

Top Ten Tips Palliative Care Clinicians Should Know About Delivering Antiracist Care to Black Americans

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Abstract

Racial disparities, including decreased hospice utilization, lower quality symptom management, and poor-quality end-of-life care have been well documented in Black Americans. Improving health equity and access to high-quality serious illness care is a national palliative care (PC) priority. Accomplishing these goals requires clinician reflection, engagement, and large-scale change in clinical practice and health-related policies. In this article, we provide an overview of key concepts that underpin racism in health care, discuss common serious illness disparities in Black Americans, and propose steps to promote the delivery of antiracist PC.

Keywords: advance care planning; health inequities; implicit bias; racial inequities, serious illness; structural racism

PALLIATIVE CARE (PC) clinicians, like others socialized within the American health care system, participate in an industry that historically and systematically disenfranchises racial and ethnic minority populations, including Black Americans. This disenfranchisement results in lower quality care (e.g., poor patient/provider communication) and worse health outcomes (e.g., higher cancer mortality) across the lifespan relative to White Americans.¹ To improve the quality of care for persons with serious illness from Black communities, PC clinicians must recognize racial disparities, understand the policies and practices that cause and

reinforce health inequities, and advocate to address inequities in their practices and institutions. National hospice and PC organizations, including the American Academy of Hospice and Palliative Medicine (AAHPM),² the National Coalition on Hospice and Palliative Care,³ and the Hospice and Palliative Nurses Association (HPNA) condemn racism and have called for measures that address inequities in PC delivery.⁴

Nevertheless, racial disparities in PC domains are well documented. When compared with White Americans, Black Americans experience worse pain treatment, less access to

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PC, including hospice, less advance care planning (ACP), and lower quality of communication.⁵⁻⁸ Although Black Americans are a heterogeneous racial group, the persistence and virulence of anti-Black racism in the United States has led to common health care experiences among those who identify or are seen as Black.⁹

In this article, we synthesize key barriers and misconceptions that hamper PC delivery for seriously ill Black patients. We also highlight historical, sociological, and medical principles that underpin health inequity and propose a foundation for the delivery of antiracist care. As an interdisciplinary team of PC and racial disparity scholars, we have organized important concepts on racism and health disparities into ten evidence-based principles and practices that promote equity in PC. By no means comprehensive, these recommendations aim to dismantle racism and driving equitable outcomes for seriously ill Black patients. The structure of the principles and practices is such that the first three points are general concepts that should be understood by all clinicians, the next three points aim to help readers better understand specific disparities in serious illness care (pain disparities, poor end-of-life outcomes, and ACP), and the final four points promote antiracist care with a summary of key recommendations.

Tip 1: Race Is a Sociocultural Construct, Not a Biological Factor

*Race is the child of racism, not the father.—Ta-Nehisi Coates, Between the World and Me*¹⁰

Race is a sociocultural construct. It does not correspond with degrees or qualities of genetic variability and cannot, therefore, explain differences in health care outcomes.¹¹ Historians and sociologists have highlighted that racial boundaries shift through time to perpetuate existing power structures, permitting or denying rights to one group or another. Clinical medicine's use of race-based risk factors and algorithms inaccurately conceptualize race as a biologic index and serve to perpetuate differences by race that can negatively impact clinical care.^{12,13} Several common decision-making tools shape the diagnosis and trajectory of serious illness.¹⁴ This includes mortality risk assessments that guide decision making, such as the "American Heart Association Get with the Guidelines," Glomerular Filtration Rates, Renal Cancer Survival Calculator, the National Cancer Institute for Breast Cancer Risk Assessment tool, and pulmonary function testing.¹² In general, treatment algorithms have embedded biases.¹⁴ Therefore, algorithms that contain race as a risk factor, rather than key individual and social indicators of health, are particularly harmful because they compound inequity in the prevention, diagnosis, and treatment of disease.^{12,14,15}

Tip 2: Racism and Other Explicit Biases Drive Health Inequities

*To be antiracist is to deracialize behavior, to remove the tattooed stereotype from every racialized body. Behavior is something humans do, not races do.—Ibram X. Kendi*¹⁶

Racism is discrimination based on beliefs of racial superiority or differences in attributes and abilities based on race.¹⁷ Racism exists in many forms, including cultural, in-

terpersonal, systematic, and structural racism. For example, the most common form of cultural racism in the United States is White supremacy, which is the valuation of whiteness over and degradation of other racial and minority groups.¹⁸ At times, racist ideas and behaviors that promote White supremacy can be unconscious, often referred to as implicit bias, which is further discussed in tip number three.

Interpersonal racism is the use of explicitly racist words, biases, or actions. Systemic, institutional, and structural racism occurs when policies, institutional practices, and systems either intentionally or unintentionally result in an advantage to one group (e.g., White Americans) or disadvantage of another (e.g., Black Americans).^{2,17} Structural racism often reinforces and perpetuates race inequalities. Structural racism can be seen in the criminal justice system, education system, and social and structural determinants of health, including employment/financial structures, education, poverty, and inadequate health care access.^{7,19}

Racism must be named as a critical driver of health inequities.¹¹ Antiracist action involves actively confronting racism by making deliberate and consistent equitable decisions.²⁰ This requires constant self-reflection and awareness.²¹ Racism is not a matter of moral character (such as naming someone as racist or not racist) but rather is about racist or antiracist behaviors.¹⁶ To bring about antiracist action requires acknowledgment of racism within our systems and ourselves. In doing so, racism becomes everyone's problem and we can be intentional and vigilant about working to fix it.²²

Tip 3: Implicit Stereotypes and Biases Contribute to Racial Inequities

Research shows that almost half of White Americans and nearly one-third of Black Americans hold pro-White bias and a negative bias toward Black Americans.²³ Implicit or unconscious biases inform our thinking, behaviors, and interactions; and may or may not result in explicitly racist behaviors or beliefs.¹¹ Implicit bias informs misattribution of disease etiology or illness behavior to an individual or community because of their race and has been linked to relatively lower quality care for chronic conditions that may benefit from PC, such as heart disease, renal disease, and cancer.^{12,24} Moreover, race inequities persist across multiple health care settings, including emergency, preventative, mental health, and pediatric care settings.²⁵ So it stands to reason that serious illness care would be no different than other health care specialties and settings.

Although many health care workers do not view themselves as racially biased, implicit biases are pervasive in U.S. culture and health care.²⁶⁻²⁸ Regardless of whether biases derive from benign distinctions between groups or more racist beliefs, they can have profoundly negative health consequences when they inform clinician behaviors and decision making.²⁵ Since a majority of Americans hold a pro-White/anti-Black bias, it is safe to assume that we hold implicit biases. To become aware of any race-based implicit biases that you may hold, an implicit assessment test may be helpful (<https://implicit.harvard.edu/implicit/takeatest.html>). Moreover, clinicians should periodically assess if their treatment recommendations and outcomes vary by irrelevant characteristics such as race.

Tip 4: Provider Implicit and Explicit Biases, Rather Than Biological Differences, Result in Observed Racial Disparities in Pain Management

Substantial evidence describes pervasive disparities in pain assessment and pain undertreatment among Black Americans.^{19,29–38} Black patients often feel that their pain complaints are not believed and data support this notion.^{39–42} A meta-analysis synthesizing evidence from 20 years of published studies on pain treatment disparities in the United States found that Black Americans were less likely than any other group in the analysis to receive analgesics.³⁰ Specifically, Black Americans were less likely to receive opioid medications for pain, and these differences persisted even for traumatic or surgical indications where there is a verifiable cause of pain.³⁰ This is likely due to the discriminatory idea that Black Americans' opioid misuse behaviors are driven by an increased risk to develop addiction.⁴³ A recent study in a racially diverse group of cancer patients explored opioid misuse, finding that behaviors were primarily related to lack of education on correct use of opioids, patients' desires to avoid opioid harms, insufficient access to alternatives to analgesics, and attempts to spare opioids overall.⁴⁴

Likewise, Black patients with cancer pain are also more likely to report a negative Pain Management Index (i.e., pain levels relative to prescribed analgesics) compared with White patients with cancer and are less likely than Whites to have a prescription of long-acting opioids for around-the-clock pain coverage.⁴⁵ The observed clinical disparities in pain management occur despite accounting for insurance type and clinical risks.³² Black Americans with cancer pain were more likely to receive an analgesic with toxic metabolites, even after controlling for private insurance type, and despite the presence of clinical risks.³¹ It is essential in clinical practice and research to find the driver of the specific gap. Such variables can be broadly termed social determinants of health and include factors such as poverty and socioeconomic position, education, health literacy, primary language, racial discrimination experiences, poor communication, and institutional racism.^{5,46}

Tip 5: Black Americans Receive Poorer Quality Serious Illness Care

Black Americans face a higher risk of developing and suffering from serious illness. Social determinants of health, including poverty, low educational attainment, low health literacy, and poor access to care, contribute to higher incidence and prevalence of chronic conditions, lower uptake of prevention and screening, later diagnosis, and insufficient treatment.^{47–51} Consequently, compared with White Americans, Black Americans die earlier, at higher rates, and suffer more complications of cardiovascular disease, renal disease, lung disease, cancer, and infectious diseases, including HIV/AIDS and COVID-19.^{5,52} These disparities persist through the course of serious illness. Black Americans experience higher rates of hospital readmission,⁵³ more intensive care and late care transitions,^{6,24,54,55} and are less likely to enroll in or stay enrolled in hospice.^{56,57} These disparities contribute to lower quality EOL care and self-reported outcomes.^{5,51,58–62}

Black Americans, like their White peers, express a desire to participate in serious illness discussions,^{63,64} but are less likely to experience high-quality communication.^{64–66} High-

quality communication is patient- and family-centered, honest, sensitive, reciprocal, and occurs when patients and family members are ready to discuss and engage in informed decision making.^{67–71} High-quality communication is a low-risk, high-value intervention that improves serious illness metrics, including quality of life, length of hospital stays, lower intensive care costs and mortality rates, adoption of comfort-focused care, and greater family members' acceptance of EOL decisions.^{67,70,72,73}

Tip 6: Racial Disparities in ACP Result from Myriad Factors, Including Access and High-Quality Communication

Black Americans are less likely to engage in ACP.⁷⁴ ACP and communication have been shown to improve patient and family outcomes,⁷⁵ such as receiving care aligned with their preferences, more satisfaction with care, and improved quality of life.^{76–78} ACP has the potential to improve Black Americans' EOL care outcomes when accompanied by high-quality communication.

Lower relative engagement in ACP among Black Americans is due, in part, to clinicians' failure to engage Black American patients in high-quality communication.⁷⁹ The quality of patient/provider communication experienced by Black Americans has a cumulative impact on their EOL care decision making and outcomes.⁸ Given the magnitude of this impact, it is essential that clinicians proactively integrate ACP early in the disease trajectory of Black American patients,⁷⁰ as well as engage them in high-quality communication and shared, family-oriented decision making.

Tip 7: Blaming Health Disparities on Issues of Distrust Masks the Role of Structural Racism

The role of distrust is overstated in explaining disparities and serves as a scapegoat that masks the fundamental realities of structural racism.⁸⁰ Furthermore, centralizing trust as key to health disparities places the blame on Black Americans for their mistreatment rather than attributing it to racism.¹¹ A disproportionate focus on trust also ignores the pertinent history of inhumane and inequitable care that has consistently occurred in the care of Black Americans.⁸¹ Indeed, some Black Americans worry that their race or other marginalized status may make them more "disposable" at EOL.⁸²

In serious illness care, lack of trust is an overimplicated explanatory variable for disparities in EOL care among Black Americans.⁸³ Research that has attempted to quantify distrust does not support the notion that Black Americans choose life-sustaining treatments because they distrust the health care system⁸³; despite the many ways in which the health care system systemically falls short in delivering equitable care to Black Americans.⁸⁴ Instead, evidence suggests there are no notable differences in trust among Black Americans compared with White Americans. In most empirical studies, trust has not been found to be associated with Black Americans' ACP outcomes.^{63,83,85–90}

Distrust continues to be commonly cited as a factor for disparities, as recently noted in the COVID-19 vaccine debate.⁹¹ Although distrust is associated with poor-quality patient/provider communication among Black Americans,^{8,81,92} rapport building, respectful communication and information sharing, and appreciation for cultural values and

faith build trust with Black American patients and their families.^{8,40,70,93} Rather than focus on patients' potential for distrust, providers must acknowledge and address systemic racism and structural barriers that have resulted in the disproportionate distribution of opportunities and mistreatment of Black American patients. Beyond acknowledgment, providers must also actively engage in high-quality interpersonal interactions that foster trust and build strong relationships with Black American patients and their families.

Tip 8: PC Consultation Can Improve Equity in Serious Illness Care for Black Americans

PC consultation has been shown to improve EOL care outcomes in a variety of ways. Specialty PC skills can fill many clinical gaps discussed above through expert communication, ACP, and improved access to hospice.^{56,57} As such, evidence suggests that Black Americans benefit from PC consultation. One recent study found that seriously ill Black Americans who engaged in PC consultation to discuss goals of care were 15 times more likely to enroll in hospice than clinically similar Black Americans who did not receive a PC consultation.⁹⁴ Likewise, another study found PC consultation was associated with four times higher likelihood of discharge to hospice among a diverse set of seriously ill patients.⁷⁹ Among a diverse group of seriously ill patients who received PC consultation, only Medicaid use (and not Black race or any racial or ethnic group) was found to be an independent predictor of discharge to hospice, with Medicaid patients less likely to enroll in hospice, further pointing to the role social determinants of health play in hospice use.¹¹³

Evidence also suggests patient/clinician communication, health literacy, and understanding prognosis and care options influence Black Americans' decision making. Additionally, knowledge of and access to services play roles in the EOL care decisions among Black Americans.⁹⁴⁻⁹⁹ Taken together, seriously ill patients across racial groups may demonstrate similar preferences for comfort-focused care when given the opportunity to discuss their care with a clinician trained to engage in high-quality communication.

Tip 9: Culturally Humble, Person-Centered Care Is Crucial to Providing Antiracist PC

Cultural humility is a process of openness, humility, and self-awareness that is necessary in a multicultural world where power imbalances exist.¹⁰⁰ Cultural humility strives for mutual empowerment, respect, and life-long learning.¹⁰⁰ The approach of cultural humility moves away from cultural competence, which can promote stereotypical thinking and "othering" of minority groups.^{101,102} Cultural competence suggests the false belief that you can be competent in someone else's culture and implies learning is finite.¹⁰² Conversely, cultural humility is a *process*, wherein learning is infinite and centered on an iterative approach of self-reflection and self-evaluation.¹⁰⁰ Cultural humility takes into account who you are, your experiences, how you live, and how you view the world.¹⁰⁰

Cultural humility seeks to challenge power dynamics and prioritizes viewing individuals as complex, and frequently evolving as result of life experiences, relationships, and interactions.¹⁰³ For example, as clinicians, we exist in and view the world through the lenses of multiple cultures, simulta-

neously.¹⁰⁴ We see the world through our discipline, our race, ethnic background(s), religion, self-identified gender, sexual identity, clinical experiences, and educational background(s). Similarly, those who we serve, view the world through their own multidimensional, unique cultural and personal lenses, which inform how they approach serious illness care and decisions.¹⁰⁵

Providing culturally humble, person-centered care to Black Americans begins with the awareness of the power dynamics that are ubiquitous in clinical interactions and how clinicians' own cultural framing influences these interactions.¹⁰⁴ Indeed, Robinson-Lane and Booker have advocated for culturally humble and responsive pain care practices for older Black Americans.¹⁰⁶ A common source of power in U.S. society and health care is White privilege, which is defined as the relative advantages that racism afford people who identify as or are perceived as White.¹⁰⁷ Because White privilege and racism are the basis for many health inequities among Black Americans, providing person-centered and culturally humble care requires internal reflective work and constant evaluation of daily practices and beliefs to avoid oppressing marginalized groups.¹⁰⁷

This reflective work requires examining the subtle assumptions that we make about people based on race, which is that Black Americans choose aggressive care at the EOL because of their racial identity, and can lead to micro-aggressions and fragmented relationships.¹⁰⁸ A more accurate and culturally humble manner to interpret EOL decisions among Black Americans should take into account that a complex set of variables interact to influence decision making along the continuum of serious illness. This manner includes not attributing care preferences to racial identity but more accurately recognize racism, systemic barriers that may shape access, and individual preferences.^{94,109} Providing culturally humble and antiracist care is a way of being and seeks to understand each individual's life experiences, goals, and values, and how they influence decisions, access, and care.¹⁰⁰

Tip 10: PC Teams Can Reduce Racial Disparities by Advocating for Policy Change and Cultivating Antiracist Environments

PC clinicians must create antiracist environments at all levels: on our clinical teams, within our institutions, in research, and within the broader health care system. Becoming an antiracist involves changing the ways we think, behave, and advocate for equity.¹¹⁰ Almost every aspect of American culture has been shaped by racism and, therefore, requires a close examination of policies and racist ideas that propagate inequities.¹¹ Antiracist actions benefit from and are amplified by collective action and energy.¹⁶ Examples of antiracist activities include (1) acknowledging that racism exists and is detrimental to societal health, (2) seeking education on the history of racism in the United States, and (3) avoiding perpetuating it through intentional beneficence. As a first step, PC clinicians can acknowledge their own racism, allow themselves time to recognize and confront racism to shift to providing antiracist care, and oppose racism in all domains (individual, institutional, and political).²¹

TABLE 1. RECOMMENDATIONS TO PROMOTE THE DELIVERY OF ANTIRACIST PALLIATIVE CARE

PC teams should respectfully and empathically treat each patient as a person with individual preferences and needs, not as someone part of a racial group.

PC teams should reject the use of race as a biological variable in clinical practice and scholarship. Antiracist actions includes self-reflection and critique of tools and studies that frames race as a biological variable rather than a sociopolitical construct.

PC teams should recognize racially biased care that reinforces health disparities and identify policies and structures that underpin racial inequities, thereby acknowledging social and structural determinants of health that directly result from racism and account for differences in serious illness care.

PC teams should periodically assess (and work to correct) if their treatment recommendations and outcomes differ by irrelevant characteristics such as race and other at-risk identities.

PC teams should hold regular forums to exchange feedback and evaluate any practices that may be inadvertently racist. Providing antiracist PC includes receptiveness to feedback on your own biases and beliefs. It is important to avoid thinking of people as racist or not racist. Instead, think of people as committing racist or antiracist acts.

PC teams should integrate perspectives of individuals, patients, and caregivers with lived experiences of racism in designing antiracist clinical care and policies. This may include community liaisons, patient champions, faith leaders, health care providers, and ethics experts.

PC teams should advocate for and participate in informing an agenda to ameliorate disparities in serious illness care by working with institutional, organizational, and public policymakers.

PC teams should hold each other accountable for attaining the common goal of achieving equity in serious illness care.

PC, palliative care.

Moreover, for PC clinicians, a close examination of power structures, systems of care, and payment policies that promote inequities in serious illness care is needed. Systems that encourage inequities include, but are not limited to, lack of diversity in the PC field, poor representation of Black clinicians in leadership positions, and less availability of PC services and training opportunities in minority-serving hospitals.^{42,111} In addition, Medicaid, the country's state-based safety-net insurance program, is a poignant exemplar of payment policy steeped in structural racism. The federal government gives states significant discretion over the health services for which Medicaid reimburses. Hospice and PC are not classified as essential benefits under Medicaid.^{112,113} Medicaid programs have also underfunded care in nursing homes, where a higher proportion of Black Americans than White Americans die.¹¹⁴

Access to PC and hospice must improve for Black Americans by requiring federal and state-level policy changes as well as correct attribution of factors related to lack of hospice use among Black Americans.^{83,115} PC interventions must directly target underserved hospitals and communities of color. Antiracist health care policies should be designed with a purview that encompasses health equity along the complete health care continuum, including disease prevention, treatment, and quality EOL care.^{116,117}

Conclusion

Dismantling racism is a continuous reflective process, which demands that clinicians understand how explicit and implicit biases and disparities are generated. It also requires vigilance and constant reevaluation of practices, policies, and systems that perpetuate or exacerbate these racial inequities. This article is strengthened by our author group, which includes a range of racial, cultural, and other under-represented identities, but we recognize inherent limitations may prevent us from seeing and addressing all levels of race-based implications. Black Americans face significantly greater barriers to high-quality serious illness care. The information in this article highlights several important drivers of race disparities and provides guidance to improve the delivery of PC to Black Americans.

We also acknowledge that while Black Americans represent a heterogeneous group, they largely have a shared experience of racism in the U.S. health care and social system. To erode the impact of racism in PC, Black Americans deserve and we all should demand high-quality, tailored care that aligns with individual patients' goals and values not race-based ideas or factors. To improve equitable delivery of serious illness care, we must also promote diversity in our field and honor and support scholars, clinicians, and researchers working to advance a national agenda to address and eradicate disparities in the delivery of PC.

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