

part 2: choosing

Expert Interview: Helen Maldonado

Helen Maldonado started in the medical field as a Community Health Representative (CHR) in 1981 for the Sonoma County Indian Health Project, Inc. She went to nursing school and became a Licensed Vocational Nurse in 1986 working for various hospitals in Sonoma County, then went back to school and graduated UC Davis as a Physician Assistant in 1999. Helen worked in a Rural Clinic as a Family Practice provider during the first year following graduation. When a position became available, she went to work for the Sonoma County Indian Health Project, Inc. (SCIHP) in 2001. She first worked as a Family Practice Mid-Level Practitioner then was given the opportunity to work as a Diabetes Specialist and create a Diabetes program starting with just herself as staff. She developed the mission and vision of the Healthy Traditions department with the input of community members and the Diabetes program grew to 12 staff becoming its own department in the organization of SCIHP. While there, Helen lectured at conferences and gatherings around the State of California on the topic of diabetes treatment and diabetes prevention. She now works as the Area Diabetes Consultant for IHS in California since 2008 utilizing all of her past work and life experience as well as professional development, to provide diabetes expertise and support to the 37 programs in California as a PA-C and Certified Diabetes Educator. Helen is also an enrolled citizen of the Lytton Band of Pomo Indians.

Cap Radio News: Are there personal reasons for your involvement in diabetes work as well?

Maldonado: My family, my community, we have a high rate of diabetes. I want to prevent diabetes in my grandchildren.

Cap Radio News: Do you have diabetes as well?

Maldonado: Yes, I was diagnosed about three years ago.

Cap Radio News: What impact has the diabetes epidemic had on the Native American community?

Maldonado: It's had a huge impact. Many people watch their family members die from diabetes or lose limbs or go through dialysis and have lots of issues to deal with. It's been an epidemic with Native people. Prior to the 1940's, there was no diabetes in Native Americans. First there was Spanish sovereignty in California, then, there were all kinds of policies against Native people around the gold rush time in the 1850's. Then they were taking children away from Indian families and placing them in boarding schools. So the traditional Indian family unit has just been ripped apart. People are struggling to try to survive.

Cap Radio News: Native Americans have a higher rate of diabetes, higher than any other major ethnic group in the US at 16%. What are the reasons behind this higher rate?

Maldonado: There are a few reasons, it's not just one or two. There's genetics or epigenetics, fetal origins, lifestyle and stress. Genetics of course is about 15% of our genes or cells are turned on at a time, but then

the epigenetics are the on-and-off switches that are on the genes that will make it difficult for people to really overcome what's going on in their bodies.

Cap Radio News: Can you tell us more about the science or research that points to the genetic factors?

Maldonado: The epigenetics is something that they've been researching more recently. It's no longer nature versus nurture, it's more nurture affects your nature. There was a study done about rat pups. One group was raised by nurturing mothers. In this case, the gene that affects the stress hormone receptors is turned on when the mom is very receptive to the babies. She's licking them and grooming them, and they grow up to be stress-resilient as pups. Then there are rat pups that are raised by neglectful mothers, where the gene that affects stress hormone receptors is turned off. So they grow up to be very stress-reactive. The same process has now shown to be true in humans. If the mom's having a hard time with her child, or the parents are young and unmarried, if they're involved with drugs or alcohol and they're not nurturing to their children, the children are not stress resilient.

Cap Radio News: And this relates to diabetes in what manner?

Maldonado: In the way that there are many factors. There are four factors that are related to diabetes: genetics, fetal origins, lifestyle and stress. So, fetal origins, for example, if the mother is stressed and she's like I said into alcohol or drugs. Also nutrition, moms may have high caloric intake but are undernourished.

Cap Radio News: Sure, junk food.

Maldonado: Yeah, or really cheap food. Smoking, maternal diabetes, toxic or infectious exposures, maternal low birth weight and maternal stress and mental health status really impacts the moms and the children. This sets them up at a low birth rate and they rebound with their weight. This causes diabetes and obesity.

Cap Radio News: Talk to us about the roles that historical trauma and oppression of Native Americans play in the population's health.

Maldonado: Historical grief and trauma is a term that came up when people were studying all the different traumas that have happened to Native people. There hasn't been a time that they can really grieve. Traditionally, Native people would take a year to grieve if they lost a loved one. Like I mentioned before about the different onslaughts of the gold rush and then the genocide of Native people, many people were being killed frequently and there were many, many different problems that happened within our communities from which people couldn't recover. And so there's inter-generational trauma that comes out in nurturing or non-nurturing of your children. Historical grief and trauma is something that people don't even know affects them until we start talking about it. And so we talk about it in talking circles or digital storytelling. Those are ways that people can heal.

Cap Radio News: We heard about the talking circles in the documentary. We heard one woman express resignation, really, about the fact that she had diabetes. She said she thought it was part of God's plan. So do you hear this kind of fatalism, this sort of resignation that fate is pre-determined in Native communities, and if so how do you deal with it?

Maldonado: Yes, I've heard that quite a bit as a provider. I always have to give the message of hope. We do have a program called the Diabetes Prevention Program. There was a diabetes prevention project that was funded by pharmaceutical companies to test Metformin (an oral medication for diabetes), and they were able to demonstrate that lifestyle change was a way to prevent diabetes or delay onset. So we've actually put that into action in the Indian Health Service. There are 36 programs around the country that have been

demonstrating that intensive lifestyle change has prevented diabetes. And also there's another initiative called The Healthy Heart. So people with diabetes are able to, with a 16-week intensive program, prevent any kind of heart disease and risk factors.

Cap Radio News: And effectively change their lives too in the process. Another one of the stories in the documentary was about Eddie, a man who says he didn't have access to medical care until he was an adult. Is this something that you hear a lot in the Native American community, and how does it come into play with the diabetes rates?

Maldonado: Across the country, people have had access to care at Indian Health Service units. In California we only have tribal and urban healthcare programs. If they don't have access to care, that really does affect people dealing with diabetes. You need to have healthcare, you need to be able to get medication or whatever you need to take care of yourself. Currently, California is funded at 52.6% of the need so there's a large unmet need for Indian health. It's something that affects all Native people. They may have a clinic that they can go to, but maybe they don't have enough gas money to get there.

Cap Radio News: It's very multi-layered. What are some of the cultural attitudes that might help diabetes management in the Native community, and on the flip side, are there also cultural attitudes that might hinder the management?

Maldonado: Talking circles are really good, and traditional dances and ceremonies. Prayer and being balanced in mind, body and spirit really help. Hindrances are when community members or medical providers are not able to recognize their own behaviors based in historical trauma, and they make decisions that affect others. So they've forgotten their traditions. I think the traditional way of dealing with illness or wellness is really important for all Native people to understand.

Cap Radio News: Research does suggest that culturally relevant care models can be the most successful in managing the diabetes epidemic. So what does culturally relevant care look like for the Native community?

Maldonado: It's patient-centered care. So it's pretty much designed around what the community wants. They would give their voice to the healthcare program saying this is what we want from you, and to be able to hold their community gatherings, to be able to come together and have a relationship with a healthcare provider.

Cap Radio News: There is currently a \$150 million annual federal grant to fight diabetes in the Native diaspora. What impact has it made for your community?

Maldonado: That's called the Special Diabetes Program for Indians. It's funding that is currently authorized through 2012, but we don't know what Congress will do in 2013. It's really improved diabetes, and it has improved blood sugar control, cholesterol levels, kidney function, healthy behaviors in youth, promoting healthy lifestyles, and it increases access to diabetes education.

Cap Radio News: Right now we're seeing rising poverty rates, elimination of or decreases in services, so how's the economy affecting the ability of your community to reduce the incidence of diabetes?

Maldonado: It has been impacted with the state cuts of Medi-Cal. Programs have been hit really hard with the inability to bill for certain services for adults like dental care and behavioral health care. It's really hard for the programs to continue. So if there was no diabetes program, they may not have any funding source to provide these services or education or dental care or anything else to adults with diabetes. It's impacted

their bottom line, because like I said before, they're really under-funded. Indian Health Service is only funded for half of what they need, and there's a huge need.

Cap Radio News: Do you anticipate that healthcare reform could play a role in providing better services to this community around diabetes prevention or diagnosis care?

Maldonado: We're hopeful and there are lots of discussions going on. There's the Affordable Care Act, which is the health reform bill, and there's an American Indian Health Improvement Act within that. So there's some items in there that will really help Indian people, and it gives them some abilities to have the diagnosis and the treatments that they need.

Cap Radio News: In your work, what does a patient's success story look like?

Maldonado: A patient's success story is somebody that sees the hope. Their eyes brighten up. They're not feeling like this is the end, and they're able to make certain changes that are important to them. And they're able to spread that news to others in their community.

Cap Radio News: That must be very rewarding to you to see the a-ha light go on.

Maldonado: It is.

Cap Radio News: What about your own personal optimism about dealing with your diabetes.

Maldonado: I'm very optimistic. I'm in good control. I'm walking 10,000 steps at least three times a week, and I've been working with my own dietician on my own request. I had never seen a dietician. I've never been treated like a patient, I've always been treated like a provider. It's like, well, you know what to do. So I'm enjoying that now, being a patient for the first time.

Cap Radio News: Does your experience give you a better perspective in your job?

Maldonado: Oh, it does. It does. My mother has diabetes, and my youngest brother died at 36. He was actually the first one diagnosed with diabetes, but he died in an accident when his blood sugar went too low and he passed out and the tractor mower he was driving went off the bridge where he was working at the golf course. It landed on top of him in the water. So this work has been something that I'm very passionate about.