

Project Title **Reducing Cultural Barriers to the Provision of Genetic Services in South Texas**

Project Number: **4 H46 MC 00109-03 S1 R3 (formerly MCJ481011)**

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ABSTRACT

The goal of this project was to improve access to, and utilization of, genetic services by Mexican Americans along the U.S.- Mexico Border. The project staff accomplished the following objectives: 1) identified and catalogued Mexican American cultural belief systems and traditional healing practices; 2) developed teaching materials for clients and their health care providers which would improve understanding and effectiveness of the provision of genetic services; and 3) implemented the teaching instruments and evaluated their effectiveness.

In 1998-2000, interviews were collected in South Texas at 3 locations along the border and in San Antonio. From 2000-2002 the project was extended to collect data from locations in West Texas, New Mexico, Arizona, and California to see if the data were different from what was found in South Texas. Ultimately, the data and relevant issues were similar all along the border except for the addition of environmental causes of illness and birth defects emerging as a significant concern in El Paso and the western states.

Using a qualitative ethnographic approach, open-ended interviews were conducted regarding cultural beliefs about health and healing practices, causes of birth defects, and attitudes regarding genetic services. Subjects represented four target groups: clients of genetic services, genetic service providers, lay midwives (*parteras*), and other folk healers (*curanderos*). The interviews were analyzed using the NUD*IST 4 program. Eighty-two subjects were interviewed in South Texas and 52 additional subjects were obtained in West Texas, New Mexico, Arizona and California.

The initial project in South Texas (1997-2000) produced results that were compiled and developed into a manual for healthcare providers (Appendix 1). A second manual for healthcare providers combined information from both phases of data collection (Appendix 2). Another product of this project is a "*fotonovela*", which is a culturally-appropriate booklet (printed in English and Spanish) meant to be given to Mexican-American clients and families to introduce the use of genetic services to the community (Appendix 3). All of these project products were developed, implemented and evaluated for efficacy and were modified as suggested in the evaluations.

The contributions and insights from this collection of interviews provide the basis for the issues and barriers which were identified. (1) Language and communication: most clients speak predominantly Spanish, while genetics specialists primarily speak English. Clients' educational level, sophistication, and literacy are often low, and technical terminology is difficult for them to understand. (2) Poverty affects access to transportation, frequent changes of residence, accessibility from rural locations, availability of childcare, lack of telephone service, etc. (3) Cultural beliefs, values and behaviors, such as spiritual and religious views of illness and healing, holistic view of body, mind and soul as a unified system, and less reliance on technology, may not be understood by some medical providers. (4) System issues such as costs, scarcity of specialized genetic providers and clinics, fragmentation and duplication of services caused by changes in health care system, etc., also interfere with utilization.

To accomplish the goal of improving access and compliance to genetic services, suggestions were made for genetics providers based on the issues identified by this

study: (1) Staff genetics clinics with fully bilingual clinic personnel. (2) Provide culturally competent genetics education resources, in English and regional Spanish, for referring physicians, genetics clinics and public health clinics to distribute to clients as anticipatory guidance. (3) Offer incentives to prevent attrition of clinic staff who are the first and most frequent contacts and convey an image of stability of services. (4) Offer continuing education in genetics for social workers, clinic receptionists, and other personnel to improve communication in the provision of genetic services. (5) Provide continuing education in cultural competency for health care providers. (6) Use *Promotoras* to educate communities about genetic services.

FINAL NARRATIVE REPORT

PROJECT IDENTIFICATION:

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I. PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V MATERNAL AND CHILD HEALTH (MCH) PROGRAMS:

Patients in need of genetic services in South Texas and along the U.S. –Mexico Border are mostly Mexican-American (MA), Medicaid recipients and are grossly underserved in this and other areas of maternal and child health care. The factors contributing to this under utilization of genetic services are complex and include the presence of cultural and language barriers which limit the access to and utilization of services. The problem is that not enough is known about these barriers and about what

the beliefs, prejudices and attitudes towards birth defects may be in the underserved population. Biology and culture matter equally in the human experience of disease. Every aspect of the illness experience, from the individual's recognition of symptoms to assessments of treatment outcome, is shaped by the cultural frameworks of the sufferer and of those to whom he or she turns for help. A multicultural perspective is essential to avoid reductionist views of disease. The political economy is also a primary epidemiological factor. A society's economic system and the political structures that support it have a critical role to play in the kinds of health risks individuals face and the treatment resources that they have available.

The purpose of this study was to identify those cultural issues relevant to Mexican Americans that influence their perceptions of health, need for medical care and causes of birth defects/genetic conditions as these issues affect behavior related to the use and access to genetic services and compliance with conventional medical recommendations.

This project originally was targeted to the San Antonio and South Texas areas. However, the funding agency recognized the benefit to extending this project to include all of the U.S. Mexico Border states (West Texas, New Mexico, Arizona, and California). Therefore, this report is reflective of the funding agency's acknowledgement.

II. GOALS AND OBJECTIVES:

The goal of this project was to improve access to and utilization of genetic services by Mexican Americans along the U.S. – Mexico Border. The project staff accomplished the following objectives: 1) identified and catalogued Mexican American

cultural belief systems and traditional healing practices; 2) developed teaching instruments; and 3) implemented the teaching instruments and evaluated their effectiveness.

III. METHODOLOGY:

Project staff identified and selected participants from the three target groups (genetics clients, healthcare providers in clinical genetics settings, and lay healers from the Mexican American communities). Genetics clinic 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. Folk healers (*curanderos*) and lay midwives (*parteras*) were identified by referrals from the healthcare providers from the communities studied as well as from other individuals with knowledge about non-traditional medicine and practices in Hispanic/Latino, Mexican, and Mexican-American cultures.

Participants followed an institutionally approved interview process after informed consent was obtained. A 50-questionnaire interview guide, composed primarily of open-ended questions, was developed for use with each of the target groups. Interview guides were developed and used in the South Texas portion of the study and were tested during the first phase of the study to confirm their usefulness as an interview tool. The same interview guides were used in the locations in West Texas, New Mexico, Arizona and California.

A bilingual medical anthropologist, who is 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 into English.

Qualitative grounded theory methodology was used for data collection and analysis in order to appreciate the richness of opinion and insights to be gained from the interviews. Interviews were entered into the NUD*IST 5 (Non-numerical Unstructured Data-Indexing, Searching & Theorizing) computer program¹ for qualitative analysis of the interview text. By its nature, qualitative analysis focuses on extracting in-depth insights from fewer participants. Therefore, 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.

IV. RESULTS/OUTCOMES:

Results

This project produced 134 interviews from three targeted groups of participants in the medical and genetic health of the Mexican-American communities (Table 1). Group 1 consists of 40 designated "clients", including families of clients, who receive genetic services. Group 2 were 42 healthcare "providers" of genetic services, including MD geneticists, genetic counselors, genetic nurses and staff of genetic clinics such as social workers, receptionists and sonographers. Group 3 were 33 folk healers (*curanderos*) and 19 midwives (*parteras*) from the local communities. The initial project began in South Texas (1997-2000) (82 interviews) and produced results that were compiled and developed into a manual for healthcare providers in South Texas entitled:

“Understanding Mexican American Cultural Beliefs and Traditional Health Practices: a Guide for Genetic Service Providers in South Texas” (Appendix 1).

Table 1: Project Cohorts

	Phase I: So. Texas	Phase 2: El Paso	New Mexico	Arizona	California	Total Phase 2	Project Total
Clients	23	6	6	0	5	17	40
Providers	25	5	5	3	4	17	42
Folk Healers	19	4	8	2	0	14	33
Lay Midwives	15	4	0	0	0	4	19
TOTAL	82	19	5	5	9	52	134

Such interesting results were obtained from the initial project that supplemental funding was requested from the granting agency to extend the project to other border areas in west Texas (El Paso), New Mexico, Arizona and California. The collection of comparable interview data would permit assessment as to whether the findings from South Texas were similar or different in other areas of the US-Mexico border. An additional 52 interviews were collected during this Phase 2.

The contributions and insights from this collection of interviews provided the basis for the issues and barriers which were identified. A second manual for healthcare providers combined information from both phases of data collection, entitled: "Understanding Mexican American Cultural Beliefs and Traditional Healing Practices: A Guide for Genetic Service Providers on the U.S.-Mexico Border". (Appendix 2) Another product of this project was a culturally appropriate booklet (printed in English and Spanish), entitled "A Love Story: the Wedding of Marisa and Carlos/*Historia de un Amor: La Boda de Marisa y Carlos*" (Appendix 3). This "fotonovela" is meant to be given to Mexican-American clients and families to introduce the use of genetic services

to the community. All of these project products were developed, implemented and evaluated for efficacy and were modified as suggested in the evaluations.

PHASE ONE: SOUTH TEXAS

In the initial phase of the study (1997-2000), 23 clients, 25 genetic service providers, 19 folk healers and 15 lay midwives were interviewed in South Texas (San Antonio and the Lower Rio Grande Valley).

In San Antonio participants were collected at the multi-disciplinary out-patient Genetics clinic at CHRISTUS Santa Rosa Hospital, staffed by a team of geneticists, social workers, nurses, and dietitians, to serve clients from San Antonio and communities throughout South Texas. An estimated 10% of the pediatric clients have private insurance and the rest are on Medicaid.

In the Lower Rio Grande Valley, pediatric and prenatal genetic services were offered at four outreach clinic sites that served clients funded primarily by Medicaid and Title V. 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. Bilingual sonographers, who resided locally, were present when needed.

Of the six geneticists interviewed in the South Texas Phase, 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. 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. Doctors commented that social workers who provide translation do not know enough genetics and would have to be trained to bring them up to a level of comfort with translating genetic counseling information.

Geneticists and other genetic service providers also described difficulties in conveying genetic information to clients who often had little understanding of basic human biology.

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. Standard medical Spanish or English terminology was seldom understood by the majority of clients.

Concern was expressed over the 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. Nevertheless, clients reported confidence in physicians who responded to their concerns and mistrust of those who did not exhibit *personalismo* and *amabilidad*. The majority of clients indicated satisfaction with their genetic service providers, sometimes wanting more time for explanations.

Although most clients could access genetic services through Medicaid and Title V, they reported difficulties in paying for pharmaceuticals, medical equipment, and supplies. 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. 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.

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 to other locations along the U.S-Mexico border and extension through 2000-2002. Interviews were conducted with 17 clients, 17 genetic service providers, 14 folk healers and 4 lay midwives from Arizona, California, New Mexico, and west Texas (El Paso). With one exception, all clients were caretakers of children with genetic conditions. The demographics of clients in this second study phase are compared with the clients in the initial phase in Table 2.

TABLE 2

Demographics of Clients	Phase One: South Texas (N=23)	Phase Two: West Texas and U.S. Mexico Border (N=17)
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 as another important site for gathering information. Six clients, 5 healthcare providers, 4 folk healers and 4 lay midwives were interviewed in El Paso.

The six clients interviewed in El Paso were receiving genetic services for their children at the genetics clinic which was operated under the auspices of the Texas Department of Health. The geneticist traveled from Austin every four to six weeks to spend two days providing services.

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 who provided them with little information about the genetics referral.

Transportation was an issue of concern for clients who had to rely on public transportation or other family members to take their children for services. Some also had to travel long distances for specialty care.

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. In spite of their difficulties, clients expressed appreciation for having the Geneticist come even once a month, but wished that there could be more genetic clinic days per month.

New Mexico

Five genetic service providers, six clients, eight folk healers and no lay midwives were interviewed in New Mexico. 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. This access to genetic resources was not available at the satellite clinic in Las Cruces. 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. The examination room and conference room there had multiple uses and were less than appropriate for genetics counseling 2 times a month. While children in New Mexico were eligible for genetic services regardless of ability to pay, processing the send-out of lab tests was complex, especially in the satellite clinic. Referrals needed to be made to Albuquerque and other long distances for surgery and specialized care which caused transportation

difficulties for client families.

As in Texas, many of the client families reflected a mixture of documented and undocumented members which caused concerns about legal status and fears of deportation that affected everything about their lives. While clients reported language and communication problems with health care providers, the majority of clients reported satisfaction with the genetic services they were receiving.

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 were interviewed in Calexico and San Diego. Folk healers and lay midwives were not able to be located during the time that researchers were in California. Interviews revealed that genetic services in California 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. The public health system in California was reported to be 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. 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 decreased their efficiency.

In Calexico the people living along the border worked in service jobs and appeared to have a higher level of sophistication which resulted in a better understanding of how to use social service systems. In contrast, in rural northern San Diego County many people had migrated from Mexico as farm workers and were far less acculturated which translated into greater difficulty negotiating healthcare systems.

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 was bilingual, discussed the need for geneticists and other health care providers to speak Spanish. Transportation was also a problem for these clients in Imperial Valley because of lack of services locally for children with disabilities.

Clients expressed a desire that services be more accessible for undocumented non-pregnant women and men, perhaps with a sliding fee scale or easier payment methods. Two of the clients described difficulties associated with undocumented status and expressed fear of deportation.

Clients and genetic service providers both described the quality of acceptance among the clients whose children had genetic conditions.

Arizona

Complexities associated with the institutional review board approval prevented interviews with clients during to the time researchers were in Arizona. However, interviews with three genetic service providers yielded useful information about the provision of genetic services in Arizona. Two folk healers were interviewed, but Arizona did not permit lay midwives to practice. Except in the border communities, the predominant population outside of the metropolitan area of Tucson was Native

American. In Tucson, approximately 25% of clients were Hispanic, 70% Anglo, and 5% Native American.

In Tucson, Arizona, three geneticists and five staff provided services through a clinic for patients who qualified for some type of medical insurance or through the state-funded Children's Rehabilitative Service outreach clinics.

The three geneticists alternated in providing services through the Children's Rehabilitative Service to 14 of the 17 Native American reservations across the state. Most of their Native American patients were English-speaking and were largely unaware of genetic services. Genetic services through the Children's Rehabilitative Service on the reservations required that the geneticists 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 each visit who was able to spend more time with them and provide continuity of care.

Genetic clinics were also offered two days per month at the public health department clinic in the border communities of Nogales and Yuma. Geneticists did not know in advance whom they would see at these clinics, making it difficult to anticipate how long it would take with patients and what care was needed. However, the genetic service providers were very proud of the fact that they provided services all over the state.

Although no clients were interviewed in Arizona, 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 these clinics. A Maternal and Child Health Bureau, Special

Projects of Regional and National Significance (SPRANS) grant supported training for the genetic service providers to improve Spanish-language skills and cultural competency, and for the development of a tool for assessing client perceptions regarding needs, concerns, and barriers to care. The genetic service providers reported that speaking Spanish was necessary to be able to better understand client perceptions and communicate with clients regarding diagnosis, treatment, and other issues.

Issues Affecting Client Perceptions and Creating Barriers to Care

The interview data 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.

As a result of the interviews conducted during the first phase of the project done in South Texas, a number of issues were identified as creating barriers to access, use and effectiveness of genetic services. These were observed again throughout the interviews done in the other border locations of El Paso, New Mexico, Arizona and California. These issues are discussed in detail in both of the manuals produced by this project (Appendix 1 and Appendix 2).

Language and Communication Issues

- _ Language (mostly 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 or unwillingness to communicate on the part of genetic service providers regarding the results of diagnostic testing, often stemming from linguistic differences.
- Cultural Issues
- Mexican Americans' view of healing is rooted in spirituality and faith in contrast to the 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.

- Accessibility and availability of genetic services is greatly limited for clients in many geographical locations, especially rural areas without bus service.
- Rural addresses make 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; physician referral preferences affect service utilization.
- HMO capitation on care reduces access to clinical genetic evaluations and genetic diagnostic tests which 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 have 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 U.S.-Mexico border communities are negotiating a way of life in both countries despite numerous barriers and restrictions.

V. 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.^{4,5,6,7} 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.^{15,16,17} If the perception of the problem is not addressed, clients will be dissatisfied and less likely to comply with the regimen prescribed.¹⁸

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.²² 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.

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.

The fotonovela developed by this project is intended to be a useful, culturally-appropriate booklet, printed in English and Spanish, which could be used for patient education about genetic issues and services. 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 staff 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 should include locally known and respected traditional healers. Geneticists and other biomedical providers in the study areas should also be encouraged to learn Spanish. It is expected that both manuals for healthcare providers, produced by this project, will be useful for education of healthcare 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. 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)*.

VI. 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.

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VII. PUBLICATIONS/PRODUCTS:

Publications

1. Fornos L. (2003) Incompatible Goals: Discordant Perceptions Between Health Care Providers and Parents of Children with Congenital Anomalies in South Texas. Masters Thesis for the University of Texas at San Antonio.
2. Urdaneta ML, Livingston J, Aguilar M, Enciso V, Kaye CI. (2002) Understanding Mexican American Cultural Beliefs and Traditional Healing Practices: A Guide for Genetic Service Providers on the U.S.-Mexico Border. San Antonio, The University of Texas Health Science Center at San Antonio/Department of Pediatrics. (Appendix 2) <http://www.genetics.uthscsa.edu/Complete%20Manual%20II%20B/Complete%20Manual%20II%20B.pdf>
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5. Urdaneta ML, Aguilar M, Livingston J, (2001) A Love Story: the Wedding of Marisa and Carlos/Historia de un Amor: La Boda de Marisa y Carlos. The

University of Texas Health Science Center Department of Pediatrics. (Appendix 3)

6. Suther S. (2000) Cultural Hindrance or Cultural Resources? Changes in Lay Midwifery Practice in the Rio Grande Valley of Texas. Masters Thesis for the University of Texas at San Antonio

Presentations with Peer-Reviewed Published Abstracts

1. Enciso V, Urdaneta ML, Aguilar M, Livingston J, Kaye C I. "Issues Affecting the Provision of Genetic Services Among Mexican American Communities Along the U.S./Mexico Border". (2002) J of Genetic Coun. 10(6): 510.
2. Aguilar M, Urdaneta ML, Suther S, Cameron E, González-Bogran S, Enciso V, Kaye CI. "Reducing Cultural Barriers to the Provision of Genetic Services in South Texas Cities". University of the Incarnate Word, Charles Marie Frank Annual Lecture Series and Poster Session, April 20, 2001. San Antonio, Texas.
3. Urdaneta ML, Aguilar M, Suther S, Cameron E, González-Bogran S, Enciso V, Kaye CI. "Cultural and Non-Cultural Barriers to the Utilization of Genetic Counseling Services by Mexican American Women in four South Texas Cities". National Institute of Health, National Human Genome Research Institute: A Decade of ELSI Research Conference, January 17, 2001. Bethesda, Maryland
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6. Aguilar M. "Cultural and Non-Cultural Barriers to the Provision of Genetic Services for Mexican-American Women in Five South Texas Cities". Ethical, Legal and Social Implications Program, National Human Genome Research Institute, National Institute of Health, Bethesda, Maryland, January 17, 2001.

Other Presentations:

1. Aguilar M. "Cultural and Non-Cultural Barriers to the Provision of Genetic Services for Mexican-American Women in Five South Texas Cities". University of Texas Health Science Center at San Antonio. Genetic Rounds, June 15, 2001.
2. Urdaneta ML. "Delivering Culturally Sensitive Nursing Care". March of Dimes Conference. Spring, 2002.
3. Urdaneta ML. "Identifying Barriers to the Delivery of Genetic Counseling Services to Mexican Americans in South Texas". University of Texas Health Science Center at San Antonio. Qualitative Research Interest Group, Dec. 2001.

VIII. DISSEMINATION/UTILIZATION OF RESULTS:

From phase one of the project, the project staff developed two educational products. The first educational intervention was the development of a teaching guide/manual, entitled "Understanding Mexican American Culture and Traditional Healing Practice: A Guide for Genetic Service Providers" (Appendix 1). The manual was directed at the healthcare providers and integrate the patient's beliefs, the folk healer's

beliefs and the modern (western biomedical) concepts of diagnosis and management of genetic disease.

The project staff has used the modification of a matrix chart developed by Hazel Weidman and Clarissa Scott in 1981. The matrix chart (Table 3) is designed to achieve the following objectives: 1) to set out visually (“at a glance”) the perceived differences in perception of a genetic disease as seen by a patient, a folk healer (*partera*/midwife or *curandero*/folk healer), and a health care provider (schooled in the biomedical model); 2) to enable the health care provider to identify quickly those points that are different and may inhibit compliance with a potentially therapeutic regimen and thereby decrease the probability of accessing genetic services; 3) to provide the health care provider with information about patient’s and/or folk healer’s beliefs of the origin of a genetic disease, as well as treatments used, in order to provide the health care provider with an alternative approach to develop productive types of interventions through negotiations when needed.

Table 3: Matrix Chart:

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

<p>Mental retardation; Down syndrome</p>	<p>Due to a missing gene; due to an extra chromosome of the father; errors in DNA</p>	<p>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</p>	<p>Many children with severe mental retardation have genetic disorders. Chromo-somal 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.</p>
<p>Spina Bifida and other NTDs</p>	<p>Venereal disease/infectious genes passed down through generations;</p>	<p>Marital stress and late diagnosis of maternal diabetes; Agent Orange; will use <i>curandero</i> 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, <i>deformado</i>; <i>nacio malito</i> (little one born sickly)</p>	<p>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, encephalocle, and spina bifida. Babies with anencephaly are born with under-developed 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.</p>
<p>Condition (in biomedical terms)</p>	<p>Traditional Healer</p>	<p>Client</p>	<p>Genetic Providers</p>

Macrocephaly	Massage the head so that it doesn't grow; infectious genes passed down through generations	Sotos syndrome was possibly caused by fright (<i>susto</i>) 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 laundry; pregnant women can protect against effects of eclipse by wearing a metal object (such as a key) pinned to outer garments	Lunar eclipse; pregnant women can protect against effects of eclipse by wearing a metal object (such as a key) pinned to outer garments.	<p>Conditions which occur early in pregnancy when tissues that usually form the lip or roof of mouth fail to grow together.</p> <p>Cleft lip is an opening in the upper lip between mouth and nose.</p> <p>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.</p>
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 <i>mandas</i> 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 incompatibility	Genetic service providers counseled client caretaker (father) that hormone injections and Rh incompatibility 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.

The manual was implemented in both the South Texas area (McAllen, TX) and in San Antonio with healthcare professionals who were interviewed. A one day workshop was held in each site. All of the participants received a copy of the manual prior to the workshop. The agenda was prepared and presentations were provided by the project staff. Suggestions and comments regarding the manual were requested from the participants and were used to modify the manual.

The second educational intervention in phase one was directed to the prospective patient. The San Antonio Metropolitan Health District consulted with the project staff and suggested the use of a bilingual *fotonovela*. A *fotonovela* is a unique, popular literature format, usually a small booklet that tells a story as a soap opera in photographs with speech bubbles. It is normally for entertainment, not education. By design, the *fotonovela* is a fun, low literacy literature format that is familiar to a large portion of South Texas' Medicaid population. The primary message is to promote the concept of using genetic evaluation and counseling for understanding risks of genetic disorders and birth defects. Supporting educational points include indicators for seeking genetic evaluation and counseling, and the importance of prevention including the use of folic acid. It is the hope that by using this format our intended population will be able to understand concepts of genetic disease and that genetics services are available to them in South Texas. The bilingual *fotonovela* developed was entitled "A Love Story: the Marriage of Marisa and Carlos/Historia de un Amor: La Boda de Marisa y Carlos" (Appendix 3).

The *fotonovela* was pilot tested with prospective patients (English and Spanish speaking) at two project sites. Suggestions and comments for modification were requested from the participants and modifications to the *fotonovela* were made.

In phase two of the project, the contributions and insights from this collection of interviews, including what was learned from interviews with lay healers (folk healers and lay midwives), provided the basis for the issues and barriers which were identified. These issues, cultural traditions and conclusions were compiled into a second manual for healthcare providers, that was modified based on data collected. The manual title was changed to "Understanding Mexican American Cultural Beliefs and Traditional Healing Practices: A Guide for Genetic Service Providers on the U.S.-Mexico Border" (Appendix 2).

IX. FUTURE PLANS/FOLLOWUP:

Replication of this project could be applied to other cultural groups (i.e., Native American, Asians, African American, etc.) for some or all of the reasons stated previously under, "Issues Affecting Client Perceptions and Creating Barriers to Care", not only for genetics services but for health care provision in general. Copies of the manual and the *fotonovela* have been sent to the healthcare providers who participated in the project and are still available to any others who are interested. The manual is also posted on the Division of Genetics website at the University of Texas Health Science Center at San Antonio:

(<http://www.genetics.uthscsa.edu/Complete%20Manual%20II%20B/Complete%20Manual%20II%20B.pdf>)

The insights and information regarding delivery of genetic services in Texas will provide background for a grant proposal submitted to HRSA: "Genetic Issues of the Hispanic Border Population" which will evaluate the provision of genetic services in Texas. This grant has been approved but is pending funding.

Key Words

Bilingual communication

Biomedicine

Border issues

Culture

Curanderismo

Genetic disorders

Genetic services

Healthcare disparities

Mexican Americans

Personalismo

Spirituality

Traditional folk healers

Listing of Equipment: No major equipment was purchased for this project.

Financial Status Report (FSR): (Appendix 4)

Appendices

1. **Understanding Mexican American Cultural Beliefs and Traditional Health Practices: a Guide for Genetic Service Providers in South Texas**

2. **Understanding Mexican American Cultural Beliefs and Traditional Healing Practices: A Guide for Genetic Service Providers on the U.S.-Mexico Border**
3. **A Love Story: the Wedding of Marisa and Carlos/Historia de un Amor: La Boda de Marisa y Carlos**
4. **Financial Status Report**