Race Roundtable Series
Tammie E. Quest, MD, Series Editor

Race Roundtable Series: Structural Racism in Palliative Care

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Abstract

This series will focus on addressing the intersection of race and racism in palliative care through a series of roundtable discussions with interdisciplinary clinicians, researchers, educators, and leaders in palliative care. These short discussions are intended to stimulate readers to examine issues of race and racism within the field of hospice and palliative care - in the various forms that it appears - as well as serve as a continual call to action to facilitate and promote equity. J Pain Symptom Manage 2022;63:e455−e459. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

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How do we Define Structural Racism?

Tammie Quest: As a field we're asking our clinicians, our students, our fellows and our researchers to wrap their heads around structural racism. To start, how do you define it?

Rodney Tucker: It's a broad term that illustrates and permeates really everything that we experience in our life, our work, our families, our healthcare. I think of organizational structures, I think of family structure, I think of policy structure. Racism is in all of those structures. It's in those policies. It might be within your family. It might be within your organization. It might be obviously within your healthcare system.

Karen Bullock: I would define structural racism as the scaffolding of micro and macro-level forces that either advantage or disadvantage individuals and communities based on phenotype or color of their skin. Racism, as Rodney alluded to, has the structural barriers that are embedded in longstanding social policies and practices, and healthcare is not immune to that.

I think many people like to prefer to think of racism as simply private prejudices. We talk about people who are racist, and many of the people whom I work with don't think of themselves as being racist. Part of it is because we have not adequately defined these structures. I think of structural racism as being those laws, rules, practices, ways of doing that are embedded in our human existence, because we've been socialized to believe and support various policies and practices.

Tamryn Gray: Often an iceberg has been used to illustrate structural racism. It's this thing that's underneath the water that you can't see, but it's often the most dangerous and often the thing that's hardest to move, because it involves the policies and the structures that have been around for generations. It's the deep-down level of racism, based on economic, social, political policies that have really impacted how people experience other people and how they experience discrimination.

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Exploration of Structural Racism in Palliative Care

Tammie Quest: Why is this important for us to explore specifically in hospice and palliative care?

Tamryn Gray: Palliative care is a form of care to improve quality of life for patients and their families who are going through a serious illness. Palliative care isn't supposed to be a hidden gem. It's not supposed to be a secret to so many people of color. Unfortunately, it is. Often I've advocated for palliative care for those close to me because they didn't know it existed. There are millions of others like my family who could benefit from palliative care. African-Americans make up 12% of the US population, but only about 8.5% of hospice patients.[1] Black individuals, even when they fill out advance directives, have a higher proportion of not having those wishes addressed by their clinical team.[2]

We also know that patients of color could receive poor pain management and symptom management in general.[3–5] Oftentimes, as clinicians, we don't believe people of color when they talk about their experiences because it may look different or it may seem exaggerated. So for me, the biggest barrier of improving awareness is palliative care and awareness and access to hospice care.

Finally, in palliative care we don't have a diverse workforce. Less than 5% of fellows in the hospice and palliative medicine identify as Black.[6]

Karen Bullock: Structural racism reaches back in our US history as far as Black and Brown people have been in this country. It's important for us to go back to the legacy of slavery. How much do we really learn about the history of racism in this country and how racism has influenced medicine, public health, social work? Faculty and students need to have a more complete view of the history of racism so that we can associate people's lived experiences with the decisions that they're making around healthcare.

We have this gold standard of care that we think everyone should receive palliative care, but we know that there are segments of the population that don't get to take advantage of it. We know that it's rooted in racism that has permeated the fabric of this country. To be dismissive of the racism that people have experienced is negligent and perpetuates inequity in care. If rather than race, ethnicity, and socioeconomic class we looked at racism as a social determinant of health, I think we would have a better starting point.

Rodney Tucker: Individuals who have serious illness are extremely vulnerable. Serious illness is not just about the patient, it's the family, it's the community. I've always been hopeful palliative care is the field that will look at a whole patient and a family as a dynamic and think about the emphasis on culture to try to achieve goal-concordant care. But look at our origins. Hospice comes from an English, Judeo-Christian, white parameter of what a good death looks like, but the way of dying we've established as the gold standard may not be that for everybody.

Look at advance directives. We harp on writing it down. Why? There are families and cultures that know their wishes but they may not trust the system and they're not going to write it down. Guess what? We don't have to do that. What we need is a conversation. Hospice focuses on revocation as being this bad thing. If somebody has to go back to the hospital, then it's a hospice failure because, of course, we assume dying at home is the gold standard. Maybe it's not. Maybe dying in the hospital is goal-concordant for this family and this patient. And why must we have one decision-maker? In my experience, many families here in the south make decisions as a group. That's the way that we should honor it.

Karen Bullock: When my mother went to the hospital they asked if she had an advance directive. She says, "I have a daughter. Why would I need that?" She thought, "All my children are far more educated than I am. Why do I need to write this document?" They said, “"It's so that we can ensure that your wishes will be honored." To her, that was just not culturally congruent. Like, "No, there's something really wrong with these people that think that they know me better than my children."

Tamryn Gray: A family may have multiple decision makers, but documentation calls for naming a single proxy. If the family lists one person, the others may not have a voice. They may choose to list no one. Either way, the structure of how we document proxies may inhibit a patient's ability to receive goal-concordant care.

Karen Bullock: We hear a lot in hospice and palliative care, "Oh, the patient is suffering." I can't speak for all Black people, but for a family like mine, African-American growing up in the south with limited resources and an overabundance of oppression and discrimination, we define suffering very different than seeing someone lying in a hospital bed appearing to be very comfortable. When I ask focus group participants, "What is suffering to you?" they say suffering is not being able to put food on the table to feed your children. Suffering is having someone spit in your face and tell you to get out of the way. People have experienced some very egregious things that they deem as suffering. Their views may diverge from what we call the gold standard, but the reasons that we perceive it as a divergence instead of something we can learn from — those are structural.

Tamryn Gray: Oftentimes Black and Brown families' experiences are deconstructed, and what clinicians take away are the pieces that feel the most comfortable or the most conforming. If a Black family complains that they had a poor experience in the hospital, someone may say, “They were at a good hospital or the family were able to actually come in and visit, which is a privilege during COVID, or they received full meals each day.” Have we really thought about their experience from their perspective? We may think they have everything they need in terms of their care, but they feel that people are less courteous or less respectful. They may feel like people think they’re not as smart as other people. If you’re a big dude in the bed, people may be intimidated. Patients may also think, “Are they being honest with me? Do they think they’re better than me?” Those little pieces are often the thing that’s really important to that patient, the family, and their experience.

Karen Bullock: Tamryn and I have been saying Black and Brown people. Many people of color have said to me, “I don’t identify as African American. Everyone who’s Black isn’t African American.” We need to be able to understand that color isn’t culture. If I’m referring to someone as African American and they identify as Nigerian American, then we’ve missed the mark.

Tammie Quest: You’ve brought up this gold standard for a good death. Our quality measures track the percentage of patients who die outside of the hospital or receive hospice care at end of life or had a DNR order. How might racism be built into the way we are even measuring quality and safety in our own field?

Karen Bullock: As Rodney said, if we’re using European, western medicine models of care for people who communicate differently and value something different, and then we try to force fit it, we’re not going to have optimal care.

I hear care teams say, “We have to get this family member to move on.” So they call for an ethics consult. I’m the person who often got called when they said a family believes in miracles. Well, I believe in miracles, too, so I’m probably a good person to talk to someone who believes in miracles. It’s hard to grow up under the conditions that I grew up in and not believe in miracles. If you’re unable to meet a family where they are, then you’re not going to be effective in moving them along the continuum of decision-making around what is a good death. That starts with deconstructing what we think a good death is supposed to look like. When my mother was diagnosed with metastatic lung cancer, the oncologist could not understand why she wouldn’t choose radiation therapy. Instead she chose to get baptized and put it in the hands of the Lord. If that’s where people want to put things, why can’t we let them?

Rodney Tucker: I agree with you, Karen. I get consults where they say, “Dr. Tucker, you’re palliative care. Come and see this patient because this family doesn’t get it,” or they’re in denial or they’re all this. I’m like, “Maybe we don’t get them.”

To Tammie’s point, enrollment in a hospice, length of time in a hospice, revocation: Those are financial data points that really don’t tell you anything. These measures are structural. If I heard from the patient or family that they were heard, respected, and had their wishes elicited in the context of their culture and their lived experience, that’s all the quality parameter that I need.

Tammie Quest: Our language, the way we frame things, perpetuates our inability to be courageous enough to ask the hard questions because we’re afraid of the answers. We need to ask, “Do you believe you experienced racism during your hospitalization?” and not just a glossed-over question about being treated with respect.

Moving from Inequity to Equity

Let’s pivot from inequity to equity. What strategies and opportunities as a field of hospice and palliative care do you think might impact structural racism to improve the care of patients with serious illness?

Karen Bullock: We need to revisit education: How are we talking about racism and preparing clinicians to work with patients and colleagues who look different from them? We also need to think about the workforce. Who gets into medical and healthcare schools? What keeps us from being more reflective of the patient populations that we care for?

Tamryn Gray: I want to emphasize the need to partner with communities. When we are dismantling structural racism, it requires an overhaul of different layers, including community. People don’t just have tough experiences once they’re in the hospital. It starts with having access to quality care. It starts in the community where they’re facing racism and discrimination.

We often think about palliative care as inpatient. But a lot of Black and Brown patients experience racism in these settings. We need to deliver palliative care in the community, because we may not see patients who really could benefit if they are avoiding the hospital. It helps dismantle racism by eliminating disparities in transportation. And if it’s in their community, they’re likely to be more receptive.

Rodney Tucker: I agree completely with Karen and Tamryn. At a macro level, I think there are three really big things. First, we have to deconstruct this idea of a good death because that’s structurally racist. We can do that as a field. The second thing is we need measures of patient experience.

The third thing is palliative care needs to have five domains of suffering, and culture and race needs to be the fifth. As a clinician, I have to get comfortable asking my patients, “What in your experience would impact our work together in this journey of your life, including discrimination and racism?” I have to look at my iceberg and start to whittle away at what I'm not comfortable with. We have to encourage each other and say, "Don't be afraid. Just ask." You're going to have a better connection than you would ever imagine, because that person will feel heard.

You can't correct what happened in their life, but you can acknowledge it. I feel guilty that I didn't start chipping away a decade ago. But I have to know that it's ok and keep doing the work. We have to help our Academy members do that.

Tamryn Gray: We're palliative care. We're best suited, in my opinion, to tackle these really complex issues. Palliative care clinicians have difficult conversations with patients and families about their prognosis, about their treatment options. If any field can really tackle this difficult subject, it should be us. Our job may not be to fix all problems related to racism, but we have to be able to identify those resources that are going to help families.

Karen Bullock: When we care for people with serious illness, they don't check their culture at the door. They come with all that they've experienced a lifetime. Part of the resistance to hospice and palliative care is because they can't trust that this institution is going to take what they put in writing and do the right thing. History has taught them something different.

We also need to think about our colleagues who are providers, who are experiencing the impact of structural racism ourselves.

Tammie Quest: It strikes me that what you all are talking about are tools and frameworks that we're really missing, that don't allow us to have patients share their lived experience. We are more comfortable hearing about their relationship with meaning making than we are about hearing that extra dimension of suffering, because we might be afraid of what we'll find.

Tamryn Gray: It's about knowing and learning who the patient is, but also self-awareness from the clinician's side. And I think it can start with something as simple as a health narrative in the EHR, about who that patient is.

I want to also emphasize how structural racism in palliative care impacts generations of people, of families. If one person has a bad experience with palliative care, they're going to tell their family members. That story is going to be told tenfold over. We have to make sure that every encounter counts because it affects future encounters with that patient and that family.

Moving Forward

Tammie Quest: What are you optimistic about in this topic?

Rodney Tucker: I'm optimistic that we're continuing the conversation, that we don't forget 400 years, that we don't forget last May, that we are going to commit to looking at some of this at a macro level and at a micro level.

As a field we can do this. We did something 20 years ago, when palliative care was one of the greatest social justice movements to at least start the process of listening to patients at end of life. We're not going to always get it right. We're going to fail. I'm going to be awkward asking questions sometimes and I'm going to get uncomfortable if I get a very angry response. But we just have to have grace in ourselves as we move forward, too.

Karen Bullock: It gives me hope when I hear someone like Rodney say the things that you've said, about asking your patients questions. Much of what I read that's negative about things like diversity, inclusion, and equity is coming from older White males who think that anything diversity and equity waters down our professions and things like that. I work with women of color like Tamryn and Tammie who are doing amazing things in clinical care and research. Change is coming.

Tamryn Gray: I'm hopeful that we're all coming together to solve this problem and we're being thoughtful about it. Just being at the table with people that I've admired and followed and really trying to model myself after is very humbling, but it's exciting, because we're all from different backgrounds, different disciplines. I'm just excited because I think we're going to continue to move forward as a field.

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