



## **Underserved Populations Project 2017-2020**

By Grace Miller, Summer Intern 2017, MSRGN

### **Summary of Literature**

The existing literature examining access to care and genetic services regarding American Indians and Hispanics is extensive. Many of the observations and issues that have been identified suggest relevant recommendations for intervention among underserved populations in the Mountain States Regional Genetics Network (MSRGN). In an effort to summarize what is known about access issues among these populations, the Mountain States Underserved Populations Project completed a comprehensive literature review in the summer of 2017. The results of the literature review follow. The findings are presented first for those identified among the American Indian population, then for the Hispanic population, and finally for issues identified among both groups. In the final section, we offer an executive summary of the findings. Throughout the paper, the sources of the information presented are cited at the end of each paragraph summary.

### **American Indians**

In the counties surrounding Tuba City, Arizona, there are two main American Indian tribes, the Havasupai and the Navajo. While these two tribes have many differences, their overall reaction to genetic testing is similar: they are extremely wary of it.

The Havasupai specifically were part of a well-publicized case regarding consent for genetic testing and ownership of genetic material. In this case, the Havasupai asserted that they were not given proper informed consent, and that their material was used inappropriately. While the Havasupai generally understood that their DNA samples were going to be used for a study on diabetes, they did not understand the extent to which their samples would be used for additional research, or how the material would be handled. Moreover, when researchers had limited findings about diabetes, they continued to use the DNA samples for research on other illnesses with genetic correlation, such as schizophrenia. This upset the Havasupai, because although the consent form included vague references to research for mental illnesses, the Havasupai felt they had not given explicit permission for such a study. They had not fully understood the concepts around consent and as a result their trust had been violated. Moreover, a majority of the tribe, approximately 400 out of the 600 members, had consented to genetic testing. When articles were published with the Havasupai Tribe given in the title, they felt their anonymity was violated since the majority of the tribe were participants in the research.<sup>1</sup>

This event fostered fears around genetic testing and the potential abuses of genetic material. Consent, however, was not the only issue raised among the tribes as a result of this case. In many American Indian groups, especially the Navajo, blood and other specimens that might be used for DNA are sacred, and tampering with the DNA could even cause psychological or physical health issues to the individual. Some of the issues voiced were changes

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<sup>1</sup> <http://genetics.ncai.org/case-study/navajo-nation.cfm>  
<http://genetics.ncai.org/case-study/havasupai-Tribe.cfm>

in personality, children's inheritance, potential progression in sickening or even death. As a result, First Nations such as the Navajo placed a moratorium on genetic testing until the elders of the tribe could get together and create a comprehensive set of rules for genetic research.

While the older generation is generally consistent about their distrust of genetic testing, younger generations have an interest in the possible benefits of genetic testing. However, many young American Indians still have concerns around genetic testing, or don't fully understand what genetic testing is and how it is used. To address this, the National Cancer Institute developed Genetic Education for Native Americans (GENA), a class that offers 24 hours of instruction covering genes, genetics, genetic testing, and possible disagreements with Native religion. This class seeks to inform college-age American Indians about genetics and does not attempt to sway them in either direction about going to a geneticist or not going to a geneticist. By the end of the course, participants have reported an increase in their overall knowledge about genetic testing. Health literacy, which is what this course is intended to accomplish, can be one barrier to care when an individual does not fully understand the implications of genetic testing or the processes involved in diagnosis.<sup>2</sup>

Also, many tribal members do not want to turn away from their traditional healing practices and continue to prefer traditional practices over western medicinal remedies. However, many studies have shown that a holistic healing approach can be as effective, if not more effective, than adhering strictly to one or the other. Combining western treatment regimens

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<sup>2</sup> Development of a Genetics Education Workshop Curriculum for American Indian College and University Students

Linda Burhansstipanov,\* Lynne Bemis,† Mark Dignan‡ and Frank Dukepoo  
2001  
Genetics Society of America (941-948)

along with American Indian healing ceremonies can prove effective for patients, and for some, can have a more positive outcome than if one relied solely on western medicine.<sup>3</sup>

In addition, many American Indians are hesitant to be seen by a physician, because available doctors typically do not share the same cultural background. Most of the Navajo and Havasupai are proficient in English, but many find it useful to speak to their doctor in their native language. However, some words in English are not translatable into native languages. For example, cancer would be roughly translated in Navajo as “the sore that never goes away”. If a physician has the same cultural background as the patient, they have a bicultural knowledge, and in general know when a concept will not be easily grasped by those outside their culture. This puts patients at ease and makes them more likely to come back to the physician. It also makes it more likely that a patient will understand their illness and be able to gather more information about it.<sup>4</sup>

Aside from consent and religious worries, Native groups face many logistical barriers to care. Overall, the Indian Health Services (IHS) has a high turnover rate of physicians. Because of this, many American Indians feel they have to keep their own records, separate from the clinic’s records. They also feel that every time they go the doctor, they are having to re-explain their child’s illness and diagnoses. This can discourage access to genetic services, as it is possible that parents do not feel the services and outcomes are satisfactory, especially considering their

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<sup>3</sup> Bridging the Divide between Genomic Science and Indigenous populations, Jacobs, 2011, Journal of Law, Medicine, and ethics

Understanding Barriers to health care: a review of disparities in health care services among indigenous populations, Marrone, 2007, International Journal of Circumpolar Health

Implementation of a Culture-Specific Intervention for an American Indian Community  
Tolman. 1998 Journal of Clinical Psychology in medical settings

<sup>4</sup> Understanding Barriers to health care: a review of disparities in health care services among indigenous populations, Marrone, 2007, International Journal of Circumpolar Health

considerable efforts. Furthermore, IHS clinics may not have enough money to care for patients. In general, IHS clinics have approximately a third of the cost of a Medicaid patient to pay for a Native patient. In addition, IHS clinics are consistently underfunded, which makes it difficult to manage their volume of patients. This lack of resources can also lead to lack of doctors or clinic staff. In general, Native patients have concerns about their inability to get an appointment or the lack of flexibility for an appointment. Moreover, the area where the Havasupai and Navajo live is fairly rural. Many are burdened by the great distances, such as a three-hour drive for some, that they undertake in order to get to an appointment, which can be a major barrier to care.<sup>5</sup>

### **Hispanics**

Overall, Hispanic barriers to genetic services are quite similar to those of American Indians.

While there is no moratorium on genetic testing within the Hispanic community, many experience the same wariness with consent and the process of genetic testing. They are worried that something about their genetics might be publicized or abused.

Moreover, many have received little education on genetics and genetic testing. They may get their medical information from families, friends, and the media (telenovelas, magazines, internet/social media, etc.) If they have not received any information from their friends, or family or media haven't said anything about genetic testing or genetic counseling, it is likely they are not aware of existing genetic services and the potential benefits. One study suggested informing the *padres* or ministers of the Roman Catholic churches in the surrounding areas, as religion is

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<sup>5</sup> MSRGN Listening Sessions

often a major guiding force for Hispanic families. Furthermore, a focus group suggested informing influential members of the community, such as barbers, as it is more likely for the information to be spread by word of mouth. Creating a telenovela about genetic services may also draw more patients, as telenovelas are very popular in the Hispanic community.<sup>6</sup>

Some members of the Hispanic community also prefer traditional healing practices. Many go to botánicas, herbal stores with healers that help with traditional illnesses. Similar to the Navajo, traditional healing practices may be combined with western healing practices in order to create comprehensive care. A few studies suggest discussing genetic services with the traditional healer in order to encourage the use of services. However, it is important for healthcare providers to be aware that some traditional medicines can actually be fatal (like mercury). It is also important that the doctor is knowledgeable on the most common illnesses and their remedies in traditional healing. *Mal Ojo*, a folk illness with symptoms like that of gastroenteritis or dehydration, may affect how the doctor interacts with a patient. Essentially, it is believed by many in the Hispanic community that people with “strong eyes” (typically blue or green, with green being the most dangerous) can cause illness in a child if they stare in admiration or jealousy for too long. This illness can be prevented if the healthcare provider touches the child while looking at him or her.<sup>7</sup>

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<sup>6</sup> Building Our Understanding: Culture Insights Communicating with Hispanics/Latinos. 2010. CDC Healthy Communities Program

A Qualitative Study Examining Latino Functional Health Literacy Levels and Sources of Health Information. Britigan. 2009. Journal of Community Health

Latin American-Trained Nurse Perspective on Latino Health Disparities, Carter-Pokras, 2008, Journal of Transcultural Nursing

<sup>7</sup> Genetic counseling and Hispanics. Czape. 2009

Traditional Medicine can be key to Latino health care. Parker. 2017. US News and World Report

Many use traditional services because they cannot afford western medical bills. A high percentage of the population in Bexar County, Texas, and its surrounding areas are on Medicaid, or do not have insurance at all. This is a major barrier to genetic services.<sup>8</sup>

Moreover, language barriers can impede access to genetic services. Many patients related that they did not have a translator, or that the translator was busy when they were trying to speak with or ask questions of their doctor. This prevented them from attaining proper care instruction and even led to frustration and the desire to go home. Moreover, many medication instructions are improperly translated or partially translated, which makes adhering to medications difficult for the patient.<sup>9</sup>

Again, cultural differences can be a major barrier to care. Overall, Hispanic families value *familismo*, *personalismo*, *respeto*, *simpatia* and *confianza*. *Familismo* is the idea that all members of a family and extended family make medical decisions together, acting as a unit. Many cultural competency handbooks suggest that allowing time for family decisions creates a

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Health Care Barriers for Latino Children and Provision of Culturally Competent Care. Lassetter. 2004. Journal of Pediatric Nursing

Latin American-Trained Nurse Perspective on Latino Health Disparities, Carter-Pokras, 2008, Journal of Transcultural Nursing

Why Many Latinos Dread Going to the Doctor, Machado, 2014, The Atlantic

<sup>8</sup> Why Many Latinos Dread Going to the Doctor, Machado, 2014, The Atlantic

<sup>9</sup> A Qualitative Study Examining Latino Functional Health Literacy Levels and Sources of Health Information. Britigan. 2009. Journal of Community Health

Medication Nonadherence in Latino Population, Language Barriers and Considerations. White. 2014

Health Care Barriers for Latino Children and Provision of Culturally Competent Care. Lassetter. 2004. Journal of Pediatric Nursing

Genetic counseling and Hispanics. Czape. 2009

Addressing the disparity of Latino research participation in genetics. Torres. 2014

Latin American-Trained Nurse Perspective on Latino Health Disparities, Carter-Pokras, 2008, Journal of Transcultural Nursing

better relationship with the doctor. Hispanic families also value *personalismo*. When going to the doctor, families want to have a personal conversation before jumping into the medical issues at hand. They value establishing a personal relationship with their care provider. Being closer than normal or touching the patient's shoulder are deemed acceptable and necessary to creating a lasting patient-doctor relationship. *Respeto* (respect) permeates everyday life. When going to the doctor, families like to be addressed with the appropriate title (*Doña, Señor, etc.*). Showing this respect also strengthens the patient-doctor relationship and builds on trust. The idea of *respeto* also refers to the deference to authority. Patients may nod their head when doctors are describing treatment or course of action, which the doctor may perceive as agreement. While it is possible that they agree with the doctor, there is also the possibility that they disagree or do not understand what the doctor is saying to them, but instead are recognizing the doctor's authority. If this miscommunication occurs, it may lead to future misdiagnosis or mistreatment, causing the patient to become very frustrated and not want to come back. Moreover, because of *respeto*, patients may refuse to tell the doctor about issues they consider indecorous, personal issues or experiences they find inappropriate to discuss. Some of these can be integral to diagnosis, and could cause a barrier to health services. *Simpatia* is being calm and kind in stressful situations. Families expect their doctor to be calm, cool, and collected since they are the authority. *Confianza* is the confidence that a family can confide in the doctor, and tell them about medical issues. It is trust in the healthcare provider and their staff. *Fatalismo*, the belief that everything is happening as God intended, is an additional cultural concept that shapes a family's outlook on genetic services. However, while this may affect their outlook on mortality, it does not affect their outlook on morbidity. Thus God is in control of death, but action can be taken to lessen the consequences of an illness. Although the Latino family is usually patriarchal, and the father



makes the overall decisions for the family, the woman usually makes the medical decisions. This can prove to be difficult for providers who may find that the mother is interested in medical services but the father is obstinate and refuses care options.<sup>10</sup>

To overcome these cultural barriers, many communities have begun using *promotoras* or patient navigators. *Promotoras*, those with at least a high school degree, and patient navigators, those usually with a bachelor's degree or more, are knowledgeable in the medical field but not necessarily formally educated or employed in it. They are intended to enhance communication between the patient and the doctors and nurses and help the patient access medical and non-medical components of their care. In the patient navigator program at the University of Texas Health Sciences Center, patient navigators help with translation, transportation, understanding complicated medical procedures or instructions, and help with other, extra-medical resources such as finding places for low priced housing, food pantries, charities, etc. Overall, clinics have seen an increase in efficiency with patient navigators. In general, lack of translation services costs \$38 a clinic visit and extends a visit by 20 minutes or more. By having patient navigators, a clinic is able to reduce the amount of time a visit takes, and therefore reduce additional expenses that would be incurred. Patient navigators, or at least translation services, may allow clinics to increase their number of appointments. This could reduce barriers to care, since Hispanic patients in general have reported issues with getting appointments scheduled with their doctors. A patient navigator model may also prove to be a viable option for the American Indian patients, who struggle to understand their western doctors and the intent of appointments or treatments.<sup>11</sup>

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<sup>10</sup> Genetic Counseling Issues in Latinos. 2001. Penchaszadeh

Why Many Latinos Dread Going to the Doctor, Machado, 2014, The Atlantic

<sup>11</sup> Patient navigation helps Latinos overcome barriers to health. Despres. 2011. Health Canal

## **Highlights from Both Groups**

As drawn from above, American Indians and Hispanic populations experience many similar issues when it comes to genetic testing. Beyond the similar cultural implications, there are other broad topics to be addressed. For example, the potential impact of genetic services on the family and associated ethical dilemmas need to be further addressed.

According to a lecture on the effect of genetic services on families, a local geneticist recounted the careful decisions she must make on what information she gives her patients and their parents. When facing the possibility of two similarly presenting genetic disorders with radically different outcomes in a patient, she may or may not tell parents about the possibility of the genetic disorders or the progression of the disease, because this information could be traumatic. This has interesting implications for both the Navajo and the Hispanic populations. Both groups, when they hear about the possible extreme rapid deterioration of health, may refuse future care, as they think it is unlikely to help. Moreover, the idea of fatalismo (fatalism) in Hispanic populations may also prevent future care.

There are also ethical dilemmas to consider when treating both groups. In this lecture, it was clear that consent, and the ability for a patient to understand the risks and benefits of a procedure, are very important. It is the doctor's responsibility to ensure that their patients fully understand any procedure. In the coming years, doctors may have to monitor if their patients are asking questions, how many, and what kinds of questions; they will have to explain the consent form and look for acknowledgment by the patient that required topics have been covered during the consent process. While this increase in requirements may seem impractical in a clinical setting, the overarching issue, making sure patients are fully informed on all services, remains of utmost importance. These groups may not understand how consent protects them, and they may

not easily understand what the consent form does or does not allow the doctor to do with their samples. While potential solutions (translators, promotoras, patient navigators, etc.) may require time and resources to implement, it is important to keep these key considerations in mind, since both groups are extremely wary of what doctors do with blood samples and other genetic samples collected from them. . Moreover, patients who fear they may be discriminated against because of their genetics (outside of their community) should be informed that they are covered by the Genetic Information Nondiscrimination Act (GINA), a federal law passed in 2008, which prohibits discrimination due to genetic makeup (except for life insurance). Some patients are worried that they will face difficulties in employment because of the genetic information revealed by genetic testing. This is not the case.

### **Executive Summary: What the Literature Suggests**

1. American Indians and Hispanics both have traditional beliefs that affect their relationship with western medicine and therefore their access to care. However, traditional beliefs can (for the most part) be combined with western medicine for a holistic treatment.
2. American Indians have a moratorium on genetic testing because of issues of informed consent and religious values.
3. Younger generations of American Indians are interested in genetic services but don't know much about genetics (solved in part by GENA).
4. Inability to get an appointment affects both groups.
5. Long travel distances are an issue for native groups.
6. Native groups feel that they have to keep all their own records, which becomes a barrier to care.

7. Translation services or patient navigators may reduce the amount of time each visit takes and therefore opens up the doctor's schedule for new patients, thereby reducing general wait time.
8. Both groups have a number of cultural preferences that affect their relationship with genetics and/or their doctor. If the doctor has knowledge of these cultural preferences, it is possible they will be more likely to retain patients in the long run.
9. There are important things to consider when discussing potential genetic diseases and symptoms with families, including their general health literacy and individual coping strategies.
10. There are a number of ethical issues pertinent to genetics including the ability to give consent and the understanding of risks and benefits associated with certain procedures.