Scrutinizing health considerations for Native Americans: A personal story of learning from a medical crisis

BALANCING RISK

Editor’s Note: The relationship between diet and health in the Native American community is the object of increasing interest from health care professionals, food scientists, and dietitians. There’s a consensus forming that the effects of abandoning a traditional diet of high-fiber, unprocessed foods may be serious and widespread in a community where there is a genetic predisposition to conditions that are often related to diet. In addition, there are many incidences of diseases where the patient has no predisposition other than being Native American.

We asked Patty Talahongva, Hopi, a seasoned journalist and frequent contributor to Winds of Change, to share her personal encounter with what may well be a burgeoning health crisis. In July 2013 she was hospitalized with diverticulitis, a digestive disease marked by the formation of pouches (diverticula) becoming inflamed and pushing through the colon wall. In the general population, it’s most common among elderly people. What Talahongva learned about health among Native Americans surprised and concerned her.

Here are three groups at risk for diverticulitis: people who are 70 or older, who are obese, and who don’t get enough dietary fiber. I don’t fit any of those categories. Since going through emergency surgery for the disease, I’ve shared my story with whoever will listen. Less than a week after telling a colleague, a 52-year-old Salish Kootenai woman, she too was diagnosed with diverticulitis. I also learned of another Native American woman in her early 50s with the same diagnosis. I found out that my own cousin takes medicine for the condition. And my nurse practitioner, Susan Brown, found an article about a 19-year-old Tohono O’odham diverticulitis patient.

It turns out that Native Americans get this disease at a much earlier age than European Americans. Brown says it’s in our genetics to be predisposed to certain illnesses. When I was only 25 I developed gallstones. The receptionist at the Phoenix Indian Medical Center (PIMC) guessed it was a gallstone attack because she had seen the symptoms so many times. The doctors confirmed it. Turns out Native Americans, especially in the Southwest, have a very high rate of gallstones.

BY PATTY TALAHONGVA
The Diet Connection

Our traditional diet has changed drastically in what is, in evolutionary terms, a short time — so no wonder we have health issues. And rebalancing diet can be problematic. Thelma Lucero, a registered dietician at PIMC, says it’s important to eat fresh fruits and vegetables, beans, and whole grains. “The goal is to get 25 grams per day plus eight glasses of water,” she says. “Most of my patients don’t eat a lot of fiber. It’s a slow process to switch from white bread to whole wheat.”

Many patients also tell her they can’t afford fresh food, but she says eating cakes, cookies, fry bread, and junk food is not the answer. She advises her patients to make one change that could be as simple as adding more vegetables. “I ask, what are they are willing to do?” she says. “When they come up with it themselves, they are more likely to follow through.” Family support is crucial, and Lucero asks couples to come in together. “Having everyone on board makes the difference,” she says. “It’s not just one person making this journey alone.”

Some of her patients are harder to advise because they rely on food boxes, are homeless, or have drug or alcohol addictions. “Some people may not eat any food for days if they’re drinking or on drugs,” she says. “I can’t make them eat, but I can talk to them.”

My Stoma Story

In July 2013 I went to PIMC in great pain. “The consult didn’t sound good, with clinical data suggestive of an acute, severe infection clinicians know as septic shock,” says surgeon Alison Davis. “In this case, the culprit was a perforated bowel from a sigmoid colon diverticulism.”

Before that diagnosis I had never heard of diverticulism or had any sign something was wrong with my colon. “You are a very sick lady,” said Dr. Davis. “If you don’t get this surgery, you will die.” I signed the consent forms, and my mind went blank.

That was a new situation for me; as a journalist I’m trained to ask questions. But this shock was just too big to process. After the surgery, hooked up to a few machines and numb with medications, I looked down at my colostomy bag, and thought, “Is this thing real?” Dr. Davis explained that she had removed eight inches of my diseased large intestine. Sticking out of my stomach was a stoma, taped to a bag that would collect my stool.

Brown — a certified wound, ostomy, and continence nurse — made living with a colostomy sound like a party, with descriptions for medical supplies like donuts (the cohesive pads) and lollipops (the no-sting barrier film). I glanced at a brochure on colostomy care, and the photos were all of elderly people, no one close to my age. I couldn’t relate and didn’t try.

My son, Nick, is a certified nursing assistant who works at a hospital. Nick kept telling me he would take care of me. “Don’t worry, Mom,” he said.

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said. “I’ve changed colostomy bags before.” I thought, “Good, whatever that means.”

Three days after my surgery, I met my colon. Brown came to show me how to change and clean my bag. The first time I saw the incision and the stoma, I cried. I didn’t want to look at it. Brown said it was just a part of me that I’d never seen before, that I couldn’t hurt it, and needed to embrace it. “Your reaction was honest,” she told me later.

I wrote in my journal that day, “This morning I met my colon. He’s very pink. It scared the hell out of me.” Dr. Davis listened to my fears. “It’s your colon. It’s not yucky. It’s not nasty,” she said.

I had cried, saying I was only 51 and my son was already having to “change my diaper.” Fear, anger, and self-pity were all emotions I dealt with for a few days before I could accept what was happening to me.

THE CULTURE FACTOR
Culture can complicate recovery from a host of diseases. “I am fortunate to be a Native American person first, and a surgeon second, so I understood some of the unique cultural difficulties you were facing,” Dr. Davis, Crow Creek Sioux and Choctaw, told me. “Surgery itself is a difficult experience for a Native person, given the sacredness of the physical body, and most tribes have stigmas regarding blood and cutting. So the emotional challenges of adjusting to life with an ostomy are understandable and even more complicated for a Native American patient. You really struggled initially, and I worked hard to offer you a way to frame the experience to honor your heritage and allow you to heal.”

According to Brown, Native American elders have the most difficulty caring for their stoma, “These are people who are already living under the care of a daughter or son. I’ve had a couple of incidences where you could really feel the cultural pull that made it hard for that elder to handle a stoma,” she says. “As long as I felt the caregiver was comfortable in the care, I respect the patient not being involved.” She recalls a patient who kept his eyes closed every time she went to his room to teach him how to change his bag. He learned how to do it, and keeping his eyes closed was just his way of dealing with the situation. “He was listening to me,” she says.

ROAD TO RECOVERY
After I was released, my family and friends rallied around me. I relied on my son, but life with a colostomy bag was not easy. Despite what the literature says, I could not fit into my regular clothes — everything felt too restrictive. I also couldn’t lift anything heavier than five pounds. And it wasn’t easy to move around with an incision nearly 10 inches long with more than 20 metal staples, plus all the glue and tape. I had to carry my small colostomy kit everywhere. At the most inconvenient times my bag “burped” and made embarrassingly loud noises. I had no control. At work I would apologize profusely. People were compassionate, and I was humbled.

About three weeks after my surgery, I was home alone, and my bag broke. With my son at work, I had no choice. I had to change my bag by myself. How quickly the frustration returned — the anger and self-pity! I had to figure out how to change it standing up using the bathroom mirror as a guide. As I fumbled through the process, I caught sight of my angry face in the mirror and burst out laughing. It was so stupid of me to be mad. I managed to get the bag on and felt pretty darn accomplished. I knew I had done a sloppy job, but it worked.

Throughout my recovery, prayer helped get me though. I took good care of myself as I let my body heal. My “take down” surgery went well and I was thrilled to be back to “normal.” I know other patients have the colostomy bag for life. I have great empathy for them and great respect for the family members willing to care for them. After healing for a month I consulted with Dr. Davis about a long-planned vacation. Was I ready to travel? She reassured me, and in November I celebrated my life in Iceland underneath the aurora borealis.

I’m slowly returning to my active lifestyle. In January I completed my third half marathon. I was filled with emotion as I crossed the finish line thinking how just five months before I was carrying around my colostomy bag and could barely walk, and now I was running 13.1 miles. The surgery has given me a new appreciation for all the intricate work my organs perform. I’m so grateful for Dr. Davis and Susan Brown, and all the medical staff, and my family and friends who took care of me for those many weeks. According to Nietzsche, “What does not kill me makes me stronger.” Diverticulitis did not kill me. I know it has made me strong enough to share my journey, and I hope that it encourages others to make at least one positive change in their lives.