Review Article

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Race-conscious serious illness communication: An interpersonal tool to dismantle racism in practice and research

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Abstract

Background. Racism significantly contributes to inequitable care quality and outcomes for people of color with serious illness, their families, and their communities. Clinicians use serious illness communication (SIC) to foster trust, elicit patients' needs and values, and deliver goal-concordant services. Current SIC tools do not actively guide users to incorporate patients' experiences with racism into care.
Objectives. 1) To explicitly address racism during SIC in the context of the patient's lived experience and 2) to provide race-conscious SIC recommendations for clinicians and researchers.
Methods. Applying the conceptual elements of Public Health Critical Race Praxis to SIC practice and research through reflection on inclusive SIC approaches and a composite case.
Results. Patients' historical and ongoing narratives of racism must be intentionally welcomed in physically and psychologically safe environments by leveraging empathic communication opportunities, forging antiracist palliative care practices, removing interpersonal barriers to promote transparent patient–clinician relationships, and strengthening organizational commitments to strategically dismantle racism. Race-conscious SIC communication strategies, skills, and examples of talking points are provided.
Discussion. Race-conscious SIC practices may assist to acknowledge racial dynamics within the patient–clinician encounter. Furthermore, race-conscious SIC may help to mitigate implicit and explicit bias in clinical practices and the exclusionary research cultures that guide them.

Racially and ethnically marginalized people experience morally unacceptable serious illness care inequities, including poorer pain-related outcomes, less hospice care, lower rates of advance care planning, greater financial burden, and higher mortality rates across several conditions (Bailey et al. 2021; Meghani et al. 2012; Suntai et al. 2022). The existential questions that serious illness may raise related to suffering, legacy, and meaning are difficult to disentangle from the toxic stress of racism. Dismantling racist structures requires empathic, tailored communication to engage and support people of color with care that is physically, psychologically, and culturally safe and goal-concordant (Bailey et al. 2021; Sanders et al. 2018, 2022a). Although targeted palliative and end-of-life interventions for racially and ethnically marginalized people may improve some related outcomes, their overall effectiveness is unclear (Jones et al. 2021). Serious illness communication (SIC) that acknowledges and validates racism's historical and current context, and recognizes and responds to the uniqueness of intersectional identities, is essential to advancing socially responsible care and research.

SIC and health equity

Serious illnesses are those conditions that either (1) carry high mortality risk, negatively impact the quality of life and function, and/or carry significant symptom, treatment, or caregiver stress burdens or (2) are not advanced but carry a high degree of clinical uncertainty (Kelley 2014). SIC involves a clinician's use of relatable language to create and foster interpersonal safety; elicit patients' values, goals, and concerns; iteratively explore patient and surrogate decision-making roles; and recommend individualized care options throughout the course of serious illness and at the end of life, among other person- and family-centered steps (Jacobsen et al. 2022). Patients' experiences with racism may strongly influence the ability of SIC to achieve health equity in the serious illness context. When considering Jones' definition of *health equity* – "assurance of the conditions for optimal health for all people … valuing all individuals and populations equally, recognizing and rectifying historical injustices, and providing resources according
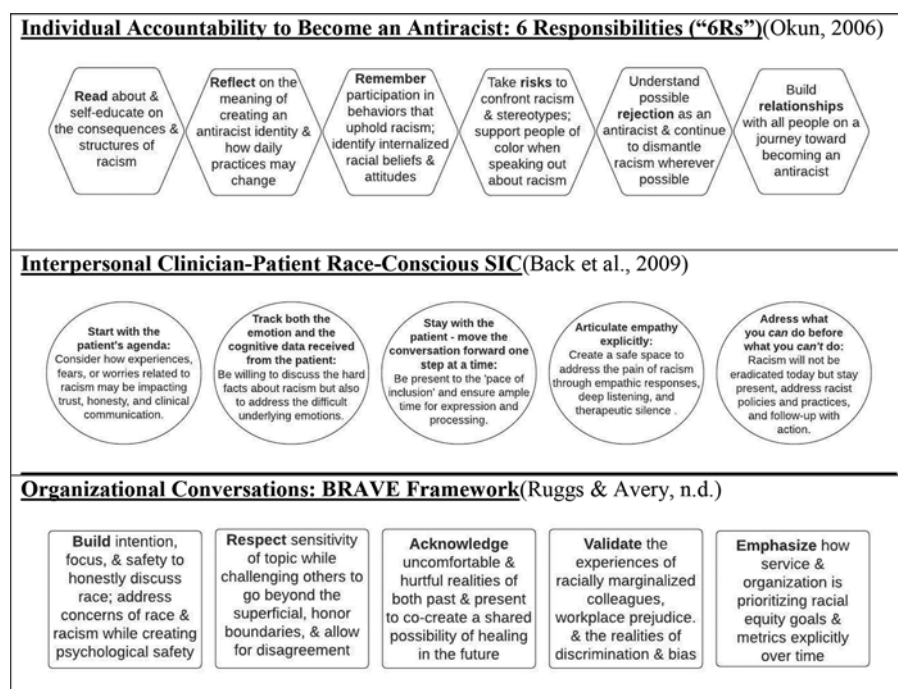
to need" – SIC becomes an interpersonal tool to address the root of health injustices and to tackle the "social determinants of equity" (Jones 2014, S74).

Why race-conscious SIC?

Health care is commonly influenced by hierarchical power imbalances (e.g., patient–physician) and racialized differences (e.g., Black–white). Evidence shows people of color frequently experience biased care provision and discriminatory behaviors during clinical encounters and while accessing health services more broadly (Akinade et al. 2023; Ben et al. 2017; Lorié et al. 2017). Interactions viewed as unsafe or racist by the care recipient may understandably curtail transparency and prohibit honest communication. Patients' fears and worries about serious illness may only not be related to a given illness but also racially motivated mistreatment as they lose agency or functional independence. In addition, community engagement in decision-making may vary across cultures in ways the health system does not accommodate. For instance, some Black communities value church ministries as a source of support at the end of life (Sloan et al. 2021). Clinicians who do not recognize the role of or actively partner with these communities risk perpetuating white supremacist culture and racist norms that may isolate and harm patients (Okun 2006).

A race-conscious approach to SIC requires acknowledgment of the racial dynamics during the clinical encounter (Needham et al. 2022; Stangl et al. 2019). Many current SIC tools do not explicitly create space for a patient's open and honest lived experiences of racism (Back et al. 2020; Bernacki et al. 2015; Bernacki and Block 2014; Childers et al. 2017; Chung et al. 2016). These shortcomings may lead to avoidance, denial, and even reactiveness or aggression from the clinician who feels threatened by the narrative or does not accept its validity. Such a situation requires the clinician to (1) recognize their own social location when communicating with the patient, (2) acknowledge that myriad levels of racism exist and impact decision-making, and (3) address how biased policies disrupt cultural safety, promote distress, and negatively affect the therapeutic alliance (Bailey et al. 2021). SIC ideally strengthens trust and supports person-centered decision-making (Jacobsen et al. 2022). But unless SIC is adapted to authentically welcome the painful truths of racism, clinicians and researchers may inadvertently violate principles of nonmaleficence and justice while disenfranchising individuals with racialized trauma. They may also unconsciously demonstrate outward biased behaviors or language despite intent (Okun 2006). Race-conscious SIC can assist to ethically engage people of color using narrative approaches (Daryazadeh 2019) (e.g., through moral reflection, witnessing patient story, and responding empathically) and gain a life course perspective that more accurately gauges the multilevel social factors that have informed a patient's lived experience with racism (Green et al. 2022). Inclusive approaches must be iteratively integrated throughout serious illness care in myriad ways, including organizational conversations to safely address racism among colleagues, individual clinician–researcher commitments to becoming an antiracist, and demonstrating race-conscious clinician–patient SIC (see Figure 1) (Back et al. 2009; Okun 2006; Ruggs and Avery 2020).

Consider Tanya – a Black transgender woman experiencing houselessness. Tanya is navigating multiple stressors related to interlocking, minoritized identities and confronts barriers to medication and service access, as well as safe opioid stewardship options in the setting of severe cancer pain (Crenshaw 2017). Not only would the highest quality, holistic care call on the clinician to integrate structural and social factors into planning but also remain conscious and sensitive to Tanya's social realities and serious illness needs. Current SIC research and tools are severely inadequate to account for or safely address Tanya's values and goals, particularly in the setting of being unhoused. Both a framework and an approach are needed to ensure Tanya's dignity and personhood are prioritized in the face of systematic marginalization.

Table 1. Public Health Critical Race Praxis principles, focus areas, and definitions

Principle	Focus area	Definition
Race consciousness	All	Attention to racial dynamics in social interactions
Primacy of racialization	Contemporary patterns of racial relations	Racial stratification, not race, contributes to societal problems
Race as a social construct	Contemporary patterns of racial relations	Race is derived from social, historical, and political forces
Ordinariness	Contemporary patterns of racial relations	Racism is embedded in everyday life of Black and Brown patients
Structural determinism	Contemporary patterns of racial relations	Macro-level forces drive and sustain inequities
Social construction of knowledge	Knowledge production, conceptualization, and measurement	Reevaluate existing knowledge with antiracist modes of analysis
Critical approaches	Knowledge production and action	Move beyond surface-level evaluations of one's own biases
Voice	Knowledge production and action	Prioritize outside perspectives of marginalized persons
Intersectionality	Conceptualization and measurement	Acknowledge the interlocking nature of multiple marginalized identities
Disciplinary self-critique	Action	Examine conventions around health disparities research

Public Health Critical Race Praxis

The Public Health Critical Race Praxis (PHCRP) is a framework based on Critical Race Theory that may broaden scientific inquiry in serious illness while improving race- and racism-related outcomes and providing key implications for SIC (Brown et al. 2022; Ford and Airhihenbuwa 2010a, 2010b). The PHCRP – guided by 4 focus areas and accompanying principles (Table 1) – posits that racism is contextualized in each society and among each race (Ford and Airhihenbuwa 2010a, 2010b). The PHCRP can aid the development and adaptation of SIC tools to address racism and poor communication in both research and clinical practice (Table 2) (Brown et al. 2022). The principle of *race consciousness* extends throughout all focus areas, giving explicit attention to racial dynamics in one's social and personal world, including in health-care spaces.

PHRCP Focus 1: contemporary patterns of racial relations

Racially marginalized patients are affected by racism in everyday life. Well-meaning clinicians engage in personal interactions with racially traumatized individuals in a health-care structure that perpetuates inequities (Bailey et al. 2021; Needham et al. 2022; Stangl et al. 2019). It is important for researchers and clinicians to take into consideration current events that disproportionately and negatively impact Black and Brown people (e.g., racialized violence and economic strain). Considering these factors allows researchers to account for how these additional stressors – in conjunction with

serious illness – shape how patients perceive clinicians and systems, make decisions, and prioritize goals of care.

PHRCP Focus 2: knowledge production

How have disciplinary conventions around research and a lack of race consciousness shaped SIC knowledge? Although SIC literature attempts to better understand communication disparities, there must be greater transparency on how racialization has biased research, reinforced negative beliefs and stereotypes about racially marginalized groups, and informed the development of SIC tools. Improving SIC communication for racially marginalized patients requires researchers to account for researcher positionality in white-predominant spaces, including research institutions and health-care systems. "Centering the margins" requires prioritizing patient and researcher perspectives that have typically been excluded from research processes, and including racially marginalized researchers beyond ornamental engagement (Rhodes et al. 2022; Sanders et al. 2022b).

PHRCP Focus 3: conceptualization and measurement

Although SIC research and tools aim to improve communication, a patient's racialized experience is often unassessed or treated as simply another variable in statistical modeling (Needham et al. 2022; Stangl et al. 2019). A race-conscious approach to SIC tool development and improvement includes an examination of race-related constructs, their hypothesized relationships to outcomes, and whether such measures can capture the sequelae of racism. Importantly, patients often have more than one marginalized identity and it will be important that SIC can create space for patients and providers to acknowledge how intersectionality shapes these narratives (Crenshaw 2017).

The need for community-based participatory research (CBPR) approaches in serious illness cannot be overstated. CBPR actively engages communities as equal partners and serves as a social justice mechanism to ensure that research endeavors are community-guided (Elk et al. 2020). Importantly, CBPR strives to ensure that scientific findings and implications will be contextually relevant to the study population.

PHRCP Focus 4: action

Existing health disparities research fails to identify a tangible plan for eliminating racist practices or forging sustainable commitments to racially minoritized communities. It is not enough to simply document that Black–white SIC disparities exist – work must be done to eradicate them starting with how we engage during the communication that connects us. Of significant importance is the need for clinicians to take accountability for their personal practices that perpetuate inequities and their conscious and unconscious justification of proliferating white supremacist ideas in health care, academia, and interpersonal engagement (Okun 2006). Such actions call for teaching and implementing antiracist SIC frameworks in research to ultimately shift knowledge, improve clinical outcomes, and enhance the quality of clinician–patient relationships informed by race-conscious SIC (Brown et al. 2022; Rosa et al. 2022; Sanders et al. 2022b).

Practical changes in SIC require action. Take, for example, an evidence-based approach to empathic communication (Pehrson et al. 2016). There are clear opportunities to integrate

Table 2. Using the Public Health Critical Race Praxis to shape serious illness communication tools for racially marginalized patients

Principle (Ford and Airhihenbuwa 2010b)	Recommendation for SIC in clinical practice	Recommendation for SIC research
Race consciousness	Identify, address, and be transparent about racial dynamics within the clinical encounter	Account for researchers' racial biases and social positionality, particularly in research with racialized populations
Primacy of racialization	Question and address how race is used to describe patients, conditions, lab values, and historical assumptions in clinical care	Include and address structural factors in health systems that perpetuate racism as relevant variables during scientific inquiry
Race as a social construct	Acknowledge race as a risk factor for racism within the clinical encounter	Explicitly address race as a social construct and all levels of racism when generating empirical outcomes and implications
Ordinariness	Acknowledge, normalize, and validate patients' experiences of racism in the ordinary clinical encounter	Identify racism as a routine exposure even within the health-care setting
Structural determinism	Acknowledge how structural, systemic, and institutional policies perpetuate racist practices and assumptions in practice	Account for structural racism and embedded racist policies and practices despite an individual health-care provider's intention
Social construction of knowledge	Invite discourse on new ways of knowing the impacts of race and racism on patients and families by engaging community stakeholders	Appraise existing literature around SIC using antiracist approaches and frameworks
Critical approaches	Question one's own implicit and explicit biases, decision-making, and identify and commit to improvements in transparent communication to mitigate racism	Consider alternative, race-conscious explanations for poor SIC in racially marginalized patients than those posited in existing research
Voice	Role model person- and family-centered communication that keeps the patient and family goals, needs, and preferences at the center of care plan development and delivery	Center the perspectives of racially marginalized patients when developing SIC tools
Intersectionality	Create safe spaces that safely support the emotional and experiential expression of patients with multiple marginalized identities	Account for intersectional identities and experiences when developing research questions and identifying sample populations
Disciplinary self-critique	Actively and iteratively reflect and seek feedback regarding antiracist clinical care and personal practices	Examine the current state of health disparities research, community engagement, and associated barriers to race-conscious SIC

Table 3. Race-conscious communication: strategies, skills, and examples of talking points (adapted Pehrson et al. 2016)

| Strategy	Skill	Process task	Clinician talking point examples
Recognize or elicit an empathic opportunity related to race and racism	• Acknowledge • Encourage expression of feelings	• Notice patients' nonverbal communication	• "It sounds like you have really experienced several instances of racism during your healthcare experience." • "It is important to me to better understand how you are dealing with the experiences of racism you described."
Work toward a shared understanding of the patient's emotion/experience related to race and racism	• Ask open questions • Clarify • Restate	• Avoid leading questions • Avoid giving premature reassurance	• "Tell me more about how your experiences with racism have affected you and how you feel about receiving care from our team." • "So, if I understand correctly, you have been upset by racist comments that have been made by health professionals?"
Empathically respond to the emotion/experience	• Acknowledge • Validate • Normalize • Praise patient efforts	• Identify patients' strengths and sources of support	• "It would be perfectly reasonable for you to be frustrated by having to talk about issues of racism at any time, but especially while you are sick." • "It is understandable that you would be upset by health professionals that have been disrespectful."
Facilitate coping and connect to social support	• Ask open questions • Endorse question asking • Make partnership statements	• Make referrals • Express a willingness to help	• "Can you tell me about what kinds of support you have from your family or community to talk with about these hurtful experiences?" • "Would you be open to us involving our social work team more actively in your care so we can ensure that you are feeling safe and supported as we move forward?"
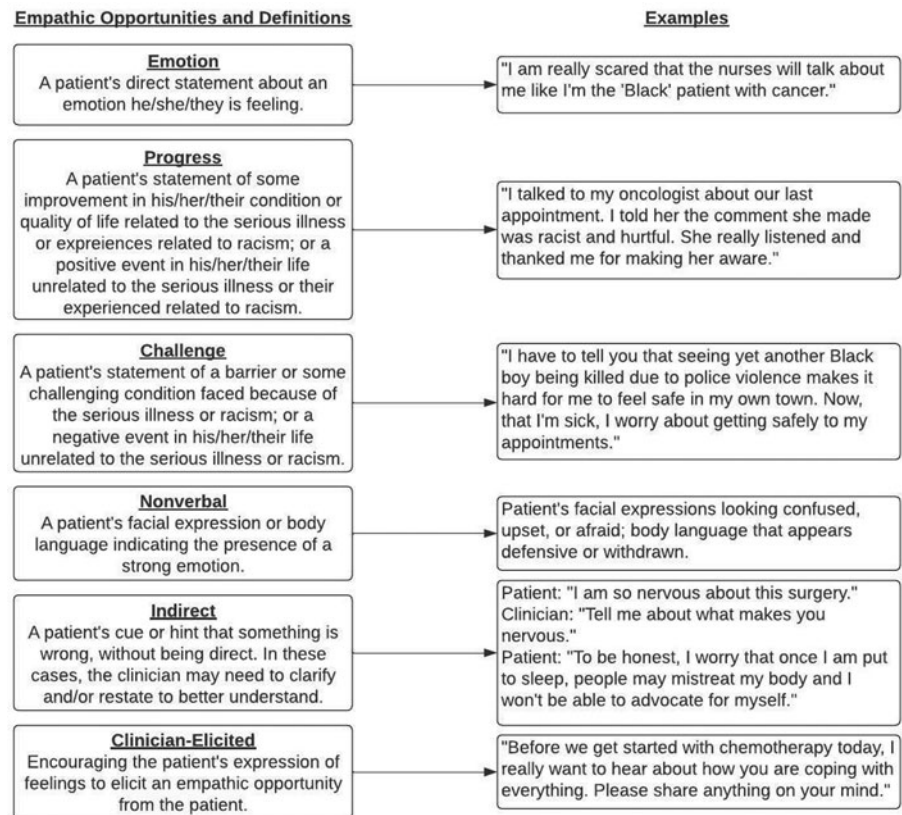
Fig. 2. Empathic opportunities, definitions, and examples related to serious illness and racism (adapted Pehrson et al. 2016).

race-conscious SIC into the encounters among patients, families, and clinicians in ways that promote relationship-building. Table 3 provides strategies, skills, and potential talking point examples of race-conscious SIC. We acknowledge that these are incredibly high-stakes questions for many patients and that the clinician may not receive an honest response or may be rejected altogether if they are not perceived as safe or genuine. Additionally, clinician–patient race discordance may be a barrier to transparency in some cases. Clinicians must take advantage of empathic opportunities to deepen trust with patients and families, even while risking rejection (Figure 2). The very premise of goal-concordant care requires a restructuring of how clinicians understand the communication process, the patient experience, and shared decision-making. Thus, one solution is to more inclusively engage surrogates and community supports – as well as considerations of racism and exclusionary policies and practices – to ensure care is aligned with patient goals and the grieving process for caregivers is intentionally supported (Johnson 2022; Sanders et al. 2018).

Conclusion

As clinicians and researchers partner with marginalized communities to dismantle barriers to health equity, it is imperative that *how* we listen and respond to patients, their families, and their communities reflects a commitment to whole-system awareness. Developing race-conscious SIC competencies may allow for hard truths to be safely spoken so that we may more effectively prevent avoidable suffering for people like Tanya, for all Black and Brown persons with serious illness, and for the families and communities that support them.

Conflicts of interest. These authors have no conflicts of interest to disclose. W.E.R. has completed disclosure and conflict of interest statements on behalf of J.R.C.

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