mexico may lack controls so that dosages may vary. Prenatal vitamins, available at much less expense in Mexico, may not have the same potency. The

practice of buying cheaper goods in Mexico is certainly not restricted to pharmaceuticals nor to Hispanics.⁸

Health care providers should be aware that patients may also use syringes to inject vitamins, medications, and contraceptives purchased in Mexico. Needles may be shared for these injections, exposing the users to infection. The health care provider must screen for the use of injectables, not only to avoid untoward drug reactions, but also possible HIV exposure. 24

Suggestions for Genetic Service Providers:

- ✓ Be aware that a patient's reference to a folk-defined illness may provide clues to identifying a physiological condition or signal a serious medical problem.
- ✓ Be aware that home remedies and over-the-counter medications are widely used to treat common folk-defined illnesses and may be beneficial or have adverse effects.
- ✓ Become familiar with the pharmaceuticals that patients commonly purchase from Mexico and other countries and their effects on other medical regimen.
- ✓ Health care providers should be aware that patients may use syringes that have been shared to inject pharmaceuticals purchased in Mexico.

VII. CLIENT PERCEPTIONS OF GENETIC SERVICES AND BARRIERS TO CARE

- This section helps provide understanding of the experiences and perceptions of medically indigent Mexican and Mexican American genetic services clients.
- Information is based on 82 ethnographic interviews conducted at 14 sites in Arizona, California, New Mexico, and Texas, primarily along the U.S./Mexico border.
- Issues affecting client perceptions and creating barriers to care are aggregated into four bulleted lists: language and communication, poverty, cultural differences, and system issues.
- A profile of genetic services in each state is provided as background for the lists.
- Suggestions for improving access to, and utilization of, genetic services are offered for consideration at the end of the section.
- Section IV. Cultural Beliefs/Values and Their Relationship to Health Behaviors should also be reviewed.

ABOUT THE STUDY

Study sites were selected based on availability and willingness of staff and clients to participate. Clients were identified by the nurses, social workers, and genetic service providers associated with the genetics clinics. Genetic service providers who were interviewed were identified by leaders of the public and privately funded genetic service institutions involved in the study.

Individuals participated in an institutionally approved interview process after informed consent was obtained. A 50-question interview guide, composed primarily of open-ended questions, was developed for use with each of the target groups. A bilingual medical anthropologist, also a registered nurse, supervised and conducted the interview sessions that lasted approximately 2 hours each. Interviews were conducted in English, Spanish or both according to the desire or need of the participants and audio taped with the knowledge and consent of the interviewees. All interviews were transcribed, and when necessary, translated verbatim and entered into the NUD*IST 5 (Non-numerical Unstructured Data-Indexing, Searching & Theorizing) computer program¹ for qualitative analysis of the interview text.

In the initial phase of the study, 23 clients and 25 genetic service providers in South Texas were interviewed. Interest in expanding the study to the other border states prompted additional interviews with 17 clients and 17 genetic service providers from Arizona, California, New Mexico, and west Texas (El Paso).

There were multiple challenges in data collection, ranging from obtaining institutional review board approvals to the complexities of scheduling interviews across the four states. Nevertheless, the information contained in this section offers valuable insights. It should be noted that generalizability of findings beyond the study is limited due to the use of a convenience sample, small sample size, and the qualitative nature of ethnographic research.

Data from the ethnographies revealed that while provision of genetic and other health care services varied between and within states, there was very little difference in the reported

experiences of the medically indigent Mexican American client population all along the U.S./Mexico border. The presence of not only cultural differences, but also the pervasive influence of socioeconomic factors and system issues affected clients' experiences with and perceptions of genetic and other health care services.

Issues Affecting Client Perceptions and Creating Barriers to Care

Language and Communication Issues

- Language (i.e. Spanish-speaking clients and English-speaking providers).
- Use of cryptic medical terminology by health care providers.
- Functional illiteracy among clients, including a lack of understanding of basic human biology.
- Limited awareness among health care providers of Mexican Americans' culturally appropriate interpersonal communication skills.
- Perceived lack of information and unwillingness to communicate on the part of genetic service providers regarding the results of diagnostic testing (e.g. results of sonography).

Cultural Differences Issues

- Mexican Americans' view of healing rooted in spirituality and faith in contrast to biomedical model that separates body from mind and soul.
- Limited awareness of beliefs, values, and behaviors of Mexican American clients among health care providers.
- Much less reliance on sophisticated technology among Mexican American clients.
- Mexican Americans' view of pregnancy as a normal, natural process that does not require immediate medical intervention.
- The concept of advanced maternal age is foreign to most Mexican American clients.

Poverty Issues

- Prevalent poverty of clients results in lack of dependable transportation and missed appointments.
- Frequent changes in residence and inability to pay telephone bills create difficulties in locating and contacting clients.

Poverty Issues

- Accessibility and availability of genetic services is greatly limited for clients in many geographical locations, especially rural areas (i.e. no bus services in rural areas).
- Rural addresses made it difficult for genetic service providers to locate clients.
- Lack of assistance with childcare affects compliance with medical appointments.
- Respite services for caretakers of children with disabilities are difficult to access or simply not available.

System Issues

- The medical politics in some geographic areas can result in lab tests being sent to outside laboratories when more complete and less costly tests may be available locally; managed care, including Medicaid managed care, dictates utilization of laboratories; physican referral preferences affect service utilization).
- HMO capitation on care reduces access (e.g. genetic diagnostic tests may not be covered)
- Clients may endure long waiting times to be seen on the day of the appointment, particularly at hospital clinics and some physicians' offices.
- There is a scarcity of trained genetic service providers and support staff who are indigenous with close ties to the local community.
- There is frequent turnover in clinic personnel, particularly clinic secretaries, sonographers, and social workers.
- Clients' lack of awareness about availability and relevance of genetic services.
- Primary care providers' lack of awareness of genetic services and how to refer patients.
- Clients have little understanding about how to use social service systems.
- Excessive medical specialization contributes to lack of communication and coordination between treatment regimens of different physicians caring for the same child.
- Some providers have an unrealistic view of the international border as a true barrier to social, cultural, and economic interaction. In fact, residents in border communities are, in fact, negotiating a way of life in both nations despite numerous barriers and restrictions.

PHASE ONE: SOUTH TEXAS

In the initial phase of the study, 23 clients and 25 genetic service providers in South Texas (San Antonio and the Lower Rio Grande Valley were interviewed. Of the 23 clients, 16 were caretakers of children with genetic conditions and seven were prenatal patients (see Figure 1 under Phase Two below for a comparison of client demographics).

Pediatric genetic services in San Antonio were provided in a multi-disciplinary clinic by a team of geneticists, social workers, nurses, and dietitians to clients from communities throughout South Texas. In addition to medical genetics and genetic counseling services, additional services including assistance in linking to school, social, medical and financial services were provided. The facility, affiliated with The University of Texas Health Science Center in San Antonio, is well established and has been offering genetic services since the early 1970s. According to one of the genetic social workers interviewed, approximately 10% of the clients have private insurance and the rest are on Medicaid.

Pediatric and prenatal genetic services were offered at the other four study sites in the Lower Rio Grande Valley that served clients whose care was funded primarily by Medicaid and Title V. The physicians were private or university-based providers who traveled with a genetic counselor from large medical centers to all four sites. With one exception, the physicians were monolingual English-speaking as was the genetic counselor. Each clinic was staffed permanently with a clinic secretary and social worker who were bilingual in English and Spanish. Sonographers, also bilingual, who resided locally were present when needed.

For pediatric genetic services, children were referred by pediatricians, family physicians, or health care providers in a public health department or the Texas Department of Mental Health and Mental Retardation. For prenatal genetic services, pregnant women in three sites were referred by obstetricians, while at the fourth site, more referrals were made by family practitioners.

Of the six geneticists interviewed, only one was able to speak conversational Spanish; however, this individual's perceived lack of expertise in Spanish made it difficult to convey to clients genetic concepts and medical information they needed to know. "I don't speak Spanish and that is a big problem.." "I have to run around and find somebody to translate..."

The majority of social workers and clinic receptionists interviewed were bilingual. Two genetic social workers described lack of time to explain information from the physicians thoroughly with families and reported that language barriers reduced the amount of time physicians spent with monolingual Spanish clients. "The doctors tend to discuss things longer if the family is English-speaking. They don't believe I can explain in Spanish thoroughly on their level." This statement was corroborated in a comment by a geneticist regarding communication with Spanish-speaking clients. "I don't speak their language well and they don't come prepared. My staff doesn't know enough genetics. Social workers have to be trained to bring them up to a level of comfort.."

Geneticists and other genetic service providers also described difficulties in conveying genetic information to clients with little understanding of basic human biology. "Many Spanish-speaking families have not heard of genetics...is it more of an educational issue than cultural."

In San Antonio, the providers reported that long periods of waiting time for clients, difficulties with managed care, language and communication barriers, the lack of access to care in rural communities (that prevents early intervention for children with mental retardation and The University of Texas Health Science Center at San Antonio/Department of Pediatrics

developmental delays), and consequences of poverty were challenges to providing genetic services. "We have mothers who are low socioeconomic with big families, they don't really have time to deal with it. If the mother doesn't have a basic understanding of what this child has, they don't see it as important. As long as the child is surviving, and eating well, and walking, that's all that matters.." The providers were most proud of the multidisciplinary team approach to care. "Patients are able to utilize the doctors from many specialties. Great emphasis is placed on patient care and meeting other patient needs."

The genetic service providers in the Lower Rio Grande Valley cited language and communication barriers, geographic distance and transportation, high unemployment, lack of health insurance coverage, undocumented status, limited state funds, managed care restrictions, and lack of awareness of genetic services as challenges to providing genetic services. "We need to offer lots of education. Maybe advertising services more, especially in the Valley. Genetic disorders are not publicized enough. It takes a lot of outreach.." "There is a problem with primary care physicians not recognizing when patients need to be referred for genetic counseling."

Results of interviews with the clients in San Antonio and the Lower Rio Grande Valley indicated that they perceived a lack of educational materials available in Spanish and/or regional Spanish. One caretaker reported signing English-language consent forms for emergency surgery for her child although she was monolingual Spanish-speaking. "I was asked to sign some papers that they said were to give them permission to operate." In three cases, clients reported that husbands served as interpreters and signed consent forms for various medical procedures and paperwork associated with Medicaid and Title V eligibility. Standard medical Spanish or English terminology was seldom understood by the majority of clients. "No one explained Down syndrome in words I understood."

Other language and communication issues were limited awareness among health care providers of Hispanics' culturally appropriate interpersonal communication practices and perceived unwillingness to communicate on the part of some genetic service providers regarding the results of diagnostic testing (e.g. sonography results). Over half of all the clients interviewed described serious communication problems during the course of their care, particularly in the early stages, and most frequently with other biomedical providers who had referred them for genetic services. One client had lost a two-day old infant with multiple congenital anomalies in the previous pregnancy. She explained that the referring physician who was the first to tell her that something was wrong had been rude and abrupt. "I was angry and wanted to kill him because I think he withheld information from me since I had a sonogram before the six months..." The father of a 4-year old daughter with Down syndrome reported that he wanted more time to discuss problems with the geneticist, having only seen the doctor briefly.

Clients referred to two of the Valley genetics clinics appeared to be less prepared, unclear, and more anxious as to what to expect from genetic services as compared with the other clinic sites. "The clinic's work on my child is not clear in my mind. The problems could be due to genetics." Prenatal clients who were interviewed at their first visit arrived even less aware of the availability and purpose of genetic services.

In the cases of clients who were in the early stages of receiving genetic services, there was an uneasiness about the use of sophisticated biomedical technology. These clients, most of whom were recent immigrants or who maintained close ties with Mexico, had limited previous

exposure to such technology. Nevertheless, these clients were usually willing to use biomedical technology but often did not fully understand the information they received during their genetic counseling session. Some clients who reported that there had been no satisfactory reason given as to the cause of their child's condition had sought their own explanations. "The doctors do not say. I don't think they know what causes spina bifida. I have heard that it is due to all the sprays used when working in the fields and that it is also due to smog." "Just like the doctors, the clinic has failed to give me a straight answer on what happened to my baby."

Caretakers of children who had long-term and more frequent interaction with biomedicine had a greater degree of familiarity with technology and medical terminology. However, they reported other difficulties with their children's care. They experienced long periods of waiting to be seen on the day of the appointment, particularly at hospital clinics and some physicians' offices. The waiting was complicated by their children's needs for timely food and fluid intake, some needing catheterization. At the same time, caretakers feared they if they took time to tend to basic needs, such as going to the hospital cafeteria to eat, they would lose their place in line.

Caretakers also described difficulty in coordinating care simultaneously among multiple health care providers. In one case, a pediatric client with Cri-du-chat syndrome had been under the care of a geneticist, psychiatrist, neurologist, and pediatrician. The child's caretaker reported difficulty with fragmented care and made treatment decisions when one of the specialists was not readily available for consultation.

The social workers and clinic receptionists had the longest periods of social interaction with clients. The social workers and clinic receptionists were the first to see clients, they interpreted for them, and often spoke with the clients after the geneticist left the room. Clients preferred to discuss issues with clinic receptionists and/or social workers that they would not readily discuss with the geneticist. Clients reported confidence in physicians who responded to their concerns and mistrust in those who did not exhibit *personalismo* and *amabilidad*. "I have confidence in Dr. X because he is one of the few that returns calls right away."

On a personal level, the majority of clients indicated satisfaction with their genetic service providers. However, several clients reported wanting more time for explanations and that staff would listen since "parents just know." They wanted to know more about their children's conditions, linkage with support groups, more opportunities to include spouses in support groups, more bilingual caregivers, and how to find and obtain medically necessary items such as special formulas and hypoallergenic diapers.

Although most clients could access genetic services through Medicaid and Title V, they reported difficulties in paying for pharmaceuticals, medical equipment, and supplies. Some families were unsuccessful in qualifying for medical disability for children diagnosed with genetic conditions. Other consequences of clients' poverty included lack of reliable transportation, frequent changes in residence, lack of basic utilities such as potable water, electricity, and phone service, and lack of childcare and respite care. Clients also reported that the distance to genetics clinics and the lack of public transportation made it difficult to reach the clinics.

Client interviews provided evidence of integration of spirituality and healing. This was the case for all clients, even those who were not actively practicing their religion. Clients wanted to make pilgrimages to shrines for healing and reported family members having done so on behalf of their

children with genetic conditions. Others described the importance of prayer in healing such as making appeals to Saint Jude, a Catholic saint who helps with hopeless causes. Eight of 16 client caretakers reported that it was God's will that they had a child with special needs saying, "God planned the situation," or "God knows what he is doing...I just accepted it."

Over 95 percent of client informants knew about *curanderos* and *parteras*, with half of them using their services while also availing themselves of genetic services. Three client informants reported seeking services from medical doctors in Mexico for the care of their children with genetic conditions and also for their own health problems. One of these clients reported crossing the border for minor health problems "like sinuses" because services were less expensive. Two of the clients had taken their children with genetic conditions for medical evaluation and promising treatments.

The majority of clients interviewed reported Mexico as their birthplace. Client families included members who had Mexican, U.S. or dual citizenship, individuals trying to recover original dual citizenship status, and undocumented persons. All of the clients interviewed maintained active ties with extended family in Mexico, traveling back and forth and, in several cases, living with family in Mexico for brief periods while continuing to work in the U.S.

PHASE TWO: EL PASO, NEW MEXICO, CALIFORNIA, AND ARIZONA

Interest in creating a resource with broader applications prompted an expansion of the original study. Interviews were conducted with 17 clients and 17 genetic service providers from Arizona, California, New Mexico, and west Texas (El Paso). With one exception, all clients were caretakers of children with genetic conditions. The demographics in this second study phase among the clients interviewed are compared with the clients in the initial phase as follows:

FIGURE 1

Demographics	Phase One: South Texas	Phase Two: Southwest
Female	78%	82%
Ages 19-35	65%	35%
Born in Mexico	65%	52%
Monolingual Spanish	82%	59%
Did not complete high school	44%	47%
Married	77%	59%
Catholic	78%	59%

EL PASO

In expanding the study, El Paso, a city on the borders of Juarez, Mexico and Sunland, New Mexico, was considered another opportune site for gathering information.

The six clients interviewed in El Paso were receiving genetic services for their children at the only genetics clinic operated under the auspices of the Texas Department of Health. The geneticist traveled from Austin to El Paso every four to six weeks to spend two days providing services in the clinic. The genetics clinic was previously located on a bus route and near a shopping center where families could accomplish several errands in one trip. The clinic was moved to an administration building with other public health programs that did not provide direct services. It was no longer near public transportation and was difficult to locate. Clients had to sign in and obtain a visitor's badge. The imposing building, with security guards and official seal of the State of Texas, was formidable to families who had undocumented family members. According to the genetic social worker, "there is an unbelievable amount of paperwork" and not enough personnel to handle all of the requirements for medical records management as well as case management.

Clients described many of the same kinds of language and communication problems experienced by clients in South Texas. These reports were not about problems with genetic service providers but other health care providers. One client reported that while a social worker was available to translate when she was meeting with a neurologist, "sometimes she has to go...This last time I was the last patient. I told her, Miss, don't go, help me to translate. She said, 'I don't have time, it is time to quit.' That time I came out crying because they could not explain to me about my daughter." Another client described insensitivity on the part of the family physician who was evaluating her son. "He came right out and said my son has defects from head to toe..." However, another client described the neonatal intensive care services for her newborn son as excellent, "They were fantastic with him. They fought with him every step of the way. They're good people."

Four of the clients did not have a diagnosis for their children's conditions and speculated about causes ranging from hormone injections taken to prevent pregnancy to drug abuse by the child's father. None had a clear understanding about the causes and treatments, "They have explained very little, that the genes were not compatible. I just don't understand." Five of the clients had been involved with multiple health care providers over the course of their children's care and would have benefited from a more comprehensive review and explanation of their cases. Two of the clients described their frustration with the lack of diagnosis, lack of new treatment modalities for their children's problems, and the sense of hopelessness they felt. "They tell us there is nothing to be done." In their perception, when medical providers reached a plateau of answering questions about causation and treatments they have to offer, they were passed off to others. One of the clients was thrilled to have good news from the geneticist that her son who had been referred was developing within normal ranges, "My son is fine, thanks be to God."

Transportation was another issue of concern. Clients who had to rely on public transportation or other family members to take their children for services had great difficulty. Some also had to travel long distances for specialty care. When asked about ways to improve services, one of the clients wished for a Children's Hospital and more frequent visits from the geneticist.

Repeat clients reported a high degree of satisfaction with the services of the bilingual and bicultural clinic secretary and social worker. They described how they went out of their way to help clients negotiate services between Juarez and El Paso.

NEW MEXICO

Five genetic service providers and six clients were interviewed in New Mexico, a state with a population of only about 1.82 million people. The genetics center was located in Albuquerque where the geneticists were able to consult with peers and search genetic databases for information related to their patient cases. Two days per month, a geneticist traveled to Las Cruces to provide genetic services to families who come from Sunland, Tornillo, Hatch, and Mesilla, communities near the U.S./Mexico border. All but one of the eleven interviews in New Mexico were conducted in this area. As described by one of the genetic service providers, the same amenities were not available at these satellite sites. Because the clinic in Las Cruces was only offered twice per month, the examination room and conference room had other uses and were less than ideal. Children were eligible for genetic services regardless of ability to pay but there were difficulties with genetic laboratory services. Lab tests had to be sent out of state through a complicated process. The frequent turnover in personnel who had to learn the process affected the efficiency in handling laboratory requests. Another concern expressed by the geneticist interviewed was that clients had to be referred to Albuquerque and other long distances for surgery and other complicated care. Long distance travel was difficult for client families.

As in Texas, many of the client families reflect a mix of documented and undocumented members. All six of the clients interviewed were receiving services for their children. Chief among their concerns were legal status and fears of deportation that affected everything about their lives. According to one client who had a work permit, "We cannot make plans to buy anything until our legal situation is resolved." Other clients reported that they did not have medical insurance and did not qualify for Medicaid, making access to biomedical care very difficult. Clients reported language and communication problems with health care providers. One client described feeling blamed for her child's condition and reported receiving conflicting diagnoses that apparently delayed referral to genetic services. However, the majority of clients reported satisfaction with the genetic services they were receiving.

When queried about the causes of their children's conditions, the genetic service clients had limited understanding regarding genetics but generated their own explanations, particularly when there was no diagnosis. The issue of environmental toxicities and effects on health, including birth defects and genetic problems, seemed more significant to clients interviewed in New Mexico and El Paso, Texas in comparison with the other study sites.

CALIFORNIA

Five clients and four genetic service providers from Calexico and San Diego were interviewed. Based on their reports, it appeared that genetic services at the California study sites were more systematic in comparison with the other study sites. Women receiving prenatal services and children in the public system had a greater likelihood of referral for genetic services than appeared to be the case in Arizona, New Mexico, or Texas. Two of the clients with children being seen in the genetics clinic had been referred because they had a family history of a genetic condition or a seemingly minor anomaly such as an ear tag. The public health system in California was reportedly strongly prevention-oriented and had a good medical records tracking system for patient follow up. As of January 2001, MediCal still covered prenatal and children's services regardless of legal status. Interestingly, it was reported that undocumented women are

solicited as prenatal clients because MediCal covers their care thereby reducing use of *parteras*. The genetic service providers appreciated the multidisciplinary approach to care in their program but reported an increase in program size and paperwork as well as onerous regulations that decrease their efficiency.

Calexico is a town of 19,000 inhabitants and just across the border from Mexicali, Mexico with more than one million inhabitants. The people living along the border work in service jobs such as convenience food restaurants and gas stations that cater to truck drivers. Consequently, they have a higher level of sophistication than the people in rural northern San Diego County, many of whom have migrated from Mexico as farm workers. With their exposure to a large urban area, the clients in Calexico seemed to have a greater understanding of how to use social service systems. In contrast, the people in northern San Diego were far less acculturated and had greater difficulty negotiating systems.

Regarding language and communication problems, the two clients who were monolingual Spanish reported that they had nurses or other personnel available who translated for them. One of the geneticists, who is bilingual, discussed the need for geneticists and other health care providers to speak Spanish. The geneticist went on to describe having to interpret consultations of other health care providers who could not communicate even through an interpreter. "Fairly often I end up seeing a patient a second or third time basically in order to translate or interpret what some other consultant has said." Two of the clients had seen multiple physicians for the care of their children and expressed frustration at having to retell their story so many times to different providers. Transportation was also a problem for these clients. "You have him go to therapy, physical therapy, speech therapy and what have you. And it was about three years that we were going to the doctors back and forth, back and forth all the time because there was really not a whole lot here in Imperial Valley for children with disabilities."

Clients expressed a desire that services be more accessible for undocumented non-pregnant women and men. Cost is a barrier for those not covered by MediCal. Clients were not asking for free services but a sliding fee scale or easier payment methods. Two of the clients described difficulties associated with undocumented status and expressed fear of deportation. Everything about their lives was complicated by this one factor. They could not own property outright, such as a car that requires a motor vehicle license. Instead, they manage their affairs through other people, some of whom took advantage of them.

Clients and genetic service providers both described the quality of acceptance among the clients whose children have genetic conditions (discussed in Section IV. Cultural Beliefs and Values under the subheading Health and Illness). One of the clients with two sons affected with the same condition had been receiving genetic services for five years. "Perhaps the boys are here because, maybe they can teach other parents, that OK, it's OK to have a disability as long as you try and do the best you can."

ARIZONA

Complexities associated with the institutional review board approval prohibited interviews with clients according to the timeline for the project. However, the interviews with three genetic service providers yielded useful information about provision of genetic services in the study area.

Except in the border communities, the predominant population outside of the metropolitan area of Tucson was Native American.

The genetic center was located in Tucson, Arizona. Three geneticists and five other personnel provided services through a clinic for patients who qualified for some type of medical insurance. These geneticists also worked with the state-funded Children's Rehabilitative Service. In Tucson, approximately 25% of clients were Hispanic, 70% Anglo, and 5% Native American.

The three geneticist alternated in providing services through the Children's Rehabilitative Service to 14 of the 17 Native American reservations across the state. A geneticist and genetic counselor spent one week per month traveling to the reservations, two days in Flagstaff, an afternoon and morning in Canyon de Chelly, and the remaining day and one half in Windowrock and Ft. Defiance. The geneticists alternated who was on service.

During their travel, particularly on the uninterrupted journey back to Tucson, the geneticist and genetic counselor spent much of the time doing case review and planning for interventions. Most of their Native American patients were English-speaking. Only rarely was translation needed. One of the genetic service providers interviewed commented that the number of Native American health care providers working in the Indian Health Service continues to increase. Indian Health Service pediatricians refer children to the genetics clinics held at the reservations. Genetic service providers reported that many Native Americans were unaware of genetic services and would not likely seek them. They access the services through the referrals within the Indian Health Service.

The system of genetic services through the Children's Rehabilitative Service on the reservations was such that the geneticists were compelled to see large numbers of patients, as many as 22 patients in one day, limiting the time they had with each client. In contrast, clients in the private genetics clinic in Tucson were able to see the same geneticist who was able to spend more time.

Genetic clinics were also offered in border communities of Nogales and Yuma. Two days per month genetic services were provided in community clinics that belong to the public health department. Geneticists did not know in advance who they would see in the clinic, particularly in the border communities, making it difficult to anticipate low long it would take with patients and what care was needed. A community clinic secretary scheduled patients but was not dedicated exclusively to genetics. The clinic had contracts not only with the state Children's Rehabilitative Service but other programs as well. Pediatricians or family medicine physicians referred patients for other services, including genetic services. The genetic service providers were most proud of the fact that they provided services all over the state.

Although no clients were interviewed, information from the providers indicated a higher concentration of monolingual Spanish-speaking clients in the border locations of Yuma, Nogales, and Douglas. A bilingual genetic counselor was actively recruited to help serve this population. Further, the genetic service providers worked to improve Spanish-language skills and cultural competency of genetic and other health care providers through the implementation of a Maternal and Child Health Bureau, Special Projects of Regional and National Significance (SPRANS) grant. Through the implementation of the grant, genetics personnel recognized the importance of assessing client perceptions regarding needs, concerns, and barriers to care (see Tool Kit for Brief Assessment of Patient/Family Perceptions of Health Problems). The genetic

service providers reported that speaking Spanish was necessary to be able to understand client perceptions and communicate with clients regarding diagnosis, treatment, and other issues.

DISCUSSION

Language and Communication Issues

In this study, the most significant factors affecting clients' perceptions of genetic services were language barriers and use of cryptic medical terminology by health care providers. The functional illiteracy in Spanish and English among clients, including a lack of understanding of basic human biology and other concepts, compounded the communication difficulties experienced between clients and their genetic service providers. As discussed in other research, genetic counseling relies on statistics that implies an understanding of abstract mathematical concepts that may not be shared by clients who have little formal schooling.² The language of biomedicine limits communication by locking providers into a discourse in which technical language predominates and the need for authority vies with the need to get the message across [ibid]. Another important consideration is that when providers cannot communicate directly with clients, their interactions tend to be briefer than with other clients.³

Reported experiences of violations of clients' cultural values underscore the need for training of biomedical providers in cultural competency, a subject of discussion in many sectors including the genetics community. A,5,6,7 Continuing education programs regarding Hispanic beliefs, values, behaviors, and political economy should be offered and include participation from locally known and respected traditional healers. Geneticists and other biomedical providers in the study areas should also be encouraged to learn Spanish.

The experience of clients whose family members interpreted for them during various medical encounters is not unusual. Although still a common practice, use of family members or untrained personnel for interpreting is regarded as unacceptable for a variety of reasons. Clients are less likely to convey personal information in the presence of certain family members, and use of untrained personnel increases risk of medical liability. ^{8,9} If interpreters are used, they should be trained and available as needed to interpret without interruption during a client's genetic counseling session as well as any other medical encounter. Materials have been developed that provide specific guidance for use of interpreters during genetic counseling. ¹⁰

Cultural Differences Issues

Clients' limited exposure to biomedical technology and lack of reliance on it for addressing health care needs may be related, in part, to the political and economic structure of Mexico, where sophisticated technology is generally accessible only by the more affluent. It may also be an issue of culture, where a high level of medical intervention is not expected for some conditions, such as pregnancy that are considered natural or normal processes. For many Hispanics, pregnancy is regarded as an important family event during which the pregnant woman receives extensive physical and emotional support from immediate and extended family members.² Yet, in Texas, approximately one-third of Mexican American clients do not seek prenatal care in their first trimester compared with 13% of whites and 26% of blacks. (Interestingly, even with later access to prenatal care, low birth weight prevalence and infant mortality are comparable to rates for whites and half the rates for blacks).¹¹ Researchers in

California have noted that lesser acculturation among Latinas was associated with greater likelihood of refusing MSAFP testing. They noted that there may be aspects of traditional Latina culture that are antithetical to accepting prenatal diagnosis testing and that for Spanish-speaking Latina women, MSAFP testing does not seem to have relevance to their pregnancies.¹²

For clients with more immediate concerns, such as how to pay for rent and groceries, the ambiguities of genetic diagnoses and use of probabilities in genetic counseling may not be perceived as practical.¹³ The demands of everyday life may make such concepts irrelevant. However, this does not mean that clients do not seek ways actively to manage the problems associated with their genetic conditions and care. Clients in this study supplemented genetic services with other kinds of interventions, such as consulting a traditional healer, which they perceived as useful based on practical experience. Although client caretakers often expressed the belief that their child's condition was "God's will," this did not translate into the passive inaction or fatalism that has often been attributed to this expression. In fact, client caretakers of children with genetic conditions were persistent in trying to obtain and coordinate their children's complex care despite the fragmented methods of service delivery and the consequences of their poverty. In studies among Latina women in California regarding amniocentesis refusal. researchers found that virtually all participants who refused amniocentesis did something in response to their positive AFP result, such as making behavioral changes or taking religious action. Researchers concluded that clients' refusal did not represent a rejection of biomedicine or evidence of fatalism. 14

Client satisfaction with genetic service providers may be due, in part, to increased opportunities for *personalismo* in the way genetic services were provided. Genetic service providers should be encouraged and supported in their efforts to establish this rapport with clients and educate their colleagues about it. Client satisfaction may also be due to the relief clients experienced in finding health care providers who could identify their problems and help them with their care. Often considered as "providers of last resort," genetic service providers should keep in mind that clients have been to numerous other biomedical providers for care and that some of their experiences were perceived as highly unsatisfactory. Some research has suggested that clients appear to respond more readily to directions when it is evident that the provider incorporates cultural beliefs into the plan of care and pays attention to their clients' perceptions of an ailment. If the perception of the problem is not addressed, clients will be dissatisfied and less likely to comply with the regimen prescribed.

Clients' spirituality, whatever their chosen faith, is integral to their view of healing and perceptions of causality. Their view of healing is deeply rooted in spirituality, a concept prevalent among many Mexican Americans and in contrast to the biomedical model that separates body from mind and soul. ^{19,20} This cultural attribute should be considered carefully in the context of caregiving. Providers should ascertain specific family religious preferences and not assume all Hispanics are of a particular faith or that their religious preferences always affect their decisions. Research on amniocentesis decisions among Mexican-origin women and their partners found that neither women's nor men's religious background were associated with amniocentesis decision. ²¹ At the same time, however, it is clear from this study that acknowledging clients' spirituality and religious beliefs can help support them in their care.

Poverty Issues

Since poverty statistics have been collected for Hispanics beginning in the 1960s, this group has had a poverty rate at least twice that of non-Hispanic families. Although clients were eligible for genetic services under Medicaid and Title V, the pervasive presence of poverty and its consequences, usually experienced cumulatively, made access to and utilization of genetic services an ongoing challenge for both clients and genetic service providers. Awareness of the challenges indigent families face can help providers understand and better manage patient care. For example, obtaining phone numbers and addresses of other reliable contacts from clients at first visit may help in locating them for follow-up. Families of children with genetic conditions may need additional assistance in linking with social service agencies, churches, and other resources for transportation, respite care, and other support services.

System Issues

While positive perceptions of genetic service providers were good news, attrition among the social workers and clinic receptionists who play a key role in communication might serve to undermine client satisfaction and trust in care. Genetics clinics would benefit by offering incentives to prevent attrition of clinic receptionists who are the first and most frequent points of contact for clients and who can convey an image of stability of services.

SUMMARY

The use of ethnographic and qualitative research techniques to identify the perceptions of genetic services among medically indigent Mexican American clients has provided important insights that may be useful in improving access to, and utilization of, genetic services.

Despite language differences and other difficulties, clients had favorable opinions of their genetic service providers on a personal level and valued the services provided by the clinics. Client perceptions were influenced by experiences with other biomedical providers and traditional healers, and by anxieties precipitated by unfamiliar concepts and approaches to medical care. Clients in the study were not passive recipients of care but actively involved in trying to find solutions to their problems, some of which lay outside the realm of biomedicine.

Suggestions for Genetic Service Providers:

- ✓ Staff genetics clinics with fully bilingual clinic personnel.

 Ideally, genetics clinics should be staffed with fully bilingual clinic personnel with expertise in genetics and skill in communicating with monolingual Spanish-speaking clients with little exposure to genetic concepts.
- Provide culturally competent genetics education resources.

 Ideally, all genetics clinics should have a glossary of frequently used medical/genetic terms expressed in English, Regional Spanish, and Castilian Spanish as a reference, particularly for new clinic personnel. Genetic educational materials, in basic English and regional Spanish, should be available in genetics clinics, including simple anatomical charts and other visuals available for clients with limited reading skills. Culturally appropriate information on genetic services (in English and regional Spanish) should be provided to referring physicians, public health clinics, documented and/or certified nurse midwives, and genetic clinics to distribute to clients as anticipatory guidance.
- Offer incentives to prevent attrition of clinic receptionists who are the first and most frequent points of contact and who can convey an image of stability of services.

Clinic receptionists and other support personnel play a key role in communication and are often more culturally affiliated with the clients and the community. Attrition among these familiar support personnel undermines client satisfaction and trust in care.

- Offer continuing education in genetics for social workers, clinic receptionists, and other personnel to improve communication in the provision of genetic services.
 - Use case studies and group learning techniques to address frequently encountered genetic service problems including ways to assuage client anxiety regarding sonograms and diagnostic tests.
- Provide continuing education in cultural competency for health care providers. Continuing education programs regarding Hispanic beliefs, values, and behaviors, should be offered, and include locally known and respected traditional healers. Geneticists and other biomedical providers in the study areas should also be encouraged to learn Spanish.

Suggestions for Genetic Service Providers:

✓ Use Promotoras(es) to educate communities about genetic services.

Genetic service providers should consider collaborating with public health agencies and community-based organizations that work with promotoras(es) on other health promotion interventions. Promotoras(es) are lay community health workers who are themselves members of the communities in which they serve, which include the Colonias along the U.S./Mexico border (see discussion on Colonias in section IX. Supplement). Because of their community and home-based educational activities, promotoras(es) are in a unique position to educate the health care community regarding the internal (emic) perspective of the residents in these communities.

All four states work with *promotoras(es)* in programs such as Project Concern International (1988) in California and, more recently, Latino Health Access in California, Arizona Department of Health Services Health Start Program, and the Migrant Health Promotion and *Comenzando Bien* in Texas. ^{23,24} As part of this study, genetic services and the use of folic acid were promoted to medically indigent Mexican Americans and Mexicans in South Texas through active collaboration with the *promotoras(es)*.

VIII. CULTURAL COMPETENCE AND GENETIC PRACTICE

Cultural competence mandates that organizations, programs, and people have the ability to:

- Value diversity and similarities among all peoples
- Understand and effectively respond to cultural differences
- Engage in cultural self-assessment at the individual and organizational levels
- Make adaptations to the delivery of services and enabling supports
- Institutionalize cultural knowledge

This section provides definitions and a rationale for cultural and linguistic competence, discusses the culture of biomedicine, and lists resources for developing cultural competence that can be found in the Tool Kit.

"During every health care encounter, the culture of the patient, the culture of the provider, and the culture of medicine converge and impact upon the patterns of health care utilization, compliance with recommended medical interventions, and health outcomes. Often, however, health care providers may not appreciate the effect of culture on either their own lives, their professional conduct, or the lives of their patients. When an individual's culture is at odds with that of the prevailing medical establishment, the patient's culture will generally prevail, often straining provider-patient relationships. Providers can minimize such situations by increasing their understanding and awareness of the culture(s) they serve."

Definitions

Culture is generally defined as a shared system of values, beliefs, traditions, behaviors, and verbal and nonverbal patterns of communication that hold a group of people together and distinguish them from other groups.² Cultural competence is defined as a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals, and enables that system, agency, or those professionals to work effectively in cross-cultural situations.³

At the individual level, cultural competence refers to the knowledge and interpersonal skills that allow genetic service providers to understand, appreciate, and work with individuals from cultures other than their own.⁴ It involves an awareness and acceptance of cultural differences, self awareness, knowledge of a patient's culture, and adaptation of skills.¹ By understanding the culture(s) of their patient populations, genetic service providers can serve their patients better and impact utilization of services.

At a system, organization or program level, cultural competence requires a comprehensive and coordinated plan. This may include consideration of the role of cultural competence as it relates to: (1) policy making; (2) infrastructure building; (3) program administration and evaluation; (4) the delivery of services; and (5) the individual, both those delivering and receiving such services.⁴

A Rationale for Cultural Competence

To some health care providers, "cultural competence" sounds like an exercise in being politically correct. To others, it may seem divisive or condescending, and there are legitimate concerns about the fine line between cultural sensitivity and stereotyping. Yet numerous reasons justify the need for cultural competence in health care at individual and system levels.⁵

■ To respond to current and projected demographic changes.

The composition of the American population is changing as a result of immigration patterns and significant increases among racially, ethnically, culturally, and linguistically diverse populations already residing in the United States.

■ To eliminate long-standing disparities in the health status of people of diverse racial, ethnic, and cultural backgrounds.

Although the reasons for continuing disparities are not well understood, it appears that disproportionate poverty, discrimination in delivery of health services, and failure of health care organizations and programs to provide culturally competent health care are contributing factors.

■ To improve the quality of services and health outcomes.

Culturally competent health services facilitate clinical encounters with more favorable outcomes, enhance potential for a more rewarding interpersonal experience, and increase client satisfaction.

■ To meet legislative, regulatory, and accreditation mandates.

Title VI of the Civil Rights Act of 1964 mandates that no person in the United States shall, on ground of race, color, or national origin, be excluded from participation in, denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance. Virtually all health care and human service institutions receive federal financial assistance such as Medicare or Medicaid funds. The Office of Civil Rights enforces Title VI after the filing of a consumer complaint.

Both the Joint Commission on the Accreditation of Healthcare Organizations, which accredits hospitals and other health care institutions, and the National Committee for Quality Assurance, which accredits managed care organizations and behavioral health managed care organizations, support standards that require cultural and linguistic competence in health care.

To gain a competitive edge in the marketplace.

The growth of managed care and competition among health care plans for members has focused greater attention on the provision of health services to people from diverse backgrounds.

■ To decrease the likelihood of liability/malpractice claims.

Lack of awareness about cultural differences may result in liability under tort principles in several ways. For example, liability for damages as a result of treatment in the absence of informed consent. Also, health care organizations may face potential claims

that their failure to understand health beliefs, practices, and behavior on the part of providers or patients breaches professional standards of care.

The ability to communicate well with clients has been shown to be effective in reducing the likelihood of malpractice claims. Therapeutic relationships are enhanced and medical personnel reduce risk of being sued for malpractice when there is effective communication.

Demographic changes, health disparities, quality of services and health outcomes, federal law, state and local regulations, accreditation standards for health care organizations, and the potential for legal liability are all important reasons for genetic service providers to incorporate in their practice strategies for cultural and linguistic competence.⁶

Linguistic Competence

Effective communication is essential for obtaining an accurate and comprehensive patient and family assessment, making a diagnosis, implementing a treatment plan, determining the efficacy and acceptability of services, and evaluating associated outcomes. It becomes much more challenging when there are cultural and linguistic barriers.

There are multiple strategies used in communicating with clients who have limited English proficiency (including those who are completely monolingual). Strategies include "getting by," using ad hoc interpreters such as family members, staff or community volunteers, bilingual staff interpreters, professional interpreters, cultural mediators, telephone language lines, and other technologies.⁶

Many of these strategies are less than ideal in the provision of health care services yet continue to persist. With concerns for improvements in quality of services and health outcomes, as well as risk management, genetic services providers should seriously reflect upon of their methods of communication with clients of limited English proficiency (LEP).

Suggestions for Genetic Service Providers 7,8

- Encourage a training program for interpreters at health care facilities and have regular in-service training.
- ✓ Have translated materials back-translated by an unbiased individual, fluent in the language and a native speaker, to assess validity of information.
- ✓ Telephone language lines such as AT&T Language Line and Pacific Interpreters, Inc. can provide access to interpreters 24 hours a day, 7 days a week. Operators are trained in medical interpreting and tested for linguistic competency. This service, which can be costly, is considered appropriate for exchanging basic information.

Suggestions for Genetic Service Providers 7,8

- ✓ Unless a provider is fluent in the target language, a trained interpreter should be used.
- ✓ Hospital personnel who speak the target language, but are not trained in interpreting and do not have knowledge of medical terminology, should only be used for providing simple directions.
- ✓ Do not use family member as interpreters. Use of a family member for interpretation can lead the patient to withhold information. In particular, **children should never be used as interpreters**. In Mexican American families, use of a child as interpreter elevates the child to a position of authority and disrupts the roles within the family. Further, it places an undue burden on children in conveying sensitive information that may be complex beyond their years. The genetic service provider should always be sensitive to patients' desires for privacy or their wish to include family members in health-care decisions.
- ✓ When using an interpreter, providers should speak directly to patients and encourage patients to direct answers to them, rather than going through the interpreter.
- ✓ Interpreters should communicate at the patient's level, and convey to the provider exactly what the patient says.
- ✓ To confirm accuracy and understanding, ask patients to repeat what they understood the provider to have said regarding important medical information. Asking the question in this manner removes the onus of responsibility from the patient to the provider and helps to put patients at ease. Write recommendations in the form of a list in simple English and give the list to both the interpreter and the patient's family.
- ✓ Encourage conversational modes rather than direct questioning.
- ✓ Learn some basic words and phrases in Spanish and become familiar with special terminology, beliefs, and practices. Be aware that regional differences exist in Spanish, e.g. U.S./Mexico border Spanish differs from that used in Central or South America.
- ✓ See Tool Kit Section for resources on Spanish-language glossaries for genetic service providers.

The Culture of Western Medicine

Western medicine has a culture of its own, with traditional codes of conduct that have been passed on from generation to generation. This culture is pervasive within the medical profession, and it often supercedes the individual practitioner's beliefs and values. The U.S. health care system has its origins in Greek (Aristotelian) and Anglo-European philosophy and scientific thought. Notions about how to demonstrate caring and compassion to others, definitions of health/wellness, and beliefs about health maintenance, prevention of illness, and cure have been formed by this same Western European tradition and modified to suit the strongly individualistic United States social system.²

Biomedical theory developed out of the possibility, following René Descartes, of a separation of the physical body from the mental and social. The body, as part of the natural world, becomes knowable as a bounded material entity; diseases similarly are physical entities occurring in specific locations within the body. The mind and body are separate aspects of human beings with the body understood as an interrelated set of component parts whose functions are mechanistic. The Western-oriented health care system is the only one that separates the body from the mind and the soul. Physical reductionism is a central tenet of biomedicine. 12

In the past twenty-five years, clinical research in mind/body interactions and emergence of disciplines such as psychoneuroimmunology have changed this perspective. Psychoneuroimmunology today covers not only disease and basic mechanisms, but also immunogenetics, neuroimmune interactions, the effects of neuropeptides, neuroendocrine products, and behavior on the immune system, developmental problems dictated by immune system molecules; and the ability of nervous system elements to function as cells of the immune system. ¹³

Biomedicine has begun to investigate the benefits of mind/body interactions. For example, Harvard Medical School's Department of Continuing Education offers a course, "Spirituality and Healing in Medicine," whose course description explains: "...when a person engages in a repetitive prayer, word, sound or phrase and when intrusive thoughts are passively disregarded, a specific set of physiologic changes ensue. There is decreased metabolism, heart rate, rate of breathing and distinctive slower brain waves. These changes are the opposite of those induced by stress and are an effective therapy in a number of diseases that include hypertension, cardiac rhythm irregularities, many forms of chronic pain, insomnia, infertility, the symptoms of cancer and AIDS, premenstrual syndrome, anxiety and mild and moderate depression...research later established that people experienced increased spirituality as a result of eliciting this state regardless of whether or not they used a religious repetitive focus. Spirituality was expressed as experiencing the presence of a power, a force, an energy, or what was perceived of as God and this presence was close to the person. Furthermore, spirituality was associated with fewer medical symptoms..." 14

Biomedicine is itself now subject to analysis as a product of particular historical and cultural processes, both from self-analysis as well as other disciplines such as anthropology. 15

Developing Cultural Competence

Suggestions for Genetic Service Providers:

Look for these items in the Tool Kit -

- 1) Self-awareness in Genetic Practice
- 2) Checklist to Facilitate Development of Culturally and Linguistically Competent Policies and Structures
- 3) Brief Assessment of Patient/Family Perceptions of Health Problems
- Glossary of Frequently Used Genetic Terms in English and Regional/U.S.-Mexico border Spanish
- 5) National Resources and Websites for Cultural and Linguistic Competence

Self-awareness in Genetic Practice

"Geneticists have recognized that their values often are not identical to those of their patients, thereby requiring that they respect patients' abilities to make decisions for themselves. The variation in approach among practitioners is part of the reason why patients must have the final decision about whether to be tested, even for disorders that are treatable...Biases are inherent in human nature and...may reflect the attitudes of health care providers about the nature and meaning of health and disease, the severity of genetic conditions and disorders, quality of life, the appropriateness of decisions related to genetic testing and counseling, acceptance of advice, and other issues of importance in genetics..."

This self-awareness tool is provided to help you examine your own values and those of your patients and identify how these may influence the decision-making process. Information is adapted, with permission, from the "Genetic Counseling and Primary Care Web Site," a research project funded by the National Human Genome Research Institute's Ethical, Legal and Social Issues Branch (ELSI). Fineman, et al (1998) is the source for topics and questions that refer to the patient and patient's family. Honda (1998) provides self-reflection questions and suggested plans. ^{2,3} Topics include:

- Locus of Control
- Childbearing
- Authority
- Family
- Fate and Destiny
- Gender
- Health Beliefs
- Invasive Procedures
- Risk
- Western Medicine

1. Locus of Control

This concept has to do with perceptions of control, external or internal. People with an external locus of control tend to function with a sense that there are things outside their ability to control. People with internal locus of control believe their behaviors can influence outcomes. There are many factors that influence this perception, such as socioeconomic status and education, with people of lower income and less schooling exhibiting external locus of control.

Questions:

*Who influences your decision-making?

*Who is involved in your patient's health care decisions? Is she the controlling figure or are there other figures of authority who may influence or even dictate a decision?

*How does the patient perceive his or her ability to manage health?

Plan:

Invite the patient's decision-making "partners" to the session.

2. Childbearing

The meaning of having children is a very personal one colored by cultural, religious, and social norms. To a man, it may be a sign of fertile "seed," a sign of machismo or competence to perpetuate self. To a woman, it may embody a whole definition of gender and self. For all who bear children, it is a growth step, a means to mature to a new level of heightened self-awareness and awareness of things beyond self.

Questions:

- *What is the medical profession's attitude toward childbearing? Toward bearing a normal child? A child with a genetic disorder? A child with a genetic disorder for which prenatal screening is available? How do these attitudes affect your ability to be nondirective?
- *How important is childbearing in the patient's culture and family?
 *Is there any stigma attached to bearing a child who is not "normal"?
 *How does your patient view gender? Would an X-linked disease which affects males make prenatal testing impossible for them?

Plan:

Anticipatory guidance is one tool to assist your patients in evaluating their ability to care for children with a disorder. Patient education materials (written or audiovisual) are often available from local, state and national resources such as the March of Dimes

3. Authority

Authority figures are very powerful within the family structure. They may not only influence, but may dictate your patient's decision. In some cultures, authority figures may be an elder within or outside the immediate family, a wise woman or healer.

Questions:

- *Do you see yourself as an authority figure to your patients? In your family? If so, how do each affect your nondirectiveness with patients?
- *What is the authority for this patient's culture? Does this conflict with your values?
- *What does authority mean in your patient's culture? How does it manifest itself?
- *Are medical professionals authority figures in their culture? Will your patient be able to accept nondirective counseling as a service provided by a "good doctor?"
- *Are you "allowed" to challenge your patient's authority figure from a cultural perspective? From a psychological perspective?

Plan:

Remind yourself that being nondirective or being an authority figure can, in some cultures, place you in direct conflict with your patient's expectations. You may need to explain to your patient the value of your role as a facilitator in the decision-making process, not as a directives coordinator.

4. Family

Family issues greatly influence the patient's interaction in the genetic evaluation process. Whether intact or estranged, past and current status in family relationships can often "make or break" the genetics evaluation. Accuracy of the historian's information and access to family medical records are key targets in family history-taking. Equally important is the degree of influence the family has on the patient's decision-making process.

Ouestions:

*What was the structure of your family? What were the relationships like?

*How does this compare with your patient's situation? How does this affect

your ability to empathize with them? Your nondirectiveness?

*What role does your patient's family have in his or her health care

decision-making?

*How does that change if your patient is a minor?

*To what degree is the patient separate from the family? If in an entwined

family relationship, what role does the caregiver have?

Plan:

Although competent adult patients have the right to make autonomous decisions, in many cultures, families greatly influence the patient's decision-making process. During the genetic counseling process, try to gain insight into how influential the

family is (including what the family will think if the patient makes an

"unpopular" decision) and which members hold power.

5. Fate and Destiny

Some cultures and some religions view disease as God's punishment or as one's lot in life. It is something that must be accepted as God's will or karma. Also, the ability to cope (in practical, as well as emotional and spiritual ways) is an important factor in genetic decision-making.

Questions:

*Within biomedical science, health care providers are in a culture that seeks to know (L scientia to know) the answers. Is it acceptable to pressure patients to seek genetic testing for a chronic disorder, if the patient believes that having this condition is an act of God? If the patient simply does not want to know?

*To what extent do your patients feel they have control or can influence events

in their lives when it comes to health-related issues?

*Once something happens, how much do they feel they can influence the

outcome?

Plan:

Exploring outcomes and providing anticipatory counseling is important, especially with a patient who has strong fatalistic beliefs.

6. Gender

Gender influences our patterns of health behavior from how much we exercise, to what we eat, to how often and under which circumstances we seek medical care. Especially for prenatal genetic testing, how women and men differ in seeing their roles as parents and physical custodians of the unborn child can greatly influence their decision-making.

Questions:

*Is there a difference between how you might counsel a female patient as opposed to a male patient when it comes to genetic issues? What about a woman seeking pre-pregnancy counseling? What if the same woman were to come in with her partner/spouse seeking the same information? Would your discussions be tailored in the presence of a partner?

*In a second situation, suppose a man were to want presymptomatic testing for a disabling genetic disorder. Would your attitude toward his "need to know" be different than that for a woman with the same request?

*For your patient, what influence does gender have in the context of culture?
*Does gender facilitate or complicate communication between you and your patient?

*How is decision-making influenced by your patient's gender? By yours?

Plan:

Identify whether gender is an issue in communicating information to the patient and, under circumstances where prenatal testing is involved, how the woman and partner feel about their roles and responsibilities toward the unborn child. This awareness will provide insight into any blame or guilt issues that may arise in genetic testing and evaluation.

7. Health Beliefs

Health beliefs include the way we feel about our bodies, mental models for what causes sickness and disease, how we think about healing, and the meaning of life and death.

Questions:

- *As health care providers, how different are our beliefs about what we can do to promote health and well-being from that of our patients?
- *What is your patient's attitude about disease?
- *What does she/he think causes disease or this particular genetic disorder?
- *Is it acceptable to have this disease?
- *Are there specific diseases that arouse negative attitudes (perhaps because they affect a particular part of the body)?
- *How is death viewed within the patient's culture? Within yours? Within the culture of biomedicine? Does the patient have beliefs in the afterlife?

Plan:

Each of these beliefs affects the patient's perception of risk - a tenet of genetic testing. Evaluate how patients' health beliefs affect their "need to know," their risk perceptions, and their attitude toward various possible test results and posttest options.

8. Invasive Procedures

Some religions prohibit the use of invasive procedures in medical care. The degree of invasiveness in medical care can range from taking a blood sample to amniocentesis and childbirth. Health care providers should take note that even "routine" tests might cause some patients to feel apprehensive and fearful.

Questions:

*As a health care provider, what assumptions do you make about the

invasiveness of a given test or procedure?

*By what criteria do patients judge whether a test is invasive? Permitted?
*Is your willingness to help a patient influenced by her or his consent or lack of consent to treatment which requires an invasive procedure?

Plan:

Show respect for the patient's issues by validating them. Discuss the risks and burdens of non-treatment. Just as informed consent is required for testing, it is also a must for non-treatment. Adequately informing them of the risks (and benefits) and limitations in downstream care are important

facets of informed consent to non-treatment.

9. Risk

Perceptions of risk are influenced by life experiences and sociocultural forces. Risk of a certain genetic disorder in a pregnancy may hold very little real value to someone whose daily existence is challenged by poverty. However, that identical risk may be perceived as substantial to a couple who are educated professionals.

Questions:

*Patients often ask, "What would you do in our situation?" You must ask yourself, "Do I fully comprehend this family's circumstances having just tested positive for a genetic disorder?" What would be an appropriate nondirective response?

*What if a couple has no prior experience with the disorder for which their unborn child has tested positive? What is their perception of risk compared to someone with a prior family history of the disorder?

*How are our perceptions of risk influenced by our health beliefs, our attitudes

toward death, toward healing?

*What is "risky" to you?

Plan:

Understanding your patient's perception of risk prior to testing often helps you to understand a patient's decision and response to testing results.

10. Western Values

If your medical education, training and cultural heritage are based on Western values, they probably have imbued your practice with Western biases. Understanding that other cultures may use alternative approaches to medical treatment is essential to your practice (See "Culture of Western Medicine" in Section VI. Cultural Competence and Genetic Practice).

Ouestions:

- *How strong are you in your beliefs that your medical training has provided you with the "correct" answers to your patient's problems?
- *What is your patient's attitude toward inheriting a genetic disorder? Is it based on the ethnocentric notion of health or is there something else you need to explore with him or her?
- *Do your patients think you can help them with their genetic problems? If so, what do they think "helping" is?
- *What is your patient's confidence in what you can provide?
- *What are your patient's expectations of "conventional" genetic testing? Are there any alternatives she/he might prefer?

Plan

During genetic counseling, ask yourself, "What is the basis for my patient's expectations of genetic testing? Of me, as the provider of the tests?

Checklist to Facilitate the Development of Culturally and Linguistically Competent Primary Health Care Policies and Structures

Does	the primary health care system, organization or program have:
ø	A mission statement that articulates its principles, rationale and values for culturally and linguistically competent health care service delivery?
	Policies and procedures that support a practice model which incorporates culture in the delivery of services to racially, ethnically, culturally and linguistically diverse groups?
	Structures to assure for consumer and community participation in the planning, delivery and evaluation of services?
0	Processes to review policy and procedures systematically to assess their relevance for the delivery of culturally competent services?
	Policies and procedures for staff recruitment, hiring and retention that will achieve the goal of a diverse and culturally competent workforce?
0	Policies and resources to support ongoing professional development and inservice training (at all levels) for culturally competent health care values, principles and practices?
	Policies to assure that new staff are provided with training, technical assistance and other supports necessary to work within culturally and linguistically diverse communities?
O O	Position descriptions and personnel/performance measures that include skill sets related to cultural competence?
O	Fiscal support and incentives for the improvement of cultural competence at the board, agency, program and staff levels?
	Policies for and procedures to review periodically the current and emergent demographic trends for the geographic area it serves?
0	Methods to identify and acquire knowledge about health beliefs and practices of emergent or new populations in service delivery areas?
	Policies and resources for the provision of translation and interpretation services?
	Policies and resources that support community outreach initiatives for limited English proficient and/or non-literate populations?
0	Requirements for contracting, announcement of funding resources, and/or development of request for proposals that include culturally and linguistically competent practices?

Source: National Center for Cultural Competence, Georgetown University Child Development Center, 3307 M Street, NW, Suite 401, Washington, D.C. 20007; http://www.dml.georgetown.edu/research/gucdc/nccc

Brief Assessment of Patient/Family Perceptions of Health Problems

- ➤ What do you think caused your problem?
- > Do you have an explanation for why it started when it did?
- ➤ What does your sickness do to you; how does it work?
- ➤ How severe is your sickness? How long do you expect it to last?
- > What problems has your sickness caused you?
- > What do you fear about your sickness?
- > What kind of treatment do you think you should receive?
- ➤ What are the most important results you hope to receive from this treatment?

Source: Tripp-Reimer, T. Brink, P.J., & Saunders, J.M. (1984). Cultural assessment: Content and process. Nursing Outlook, 32(2):78-82. Used with permission from Tripp-Reimer (2002).

Glossary of Frequently Used Genetic Terms in English/Regional (U.S./Mexico Border) Spanish

Dietary and GI

Amino Acids

Aminoácidos

Calories

Calorías

Carbohydrates

Carbohidratos

Enzyme

Enzima

Gall bladder Gastritis

Vesícula

Gastritis

Metabolic

Metabólico (del metabolismo)

Protein Supplement

Proteína Suplemento

Genetics

Carrier

Portador

Cell

Célula

Chromosomes

Cromosomas

Deletion

Tachadura (se borro, no existe)

Dominant

Dominante

Genes

Genes

Genetics

Genética

Hereditary

Hereditario: Herencia

Malformation

Malformación (mal formado, mal hecho)

Mutation

Cambio; Mutación

Recessive Trait

Rasgo recesivo

Syndrome

Síndrome

Trait

Rasgo; Característica

Translocation

Desplazamiento

X-Linked

Un gene en que la mujer es portadora

Lab

Biopsy

Biopsia

Bloodwork/Labs

Análisis de Sangre; Laboratorio

MRI

Magnética Resonante; Imagen Magnética Resonante

Sonogram

Sonograma; Sonografía ultrasonido

Ultrasound

Ultrasonido

Urine analysis

Análisis de orina

X-Rays

Radiografía; rayos X

Medical Conditions and Associated Words

Down syndrome Síndrome de Down Cerebral Palsy Parálisis cerebral Hydrocephalus Hidrocefalia Muscle Músculo

Muscular Dystrophy Distrofia Muscular

Shunt/Valve Válvula Spina Bifida Espina bifida

Medical Specialties

Cardiologist Cardiólogo; Doctor del Corazón

ENT Oídos, Naris, Garganta GI Gastroenterología

Geneticist Genetista; Especialista en Genética Neurologist Neurologo; Doctor del Sistema Nervioso

Opthamologist Oftalmólogo; Doctor de Los Ojos Orthopedic Ortopédico; Doctor de Los Huesos Pulmonologist Pulmonólogo; Doctor de Pulmones

Organs

Brain Cerebro; sesos Heart Corazón

Lungs Pulmones

Renal

Bladder Vejiga

Catheter Cateter; Sonda; Tubo

Kidneys Riñones

Reproductive

Premature Prematuro

Vaginal Vaginal; Parte Privada

Questions You May Have for Your Genetic Specialist

Genetic specialists can often provide answers to the questions below. However, limitations do exist and finding answers is not always possible.

You will probably be asked questions about medical history and family health history. These questions may seem personal, but they are important to help the genetic specialist search for answers.

This list of questions will help you be prepared when you arrive at the genetics appointment and assist you in getting as much information as possible from your visit with a genetic specialist. Consider taking notes or using a tape recorder. Ask about follow-up appointments or telephone calls, if needed, and allow yourself plenty of time to take in all the information.

List of Important Questions

0	What is the diagnosis and what does it mean?
0	Is there a cure for this condition?
	How does an individual get this condition?
	What tests are available to see if a person has or carries this condition?
	Is there a prenatal test and are there any special pregnancy precautions?
O	What diagnostic procedures are recommended and what are their risks?
	How accurate is this diagnosis?
	Where can I obtain a second opinion?
_	What are the characteristics of this condition?
	What is the treatment for this condition?
	What other specialists will I need to see? University of Texas Health Science Center at San Antonio/Department of Pediatrics

	How do you care for a person with this condition?	
	What are the medical costs likely to be?	
	How is this condition passed from one generation to the next?	
	Can a person not have this condition and still pass it on to his/her children?	
	Will my other children or siblings be affected?	
	How will this diagnosis affect my health insurance?	
J	When would it be appropriate to see you again?	
	Are there services, programs or financial assistance for those who have this condition?	
	Where can I get additional information about this condition?	
	How can I contact other people or families in a similar situation?	
	What research is being done on this condition? Where?	
0	Your other questions:	
This information, produced with permission from the Mountain States Genetics Network, is provided through grant #MCJ-081002 from the U.S. Maternal and Child Health Bureau.		

Preguntas Para Su Especialista en Genética

Las preguntas en este folleto le ayudarán a recibir cuanta información sea posible en su visita con un especialista en genética. Le puede preguntar por qué ocurrió la condición, cuál tratamiento está disponible, y si puede volver a ocurrir. Los especialistas en genética le pueden dar esta información. Sin embargo, existen algunas limitaciones y no es siempre posible encontrar las respuestas.

A usted se le harán algunas preguntas sobre su historia médica y la de su familia. Estas preguntas le pueden parecer personales pero son importantes para ayudar al especialista a encontrar las respuestas.

Si usa este folleto, puede asistir a su cita con una lista ya hecha de preguntas e inquietudes importantes para usted, y con la información familiar necesaria. Tome apuntes o use una grabadora. Pida otra cita si hace falta y pregunte si puede llamar si tiene más preguntas. Permítase el tiempo necesario para entender la información.

Lista de Preguntas Importantes

☐ ¿ Cuál es el diagnóstico y qué significa?
🗖 ¿Existe un remedio para esta condición?
☐ ¿Cómo contrae uno esta condición?
☐ ¿Que exámenes existen para ver si uno tiene o es portador de esta condición?
☐ ¿Existe un examen prenatal o hay precauciones especiales durante el embarazo?
☐ ¿Cuáles procedimientos diagnósticos se recomiendan y cuáles son los riesgos?
☐ ¿Que tan exacto es el diagnóstico?
☐ ¿Dónde puedo obtener una segunda opinión médica?
☐ ¿Cuáles son las características de esta condición?
☐ ¿Cuál es el tratamiento para esta condición?
☐ ¿Qué otros especialistas adicionales tendré que ver?
The University of Texas Health Science Center at San Antonio/Department of Pediatrics

☐ ¿Cómo cuida uno a una persona con esta condición?
☐ ¿Más o menos cuanto serían los costos médicos?
☐ ¿Cómo se transmite esta condición de una generación a otra?
☐ ¿Podrá una persona sin esta condición pasársela a sus hijos?
☐ ¿Estarán afectados mis hijos o hermanos?
□ ¿Qué impacto tendrá este diagnóstico en mi seguro médico?
☐ ¿Cuándo sería apropiado verlo otra vez?
☐ ¿Hay servicios, programas o ayuda económica para personas que tienen esta condición?
☐ ¿Dónde puedo conseguir más información sobra esta condición?
☐ ¿Cómo puedo comunicarme con otras personas en una situación parecida?
☐ ¿Se ha hecho alguna investigación sobre esta condición? ¿Dónde?
☐ Otras preguntas que tenga usted:
Este folleto ha sido producido con permiso del Mountain State Genetics Network y apoyado por el Projecto MJC- 081002 del la Oficina Estadounidense de Salud Maternal e Infantil.

National Resources and Web Sites (Genetic Issues, Disabilities, Cultural Competence)

Centers for Disease Control and Prevention National Center for Environmental Health Division of Birth Defects and Developmental Disabilities

http://www.cdc.gov/ncbddd

(770)488-7150

Provides national leadership for preventing birth defects and developmental disabilities and improving the health and wellness of people with disabilities. Provides information (English and Spanish) on birth defects prevention, neural tube defects, spina bifida, anencephaly, fetal alcohol syndrome, and related topics.

Genetic Alliance

http://geneticalliance.org

A national coalition of voluntary genetic organizations, consumers and professionals. Offers a forum for addressing family needs across a spectrum of disabilities. Linkage to support groups, disability resources, online directory of genetic resources, and disease information resources. (800)336-GENE (4363) – Helpline staffed with genetic counselors to answer questions about genetics and link to other resources.

March of Dimes Education Resource Center 1-888-MODIMES (663-4637)

http://www.resourcecenter@modimes.org

Provides staff and trained professionals who, on a one-to-one basis, address personal and complex problems relating to birth defects, infant health problems, pre-pregnancy, pregnancy, teen pregnancy, newborn care, teratogens, support groups, genetic disorders.

Maternal and Child Health Neighborhood

http://mchneighborhood.ichp.edu

Sponsored by the Maternal and Child Health Bureau, Department of Health and Human Services. Provides links to various maternal and child health websites in the areas of child, adolescent, and family health; children with special health care needs; perinatal systems and women's health; research, policy, and programs; state and community health; training and education.

National Council of La Raza

(202)785-1670

http://www.nclr.org

Private, non-profit, non-partisan organization established in 1968 to reduce poverty and discrimination, and to improve life opportunities for Hispanic Americans.

National Down Syndrome Society

(800)221-4602

http://www.ndss.org

Works to ensure all people with Down syndrome have the opportunity to achieve their full potential in community life. Services include referrals and educational information (English and

Spanish) about Down syndrome. Also promotes public education, advocates on behalf of families, and supports research.

National Hispanic Prenatal Hotline 1-800-504-7081

Operated by the National Coalition of Hispanic Health and Human Services Organizations. Provides culturally appropriate bilingual information and local referrals to Hispanic callers.

National Information Center for Children and Youth with Disabilities

1-800-695-0285 voice/TTY

http://nichcy.org

National information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals, with a special focus on children and youth (birth to age 22). Many publications available in Spanish and available off the Internet site.

National Newborn Screening and Genetic Resource Center

(512)454-6419

http://genes-r-us.uthscsa.edu

Provides information and resources in the area of newborn screening and genetics to benefit health professionals, the public health community, consumers, and government officials. Hosts the Genetics Education Materials (GEM) database, a searchable listing of clinical genetics educational materials and public policy documents. The NNSGRC is a cooperative agreement between the Maternal and Child Health Bureau, Genetic Services Branch, and The University of Texas Health Science Center at San Antonio, Department of Pediatrics.

National Organization on Fetal Alcohol Syndrome

(800)666-6327;

http://www.nofas.org

Non-profit organization dedicated to eliminating birth defects caused by alcohol consumption during pregnancy and improving the quality of life for those affected. Takes a multicultural approach to prevention and healing. Maintains a clearinghouse and free on-line publications.

Spina Bifida Association of America

(800)621-3141;

http://www.sbaa.org

Provides information and referrals. Includes a professional advisory council on education, medicine, and legislation.

Resources for Cultural Competence and Communicating with Clients of Limited English Proficiency

Center for Cross Cultural Health: Resources for cultural competency in health care http://www.crosshealth.com

Center for Human and Molecular Genetics/University of Medicine & Dentistry of New Jersey: Produces a Spanish Translation of English Terms genetic counseling glossary for genetic counselors and other medical personnel as well as other patient education materials. http://www.umdnj.edu/genesweb/multilingual/glossary_form.html

Diversity Rx: Information on models of interpreter practice, case law, policies, database of cultural competence models http://www.diversityrx.org/HTML/DIVRX.htm

Multilingual Glossary of Technical and Popular Medical Terms in Nine European Languages http://allserv.rug.ac.be/%7Ervdstich/eugloss/firsttime.html

National Center for Cultural Competence: Training and technical assistance, networking, linkages, knowledge and product development, and dissemination http://www.dml.georgetown.edu/research/gucdc/nccc

National Council on Interpretation in Health Care: Promotes culturally competent professional medical interpretation to support equal access to health care for individuals with limited English proficiency.

http://www.ncichc.org

Office of Civil Rights, Department of Health and Human Services http://www.hhs.gov/ocr

Office of Minority Health Resource Center, DHHS: Defines and describes culturally competent programs

http://www.omhrc.gov

X. Supplement

A. A Brief History of Mexican American Population Sources

In the 16th century, when the Spanish established settlements in what is today the U.S. Southwest, a considerable number of Native North Americans came under the domain of Spanish rule. Spain sought economic development through acquisition of land and souls. As soon as an Indian walked into any one of the Spanish missions, he received a Spanish name and was taught a new religion, Roman Catholicism, and the Spanish language. He was also given land to work for his subsistence. By these very acts, the natives became citizens of the Spanish empire. Although many learned to speak Spanish and learned how to work the land (a dramatic change from being hunters and gatherers), they remained more Indian than Spanish. The Tohono O'Odham, Pascua Yaqui, and Jumano are some of many Native American groups that are part of today's U.S. Southwest which from 1810 to 1848 were part of the Republic of Mexico. Prior to this time, from the early 1500's to early 1800's, these groups were part of the Spanish kingdom in the New World. Consequently, many of their religious beliefs and traditional healing practices represent a melding of the Native American of the U.S. Southwest, Native Americans of the North of Mesoamerica, and of Spanish Colonial lore. Southwest

Spanish colonists received land grants from the Spanish monarchy as a way to populate New Spain. For 300 years (1521-1821), Spain controlled the territory that would later become Mexico (1821), Texas (1836) and the rest of the U.S. Southwest.² The descendants of the Spanish colonists became U.S. citizens *ipso facto* when Mexico ceded 50 percent of its territory to the U.S. in 1848. 7,8 Many of these new citizens never learned English and continued their traditional Spanish/Mexican culture. 9

The coming of Spanish colonizers also initiated the development of the Mestizo, people of mixed European and Native American ancestry with a smaller proportion of African ancestry. Africans, enslaved by Europeans, were brought to Mexico to supplement the indigenous labor force which was reduced by war and disease during the conquest. By the time Mexico gained independence from Spain, the Mestizo population was already numerically superior. ^{2,3}

Elite Mexicans were exiled for political reasons during the years of the Mexican Revolution, 1910-1920.² These Mexican professionals immigrated easily to the U.S., assimilated readily, and assumed positions of renown and prestige in cities such as San Antonio and Los Angeles.⁴

Agricultural laborers in the U.S. derive from two groups. The first group came from the Spanish haciendas in the U.S. Southwest and Mexico. These huge tracts of land, granted to Spanish colonists, included the indigenous inhabitants who remained there as indentured laborers. The other group of laborers were those who immigrated seasonally looking for agricultural work during the dictatorship of Porfirio Diaz (1876-1911) and its aftermath.^{2,3,5}

Colonias, the Spanish word for "neighborhoods," are quasi-legal housing developments in rural and unincorporated areas along the 2,000-mile U.S./Mexico border. Developers purchased land outside city limits where there was little zoning enforcement. They subdivided the land but did not put in the roads, water, or electricity. Lots are financed under a contract for a deed,

which is a rent-to-own form of ownership, but the land was not legally subdivided. Over the past 10 years, the Texas Attorney General has filed 45 lawsuits against *Colonia* developers for deceptive trade practices, illegal subdividing, and health nuisances. Cities have been reluctant to provide assistance, taking the position that until lots are legally platted, *Colonias* do not qualify for assistance with infrastructure improvements. *Colonia* residents, most who cannot qualify for bank loans, put a down payment and make monthly payments on the property. ¹¹ Property ownership is deeply rooted value in Mexican culture, extending back through many generations. ¹²

Texas has an estimated 1,800 *Colonias* along its 1,248 mile stretch of borderland while another 1,000 of these settlements can be found along the borders of New Mexico, Arizona, and California. Contrary to popular belief, approximately two-thirds of the 500,000 *Colonia* residents are U.S. citizens and not illegal immigrants. The vast majority of residents under the age of 18 were born in the United States, although the head of household was most likely born outside the U.S. The median annual income for *Colonia* families is estimated at \$7,000 - \$11,000 per household. Typical family size is five to six people. It

A Colonia community is a highly concentrated pocket of poverty that is physically and legally isolated from neighboring cities. The single or double room dwellings that serve as residences for families were built on land that was never registered or legally platted with city or county governments. As a result, these communities exist without fundamental services such as water and electricity. Because of economic poverty, low educational attainment, substandard housing, inadequate plumbing and sewage disposal, and limited access to clean water, Colonias are plagued with a multitude of health problems, such as Hepatitis A epidemics, that are reflective of third-world communities. ^{10,12,13}

B. Religion

The medieval Catholicism of invading sixteenth century Spanish explorers was met by Mesoamerican religious belief systems equal in spiritual energy. Mexican native cultures practiced religions which seemed bizarre and at the same time disconcertingly familiar to Europeans. In fact, critical aspects of the two religious systems were indistinguishable. For example, fundamental to Mexican native belief is the concept of the incarnation of god, including god's appearance on earth, his life and teachings while incarnate, followed by his departure and promise of return, and the dream of a messianic utopian society. Moctezuma, the Aztec emperor, welcomed Cortés, the Spanish conquistador, with gifts, believing him to be Quetzacóatl, the most powerful Aztec god.

The virgin goddess is another concept which is essential in both belief systems, as is the belief in a pantheon of lesser gods or saints who are physically capable of affecting the lives of the living. Central to both traditions are sacred sites that are dedicated to the honor of saints. The faithful are required to propitiate their saints and make pilgrimages to the sacred sites at regular intervals.⁴

With the conquest, the provincial Catholic Church was charged with salvation and pacification of the native populations, essential for economic productivity of the land. Native Mexican cultures were brought into the church symbolically and physically. What emerged was a blend of native beliefs and traditional sixteenth century Spanish Roman Catholicism, often called Folk Catholicism. In many instances, native beliefs and rituals were literally incorporated

into the Roman Catholic belief system (e.g. Virgen de Guadalupe). There was polarization between adherents of Spanish Catholicism and the Mestizos and Indians who practiced Folk Catholicism. This division guaranteed the perpetuation of folk religious practices within lower classes.¹

Within Folk Catholicism there have been numerous miracle workers and prophets. Two famous healers who have become folk saints were Don Pedrito Jaramillo and El Niño Fidencio Constantino.⁵ Don Pedrito was born in 1829 in Mexico. In 1881, he came to live at Los Olmos (The Elms) Ranch near Falfurrias, Texas. He was a sheepherder who received the gift (don) of healing from God after an accident that left him unconscious. He devoted the rest of his life to healing others. He did not charge for his services since doing so risked losing the don. People repaid him with prayers and gifts. When he died in 1907, he left the ability to prescribe (recetar) to a few believers. Healing in the name of Don Pedrito is still practiced actively in South Texas. Healings (sanaciones) are performed inside Don Pedrito's shrine every Saturday.⁶

José Fidencio de Jesús Constantino Sintora settled in the village of Espinazo in the northern Mexican state of Nuevo Leon in 1921, when he was twenty-three years old. In 1928, he gained national attention as a healer with reports of miraculous cures. He made extensive use of medicinal plants, particularly the pirul tree, and went into a trance to heal. He performed his cures publicly, allowed photographs and gave interviews. In a short time, he became a world figure. Before his death in 1938, at the early age of 40, he appointed some of his followers (Fidencistas) to continue his work.^{5, 7, 8} To this day, tens of thousands of pilgrims visit his shrine each year. Fidencista missions are found throughout South and West Texas, and his spirit is believed to continue to cure the ill through Cajitas or Materias (conveyors). Dressed in white shirts with red scarves, they go into a state of trance, healing in the name of El Niño Fidencio. ^{6, 8, 9}

C. Curanderismo: An Elaboration on Curanderos, Parteras, Herbolarios, and the Traditional Healer-Patient Encounter

This section elaborates on the material found in Section IV. "What is Curanderismo?" and is based on information from the study and the literature.

Curanderos

Other rituals used by curanderos are the sahumerio, sortilegio and velaciones. ^{1, 2, 3} Sahumerio is a ritual incensing that serves as a purification rite and is intended to treat the social environment. Sahumerios are conducted on homes, places of business and patients. A sortilegio (positive form of bewitchment) addresses negative influences such as excessive drinking, infidelity, or problems imposed by antisocial magic. Velaciones (candle burning) is a ritual intended to influence people from a distance. Color, position, and arrangement of multiple candles are important considerations. Color is also significant in the environment, with many of the folk healers' rooms painted a bright blue or sky blue. ¹ The color blue is often associated with the Virgin Mary. Light blue is also thought to emit emotions of peace and serenity. ⁴

At the spiritual level, the *curandero* serves as a medium to communicate with the spiritual world. Practice at this level rests on the soul concept. The soul is the life and personality force of a human being. It is sacred and when violated terribly can cause an individual to cease being who he or she is truly called to be. For some healers, treatment involves identifying lost parts of the soul and calling them back to the patient. According to some researchers, diagnosis is made by sending the *curandero*'s soul to look at the patient's soul or asking spirits with whom the medium is in contact to check the patient. Treatment may include performance of psychic surgery. This surgery involves symbolic excision of diseased tissue by changing energy fields in the client's body. A crucifix or other object may be used as the excising tool. Whatever the treatment, *curanderos* credit the spirits or God acting through them for whatever healing is accomplished.

The mental level is the least commonly practiced and the one considered most dangerous to both the healer and the patient. Curanderos may observe a patient's aura or use mental telepathy to diagnose the patient's problem. To cure, they either dominate the patient mentally to eliminate social and psychological problems or channel mental vibrations at the affected part of the patient's body. Diagnosis can be done at a distance on the spiritual and mental levels. 1,3

The three levels, material, spiritual and mental, are not mutually exclusive. The curandero will use whatever level is called for by the particular situation. Although most curanderos know how to use and are comfortable using both material and spiritual levels to diagnose and treat their patients, few feel comfortable and adept with healing at the mental level. Most of the healers interviewed have heard of it and have heard of a few people who practice it. However, they relate it to spirits of the dark (obscuridad) and magic used in sorcery and witchcraft. These are areas which they felt dealt with manipulation of powerful forces, requiring prolonged special training, and knowledge of specific ways of protecting themselves from harm.

Parteras

Parteras practicing on both sides of the border have many tools and techniques in common. Sixteen parteras and three curanderas interviewed for this study described their work delivering children.³

They counsel against alcohol and drug use during pregnancy, interestingly for the fathers as well as the mothers. They also promote breast feeding. Perineal massage with olive oil or vegetable oil is used to reduce perineal tears and trauma during delivery. Parteras stay by their patients during labor and delivery to provide continuous emotional support. Parteras in the study reported that patients cried and they would cry with them. They would comfort their clients by praying with them when asked or making reassuring comments. They would also hold, hug or caress their clients. Patients can choose the position for delivery and whether there are others present. One partera reported allowing whomever the patient wanted present but indicated that "Mexican women don't want to be watched delivering." Parteras take direction from their multiparous patients who know what to expect from their own bodies. All of the parteras in the study used a sliding fee scale and worked with patients on schedule of payment. Parteras interviewed in Arizona, New Mexico, and Texas charged an average of \$550 dollars per delivery. However, documented or certified nurse midwives in major urban areas of these states charged \$1,200-\$1,600 dollars per delivery³ and in New Mexico, some healers among the Native Americans provide midwifery services to tribal members at no cost. Over the four-year

course of the study (part A and part B) the average fee increased \$100-200 dollar per delivery. The increase in fees was attributed to increases in laboratory and licensing fees. *Parteras* in Mexico charged 300-500 pesos or \$40-50 dollars.

The Mexican parteras who were interviewed described obstetrical care in Mexican hospitals as being similar to the United States, an environment that is not viewed as comforting by their clients. They indicated that people are "afraid they will be separated from their families." Mexican parteras also reported physicians' overuse of caesarean section due to financial incentives and the desire to spend less time with the patient. A new trend among the Mexican partera is the inclusion of the husband in the delivery. Two of the parteras in the study described having the husband provide massage during labor, supporting the mother when pushing and cutting the umbilical cord. These two parteras believe that by witnessing and participating during labor and delivery the husband becomes much more aware of the physical and emotional demands that birthing exerts on his wife. 9

Mexican parteras in the study made extensive use of herbal medicine and practiced folk medicine techniques³ such as:

- Gentle abdominal massage and moxibustion strategies used to turn babies from the breech position; massage is also used to decrease labor pains and to expedite deliveries
- Temascali (medicinal sweat bath) used for women who cannot conceive to "warm the
 coldness" of the uterus and open blocked oviducts; also, used beginning at 15 days
 postpartum to return tissues back to normal (nursing babies are brought in to the temascali
 for the last ten minutes of the 15-25 minute session in order to become as warm as the
 mother. This is to prevent a shock to the baby due to temperature differences between the
 baby and mother's breast milk);
- Acupressure/foot massage used to restore the vaginal fornix;
- Blanket tossing a technique, using a shawl, to change position of the fetus that may be
 causing pain and discomfort in the pregnant woman in the last trimester. A shawl in doublethickness is used as a sling under the supine pregnant woman. Rolled edges of the shawl are
 raised up perpendicular to the hips, rocked gently to relax the patient and then tugged on
 abruptly. Blanket tossing was reported as used by two Mexican parteras and avoided by
 another as being dangerous;
- Cuarentena a practice whereby, for forty days, the mother avoids bending, heavy lifting and overexertion. Other members of the family take care of things while the mother heals and regains strength. She also abstains from sexual intercourse;
- Prenatal nutrition black radishes are recommended for high iron and mineral content.
- Recommendations concerning foods to eat after delivery "warm" foods are recommended, since the uterus is "cold," having been weakened by labor and delivery. Warm foods referenced by a curandera/partera were garlic, onion, guajillo chile, pasilla chile. Cold foods such as watermelon, avocado, jicama, and chayote squash are to be avoided. One curandera/partera who was interviewed reported that just after childbirth, women are given a chicken broth with ground sesame (for calcium) and chile seeds (capsaicin has antibiotic properties). Amaranth is also recommended as it is a complete food and provides needed vitamins to restore strength.

Mexican Parteras

Two of the Mexican parteras in the study used a stethoscope and sphygmomanometer in prenatal care. Six parteras were aware of folic acid, most having learned it from interaction with the public health programs and/or through their midwifery training. All were aware of prenatal vitamins and iron and three were trained to give vitamin injections. One reported using aerosol spray anesthesia on the patient's perineum. The Mexican parteras also reported that their Health Department had trained them in the use of sterile umbilical tape and provided them with tape along with gloves.

Mexican parteras were also trained to recognize high risk women and refer them to the hospital system. Parteras described high risk as women under age 18 and those with problems such as diabetes, hypertension and toxemia.

South Texas Parteras

Four of the parteras practicing in South Texas had their own birthing centers. Most of the South Texas parteras were highly acculturated in biomedical practices. In providing prenatal care, they checked weight, blood pressure, and respiration and did blood tests, with one partera specifically referencing CBC and HIV tests. One reported taking a history and making physical assessments. They counseled on nutritional practices and avoidance of alcohol, tobacco, and drugs. As instructed by the Texas Midwifery Board, they referred high risk women (over age 35 and under age 18) to other providers for care. One reported that clients frequently do not seek partera services until the fourth month. They were aware of folic acid and vitamins for decreasing birth defects. One was aware of special programs for women with children born with birth defects. They indicated that patients choose a partera over hospital delivery because "they think it is very traumatic in the hospital. They don't like the medicine... They dislike the frequent vaginal exams... doctors are too quick to use the forceps or perform caesarean sections."

Similar to their Mexican counterparts, South Texas parteras made use of herbal medicine and practiced folk medicine techniques such as:

- Using herbs during and after childbirth, such as cinnamon to prevent stomach ache or anise tea to prevent coughing;
- Placing a band with a clean silver or gold coin on the infant's umbilicus for protection;
- Using metal in the form of keys, coins, or medals to protect against cleft palate during a lunar eclipse;
- Drinking the water in which gold jewelry has been boiled to prevent spontaneous abortion;
- Using a small slice of boiled dehydrated umbilical cord to treat patients with seizures, asthma
 and allergies. The cord does not have to belong to the baby and it can be several years old;
- Practicing cuarentena which provides the mother an opportunity to rest and recuperate;
- Recommending foods to eat or use during cuarantena: rice, chickpeas, cream foods like oatmeal, lamb (for its antibacterial, antipyretic properties), olive oil or cooking oil on breasts to moisten and prevent cracking of nipples. Foods to avoid: beans and eggs (colic, diarrhea), spicy foods, chili (rash), pork (a cold food that may be too heavy for the infant and also creates gas).

Three of the four parteras interviewed in the extension study are faculty members of one of the largest schools for documented midwifery in the Southwest. Midwifery students come from all over the U.S. and Canada to train and prepare for the midwifery examination offered through the North American Registry of Midwives (NARM) which, once passed, makes them certified midwives (in Texas, the term used is "documented"). This facility, accredited by the Midwifery Education Accreditation Council, comes under the aegis of the Midwives Association of North America. Two of the birthing centers in El Paso (West Texas), including this one, are operated by parteras. The majority of the parteras at these centers are Anglo but are bilingual. The facilities and services at these two centers are more medicalized than those of the traditional parteras working on their own. The parteras at the birthing centers described the importance of strict adherence to state midwifery regulations, providing prenatal HIV, Hepatitis B, and syphilis testing, newborn screening, and other tests as required.

Several factors were identified through the ethnographic interviews that have influenced the use of parteras along the U.S./Mexico border. First and foremost is the regulation of midwifery practice in all four states. Although each state varies in its requirements for licensing, documentation of practice, and laboratory services, the effects on traditional parteras has been similar. It is increasingly difficult to locate them although they can still be found through an informal barrio network (comadreando). Only in New Mexico, where the environment appears less restrictive toward alternative medicine in general, were fewer problems for parteras reported. Another factor is the recent phenomenon of Mexican physicians, eager to practice in the United States, opting to obtain certification as midwives. This practice has created a cultural anomaly in that a new word, "partero," meaning male midwife, has come into use. In all four states, certified nurse midwives and parteras who practice through birthing centers, in closer affiliation with biomedical practitioners and the biomedical model, have less difficulty in practice than the traditional parteras. There remains an uneasy alliance between the organizations of certified nurse midwives and other midwives.

In Texas, state law prohibits hospitals from denying emergency care because of inability to pay, including delivery of newborns. This makes it possible for women, who can manage it, to deliver at no cost and also ensure their children receive the coveted U.S. citizenship.

Interestingly, while parteras and the birthing centers struggle in South Texas, the three birthing centers in El Paso appear to be managing well with at least one of the centers averaging 40 births per month. One possible explanation for this difference is El Paso's proximity to Juarez, Mexico, one the largest industrialized cities in Mexico. U.S. companies have established textile, apparel, electronic assembly and other factories (maquiladoras) all along the Mexican side of the U.S./Mexican border, including Juarez. Young women make up the primary labor force in many of the maquiladoras. These women who earn three or four times as much as they could earn at other jobs have no medical insurance but enough cash to pay for midwifery services at a facility where U.S. citizenship for their newborns is ensured. Their modesty (pudor) is protected and services are rendered in home-like surroundings with Spanish-speaking providers.

Herbolarios

Although herbal medicine is used by a number of different types of professional *curanderos*, the *herbolarios* indicate that they specialize in the knowledge, cultivation, harvesting, drying, preserving, preparing, packaging and dispensing herbs, roots and barks to clients. Four of the healers interviewed for this study were self-identified as *herbolarios*.³

After gathering the plants, healers "have to get them home, hang them up, prepare (as in making a tincture) or dry them." Herbal medicine is produced and used in the form of salves, tinctures (herbs combined with 20 percent water and 80 percent alcohol), extracts, syrups, drops, ointments, and soaps. There is also the process of making microdoses which involves using a few drops of a base extract from a medicinal plant in water. Informants likened the use of microdoses to homeopathic medicine, "although we work with opposites and homeopathy works with similar." Some physicians in Mexico are now actively using and teaching the use of microdosis (http://www.tlahui.com/herbal). The illness and degree of illness determines the form in which the herbal medicine is used. In addition, plants are grouped in categories of use according to body systems. In addition to using medicinal plants to treat illnesses affecting a particular body system, there is an idea that some plants are stronger than others. Healers should start with those that are less potent and work up. For children, there are plants which are not as strong as those needed by adults.

It is common for people, not just traditional healers, to cultivate a small bed or plot of herbs. For those herbs which cannot be cultivated or collected, there are also the botánicas, yerberías and candle shops. These shops, readily identifiable in the local yellow pages under herbal and/or candle shops, sell herbs (fresh and dried), candles and other supplies. The two distributors for the herbs found in most botánicas throughout Texas are La India Packing Company in Laredo and Azhar's Products in San Juan, Texas. Some of the most frequently used commercially prepared herbal medicines are the Bach Flower Essences. These 38 homeopathic flower essences are based on single wild flowers and tree blossoms, developed by Dr. Edward Bach (1886-1936), a physician and homeopath who trained in London. Healers in New Mexico and Arizona who were interviewed for this study reported that they purchased some of their herbal remedies in extract form through a company based in Phoenix, Arizona. They described using the extracts to create their own blends customized for their clients.

The Traditional Healer-Patient Encounter

Patients are usually accompanied by a family member or someone who knows the healer. As indicated in other sections, health decisions are made within the context of the family. Once a patient is seated with the healer, the participants sit and chat as in any other personal social encounter. This is the *personalismo* so highly valued in Hispanic/Mexican American cultures. When sufficient time has passed for an exchange of cordialities and to establish rapport and confidence, the healer gently directs the conversation to the problem (i.e... A ver hijo(a) jen qué puedo ayudarte? Let's see son/daughter, how can I be of help?) The patient describes symptoms and asks the *curandera* to identify the problem. The *curandera* uses an assessment process to determine whether the cause is natural or supernatural and to establish a treatment plan. For some patients, treatment may involve three to four visits. 1,3

When asked the question, "How do you start healing?," some folk healers described beginning the encounter by first asking God to help them in their work: "I ask God to enlighten me." The healer asks the patient questions. "I begin to ask the individual what is wrong, what he expects of me, what it is he wants me to do for him. Then, people begin to talk, they begin to let it out. Just by listening and asking questions, like 'How do you live? How was your childhood? How do you get along with your family? What do you do? Why are you sick? When did this start? Where do you think the illness comes from?' people will start to tell you the whole story of their

lives and some cry. People relax and start feeling better because there is someone to listen to them and to hear about their problems or who will even participate in their problems." As part of this encounter, it is very typical for the folk healer to embrace, touch and be physically close to the patient.³

While establishing *personalismo* and listening to understand what the patient feels is the problem, healers observe the patient's physical appearance. They conduct a physical assessment such as looking at the eyes, skin color and texture, evidence of swelling or fluid retention (e.g. bags under the eyes may signal kidney problems; *ojeras* or dark circles under the eyes may suggest internal bleeding; dry, brittle hair may mean thin blood or anemia). They also ascertain whether a biomedical diagnosis had already been given or if there have been other interventions. 1,3

There are situations, however, that present a need for immediate intervention. Curanderas in the study reported that they could tell at once that they needed to begin treatment and would bypass many of the usual steps in their healing process. "At first, most people want to explain their case. Sometimes, there is not time to listen...We see the unfocused look in his eyes, the pale dry lips, the pallor of cheeks, the lack of strength in his hands, how they fall. In all this I recognize his case is one of great weakness...and I say, 'Let us not waste time and let's start healing. We have the plants and we better take advantage and start healing and you can talk to me while we are working."

In his 1968 book, Curanderismo: Mexican American Folk Psychiatry, Ari Kiev, M.D., wrote, "In that curanderismo occurs within the context of other social relationships and not in a separated and highly specialized form of relationship ordered by universalistic, rational, and scientific criteria, it meets certain needs of the Mexican patient which modern Western medicine, with its notions of privacy, cannot." For many Mexican Americans, this maxim still holds true.

D. Compendium of Herbal Medicines

The following lists of herbal medicines were obtained from unpublished data from interviews of 45 traditional healers in Arizona, California, New Mexico and Texas from 1999-2001¹ and La India Packing Company, Laredo, Texas.² Readers are directed to Healing with Plants in the American and Mexican West³, Medicinal Plants of the Desert and Canyon West⁴, and other nerbal medicine references provided in the bibliography.^{5,6,7,8,9,10,11,12,13}

1. HERBAL MEDICINES USED BY FOLKHEALERS OF THE U.S. SOUTWEST AND MEXICO Source: Unpublished data from interviews with 45 traditional healers in Arizona, California, New Mexico, Texas, and Mexico; compiled by María Luisa Urdaneta, PhD, Associate Professor, Department of Anthropology, The University of Texas at San Antonio

TU- Traditional uses as described by informants

7 AZAHARES

See "COPAL".

7 AZAHERES TEA BAG

TU---To calm the nerves and for digestion.

ACEITILLA

TU---To calm the nerves, diuretic, general nerve tonic.

JENGIBRE

TU---To promote sweating, calm nervous stomach, for nausea and vomiting, as a digestive, and for motion

sickness.

AJENJO

TU---to improve appetite, as a stimulant, digestive, for fevers and

intestingal worms.

AJO

TU--- To lower risk of heart disease by preventing build-up

of plaque on arteries; antibacterial.

ALBACAR

TU---Stomach problems, nausea, vomiting, coughs.

ALHUCEMA

TU---

ALFALFA

TU---To improve the appetite, diuretic, tonic, urinary tract problems.

ALTAMISA

TU---For fevers, intestinal worms, muscular aches.

ANIS ESTRELLA

TU---For Indigestion, gas, and colic.

ARNICA

TU---For minor bruises, abrasions, and muscular aches and pains.

External use only.

ANIS

TU--- To improve digestion; decrease gas

AZAFRAN MEXICANO

TU---For the appetite, condiment.

AZAR DE NARANJO

TU---For nerves, insomnia, digestion.

AZUFRE

TU---

BARBA DE ELOTE TU---As a diuretic for kidney and urinary tract problems, and water

retention.

TU---

BARBA DE CHIVO

BILBERRY TU---

BLACK COHOSH TU---

BORRAJA TU---As a diuretic, to promote sweating, and also for coughs, colds,

and fevers, and as a tonic.

CACHANAS TU-Diuretic, sore throat gargle, conception.

CACHANOS TU---Same as "CACHANAS", except for the male.

CALENDULA TU---To induce sweating, menstrual problems, rheumatism, gout, skin

problems.

CAÑA AGRIA TU---For diarrhea, dysentery, antiseptic.

CANCERINA TU---For improving circulation, varicose veins, skin problems.

CANDELILLA TU---Strong purgative, venereal diseases.

CANELA TU--- As a stimulant, digestive aid, and anti-gas.

CAPITANEJA TU--- Externally for skin problems, minor wounds, etc.

CASCARA DE ENCINO ROJO

TU--- For gum disease, inflamed tonsils, kidney and stomach

problems, diarrhea.

CASCARA DE GRANADA TU--- For diarrhea, mouth, gums, and throat irritations.

CASCARA DE NOGAL TU--- For anemia, intermittent fevers, to promote wound healing

(externally),

CASCARA SAGRADA TU--- As a laxative

CENIZO TU--- For colds, flu & cough, liver problems, hepatitis, sclerosis.

CHANGARO TU---Heart tonic, diuretic, nervous disorders, weight loss, diabetes,

kidney problems.

CHAPARRO AMARGO TU---As a liver decongestant, to increase bile production, dysentery,

colic.

CHARRAQUILLA TU---For kidney stones, diuretic.

CHAYA TU--- Weight loss, energy, circulation, blood sugar.

CHIA TU--- As an energizing tonic and for intestinal problems.

CHUCHUPATE TU--- Stomach problems, gas, menstrual problems, appetite.

CINNAMON TU---Tonic, stimulant, for rheumatism, menstrual and stomach

problems.

COCOLMECA TU---As a diuretic and for weight loss

COLA DE CABALLO

TU--- For kidney and urinary tract problems, as a blood purifier.

CONTRA YERBA

TU--- Stimulant, tonic, to induce sweating, for measles.

COPAL

TU--- Uterus problems, skin problems, as an astringent, for headache.

COPALQUIN

TU--- Laxative.

CORN

CUACHALATE

TU---For gastritis, gastro-intestinal ulcers and cancer, gum disease.

CUASIA

TU---Bitter tonic, improves appetite and digestion, and for gall bladder

problems.

CULANTRILLO

TU---A pectoral tonic, mentrual problems, for hair growth.

DAMIANA

TU---Bitter tonic, aphrodisiac.

DARADILLA

TU---Diuretic, liver and kidney problems.

DIABETINA

TU-As a bitter tonic, improves appetite, for high blood sugar.

DIENTE DE LEON

TU---For anemia, diuretic, liver tonic, kidney inflammation.

DONG OUAI

TU---

DRACONTIUM

TU---

ENCINO ROJO

TU---As a diuretic, Astringent, gargle, gum disease.

ESCOBA DE LA VIBORA

TU---For insect bites, arthritis pain, sore muscles. External use only.

ESTAFIATE

TU---For intestinal parasites, gall bladder problems, stomach aches, poor digestion, and to stimulate the appetite.

ESTORAQUE

TU--- Used as incense only.

EUCALIPTO

TU--Coughs, colds, and respiratory problems.

FLOR ALUCEMA

TU---For gas and stomach problems, dizziness & headache, and for

minor abrasions

FLOR AMARILLA

TU---

FLOR ANACAHUITA

TU---Pectoral tonic, expectorant, for coughs and colds.

FLOR AZAHAR

TU---To calm the nerves, for digestion.

FLOR DE JAMAICA

TU---As a natural refreshing beverage and to reduce fevers.

FLOR DE TILA FLOR HUIZACHE TU---Insomnia, stress, to calm nerves, indigestion, menstrual cramps,

TU---For dyspepsia (poor digestion).

FLOR JICARO

TU---For coughs and colds.

FLOR MANITA

TU---

FLOR SAUCO.

TU---To promote sweating, against fevers, colds, flu, bronchitis, and

coughs.

FRESNO

TU-For fevers, as a diuretic, to promote sweating.

GARANONA

TU-Stomach problems, diuretic, digestion, blood purifier, sexual

debility.

GINGER

TU---To prevent motion sickness

GINSGENG

TU---

GOBERNADORA

TU---Externally for athletes foot and nail fungus, bruises, rashes, minor wounds & abrasions, and dandruff. As a mouthwash. Internally for

kidney & gall stones, respiratory illness, etc.

GOLONDRINA

TU-For gastritis and general digestive inflammation, sore throat,

hemorrhoids.

GORDOLOBO

TU---For diarrhea, coughs and sore throat, and minor abrasions.

GRANADA

TU---Astringent, for diarrhea.

GUARUMBO

TU-Heart tonic, diuretic, nervous disorders, weight loss, kidney

problems

HABAS DE SAN IGNACIO

TU---Very strong purgative. Use with much caution.

HAMULA - PRODIGIOSA

TU-Antiseptic, increases saliva production and gastric juices,

stimulates digestion, fights fevers, and high blood sugar.

HINOJO

TU---For stomach problems, gas, diuretic, menstrual problems.

HORGANO MACHO

TU---For hair health/as a rinse

HOJAS DE MESQUITE

TU---Used for digestive inflammation and respiratory problems.

HOJAS DE NARANJO

TU---Used for fevers, nerves, and stomach disorders.

HOJASE

TU--For indigestion, as a laxative.

HOJASEN

TU---

HORMIGA

TU---For coughs.

HORTIGUILLA

TU---

HUACHICHILE

TU---To induce sweats, against chills and fevers, as a diuretic, to

induce vomiting, as a laxative.

HUIZACHE

TU---For bad digestion.

INCENSO

TU---

INJERTO DE MEZOUITE

TU---Externally for aches; to cause vomiting.

·		
 . .	 -	

IPAZOTE DE COMER

TU---As a condiment for black beans, intestinal parasites, gas,

digestive, problems, menstrual problems.

IPAZOTE DE ZORILLO

TU---To expel intestinal parasites, for digestion, and for menstrual

problems.

JARITA

TU---

LA PASTOR

TU---

LAUREL

TU---As an anti-spasmodic, for general stomach problems, and gas.

Also as a condiment.

LICORICE ROOT

TU---

LINAZA

TU---For constipation and stomach problems, digestive and urinary

tract problems.

LOBELIA

TU---

MALA MUJER - ZUMAQUE

TU---

MALAVAR

TU---

MALVA DE CASTILLA

TU---For colds, diarrhea, skin disorders.

MANZANILLA

TU---For tension, stress, insomnia, indigestion, menstrual cramps,

colds and flu, minor wounds and abrasions.

MANZO

TU---

MARIOLA

TU---Bitter tonic, liver problems.

MARRUBIO

TU---For digestion, weight loss, coughs, stomach problems, menstrual

problems.

MASTRANZO

TU---

MATARIOUE

TU---For rheumatism, neuralgia, laxative, diabetes

MEJORANA

TU---For indigestion and gas, and externally for arthritis and

rheumatism discomfort. Also as a condiment.

MENTA

TU---As a refreshing tea and for stomach problems.

MIRRA

TU---As a gargle, antiseptic, for gas and stomach problems.

MIRTO

TU---

MISPERO

TU---Sore throats and as an astringent.

MORDAILLA

TU---

MOSTAZA AMARILLA

TU---As an appetizer, digestive, purgative, for bronchitis.

MOSTAZA NEGRA

TU---For improving appetite, and as a tonic.

NERVINA

TU----

OCOTE

TU---For pain & rheumatism

OJO DE VENADO

TU---To combat 'Mal de Ojo'. Used in ritual

OREGANO HOJA LARGA

TU---Stomach aches, diarrhea, externally for pain, condiment.

OREJA DE RATON

TU---Stomach and liver problems.

PALO 3 COSTILLAS

TU---Diuretic, urinary tract problems.

PALO AMARGOSO

TU-

PALO AZUL

TU---For kidney stones and as a diuretic.

PALO BARADU

See "PALO AZUL"

PALO BRAZIL

TU-For improving circulation, hemorrhoids, to whiten the teeth, to

firm the gums.

PALO DE HUIZACHE

TU-For diarrhea.

PALO DULCE

TU-For Kidney and gall bladder problems, diuretic, decongestant,

coughs and colds.

PALO GUAYACAN

TU---Blood purifier, to induce sweating, for rheumatism.

PALO MUERTO

TU---To combat paralysis.

PALO OROZUS

TU---

PALO SANTO

TU---

PASIFLORA

TU---For nerves, insomnia, stress.

PATA DE VACA

TU---For asthma, diabetes.

PELITRE

TU----

PEPPERMINT

TU--indigestion.

PEREJIL

TU---stimulate the appetite, to induce sweating, as a diuretic, for kidney stones, for menstrual problems, and as a stimulant.

PERICON AMARILLO

TU---See "YERBANIZ".

PIMENTON

TU---For gas, as a stimulant, and as a condiment.

PINGUICA

TU---For kidney, bladder problems, bronchial infection.

PIRUL

TU---For urinary tract problems, bronchitis, gum disease, sore throat.

POLEO

TU-For fevers, stomach aches, gas, to induce sweating, tonic,

menstrual problems.

POPOTILLO

TU---

PRIMROSE OIL

TU---

PRODIGIOSA

TU---For lowering blood sugar, indigestion, and gall bladder problems.

PULMONARIA

TU---As a diuretic and for respiratory problems.

QUINA ROJA

TU---Bitter tonic, antiseptic, and for intermittent fevers.

RAIZ ANGELICA

TU---

RAIZ DEL INDIO

TU---

RAIZ GENCIANA

TU---Bitter tonic, for digestive problems, fevers, intestinal parasites.

RAIZ INMORTAL

TU---

REGALIS

TU---

RETAMA

TU---As a diuretic, blood purifier, for diabetes.

ROMERO

TU---As a digestive, coughs and colds, menstrual problems.

ROSA DE CASTILLA

TU---For diarrhea, colic, gargle, mouthwash, eye wash.

RUDA

TU---For stomach ache, ear ache, menstrual problems.

SALVIA

TU---For stomach problems, as a tonic, and a stimulant.

SAN FRANCISCO

TU---

SANGRE de DRAGO

TU---

SANGRE de VENADO

TU---

SAN NICOLAS (YERBA DE)

TU--- As an antiseptic, anti-inflammatory & cardiac stimulant.

SAN PEDRO

TU---As a diuretic, for fevers, external abrasions.

SEMILLA DE CILANTRO

TU-For indigestion, gas, urinary tract problems. As a condiment.

SIBERIAN GINSENG

TU----

ST. JOHN'S WORT

TU---

SPIKENARD

TU----

TE COMANCHE

TU---For stomach problems.

TE DE CENA

TU---As a mouthwash, laxative, diuretic & to expel worms; works

like Hojase and Hojasen.

TE DE LIMON

See "ZACATE DE LIMON".

TE DE MILAGROSO

TU---

TEJOCOTE

TU---As a diuretic for kidney problems.

TEQUESQUITE

TU---As a diuretic for kidney and urinary tract problems.

TIAZANA VITAL

TU---To calm the nerves, improve circulation (for hemorrhoids),

diuretic

TLANCHICHINOLA

TU---Internally for digestive problems, ulcer, externally for skin

disorders and wounds.

TOMILLO

TU---for stomach problems, as a stimulant, tonic, to promote menstrual

flow.

TOLOACHE

TU---

TORONJIL

TU---For indigestion & gas, and to stimulate appetite.

TOROTE

TU---

TRONADORA

TU---

TUMBA VAQUERO

TU---Used as a sedative, and in combating obesity.

UÑA DE GATO

TU---For arthritis, diabetes, to boost the immune system.

UVA URSI

TU---Mainly used as a diuretic, tonic, astringent. Also used to reduce

uric acid, kidney stones, and gall stones.

VALERIANA

TU-Used for insomnia, stress, fevers, and menstrual problems.

VENTOSIDAD

TU---For gastritis.

VERBENA

TU---For fevers, and to strengthen the hair (externally).

VISVIRINDA

TU---

VITEX

TU---

YERBA BUENA

TU---As a cordial, for indigestion and nausea, coughs and colds.

YERBA CAPITANA

TU---For boils or skin problems.

YERBA DE CRISTO

TU-For rheumatism and for the stomach as a tonic.

YERBA DE LA MULA

TU---For fevers and colic.

YERBA DE LA VIBORA

TU---See ESCOBA DE LA VIBORA. External use only.

YERBA DE SANGRE

TU---

YERBA DEL BALLAZO

TU---

YERBA DEL CANCER

TU---To cure wounds and abrasions (externally), boils, tumors, etc.

YERBA DEL GATO

TU---To calm the nerves.

YERBA DEL LOBO

TU---

YERBA DEL PASMO

TU---

YERBA DEL PERRO

ŤU---

YERBA DEL SAPO

TU---

YERBA DEL VENADO

TU---

YERBA MATE

TU---Used as a blood purifier, diuretic, stimulant, and for headaches.

YERBA MORA

TU---For inflammation, pain, and irritation of the skin, burns, etc.

YERBA MUICLE

TU---Used as a stimulant and against dysentery and diarrhea.

YERBA POLEO

TU---Used during coughs and colds, for insomnia, calming nerves,

headaches, and gas.

YERBANIZ

TU---For stomach ache & cholic, for bathing.

ZACATE DE LIMON (Te Limon)

TU-For gas, upset stomach & nausea, hypertension, rheumatism,

fever.

ZAPOTE BLANCO

TU---Used as a sedative, for insomnia, high blood pressure, as a

diuretic.

ZARZAPARILLA

TU---As a blood purifier, for gas, diuretic, colds, gout, skin problems.

ZASAFRAS (SASAFRAS)

TU--For body aches and pains, fevers, rheumatism, gout, arthritis,

skin problems, as a tonic, diuretic, stimulant, blood purifier.

ZIMONILLO (SIMONILLO)

TU-For general stomach problems, nausea, vomiting.

2. LA INDIA PACKING COMPANY - LIST OF HERBAL MEDICINES

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Source: La India Packing Company in Laredo, Texas; Integrated into document in original format and reviewed by Maricela Aguilar, RN, MSN, Assistant Professor, The University of Texas Health Science Center, Department of Pediatrics, Division of Genetic and Metabolic Disorders

 $TU = Traditional\ Uses$ $P \& U = Preparation\ \&\ Uses$

1. 7 AZAHARES

See "COPAL".

2. 7 AZAHERES TEA BAG

TU-To calm the nerves and for digestion.

P&U - 1 tea bag per cup.

3. ACEITILLA

Nair nit Tree/Satinwood

Bideus Pilosa

TU---To calm the nerves, diuretic, general nerve tonic.

P&U-1 tsp. per cup.

4. ACOTE

TU---

P&U -

5. AGRIMONIA Grove Bur Agrimonia Euptoria

TU---As a digestive, astringent, problems with the liver and spleen.

P&U - 1 tsp. per cup.

6. AJENGIBLE (JENGIBRE) Edible Ginger

Zingeber Officianle

TU---To promote sweating, calm nervous stomach, for nausea and vomiting, As a digestive, and for motion sickness.

P&U - ½ tsp. per cup.

7. AJENJO

Common Wormwood/Mugwort
Artemissia Absinthium

TU-to improve appetite, as a stimulant, digestive, for fevers and

intestinal worms. P&U - 1/4 tsp. per cup

8. ALBACAR

Basil

Ocimum Basilicum

TU--Stomach problems, nausea, vomiting, coughs.

P&U - 1-2 tsp. per cup

9. ALFALFA

TU---To improve the appetite, diuretic, tonic, urinary tract problems.

P&U-1 tsp. per cup.

10. ALFILERILLO

Alfilaria – Stork's Bill Erodium Moscatum TU-Stomach problems, fevers, diuretic.

P&U - 1-2 tsp. per cup.

11. ALTAMISA

TU-For fevers, intestinal worms, muscular aches.

P&U - 1 tsp. per cup.

12. AMOLE

Soaproot

Stesonosperma Halimifolium

TU---Used for hair health, as a rinse.

P&U - 1 - 2 tsp. per cup as a rinse for the hair.

13. ANIS ESTRELLA

Star Anis

Illiclus Anitasum

TU-For Indigestion, gas, and colic.

P&U - 1 tsp. crushed seed per cup.

14. ARNICA

TU---For minor bruises, abrasions, and muscular aches and pains.

External use only.

P&U - 1-2 tsp. per cup of water, used externally.

15. AXOCOPAGUE

Scarlet Runner Bean Gaultheria Acuminata

TU---For rheumatism, diuretic, laxative, deodorizer.

 $P\&U - \frac{1}{2}$ tsp. per cup.

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16. AZAFRAN MEXICANO

TU---For the appetite, condiment.

Mexican Saffron
Carthamus Tinctorius

P&U - A pinch.

17. AZAR DE NARANJO

TU---For nerves, insomnia, digestion.

P&U - 1 - 2 tsp. per cup.

18. AZUFRE Sulfer

TU---P&U -

19. BARBA DE ELOTE

Corn Silk
Zea Mays

TU---As a diuretic for kidney and urinary tract problems, and water

retention.

P&U-1-2 tsp. per cup.

20. BOLDO Boldo TU---As a stimulant, tonic, for fever, indigestion, stomach problems,

and for liver and urinary tract problems

P&U - ½ tsp. per cup

Boldo Peumus Bodus

21. BORRAJA

Borage Borago Officinales TU---As a diuretic, to promote sweating, and also for coughs, colds,

and fevers, and as a tonic.

P&U-2-3 tsp. per ½ cup of water.

22. BOTON CORAZON Magnolia Flower

Magndia Macrophylla

TU---Anti-spasmodic, cardiac stimulant (topic).

P&U - 1-2 tsp. per cup.

23. CACHANAS

Gayfeather Liatris Sp. TU-Diuretic, sore throat gargle, conception.

P&U - 1 tsp. per cup

24. CACHANOS

Button Snake Root Liatris Sp.

TU---Same as "CACHANAS", except for the male.

25. CALCOMECA Sweet Fern

Smilax Cardifolia

TU---As a diuretic, and for weight loss.

P&U - 1 small piece per cup.

26. CALENDULA

TU-To induce sweating, menstrual problems, rheumatism, gout, skin

problems.

P&U - 1 - 2 tsp. per cup, internal and external.

27. CANA AGRIA

Spiral Flag
Rumex Hymendsepalus

TU---For diarrhea, dysentery, antiseptic.

P&U-1-2 tsp. per cup

28. CANA FISTULA

Golden Shower Cassia Fistula TU---As a laxative.

P&U-1-2 ounces per cup.

29. CANAHUALA

TU---For kidney, heart, respiratory, skin, and scalp problems.

P&U - 1/2 to 1 tsp. per cup, internally or externally.

30. CANCERINA

TU-For improving circulation, varicose veins, skin problems.

 $P\&U - \frac{1}{2}$ tsp. per cup.

31. CANDELILLA

TU---Strong purgative, venereal diseases.

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Wax Plant

 $P\&U - \frac{1}{4}$ tsp. per cup.

Euphorbia Antisyphilitica

32. CANELA Cinnamon TU - As a stimulant, digestive aid, and anti-gas. $P&U - \frac{1}{2}$ to 1 tsp. per cup.

33. CAPITANEJA

TU - Externally for skin problems, minor wounds, etc. P&U-1-2 tsp. per cup externally.

34. CASCARA DE ENCINO ROJO Birch Leaf - Red Oak Quercus Sp.

TU - For gum disease, inflamed tonsils, kidney and stomach problems, diarrhea.

P&U-2 tsp. per cup as a gargle; 1 tsp. per 2 cups as tea.

35. CASCARA DE GRANADA Pomegranate Rind Punica Granatum

TU - For diarrhea, mouth, gums, and throat irritations. P&U-1 ounce per 2 cups for gargle: 1 tsp. per cup as tea.

36. CASCARA DE NOGAL Pecan Shell Carva Illinoinesis

TU - For anemia, intermittent fevers, to promote wound healing (externally).

P&U-1 tsp. per cup internally; 2 tsp. per cup, externally.

37. CENIZO White Goosefoot Leucophyllum Frutesdens TU - For colds, flu & cough, liver problems, hepatitis, sclerosis. P&U-1 tsp. per cup.

38. CHANGARO Cecropia Obusifolia TU - Heart tonic, diuretic, nervous disorders, weight loss, diabetes, kidney problems. P&U - 1/4 tsp. per cup.

39. CHAPARRO AMARGO

TU – As a liver decongestant, to increase bile production, dysentery,

colic. P&U - I tsp. per cup

40. CHARRAQUILLA

TU - For kidney stones, diuretic.

P&U-1 tsp. per cup.

41. CHAYA

TU - Weight loss, energy, circulation, blood sugar. P&U - ½ tsp. per cup.

42. CHIA Seed of the Lime Leafsage Slavia Sp.

TU - As an energizing tonic and for intestinal problems. P&U - Sprinkle on food or mix 1/2 tsp. in a glass of water and allow to

thicken before drinking.

43. CHUCHUPATE Osha

TU - Stomach problems, gas, menstrual problems, appetite. P&U-1 tsp. per cup

44. CINNAMON

TU - Tonic, stimulant, for rheumatism, menstrual and stomach problems.

 $P\&U - \frac{1}{2} - 1$ tsp. per cup.

45. COCOLMECA Colcomeca Sp. Smilax Cordifolia See "CALCOMECA".

46. COLA DE CABELLO Scouring HorseTail Equisetum Hyemale

TU-For kidney and urinary tract problems, as a blood purifier.

P&U-1 tsp. per cup.

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47. CONTRA YERBA

Arizona Root

Dorstenia Contraie

TU - Stimulant, tonic, to induce sweating, for measles.

P&U- 1/2 to 1 ounce per cup.

48. COPAL

Copal Elaphrium Jarullense TU – Uterus problems, skin problems, as an astringent, for headache.

P&U - A pinch per cup, as incense for headache.

49. COPALOUIN

Copal Tree – Tree of Heaven
Rhamus Purshiana

TU - Laxative.

P&U-1 tsp. per cup.

50. CUACHALATE

TU---For gastritis, gastro-intestinal ulcers and cancer, gum disease.

 $P\&U - 1 \frac{1}{2}$ tsp. per cup.

51. CUASIA

Quassia Quassia Amara TU-Bitter tonic, improves appetite and digestion, and for gall bladder

problems.

P&U-1 tsp. per cup.

52. CULANTRILLO

Adiantum Capillus Veneris, L.

TU-A pectoral tonic, mentrual problems, for hair growth.

P&U - 1 tsp. per cup internally and externally.

53. DAMIANA

Damiana Mariola Turnera Aphredisiaca TU---Bitter tonic, aphrodisiac.

P&U-1 tsp. per cup

54. DARADILLA

TU---Diuretic, liver and kidney problems.

 $P\&U - \frac{1}{2}$ ounce per cup.

55. DIABETINA

Yellow Elder (Yellow Bells) Tecoma Stans Molle TU---As a bitter tonic, improves appetite, for high blood sugar.

P&U - 1 - 2 tsp. per cup.

56. DIENTE DE LEON

Dandelion

TU---For anemia, diuretic, liver tonic, kidney inflammation.

P&U - 1/2 tsp per cup.

57. ENCINO ROJO

TU--As a diuretic, Astringent, gargle, gum disease.

 $P\&U - \frac{1}{2} - 1$ tsp. per cup.

58. ESTAFIATE

TU---For intestinal parasites, gall bladder problems, stomach aches,

poor digestion, and to stimulate the appetite.

P&U 1 - 2 tsp. per cup59.

59. ESTORAQUE

Storax (Balsam)

Used as incense only.

60. EUCALIPTO

Gum Tree Eucalyptus Eucalyptus Golbulus TU---Coughs, colds, and respiratory problems.

P&U - 1 - 2 tsp. per cup.

61. FLOR ALUCEMA

Lavender

Lavandula Officinalis

TU-For gas and stomach problems, dizziness & headache, and for

minor abrasions and burns.

P&U - 1 tsp. in ½ cup of water, both internal and external.

62. FLOR AMARILLA

Esperanza – Yellow Elder Tecoma Stans Molle TU----P&U Source: La India Packing Company in Laredo, Texas; Integrated into document in original format and reviewed by Maricela Aguilar, RN, MSN, Assistant Professor, The University of Texas Health Science Center, Department of Pediatrics, Division of Genetic and Metabolic Disorders

63. FLOR ANACAHUITA Anacahuita Flower Cordia Boissieri TU---Pectoral tonic, expectorant, for coughs and colds. P&U - 1 tsp. per cup.

64. FLOR AZAHAR Orange Blossoms Citrus Sp.

TU---To calm the nerves, for digestion. P&U - 1 tsp. per cup.

65. FLOR DE JAMAICA Jamaica Sorrel Hibiscus Sabdariffa TU---As a natural refreshing beverage and to reduce fevers. P&U-1 tsp. per 2 cups water or to taste.

66. FLOR DE TILA Linden Flower Tilla Sp. TU-Insomnia, stress, to calm nerves, indigestion, menstrual cramps, painful hemorrhoids, bronchitis.

P&U - ¼ to ½ tsp. per cup.

67. FLOR HUIZACHE Huizache Flower Acacia Farnesiana TU---For dyspepsia (poor digestion). P&U - 1 tsp. per cup.

68. FLOR JICARO Resurrection Plant TU---For coughs and colds. P&U - 1 tsp. per cup

69. FLOR MAGNOLIA Magnolia Flower Magndia Macrophylla See "BOTON CORAZON".

70. FLOR MANITA Mannitol Flower Chiranthodendron TU---For the heart, epilepsy, hemorrhoidal pain, eye inflammation. P&U-1 tsp. per cup.

71. FLOR PENA
Resurrection Plant
Selaginella Lepidophylla

See "DORADILLA".

72. FLOR SAUCO. Elder Flower Sambucus Sp. TU---To promote sweating, against fevers, colds, flu, bronchitis, and coughs. P&U-1 tsp. per cup.

73. FRESNO

TU—For fevers, as a diuretic, to promote sweating. P&U-1-3 tsp. per cup.

74. GARANONA Myrtle Castilleja Canascens TU---Stomach problems, diuretic, digestion, blood purifier, sexual debility.

P&U - 1 tsp. per cup

75. GOBERNADORA Covelle/Chaparral Larria Mexicana TU—Externally for athletes foot and nail fungus, bruises, rashes, minor wounds & abrasions, and dandruff. As a mouthwash. Internally for kidney & gall stones, respiratory illness, etc. P&U - 2 tsp. per quart of water for tea, gargle, or external use.

76. GOLONDRINA Celandine Euphorbia Maculata TU---For gastritis and general digestive inflammation, sore throat, hemorrhoids. P&U - 1 - 2 tsp. per cup.

77. GORDOLOBO

TU---For diarrhea, coughs and sore throat, and minor abrasions.

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Cudweed – Everlasting Verbascum Thapus P&U-1 tsp. per cup of water for internal/external use.

78. GRANADA

TU---Astringent, for diarrhea.

P&U -

79. GUARUMBO

See "CHANGARO".

80. HABAS DE SAN IGNACIO San Ignacio Fava Bean TU-Very strong purgative. Use with much caution.

P&U- Use only 1/4 of a nut.

81. HAMULA – PRODIGIOSA

Bricklebrush
Brickellia Cavanillesii

TU—Antiseptic, increases saliva production and gastric juices, stimulates digestion, fights fevers, and high blood sugar.

P&U-1 tsp. per cup.

82. HINOJO Fennel

Foeniculu Vulgare

TU-For stomach problems, gas, diuretic, menstrual problems.

P&U - 1 tsp. per cup.

83. HORGANO MACHO

See "AMOLE".

84. HOJAS DE MESQUITE

TU---Used for digestive inflammation and respiratory problems.

P&U - 2-3 tsp. per cup.

85. HOJAS DE NARANJO Sour Orange Citrus Sp. TU---Used for fevers, nerves, and stomach disorders.

P&U-1 tsp. per cup.

86. HOJASE
American Tarbu

American Tarbush Flourensia Cermua TU---For indigestion, as a laxative. P&U - 5-10 leaves per cup of water.

87. HOJASEN

See "HOJASE".

88. HORMIGA Wormseed TU---For coughs.

 $P\&U - \frac{1}{2}$ to 1 tsp. per cup.

89. HORTIGUILLA

TU---P&U-

90. HUACHICHILE Loeselia Coccinea

TU---To induce sweats, against chills and fevers, as a diuretic, to induce vomiting, as a laxative.

P&U-1 tsp. per cup.

91. HUIZACHE

TU---For bad digestion. P&U -1 tsp. per cup.

92. INCENSO Incense

TU----P&U

93. INJERTO DE MEZQUITE

Mistletoe
Viscum Album L.

TU—Externally for aches; to cause vomiting. P&U-Use only externally; can be toxic.

94. IPAZOTE DE COMER

TU---As a condiment for black beans, intestinal parasites, gas,

digestive, problems, menstrual problems. $P\&U - \frac{1}{2} - 1$ tsp. per cup.

2. LA INDIA PACKING COMPANY – LIST OF HERBAL MEDICINES

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Source: La India Packing Company in Laredo, Texas; Integrated into document in original format and reviewed by Maricela Aguilar, RN, MSN, Assistant Professor, The University of Texas Health Science Center, Department of Pediatrics, Division of Genetic and Metabolic Disorders

95. IPAZOTE DE ZORILLO

TU-To expel intestinal parasites, for digestion, and for menstrual problems.

 $P\&U - \frac{1}{2}$ to 1 tsp. per cup.

96. LA PASTOR

See "DAMIANA".

97. LAUREL Bayleaf Laurus Nobilis TU---As an anti-spasmodic, for general stomach problems, and gas. Also as a condiment.

P&U - ½ to 1 tsp. per cup.

98. LINAZA Linseed or flax seed Linum Usitatissimum

TU-For constipation and stomach problems, digestive and urinary tract problems.

P&U-1 tsp. cooked in 1 quart of water.

 MALA MUJER - ZUMAQUE Soapwort - Seaholly

TU---Not recommended

100. MALAVAR

Malabar Officinalis

TU---P&U -

101. MALVA DE CASTILLA Common Mallow Malva Sylvestris

TU---For colds, diarrhea, skin disorders. P&U - 1 tsp. per 2 cups of water.

102. MANZANILLA Chamomile Matricaria Chamomilla

TU—For tension, stress, insomnia, indigestion, menstrual cramps, colds and flu, minor wounds and abrasions.

P&U – 2-3 tsp. per cup, both internally and externally.

103. MANZO Golden Eye TU---P&U -

104. MARIOLA Damianita Parthenium

TU---Bitter tonic, liver problems. P&U - ½ tsp. per cup.

105. MARRUBIO
Horehound
Marubium Vulgare

TU---For digestion, weight loss, coughs, stomach problems, menstrual problems. P&U-1 tsp. per cup.

106. MASTRANZO Applemint Mentha Roundifolia TU---P&U -

107. MATARIQUE Indian Plant Cacalia Descomposita

TU---For rheumatism, neuralgia, laxative, diabetes P&U-1 tsp. per cup.

108. MEJORANA Sweet Marjoram Majorana Hortensis TU—For indigestion and gas, and externally for arthritis and rheumatism discomfort. Also as a condiment.

P&U - ½ to 1 oz. per 16 oz. of water, both internally and externally.

109. MENTA
Mint
Menthapiperita

TU—As a refreshing tea and for stomach problems. P&U-1 tsp. per cup or to taste.

110. MIRRA
Myrrh/Myrrh Gum
Commiphora Myrrha

TU—As a gargle, antiseptic, for gas and stomach problems. P&U - ½ tsp. per cup.

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111. MIRTO Myrtle Myrica Sale See "GARANONA".

112. MISPERO

TU---Sore throats and as an astringent.

P&U-1 tsp. per cup.

113. MOSTAZA AMARILLA Yellow Cooding Mustard Sinapis Alba TU---As an appetizer, digestive, purgative, for bronchitis.

P&U - A tiny pinch mixed with food.

114. MOSTAZA NEGRA Black Mustard Sinapis Nigra

TU---For improving appetite, and as a tonic. P&U – Use only a tiny pinch mixed with food.

115. NERVINA

TU---P&U -

116. OCOTE Pincus Teocote TU---For pain & rheumatism P&U - Rub on skin, externally.

117. OJO DE VENADO

TU---To combat 'Mal de Ojo'.

P&U - Ritual

118. OREGANO HOJA LARGA Long Leaf Oregano Origahum Vulagare TU-Stomach aches, diarrhea, externally for pain, condiment.

P&U - 1 tsp. per cup.

119. OREJA DE RATON

TU---Stomach and liver problems.

Rhatany

120. PALO 3 COSTILLAS

P&U - 1 tsp. per cup.

Sishondra Repens

TU---Diuretic, urinary tract problems.

P&U-1 tsp. per cup

Serjania Triquetra

Authorn/Goatbrush

121. PALO AMARGOSO

See "CUASIA".

122. PALO AZUL
Blue Paloverde
Eysenhardria Polystachya

TU---For kidney stones and as a diuretic.

P&U-1 tsp. per cup.

123. PALO BARADU Blue Paloverde See "PALO AZUL"

124. PALO BRAZIL
Bloodwood – Campeachy Wood
Haematoxylon Campechianum L.

TU-For improving circulation, hemorrhoids, to whiten the teeth, to firm the gums.

P&U - 1 tsp. per cup.

125. PALO DE HUIZACHE Acacia Farnesiana

TU--For diarrhea. P&U - 1 tsp. per cup.

126. PALO DULCE Licorice Glycirrihiza Glabra TU---For Kidney and gall bladder problems, diuretic, decongestant, coughs and colds. P&U-1 tsp. per cup.

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127. PALO GUYACAN Guaiacum Stick Guaiacum Coulteri TU---Blood purifier, to induce sweating, for rheumatism. P&U-3 tsp. per cup.

128. PALO MUERTO

Ipomoea Murucoides

TU--To combat paralysis. P&U - 1 tsp. per cup.

129. PALO OROZUS Licorice Regaliz See "PALO DULCE".

130. PALO SANTO Guaicum Sanctum L.

See "PALO GUAYACAN".

131. PASIFLORA

TU--For nerves, insomnia, stress. P&U - 1 tsp. per cup.

132. PATA DE VACA

TU---For asthma, diabetes. P&U - 1 tsp. per cup.

Bauhinia Variegata

133. PELITRE
Pellitory of Spain
Caclia Decomposita

See "MATARIQUE".

134. PEREJIL
Parsley

TU—stimulate the appetite, to induce sweating, as a diuretic, for kidney stones, for menstrual problems, and as a stimulant. P&U-1 to 2 tsp. per cup.

135. PERICON AMARILLO Yellow Periwig Tasetes Florida

Paeroselinum Satiuum

TU---See "YERBANIZ".

136. PIMENTON Allspice TU---For gas, as a stimulant, and as a condiment. P&U-1 or 2 pieces per cup or to taste.

137. PINGUICA(Used like Uva Ursi)

TU—For kidney, bladder problems, bronchial infection. P&U - 1 - 2 tsp. per cup.

138. PIRUL
Pepper Tree
Schirus Molle L.

TU---For urinary tract problems, bronchitis, gum disease, sore throat. P&U-1 tsp. per cup.

139. POLEO Germander/Penny Royal Teucrium Pulium TU—For fevers, stomach aches, gas, to induce sweating, tonic, menstrual problems.

P&U - ½ tsp. per cup.

140. POPOTILLO Groundseed Tree - Falsewillow TU---P&U

141. PRODIGIOSA
Bricklebrush
Brickellia Cavanillesge

TU---For lowering blood sugar, indigestion, and gall bladder problems. P&U $-\, \frac{1}{2}$ tsp. per cup.

142. PULMONARIA
Lungwort
Pulmonaria Officionales

TU-As a diuretic and for respiratory problems. P&U - 1 -2 tsp. per cup.

2. LA INDIA PACKING COMPANY – LIST OF HERBAL MEDICINES

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143. QUINA ROJA Red Chinchona Bark Chinchona Succiruba TU---Bitter tonic, antiseptic, and for intermittent fevers. P&U - ½ tsp. per cup.

144. RAIZ ANGELICA Angelica Angelica Archangelica "See "CHUCHUPASTE".

145. RAIZ DEL INDIO Dutchman's Pipe Rumex Hymenosepalus See "CANA AGRIA".

146. RAIZ GENCIANA

TU-Bitter tonic, for digestive problems, fevers, intestinal parasites. P&U-1 tsp. per cup.

147. RAIZ INMORTAL Arizona Root See "CONTRA YERBA".

148. REGALIS Licorice Glycirrhiza Glabra See "PALO DULCE".

149. RETAMA

Parkinsonia Aculeata

TU---As a diuretic, blood purifier, for diabetes. P&U - 1 tsp. per cup.

Parkinsonia Acideata
150. ROMERO

Rosemary

TU---As a digestive, coughs and colds, menstrual problems. $P\&U - \frac{1}{2}$ tsp. per cup.

151. ROSA DE CASTILLA Apothecary's Rose Rosa Gallica Oficinali

Rosmarinus Officinalis

TU---For diarrhea, colic, gargle, mouthwash, eye wash. P&U – $\frac{1}{2}$ to 1 tsp. per cup.

152. RUDA Rue Ruta Graveolens TU---For stomach ache, ear ache, menstrual problems. $P\&U - \frac{1}{4}$ tsp. per cup.

153. SALVIA Sage Salvia Officinalis TU---For stomach problems, as a tonic, and a stimulant. P&U - ½ tsp. per cup.

154. SALVILLA Comfrey TU---For diarrhea, as an expectorant. P&U - 1 --2 tsp. per cup.

155. SAN FRANCISCO

TU---P&U -

156. SAN NICOLAS (YERBA DE) Mariola Piqueria Trinevia TU---As an antiseptic, anti-inflammatory & cardiac stimulant. P&U - 1-2 tsp. per cup.

157. SAN PEDRO Solanum Verbascifolium L. TU---As a diuretic, for fevers, external abrasions. P&U-1 tsp. per cup.

158. SANTA MARIA Costmary; Tan Sv. See "YERBANIZ".

Source: La India Packing Company in Laredo, Texas; Integrated into document in original format and reviewed by Maricela Aguilar, RN, MSN, Assistant Professor, The University of Texas Health Science Center, Department of Pediatrics, Division of Genetic and Metabolic Disorders

159. SEMILLA DE CILANTRO Coriander Seed Coriandrum Sativum TU---For indigestion, gas, urinary tract problems. As a condiment. P&U-1-3 tsp. per cup.

160. SUELDA Larkspur Delphinium Ajacir See "SALVILLA".

161. TE COMANCHE

TU---For stomach problems. P&U - I tsp. per cup.

162. TE DE CENA Silk Tree/Lead Tree Cassia Sp.

TU-As a mouthwash, laxative, diuretic & to expel worms. (Works like Hojase & Hojasen).

P&U - 1 tsp. per cup.

163. TE DE LIMON

See "ZACATE DE LIMON".

164. TE DE MEDIA NOCHE

TU—For insomnia, nerves. P&U – 1 tsp. per cup.

165. TE DE MILAGROSO

TU----P&U -

166. TEJOCOTE Crataegus Mexicana TU---As a diuretic for kidney problems.

P&U - 2- 3 tsp. per cup.

167. TEQUESQUITE Arctostaphilos Pungens

TU---As a diuretic for kidney and urinary tract problems. P&U-1 tsp. per cup.

168. TIAZANA VITAL

TU-To calm the nerves, improve circulation (for hemorrhoids), diuretic, digestive.

P&U - 1 tsp. per cup.

169. TLANCHICHINOLA Kokler Deppeana

TU—Internally for digestive problems, ulcer, externally for skin disorders and wounds.

P&U – 3 tsp. per cup.

170. TOMILLO
Thyme
Thymus Vulgaris

TU---for stomach problems, as a stimulant, tonic, to promote menstrual

 $P\&U - \frac{1}{4}$ to $\frac{1}{3}$ tsp. per cup.

171. TORONJIL Lemon Balm Melissa Officinalis TU—For indigestion & gas, lack of appetite, also to promote seating. P&U - ½ to 1 tsp. per cup.

172. TRONADORA Trumpet Flower Tecoma Stans L.

See "DIABETINA".

173. TUMBAVAQUERO Ipomoea Ipomoea Stans

TU---Used as a sedative, and in combating obesity. P&U-1-2 tsp. per cup.

174. UNA DE GATO Cat's Claw Acacia Greggii TU---For arthritis, diabetes, to boost the immune system.

P&U - ¼ ounce per gallon.

Source: La India Packing Company in Laredo, Texas; Integrated into document in original format and reviewed by Maricela Aguilar, RN, MSN, Assistant Professor, The University of Texas Health Science Center, Department of Pediatrics, Division of Genetic and Metabolic Disorders

175. UVA URSI Bearberry – Manzanite Artostaphylos Uva Ursi TU---Mainly used as a diuretic, tonic, astringent. Also used to reduce uric acid, kidney stones, and gall stones.

P&U - 1 tsp. per cup.

176. VALERIANA
Wild Valerian Root
Valeriana Officinalis

TU--Used for insomnia, stress, fevers, and menstrual problems.

 $P\&U - \frac{1}{4}$ to $\frac{1}{2}$ tsp. per cup.

177. VENTOSIDAD

TU—For gastritis. P&U – ½ tsp. per cup.

178. VERBENA
Vervain
Verbena Officinalis

TU---For fevers, and to strengthen the hair (externally). P&U - 1/4 tsp. per cup. of water, internally or externally.

179. VISVIRINDA

See "CHAPARRO AMARGO".

180. YERBA BUENA

TU---As a cordial, for indigestion and nausea, coughs and colds.

P&U-1 tsp. per cup.

181. YERBA CAPITANA Crown Beard

TU---For boils or skin problems.

P&U - 1 tsp. per cup as an external wash.

182. YERBA DE CRISTO

TU---For rheumatism and for the stomach as a tonic.

P&U - 1 tsp. per cup.

183. YERBA DE LA MULA Lippia Umgellate TU---For fevers and colic. P&U - 1 tsp. per cup.

184. YERBA DE LA VIBORA Snake Apple – Wild Pomegra Aplopappus Spinolosus TU-For insect bites. External use only. $P\&U - \frac{1}{2}$ tsp. per cup of water, applied externally.

TU---P&U –

186. YERBA DEL CANCER Tarweed/Waxbush Cuphea Aeguiptala

185. YERBA DEI BALLAZO

TU---To cure wounds and abrasions (externally), boils, tumors, etc. P&U-1 tsp. per 2 cups of water as an external wash.

187. YERBA DEL GATO Catnip

Nepota Cataria

TU—To calm the nerves. P&U-1-2 tsp. per cup.

188. YERBA DEL PERRO Groundseed Coleosanthus Veronicaefolius See "SUELDA, SALVILLA".

189. YERBA DEL SAPO Soapwort - Seaholly Eryngium Comosum See "MALA MUJER".

190. YERBA DEL VENADO Damiana Mariola Turnera Afrodisiaca See "DAMIANA".

2. LA INDIA PACKING COMPANY - LIST OF HERBAL MEDICINES

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191. YERBA MATE Llex Paraguayensis TU---Used as a blood purifier, diuretic, stimulant, and for headaches.

 $P\&U - \frac{1}{2}$ to 1 tsp. per cup.

192. YERBA MORA

TU---For inflammation, pain, and irritation of the skin, burns, etc.

P&U - 1/4 oz. per cup used externally only.

193. YERBA MUICLE

Mexican Indigo - Honeysuckle Jacohinia Spicata

TU---Used as a stimulant and against dysentery and diarrhea.

P&U - 1 tsp. per cup.

194. YERBA POLEO

Penny Royal - Brookmint

TU—Used during coughs and colds, for insomnia, calming nerves.

headaches, and gas. P&U - 1 tsp. per cup.

195. YERBANIZ

Tagetes Florida Artemisia Dracunculus TU-For stomach ache & cholic, for bathing.

P&U-2 tsp. per cup.

196. ZACATE DE LIMON (Te Limon)

Lemon Grass Andropogon Citratus TU---For gas, upset stomach & nausea, hypertension, rheumatism.

fever.

P&U-1 tsp. per cup.

197. ZAPOTE BLANCO

White Sapoilla Tree Casimiroa Edulis

TU—Used as a sedative, for insomnia, high blood pressure, as a

diuretic.

 $P\&U - \frac{1}{2}$ tsp. per cup.

198. ZARZARARRILLA

Sarsaparrilla

Smilax Aristolochaefolia

TU-As a blood purifier, for gas, diuretic, colds, gout, skin problems.

P&U-1 tsp. per cup both internal and external.

199. ZASAFRAS (SASAFRAS)

Sasafras

Sassfras Albidum

TU-For body aches and pains, fevers, rheumatism, gout, arthritis, skin

problems, as a tonic, diuretic, stimulant, blood purifier.

P&U-1 tsp. per cup.

200. ZIMONILLO (SIMONILLO)

Conyza Filaginoidos

TU-For general stomach problems, nausea, vomiting.

P&U-1 tsp. per cup.

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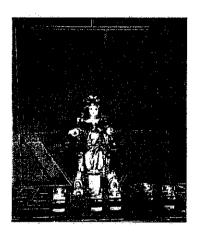
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El Santo Niño de Atocha

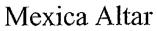
In the U.S. Southwest, a revered patron saint of persons in need. Arizona, 2001.

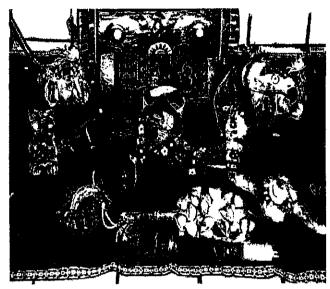


Virgén de San Juan del Valle

- Sacred Catholic shrine located in San Juan, near McAllen, Texas.
- It started as a small chapel and is now a Basilica. 2002.







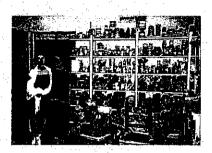
Midwife (Partera)

Third generation traditional birth attendant, Rio grande Valley, Texas. 2001.



Workroom

Herbolarios workroom in government approved school for traditional and indigenous medicine, Morelos, Mexico.
Graduate anthropology student & one of the traditional healers interviewed in the study. Morelos, Mexico, 2000.



Herbs with Nahuatl Names

 Medicinal herbs with Nahuatl (Aztec language) names. XII International Congress of Traditional and Indigenous Medicine, Albuquerque, New Mexico, August, 1998.



Market display of medicinal herbs

 Public market display of medicinal barks with information labels indicating their usage. Oaxtepec, Mexico, 1999.



Bóticas Guadalupana A Mexican Tradition

- In existence for over 70 years.
- A Mexican national chain of "drugstores" that offer medicinal substances of five alternative therapeutic modalities: herbolaria, allopathic medicine, homeopathy, natural foods and over-the-counter medicines. This one in Mexicali, Mexico, 2001.



Interior of a Bótica Guadalupana

- Until the late 1970's, Bóticas Guadalupana could be found in cities throughout the U.S. southwest.
- Notice abundant supply of yellow-green colored prepackaged medicianl herbs on the left foreground.



Packaged Medicinal Herbs

Some of the most commonly used medicinal herbs, packaged and government approved. Readily available in botánicas, public market stands, in Bóticas Guadalupana, Mexico, and in some botánicas in the U.S.. Photo taken in San Antonio, Texas, 2002.



Mobile Herbalist Vendor

(Usually follows a regular scheduled service route. This one in Mexicali, 2001)



License to practice traditional medicine in Morelos, Mexico



Yerbería in South Texas

- Offers a wide assortment of traditional medicinal herbs, candles, perfumed oils, incense, and Tarot cards.
- Limpias and rifera services available upon request. 2001.



Yerbería

 Another yerbería offering similar articles and services in South Texas, 2001.



Aztec Temezcal

Source:

Arreola, J. "El temezcal o baño mexicano de vapor". Ethnos. Mexico. 1 (2): 28-33. 1920.

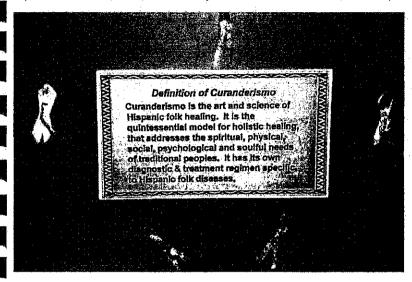


Newly built Temezcal

- Temezcal in last stages of construction. Morelos, Mexico, 1999.
- Derived from Aztec and Mayan medicinal sweat baths used for medically therapeutic & religious reasons.



Curanderismo: Quintessential model for holistic healing (As described in a poster presentation by a R.N. and traditional healer, N.M. 2001)



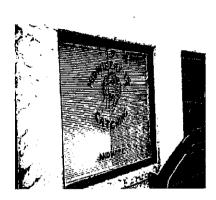
Maternidad La Luz

 One of busiest and largest birth centers attended by Spanish speaking documented midwifes. Southwest, Texas, 2002.



Birthing Center

 One of several birthing centers in the Rio Grande Valley, Texas, 2001.



Rábano Negro (Black Radish)

Instead of vitamins which are expensive, hence not readily accessible, Mexican parteras instruct expectant mothers to eat food rich in vitamins and other minerals. Rábano Negro, rich in iron and other nutrients, is one of these prescribed foods.

Photograph taken at Mercado Sonora, one of largest traditional medicinal herbs (and other healing paraphernalia) public markets in Mexico City, December, 2001.



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