How We Care: Confronting Racial Disparities in Post-Acute and Long-Term Care

By Diane Sanders-Cepeda, DO, CMD

When I was eight years old, I remember walking through two oversized doors into a grand foyer with yellow-kissed walls, lush rugs bespeckled with tiny flowers, and shiny wood floors. The wonder of this room was eclipsed only by a sea of smiling faces, and the question that dominated my thoughts: Had I found the place where grandparents are made?

As I followed my parents to the place where our Great Uncle Jabo sat, a chorus line of cascading hands filled with tightly wrapped peppermints and golden butterscotch candies were presented for my choosing.

I didn’t realize that I was in a nursing home; that understanding wouldn’t come until years later. Now, not only do the rugs and shiny floors set off alarms in my mind over fall hazards, but that day echoes through my brain with understanding. Phrases such as “we have to make sure he is okay,” “you know they don’t take care of us,” and “they will let him get sicker” did not mean anything to me then. Now, these words speak to the fear that care will not be delivered.

Many may say that this fear only speaks to the stigma of skilled nursing facilities that persists today, but I have heard these statements and more shouted loudly and whispered in tears across multiple care settings by people...

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The Unique Needs, Challenges of Native American Long-Term Care Residents

By Joanne Kaldy

What would you do if one of your residents wanted buffalo jerky? This request would not be uncommon at one of the many tribal nursing homes in the United States. These facilities are under the same federal oversight as other facilities, but they face unique challenges; their residents have specific cultural needs and preferences, and these sometimes clash with surveyor and regulatory guidance.

“The greatest challenge we have is funding. When you build a nursing home in a reservation, you have to comply with [Centers for Medicare & Medicaid Services] regulations, and many of these don’t fit in with language, culture, and traditions,” said Wayne Claw, CEO at NavajoLand Nursing Home, Inc., in Chinle, AZ. For instance, they have many residents who have lived on the reservation their entire lives and have never been traditionally employed or had a taxable income. “There is nothing you can take from them to pay for care and...”

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services,” he said, and they’re not eligible for Social Security or Medicare.
“We have to find money for them all the time; the regs aren’t made for us,” Mr. Claw said, adding, “We just got hit with a second wave of COVID, and we don’t have money for PPE [personal protective equipment]. We are struggling. Although they comply with CMS regulations and work hard to serve their residents, he stressed, “We are isolated. The closest shopping center is 100 miles away. It’s really tough.” Nonetheless, he is proud of what he and his team have been able to accomplish. “In 2020, we didn’t have a single elder with COVID or a single death from the virus,” Mr. Claw said.

At the same time, he said, “a lot of regulations don’t relate to the traditional food and culture that are part of life for our residents.” For instance, he noted, “A lot of our elders use Navajo medicine and work with traditional healers.” Many also smoke with herbs and cedar, and the regulators don’t understand that. Mr. Claw said, “We get surveys from San Francisco who have never been on a reservation. We need people who know the area, the people, and the reservation.”

This may be slowly changing. According to Tami Reed, administrator at the Morning Star Care Center in Fort Washakie, WY, a group of tribal-owned facilities got together and formed U.N.I.T.E. — “a collaborative of tribal nursing home stakeholders who network, discuss best practices, promote evidence-based education and trainings, and work on quality improvement initiatives” (see https://unitenatives.org/about-us). As past-president and the current vice president of the board, Ms. Reed said, “We have come a long way to get CMS to hear our voice. We have worked to get people to understand our traditional ceremonies, foods, and medicines.”

Best Practices Offer Insights

The U.N.I.T.E. collaborative worked with CMS develop a series of “tribal nursing homes best practices” in an effort to address some of the issues related to care for Native Americans (see “Tribal Nursing Homes,” CMS, gov, updated Aug. 9, 2022, https://go.cms.gov/3QNY3Vd). For instance, one addresses traditional foods such as caribou and moose and says that a benefit of serving traditional foods is that it makes residents feel more at home. Ms. Reed said, “The residents love it. They’re excited when we bring in something different or something that they requested.” Dried meat is a particular favorite, she said, because it’s ground up and easy to chew. She added, “Sometimes it’s mixed with lard or berries, so it’s a good source of protein for them.”

The CMS best practices document also notes, “Serving traditional foods can lower costs by reducing food waste, because elders eat more of the foods that they like. In addition, traditional foods can be higher in fiber and denser, meaning elders are often satisfied by eating less than more processed foods.”

Ms. Reed observed that when it comes to foods, different tribes have their own specific preference. “The Alaskan Tribal Nursing Homes have worked hard to be allowed by CMS to serve their Elders seal oil. They also enjoy fresh salmon. In Wyoming, our Elders enjoy elk, deer, bison, and choke cherries,” while squash varieties, cacao, nuts and berries, and pumpkins may be popular with other tribes.

Death and Dying on the Reservation

Various tribes and groups of indigenous people also have different beliefs about death and dying, and it is important to know what these nursing home residents want when it comes to end-of-life and palliative care. “We have people here for hospice care because family members don’t want their loved ones to go off the reservation for end-of-life care. We have residents from other tribes here as well, and we comply with their ceremonies,” said Mr. Claw. For instance, he noted that many families don’t want relatives to go to the morgue right away after their passing. “There are some traditions and beliefs that people from the outside need to understand.”

死亡 and Dying on the Reservation

各种部落和群体的土著人民也有不同的关于死亡和安宁的信念，重要的是要知道这些养老院的居民们希望何时结束生命和缓和的照顾。“我们有人在这里接受安宁护理，因为家庭成员不希望他们的亲人离开保护区结束生命。我们也为来自其他部落的居民提供服务，我们遵守他们的习俗。”克拉夫先生说。例如，他指出，许多家庭不想让亲人去解剖室。他说，“有些传统和习俗是人们从外地人需要理解的。”

Staffing is Challenging Here, Too

As in most facilities, tribal-run nursing homes face staffing challenges. As Ms. Reed noted, “Most of us are in very rural areas, and it’s harder to find licensed nurses, certified caregivers, and other staff. It’s especially hard to get people to come onto the reservation to work.” She said that only about 50% of the staff is Native American, so training needs to be a priority. “We explain ceremonies to non-Native staff and help them understand the reasons behind these,” she added.

The “Tribal Nursing Home Best Practices: Cultural Sensitivity” (CMS, March 1, 2018, https://go.cms.gov/3poclQH) guidelines observe, “Staff training sets a foundation for culturally appropriate care.” During orientation, it is appropriate for staff to learn about traditional lifeways related to the tribal affiliations of residents, and discussion should be encouraged to understand residents’ needs and preferences. In some facilities, a traditional medicine person works with staff to teach them to interact with residents in a way that is culturally respectful.

Keys to Understanding

Ms. Reed advises practitioners everywhere to be culturally sensitive and work to understand the needs and preferences of Native American patients and their family members. She suggested, “Sit down and have conversations with them. Find out what traditions are important to them. What are their food preferences? Do they want pow-wow or other traditional music?” She also noted that room setup may be important to some individuals. She explains, “Some Native Americans prefer their bed to face the rising sun. It’s important to ask about and accommodate things like this.”

It is very important not to make assumptions, Ms. Reed stressed. That is why these conversations are so important. Particularly if there are few or no other residents who share their heritage, it is important for these residents to have access to the traditions, foods, music, and artifacts they grew up with and value. While some of these things may not be easily accessible, she said, “There are lots of websites where you can get things such as buffalo jerky. It’s worthwhile to make the attempt to get something if someone wants it.”

No one expects you to know everything; there will be a learning curve, Ms. Reed said. “It’s okay to say that you don’t know about their culture but want to learn. It can be a very enlightening experience for everyone involved.”

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