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

Confronting racial disparities in long-term care involves changing our mindset about race and reconsidering how we provide care.

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 Navajoand Nursing Home, Inc., in Chinue, 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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The problem is not our situation but our perception of our situation.
— Graham Cooke

It was the third attempt to access an intravenous line this week for Ms. Sue (name changed to maintain confidentiality). She had stopped eating and drinking a week earlier, secondary to her cerebrovascular accident sequelae and progressive dysphagia. Providers, including the nursing team, could clearly see that she was entering into her terminal stage of life. Her husband (who was also the power of attorney) was adamant about continuing IV hydration. Ms. Sue had been receiving IV hydration on and off for the previous four weeks. After I finished seeing the patient, the nurse turned around and asked me, “Doctor! Can you help him understand that these 20 milliliters of intravenous fluid will not save his wife’s life?” I could sense disappointment and frustration in her tone, as if she was looking for a better direction.

The complexities of initiating and navigating advance care planning discussions require a combination of art and science. As Rebecca L. Sudore, MD, and colleagues of a multidisciplinary Delphi panel on advance care planning noted, “Advance Care Planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care” (J Pain Symptom Manage 2017;53:669–681). Of course, post-acute and long-term care facilities face many challenges, which can become roadblocks for some providers and an impediment to practicing effective advance care planning for others. Limited resources and time constraints are a few of the many barriers. Despite these barriers, a successful provider–patient relationship can exist.

The four ethical principles of autonomy, beneficence, nonmaleficence, and justice should always be a part of any advance care planning discussion. As providers in PALTC settings, it is worth adding the fifth ethical principle of “respect for the person,” especially if autonomy is compromised by aging. Respecting the full person means recognizing where a person comes from. Providers and the team should explore the intrinsic values that stem from a patient’s perception — their cultural, spiritual, and personal belief systems. This respectful patient–provider relationship is part of the person-centered care approach. When used during advance care planning conversations, the person-centered care approach acts as an important and necessary bridge between the personal and technical poles of informed care planning (Figure 1).

In an interview with The Guardian, physician, psychologist, and thinker Edward de Bono stated, “Studies have shown that 90% of error in thinking is due to error in perception. If you can change your perception, you can change your emotion, and this can lead to new ideas” (April 23, 2007, https://bit.ly/3OjUsrU). Part of changing our perception with respect to cultural diversity in advance care planning is to start with open-ended questions and to have an open, honest, and empathetic conversation. This includes sharing one’s own ignorance in terms of diversity awareness, and sharing one’s own uncertainties in terms of disease progression despite all of one’s knowledge and skill set. Committing to understanding culturally specific health and illness belief systems will permit us to be better advocates for our patients, especially during ongoing advance care planning discussions.

The presence of the entire interdisciplinary team was very helpful during advance care planning discussions because this helped all the team members understand Ms. Sue and her husband’s past traumatic experiences and their impact on her care planning. Afterwards, she kept a close eye on Ms. Sue to ensure that she remained comfortable and pain-free. The nursing team monitored the IV site regularly for unwanted side effects, including local swelling and edema around the IV line. It became easier for the staff to run those 20 milliliters of normal saline, which only lasted for another 48 hours. She passed away peacefully, leaving behind her grieving yet contented husband, and deeply satisfied staff members.

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Disparities
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of color. These are the words of ones who have experienced inequities. These are the words from those who journey through our health care system, rife with disparities.

Racial Disparities and Health Care Today
Of all the forms of inequality, injustice in health is the most shocking and the most inhuman because it often results in physical death. — Martin Luther King Jr.

These words uttered by Dr. Martin Luther King Jr. in 1966 recognize the desperation that many have experienced around racial disparities and health inequities. Now as we sit here in 2022, nearly 60 years later, Dr. King’s words ring with a continuing, resounding truth as we wrestle with the COVID-19 pandemic and the disproportionate impact that it has had in communities of color, including more cases of COVID-19 infection, higher rates of death, and poorer outcomes (see Figure 1 on next page). Within our post-acute and long-term care community, increased rates of infection and outbreaks were seen in facilities with higher populations of Black and Latino residents (Priya Chidambaram et al., “Racial and Ethnic Disparities in COVID-19 Cases and Deaths in Nursing Homes,” Kaiser Family Foundation, October 2020, https://bit.ly/3rLHx6).

In the early days of the pandemic, common explanations for such findings revolved around access to care, health coverage, and poor living conditions. Yet, although these conversations were all necessary and the statements are true, a social reckoning was yet to come. In the summer of 2020, we would come to learn the names Ahmad Arbery, Brenna Taylor, and George Floyd. In the months that followed more names — from both past and present — would be added. This tumultuous moment in history would be the genesis of conversations once avoided about the long-standing erosive impact of systemic racism.

For health care, this meant further acknowledging systematic racism — particularly the conscious and unconscious bias of health care providers, and the ways that racial bias has long been infused in medical research and education. In an effort to accomplish this, I

Continued to next page
One: Accept That Race Is a Social Construct, Not a Biological Phenomenon

I recall a conversation I had as an intern with my attending physician while I was presenting a case. I explained that my patient wasn’t responding well to the hydrochlorothiazide (HCTZ) prescribed, I suggested laboratory tests and possibly changing to a different antihypertensive medication. My attending physician kindly admonished me while reminding me of the Seventh Report of the Joint National Committee (JNC 7) guidelines that had been published a few months before the start of my internship. You see, my patient was a Black woman; per the JNC 7 guidance, diuretics worked best for Black people. I accepted the correction but not before expressing my frustration that every Black person isn’t the same. My attending and I went back into the room together to inform the patient that we would check her bloodwork, but she was to remain on the HCTZ. Her results came back positive for hypotension; our clinic contacted her multiple times, but she never returned.

This haunting example of the race-based medical approach is one where race is the defining and limiting factor of medical care and management. Consider the number of equations that utilize race correction, the numerous screening and diagnostic tools that utilize these equations, and even the algorithms that health plans and clinical programs use to score patients based on this guidance. This race-based approach is everywhere, yet biological anthropologists, sociologists, and historians have long agreed that race is not a biological phenomenon but a social construct—citing the fact that humans share 99.9% of DNA in common (American Association of Biological Anthropologists, “AABA Statement on Race & Racism,” 2022, https://bit.ly/3TH8EU3). The genetic variations seen more within racial and ethnic groups are related to migratory patterns, not skin color.

Unfortunately, the belief in racial biological differences has been a mainstay of modern health care, and it has been used to reinforce many discriminatory actions, thoughts, and biases. While we cannot deny that people of color in the United States have higher rates of chronic medical conditions, morbidity, and mortality than white Americans, we cannot deny that people of color in the United States have higher rates of chronic medical conditions, morbidity, and mortality than white Americans, including staffing challenges, long-standing unfavorable nursing home policies, and inadequate financial models (J Am Med Dir Assoc 2021;22:886–892).

Reclassifying race as a social construct is the foundation for inclusive care, allowing us to define social ailments as a clinical problem.

In 2021, Philip D. Sloane, MD, MPH, and colleagues highlighted the multifaceted challenges we in the PALTC community must address to combat systemic racism, including staffing challenges, long-standing unfavorable nursing home policies, and inadequate financial models (J Am Med Dir Assoc 2021;22:886–892).

Two: Target the Social Determinants of Health and Recognize the Long-Term Impact They Have on Patients and Residents

In moving away from models of biology, we see that many of the disadvantages and barriers people of color face in health care are closely linked to the social determinants of health (SDOH), including economic stability, neighborhood environments, education, social or community contexts, and access to food and health care (Nambi Nduga and Samantha Ariga, “Disparities in Health and Health Care: 5 Key Questions and Answers,” Kaiser Family Foundation, May 11, 2021, https://bit.ly/3QaR08u). The impact of SDOH on PALTC facilities can be seen at every touchpoint: admissions, discharge, transitions from skilled to long-term care, and chronic disease management.

If we are to address racial disparities in health care, we need to understand the upstream and downstream challenges of SDOH with recognition that these issues aren’t left on the doorstep of the facility.

We can look to facilities such as Maryland Baptist Aged Home — highlighted for their early successes with COVID-19 in 2020 (Washington Post, July 14, 2020, https://wapo.st/3QqBHo1). They fit the description of a facility that should have suffered from the aforementioned challenges, but their successes can be attributed to their awareness of the struggles that the residents, staff, and community have suffered in the past.

Three: Create a Culture of Trust, Not Mistrust, in the Care Experience

You may have already considered the journey of our residents through the health care system to our PALTC facilities. How many clinicians have they interacted with? How many hospital stays, emergency department visits, and office visits have they had during this journey? Now, imagine that journey intertwined with unconscious and conscious racial bias from health care providers. Imagine their journey littered with microaggressions: insensitive comments, nonverbal and verbal disrespect, stereotypes, and rejection. If this was your journey, who would you trust?

Of course, there is nothing micro about microaggressions. The impact of these interactions is cumulative and can lead to patients’ expectations that they will not get the truth or will be denied care, breeding mistrust in the health care system. When many of our residents arrive at our PALTC facilities, they have already been traumatized by this poor health care experience. I am sure that many of us have heard about the horrors of the Tuskegee syphilis study or now know the sacrifice of Henrietta Lacks, but it is these ongoing experiences that reinforce the fears and concerns for people of color.

So how do we create a culture of trust rather than mistrust? Often I am asked how do we “talk to Black people” about hospice or “talk to Hispanic people” about do-not-resuscitate orders (DNRs).

• Build and restore trust by individuating care and management. Refrain from generalizations, and look for what individual people value and what they want in their care.

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**Figure 1: Risk for COVID-19 Infection, Hospitalization, and Death by Ethnicity**

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Rate Ratio Compared to White Non-Hispanic</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>1.15</td>
<td>0.99 to 1.30</td>
</tr>
<tr>
<td>Black or African American</td>
<td>1.22</td>
<td>1.03 to 1.43</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>1.21</td>
<td>1.02 to 1.42</td>
</tr>
</tbody>
</table>

*Protective factors include: age ≥ 65 years, sex (men), the presence of cardiovascular disease, diabetes, chronic lung disease, chronic kidney disease, obesity, and smoking. The mortality rates for other race/ethnicities were not available.*

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