



Will You Hear Me? Have You Heard Me? Do You See Me? Adding Cultural Humility to Resource Allocation and Priority Setting Discussions in the Care of African American Patients With COVID-19

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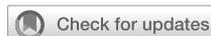


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COVID-19 Content

Will You Hear Me? Have You Heard Me? Do You See Me?

**Adding Cultural Humility to Resource Allocation and Priority Setting Discussions in the Care of African American Patients With COVID-19**

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The coronavirus disease 2019 (COVID-19) pandemic has refocused our attention on health care disparities affecting patients of color, with a growing body of literature focused on the etiology of these disparities and strategies to eliminate their effects. In considering the unique impact COVID-19 is having on African American communities, added measure must be given to ensure for sensitivity, empathy, and supportive guidance in medical decision making among African American patients faced with critical illness secondary to COVID-19. In this article, we explore the applications of cultural humility over cultural competency in optimizing the care we provide to African American patients faced with critical health care decisions during this pandemic. In turn, we charge one another as health care providers to consider how ethical principles and guidance can be applied to honor African American patients' unique stories and experiences. *J Pain Symptom Manage* 2020;60:e11–e14. © 2020 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.

Key Words*COVID-19, health disparities, diversity and inclusion, communication, resource allocation, palliative care***Reflections Between Mother and Daughter**

Me: As you consider your own health at these times, mom ... what worries you most?

Mom: I press on doing the best I can managing my health. But I'm never sure if I'm getting all the information I need from the doctors. They taper the information down, because they think I won't understand it. That scares me. I have been left in a hallway of a hospital before, unattended to, with questions that I never got to ask. Now I wonder, if I get sick with COVID-19, will I be fairly presented with all my options?

These heartfelt words were shared in a tender conversation between my mother and me in early April,

as we discussed the realities she, a senior-aged African American woman with multiple underlying comorbidities, faces during the coronavirus disease 2019 (COVID-19) pandemic. As a palliative care physician and her daughter, I want nothing more than to be prepared to honor and respect her wishes should she fall ill with COVID-19. The painful reality that is inextricable from our experience, which we have no choice but to confront, is that her race may inevitably impact the care she receives and ultimately whether she lives or dies. As I engaged in this dialogue and decision making with my mother, I also bore witness to the stories of other palliative care colleagues who were having similar conversations with their African American patients admitted to the hospital, often critically ill, wondering what their fate would be in the midst of this global crisis. In evaluating the impact of the

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pandemic across the U.S., communities of color are disproportionately affected, with a higher burden of morbidity and mortality seen among African Americans.¹ Published reports show death rates from COVID-19 three times higher nationally in predominantly black counties compared with predominantly white counties, and as much as 70% of deaths occurring among blacks in certain states.^{2,3} Simultaneously, health care systems across the nation are creating approaches and policies to determine how life-sustaining resources, such as ventilators, dialysis, and blood, may have to be reallocated if scarcity arises. In the wake of these challenging times, we as authors offer this reflective piece with the goal of helping to equip the palliative care community with tools and strategies for thoughtfully approaching the communication and care of African Americans with COVID-19 facing life and death decisions.

Consider the Role of Cultural Humility in Shared Decision Making With African Americans With Suspected or Confirmed COVID-19

The decisions surrounding how one wants to be cared for in critical illness and at the end of life are notably sensitive. Before COVID-19, African Americans have expressed concerns that their wishes in the face of serious illness will not be respected.⁴ Although not yet studied, one might expect this would be heightened at this time. Shrouded in a veil of mistrust and amplified by media reports that person of color have higher death rates, discussions around life-sustaining therapies may be more strained.

Historically, how African Americans view their lives is inseparable from connections to family and community, the roles played in caring for others, and the injustices experienced throughout life because of one's race. As African Americans are confronted with life or death decisions in the consideration of advance care planning, questions may inevitably arise for them that are difficult to impossible to verbalize to their health care providers because of the pain and complexity with which they are associated. *Will I be denied life-sustaining therapies because I am viewed as less than? If I opted not to be resuscitated as my condition worsens, am I letting down my family, my people, God? Will the injustices in access to care lived by others I have known and loved also play out for me? Am I worth saving?* Often, these questions are rooted in social, cultural, and spiritual traditions and constructs that extend across generations and experiences that are supported by anecdotal evidence as well as qualitative and quantitative data.⁵ These questions may be more present to varying degrees in the conscience minds of our black patients as we engage them in open conversations

about prognosis and the application of life-sustaining therapies in COVID-19. We must recognize that African Americans are not monolithic; their experiences are not shaped alone by their blackness. Compounded by the lack of visitors allowed in acute care settings and an inability to access support for shared decision making, such as family, friends, and spiritual communities, providers may find engendering trust and respect to be complex and difficult at times.

Dr. Cicely Saunders, the founder of the modern hospice movement, espoused that every individual is worthy of the chance to self-actualize through the end of life, regardless of whom they are and what illness they ultimately succumb to.⁶ The process of exploring patients' hopes and wishes should begin with cultural humility, in which we step outside ourselves as health care providers and acknowledge our African American patients' authority over their own experiences, despite the lack of control we all have in these unprecedented times. It is important to hear what losses individuals in black and brown communities have already endured through the pandemic and to acknowledge the emotions that arise for them.

Depending on cultural competence for effective communication is not enough for health care providers to rely on when attempting to have meaningful communication. A recent qualitative study evaluating views of health disparities experts, community members, and African American patients and caregivers facing serious illness found that patients and caregivers trusted their medical teams; wanted prognostic information communication; and expressed a desire to prepare for the end of life.⁷ Health disparities experts echoed themes of mistrust, spirituality, religiosity, desire to limit prognostication, and fatalism as barriers to effective advance care planning. These varying points of view call our attention to the pitfall of leaning too heavily on cultural competency as opposed to leading with cultural humility.

Leverage Cultural Humility Over Cultural Competency and Apply Established Frameworks to Engage in Shared Decision Making

There are several excellent tools that have been developed to facilitate communication in COVID-19 as well as frameworks and interventions presented in the literature to address end-of-life decision making in under-represented groups.⁸⁻¹⁰ In applying cultural humility as the foundational step before using these frameworks, we take the time to understand how an individual fits into their family and community and consider, What are they losing if death occurs? We as providers may have a patient with poor prognostic indicators and limited function, and therefore, our hope

is to mitigate their suffering by avoiding life-sustaining measures that may not be successful. However, the patient's family may see that person as the glue that binds the family, their purpose in life, a grounding force, and someone deserving of everything we have to offer.

If we start medical decision-making conversations with the question, What is most important to you? before we understand who we are talking to and about, we can receive answers that are incongruent, confusing, personally frustrating, and difficult to advocate for and abide with. This approach can result in tension within ourselves and with patients and families, inevitably fostering mistrust. Do-not-resuscitate discussions in our society are not purely medical decisions—they cross the boundaries of one's self-worth and core values.¹¹ In affirming someone's life by asking who they are first and subsequently what is important to them, we demonstrate empathy. This lays the groundwork for more difficult conversations and prepares us for the response. It will also allow us to make recommendations from a place of awareness, which can set the foundation for trust; the kind of trust that bridges differences in culture, ethnicity, and religion. This trust will be imperative to heal the relationship between health care and the community if we are placed in a position that requires us to allocate limited resources within demographics hardest hit by the pandemic.

Apply the Human Connection to Ethical Frameworks and Resource Allocation

Although we are guided in medical practice by the ethical principle of distributive justice, we are charged with applying the unique circumstance of each patient to the resource constraints we are facing at any given moment. Ultimately, this is a time when we cannot separate our humanness from the practice of medicine and how we attend to patients, particularly those who are disproportionately affected by the pandemic. Cultural humility enables us to remain present to the individual patient's reality, so we can assist them in making decisions that best align with their values regardless of prognosis and resource allocation limitations we may be unable to change during this pandemic.^{12,13}

As authors and leaders in this field who happen to be African American women, we continue to reflect on our clinical experience, the current evidence base, and recent conversations with our own patients and family members. We believe the palliative care community is uniquely positioned to lead the way in acknowledging the role that race can play in critical end-of-life decision making, particularly in the setting

of COVID-19. We hope that in sharing our perspectives openly, we can encourage clinicians in our field and across disciplines to hold the stories of their patients at the center of the care they provide in this unprecedented era.

Reflections between mother and daughter:

Me: What might ease your mind at this time, as you thinking about sharing your medical wishes with your doctors?

Mom: Knowing that my doctors recognize the stress I am under. It is hard managing chronic illness, and I know if I got COVID-19, I might not fare as well as someone younger or of a different racial background. But I still want to live. I still have life and I still love. Can we acknowledge that, and then talk through the decisions and options from there?

Me: I hear you mom. You are loved.

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