

Cultural Competency and Access to Genetic Services for Special Populations

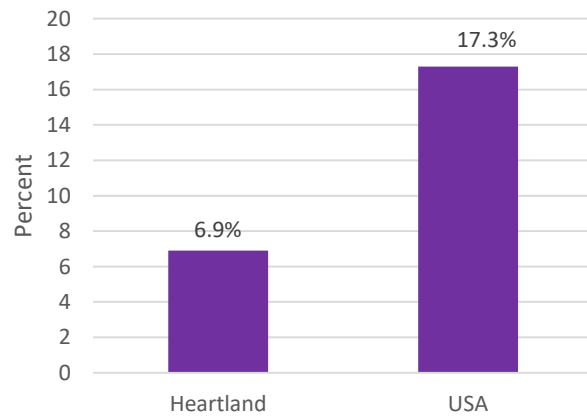
Mary Ann Coffman
Anita Lena
MSRGN Annual Meeting
October 2, 2018



Heartland's Hispanic Population

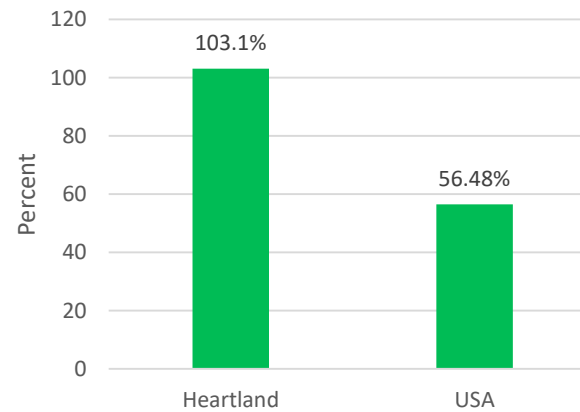
Percent of Hispanics

(US Census 2016)



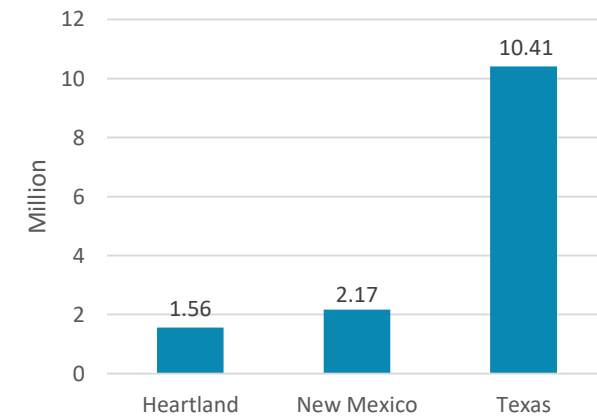
Percent Increase of Hispanic

(US Census 2000-2016)



Total Number of Hispanics

(US Census 2016)



Hispanics in Heartland

Our Story

- Underserved
- Limited resources

Hispanic Access Project

1. What are the barriers for Hispanic families to accessing genetic services?

- Qualitative research project (2013-2015)
 - Interviewed 26 Spanish speaking families in Spanish in three states.
 - Presented results at MSRGN 2017 annual meeting

2. What can genetics services providers do to provide culturally competent quality care for Hispanic patients?

- Established the Hispanic Access Advisory Committee (HAAC) in 2015- present

What is culture?

Culture refers to a system of shared meanings. It is expressed through patterns of customs, practices, and thoughts. Both health care clients and health professionals identify with particular cultures.

A person's culture includes some or all of the following things such as their:

- Age
- Educational level
- Ethnicity
- Geographic origin
- Gender
- Group history
- Language
- Life experiences
- Religion, spiritual beliefs and practices
- Sexual orientation
- Socio-economic class

What is cultural competency vs cultural humility?

There are significant **differences between cultural competence and cultural humility**. **Cultural humility** is a process that one engages in, rather than a level of education one seeks to attain.

Some say the cultural competency is the ability to interact effectively with people of various cultures. It means acknowledging *differences* and accepting that person for who they are, open-minded, listening, and a posture of **humility**

Four key practices form the foundation of adapting a cultural humility approach in your practice

- Maintain Life long learning
- Engage in continued self- reflection
 - Become aware of your *personal history* and *bias* in an effort to become conscious of the *assumptions* you hold about people of culturally and linguistically diverse patients.
 - What seemed to work for you in a particular situation? What did not?
- Become comfortable with not knowing
- Recognize that there may be power/privilege dynamics

So who am I? (Mary Ann)

- Age (mature)
- Educational level (Genetic counselor)
- Ethnicity (Hispanic, Peru)
- Geographic origin (USA but...)
- Language (Spanish and English)
- Life experiences
 - Professional: Public Health and Research
 - Personal: Guillermo Polo-Ilaborda Castro,....Polo Ilaborda,Polo, Mary Ann Coffman! (Assimilation!)
 - Personal: Christian minister that was assigned to a Spanish speaking Mexican church for two years
- Religion, spiritual beliefs and practices

What have we learned from the Hispanic Access Project?

1. What are their cultural norms about relationships?
2. How does a Hispanic Family care for a child with a Special Health Care Needs?
3. What are the communication issues?
4. What genetic information are needed by the families?
5. What are other support and information systems are needed by the families?
6. What may be unique about Spanish speaking families in our region that are not related to the questions listed above?

Communicating with the Hispanic Family in the Genetics Clinic Visit

Presenter: Mary Ann Coffman MS CGC
Panelists: Erica Herrera
Gene Hallford PhD
Jennifer Roberts MS CGC

May, 2017

*To view this video, please visit Heartland's YouTube channel :
<https://youtu.be/hhoM-8Y5Y0A>*



TIPS FOR HEALTH CARE PROFESSIONALS WORKING WITH HISPANIC FAMILIES

What Hispanic Family Members of Children with Disabilities Are Saying



These tips were developed primarily by Hispanic family members who have personal experience with health care professionals providing care for their children with disabilities. This document is designed to provide guidance about how to more effectively work with Hispanic families. However, it is important to remember that Hispanic culture includes a wide array of national origins, dialects, religions and customs.

COMMUNICATION

- Allow more time for appointments with Hispanic families to provide opportunities for discussion and clarification. This additional time can help ensure they can process and understand the information you give them.
- If possible, ask the family if they need an interpreter before the appointment so interpretation services can be arranged ahead of time.
- When using an interpreter, make eye contact with the family member, not the interpreter. Direct your questions to the family member and give the interpreter time to explain what you are saying and get a response from the family member.
- Only give a Spanish-speaking family member information about their child's medical status or treatment with an adult interpreter present. Doing so can help ensure the family member fully understands the meaning of the information.
- When delivering a diagnosis, offer information about the causes and symptoms of the disability or illness as fully as possible. Do not assume the family member understands medical terms.
- After delivering a diagnosis, offer support by providing information to help them understand what to expect. Let the family member know what treatments, therapies and support groups are available. Provide written information in Spanish about the diagnosis, symptoms and treatments.
- Encourage family members to keep a health record for their child that includes information about the child's medications and dosages.
- Encourage family members to ask questions about any concerns they have about their child, and take time to answer them.



What are the Hispanic cultural norms about relationships ?

1. Families value relationships, personalized care and respect for authority.

In our culture we are very physical, we like to be greeted,, [We need to] trust them and to tell them more about what is happening with the child. ... Because we are seeing that the provider has an interest in curing himbut also has a personal interest.. They are interested not only in the symptom, but they are also interested in the person, ... [HAOK09]

“No me piden atencion” “No se preocupan”

TIP: Greet every family member with a handshake and refer adults as “Sr.” or “Sra.”

2. Families value strong family ties (collectivist)

My mother says

TIP: Allow time for the family to discuss medical treatment which may take more than one session

How does a Hispanic family care for a child with a special health care needs? (Like everyone else!)

1. Families may choose to delay or ignore medical advice.

the doctor told me we are going to wait until six months to see if he can eat, but my mom said, how will he learn to eat if he is not eating?.....It was more about my time. I told them I cannot come here every week, so here at home we started giving him egg, broths, soups, everything.....so then by the time they did the swallow study, they said "oh, he can eat! But make sure he does not eat too much." However, I already knew he could eat because I was feeding him all the time, only I did not give him liquid things [HAKS24]

- May rely more on the advice of a trusted family member or physician from their country of origin.

3. Families may seek care from *Curanderos* (or other folk healers) or use Herbal remedies/antibiotics/Vitamins (literature)

- Mexican Pharmacy

TIP: ASK!

What are the Communication Issues?

1. Genetic and medical concepts, in addition to language barrier and literacy level represent a challenge to interpretation.

Yes because most of the people who come here, are neither doctors nor lawyers. The people that come here are modest people for example, their father [of their daughters] finished grade school. If I ask for information in Spanish they will give to me, I will read it and he [ex-husband] won't understand anything, even if it's in Spanish [HANE 68]

2. There is inequitable availability of interpreters across institutions and states.

3. Wide variation among families of speaking or understanding the English language. "I know a little English"

4. Wide variation of health care providers of speaking and understanding the Spanish language. "I know a little Spanish". "I use my smart phone."

5. Families question the quality of translation

They interpret very badly..., I understand the doctor and I understand the interpreter but the interpreter is not saying anything of what the doctor is saying. [HANE68]

What are the communication issues? TIPS*

1. When using an interpreter, make eye contact with the family member, not the interpreter. Direct the questions to the family member and give the interpreter time to explain.

5. Do not assume that family (and possibly the interpreter) understand medical or genetic terms in Spanish or in English

nodding their heads

**Tips for Health Care Professionals Working with Hispanic Families, Erica Herrera*

What Genetic and other information are needed by family?

1. Families have lack of understanding or appreciation of the benefits of genetic services.

In 2007 it was the last time that we went [to genetics], and I just came back this year because my husband said, “what, are they going to cure her? they are not going to do anything for the girl. They are going to prick her, draw a lot of blood, [daughter] will cry, and will be in a bad mood all day.” [HAOK09]

2. Families do not understand or recognize the implications of a genetic diagnosis.

Until now, I do not know why the girl was born like this. Until now—to be honest with you—until now, I didn’t even know the reason she was born like this or what I did or what, was it something I took or what happened? I never knew why! The doctors only asked me that, if it was hereditary, but I said no, because no one in my family is like that. [HAKS23]

3. The use of a non-neutral Spanish makes it difficult for some Hispanic groups to understand*

*Health literacy for Hispanic Families (literature)

What Genetic and other information are needed by the family?

4. Lack of written information in Spanish of specific genetic conditions, laboratory testing and other.
Identified by genetic service providers
5. Too much information at the wrong time

Spanish speaking families and social media

Smart Phones

- What's App
- Facebook



Computers (e-mails) not used as much.



What Genetic and other information are needed by the family? TIPS

- 1. Description of genetic services both in writing and video from the “families perspective”.**
 - a. Family Friendly Genetic Description (6th and 9th grade)
 - b. Video

What other support and information systems are needed by the families?

1. Families learn about Genetic services and form strong relationships with the Hispanic (bilingual coordinators) from the Parent to Parent organizations and home visiting programs such as early Intervention. (trust!)

3. Community leaders and other support groups can assist families in finding resources for the family and increase awareness of genetic services. (community health workers or promotoras?)

Hispanic Access Advisory Committee

What may be unique about Spanish speaking families that are not related to the questions listed above?

1. Are not familiar with other health professionals other than a doctor or a nurse.

Now I know they are students, at that moment I did not know, at that moment I believed that they were all doctors, they were all nurses, but now I know they are students, why, because they wear their name tag.? it says there. I did not know how to read to it or even why the wore one. [HAOK06]

2. Families have an and expectation to receive medication or other visible interventions.

3. Families have expectations of receiving similar care a their country of origin (personalized)

4. Families may have a higher expectation of bilingual staff and being treated well by them.

5. Families have fear because of their undocumented status (trust)

Accessing other medical or financial services for their child

Accessing Genetic Services (Driving around the block)



Cultural Humility

Each and everyone of us have
our own story and our
individual journey!

(Bias and Assumptions!)

i Muchas



Gracias!

Oklahoma Native American Community

- Tribes
 - 39 Federally Recognized Tribes
 - Population of 321,687 Native American people
- Reservation vs Tribal Jurisdiction
- Tribal Identity

Oklahoma Native American Community (cont.)

- Historical Trauma
 - Boarding schools
 - Humility and Shame
 - Substance Abuse
- Language
- Religion, spirituality and ceremonial
- Education

Who Am I?

- Ethnicity
- Family history
- Language
- Religion, spiritual beliefs and ceremonies
- Life experiences Professional and personal
- Educational level

Journey to Heartland

- Oklahoma Family Network
 - Referrals from OU Children's Hospital Genetics Clinic
 - Provide Resources and Parent match
- Tribal Health System in Oklahoma
 - Indian Health Service
 - IHS and Tribal Clinics
 - Tribal Hospitals

Journey to Heartland (cont.)

- Heartland
 - Heartland Annual Conference (January 17-19, 2018)
 - Cultural Humility Panelist
- Collaboration
 - Heartland and OFN
 - Talking Circle
- Southern Plains Tribal Health Board
 - Conference
 - Annual Meeting



The Invisible Child



“He Can Fancy Dance”

by Cindy Paul

Questions



Objectives

- Describe the differences between the terms of cultural competency and cultural humility
- Identify cultural barriers to access to genetic services for underserved populations
 - Spanish Speaking Hispanics
 - Native Americans
- Modify our approach in providing medical services to underserved populations.