AETC AIDS Education & Training Center Program
Mountain West

A race conscious approach to serious illness

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Project ECHO®

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Data Considerations

Data in this presentation offer a limited perspective of how systemic, social, and economic factors impact health. We recognize that racism, not race, creates and perpetuates health disparities.

To Learn More:
https://www.cdc.gov/minorityhealth/racism-disparities

Overview

- Provide broad description on racial inequities in serious and end-of-life
- Discuss color-blind/race-neutral approaches to research vs race-consciousness
- Briefly describe a pragmatic version of Critical Race Theory
- Qualitative findings of interviews with Black patients with serious illness
- Describe epistemic injustice and provide examples
- Discuss physician perspectives around talking about racism with patients
- Patient-provider tensions and final thoughts

Black patients and serious illness and EOL

MORE LIKELY

- Visit the ED
- Hospitalized
- Long length of stay
- Mechanical ventilation, CPR
- Die in-hospital

LESS LIKELY

- DNR
- Withdraw LST
- Receive palliative care
- Enroll in hospice

Worse quality of life, higher symptom burden, financial strain

Brown J Pain Symptom Manage 2022

A ”colorblind” approach

- Many factors account for inequity:
  - Health literacy
  - Preferences
  - Trust
  - Acculturation
  - Spirituality/religion

Brown, Curtis, Doll J Pain Symptom Manage 2022

Racialized experiences of Black patients with HIV

Traditional research focuses on individual factors or use deficit-based approaches toward Black patients with HIV (e.g., lower engagement related to lack of knowledge, sexual risk, poverty, stigma)

Incorporating racialized experiences brings attention to

- Structural racism that patients navigate: promotion of racial discrimination and limitation of opportunities, access, resources, power, and well-being
- Racial trauma patients endure: emotional injury from exposure to various forms of racism, discrimination, and bias

Burton et al AJPH 2023

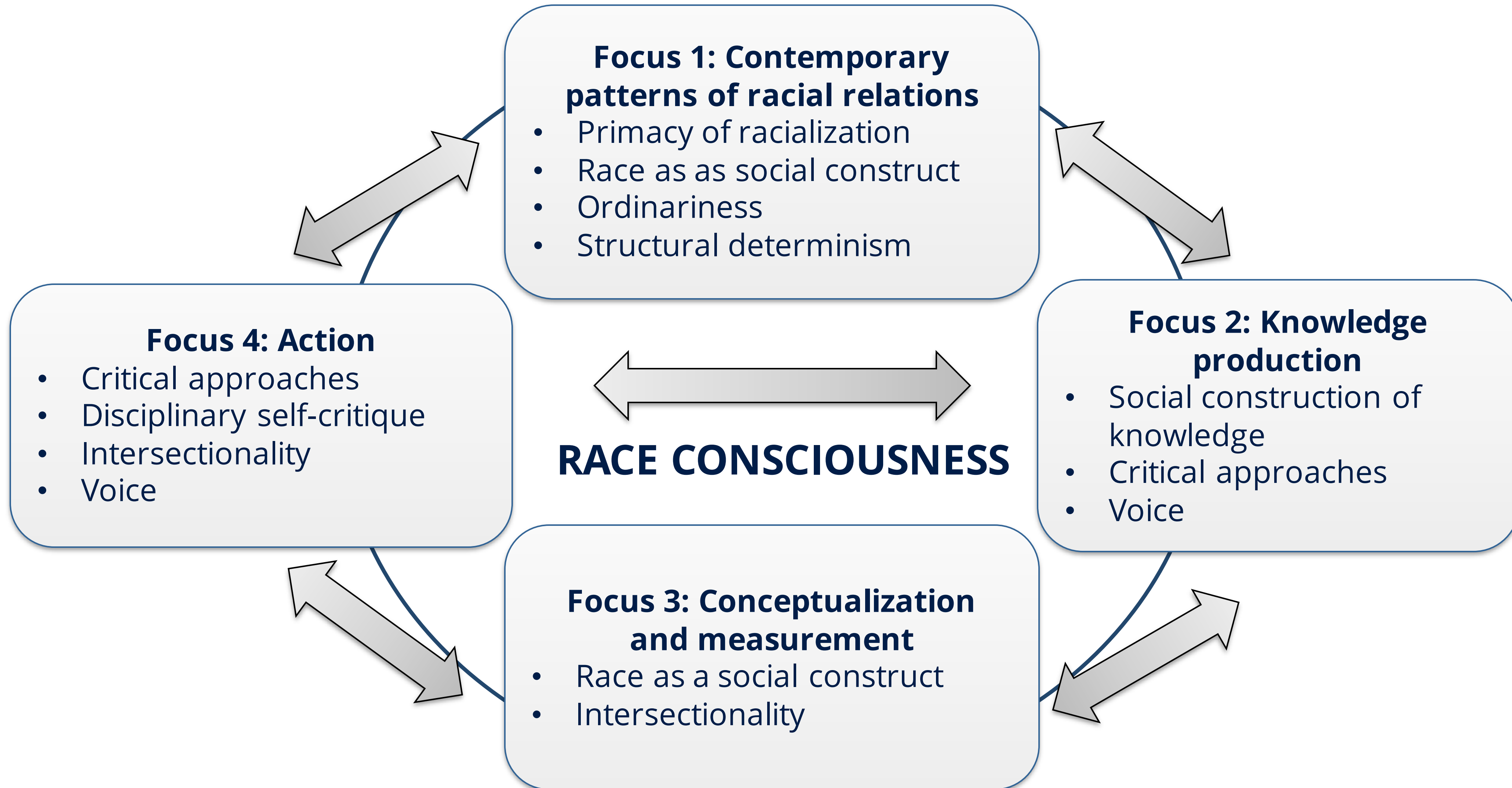
A race-conscious approach to serious illness

Little research examines factors and experiences *within the context of a racialized medical system.*

How do the lived experiences of racism impact patient-clinician communication and medical decision-making?

Brown, Curtis, Doll J Pain Symptom Manage 2022

Public Health Critical Race Praxis



Ford 2010, Ford 2018

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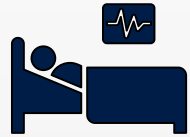
Interviewing Black patients with serious illness



Identify Black patients with serious illness

Complete surveys measuring trust, discrimination, microaggressions

Perform 1-on-1 semi-structured interviews

Perform thematic analysis

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Methods

- Interviewers:
  - CEB: Black and Korean pulmonary and critical care physician, mixed methods
  - ARM: multiracial, Asian and Pacific-Islander research coordinator
- Inductive coding and codebook development
  - CRS: multiracial Black qualitative researcher, health equity research, PHCRP
  - CCP: multiracial Hispanic RC with experience in qualitative health research
  - KLC: Filipina American internal medicine resident
- Research team also included:
  - Biracial Black woman, retired Major in Army
  - Black woman gynecological oncologist, expert in PHCRP
  - Black woman, endocrinologist, health equity researcher
  - Black man, pulmonologist, TB and health disparities
  - Black woman, nephrologist, health equity researcher
  - White man, pulmonary, critical care, and palliative care researcher

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Patient Demographics		
Variable	**N**	**Statistic**
Female	25	5 (20.0)
Age	25	62.0 (10.3)
Diagnosis[a]	25	
NYHA III or IV CHF		13 (52.0)
Charlson ≥6		8 (32.0)
Metastatic cancer		2 (8.0)
COPD FEV1<35% or on O_2		1 (4.0)
ESRD and DM or albumin<2.5		1 (4.0)
Age 75 or older[c]		1 (4.0)
Income/year [a]	24	
<$25,000		19 (79.2)
$25,000-34,999		2 (8.3)
$35,000-44,999		1 (4.7)
$50,000-74,999		2 (8.3)

Patient Demographics		
Variable	**N**	**Statistic**
Years of schooling[b]	24	13.4 (2.7)
Religion[a]		
Christian		17 (68.0)
None		6 (24.0)
Other		2 (8.0)
Insurance[a]	25	
Medicaid		9 (36.0)
Private		8 (32.0)
Medicare		6 (24.0)
Other		1 (4.0)
Uninsured		1 (4.0)

Patient Medical Racism Experiences		
Variable	**N**	**Statistic**
REALM-SF	19	5.8 (2.0)
Group Based Medical Mistrust	23	40.1 (8.3)
Discrimination in Medical Settings	21	21.0 (7.5)
Microaggressions in Healthcare	23	1.9 (0.6)

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Theme 1: Experiences with racism

Experiences with racism

Systemic racism: “It’s **too engulfed in racism. It’s too money-driven and controlled by racist people with agendas**.”

Personal experiences: “But yeah, this doctor. He was a doctor! He kept saying ‘Yeah, what’s up boss! You okay boss?’ Grab me or something, ‘You okay boss?’ It’s just like, **you know, we’re not street folks**.”

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Experiences with racism

Intersectionality: "The more doctors perceive you as educated, and they more they perceive you as being affluent. It's a milking of the cow. **I think that there are people that are making decisions for poor people that should not have been made**."

Vicarious experiences: I remember a time when we didn't go to the emergency room, we didn't go see a doctor. We did home remedies or whatever. Like my brother. **He died of colon cancer. And if he went in time, that could've been stopped."**

Intersectionality: "**Because of my insurance or something, I might not be accessing certain medical treatments,** you know? And that sucks. I mean, everything is just designed for us to fail."

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Theme 1: Experiences with racism

Theme 2: Trauma-informed communication and decision-making

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Communication and decision-making

Poor communication: “I don’t say anything sometimes because **I don’t want to disrupt things or create a problem even though there is a problem.”**

Life-sustaining therapies: “The medical community is very strong has a lot of things which are even better today than the human brain. **And they are helping people to survive death. But those are not applied to people of color.”**

Quality of life: “The idea of do-not-resuscitate, the idea of, well, if this happens, don’t do heroic measures, don’t feed me with a tube in this situation, yes! **Because all of that is an impact on your dignity and your quality of life.**”

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Theme 1: Experiences with racism

Theme 2: Trauma-informed communication and decision-making

Theme 3: Epistemic injustice and mistrust

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Epistemic injustice and mistrust

Dismissal: "I wish [doctors] would listen more and get over their god complex. 'I went to school for this, so I know.' **Well, this is my body, and I'm going through it."**

Double consciousness: "I've been a bartender for 25 years, so I'm pretty good at reading people, body language, and things like that. So, **if doctors are looking down their nose at me, I can tell.**"

Vulnerability: "I woke up in MICU. I asked, 'Where am I?' He said, 'You're in the MICU. Your blood pressure bottomed out.' The tears rolled up. **I [thought] about that doctor telling me to 'go home."**

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Epistemic injustice and mistrust

Mistrust: “I’m not valued so your brain isn’t at 100% capacity trying to figure out what you can do for me. **I don’t see a person that puts energy into being racist coming to conclusions that are medically good**.”

Self advocacy: “I don't like to come across as if I know everything, but I'm always inquisitive. **I'd rather pretend I’m stupid than smart so I can gather as much information.”**

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Epistemic injustice

A HCW does not take seriously the assertions and beliefs of a patient because of irrelevant features of their social identity or condition.

Epistemic injustice

Testimonial injustice: A HCW does not take seriously the assertions and beliefs of a patient because of their social identity or condition.

Testimonial quieting: A HCW fails to acknowledge or recognize the patient as a knower of their own body or diagnosis.

"I was retaining fluid. **They said there's nothing to do and I could leave. Obviously, there was something wrong with me.** I went to [hospital]. They pumped out 15L of out of me."

Testimonial smothering: The patient perceives a HCW as unable or unwilling to listen to them. Patients truncate what they have to say or don't say anything at all.

"I'm very aware if [doctors] are going to be listening to me or talking at me and not trying to help me work out what I came there to do. **I choose to not talk to a lot of them."**

Hermeneutical injustice: A structural problem where certain populations have been excluded in any meaning-making activities or contributions. This makes it difficult for patients to convey their experiences to others or make sense of it.

"Sometimes we have a problem advocating for ourselves."

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Impact on serious illness communication

Values-based discussions on values, preferences, *without concern over controlling influences*

- Patients navigate "multiple consciousness" and hypervigilance
- Patients experience the everyday silencing of their voices

Values and preferences may be borne out of unjust conditions, unequal power relationships

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What about healthcare workers?

Black patients identified clinicians' lack of receptivity and appeasement as a significant barrier to repairing the harm of racism.

Interview physician subspecialists

Elicit physician perspectives on addressing concerns from Black patients about interpersonal racism involving them or their team

Physician participants

Physician Participants	
Variable	**Statistic**
Age[a]	44.2 (7.8)
Female[b]	14 (66.7)
Years in practice[a]	10.8 (7.4)
Self-reported race[b]	
White	14 (71.4)
Black	3 (14.3)
Asian	4 (19.0)
Specialty[b]	
Pulmonary and Critical Care	8 (38.0)
Nephrology	5 (23.8)
Infectious Disease	3 (14.3)
Gastroenterology	3 (14.3)
Cardiology	2 (14.3)
Rank[b]	
Assistant Professor	9 (28.6)
Associate Professor	6 (28.6)
Professor	4 (19.0)

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Interviewing medical subspecialists

Physicians purposefully identified from Division websites

Experiences discussing racism with seriously ill Black patients

Semi-structured, 1-on-1 interviews, included scenarios

Analyzed using thematic analysis

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Scenario

Mrs. Johnson is a 59-year-old Black woman with stage 3 HIV. She has been admitted multiple times with various infections. Each time she is admitted, her care team attempts to discuss her goals of care and whether or not she would like to be intubated. Mrs. Johnson wants to be intubated and has always wanted CPR and wondering doctors continue to ask this question because they do not want to her to live because she is Black and has a history of using illicit substances in the past. While she is curious about this, she doesn't ask about it because she is afraid that her doctors and nurses will retaliate against her by withholding more treatment.

Takeaways from physician interviews

Physicians are ill-equipped, emotionally unprepared to talk about racism

“Black patients shouldn’t call out racism, but I don’t want to do it”

We need help managing defensiveness and embracing humility

Clinicians and patients both could benefit from coaching and support

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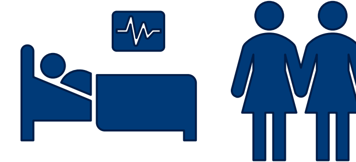
Tensions between provider and patient needs

- Unaware or appeasement of concerns
- Lack of framework, language
- Paternalistic practices
- Lack of data and evidence



- Unequal power dynamics
- Fear of speaking up
- Intersectionality, lack of workforce representation

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Final thoughts

- Patients may process information and make decisions within the context of multiple marginalized identities and poor healthcare experiences
- The importance of hearing and discussing patients' concerns with racism or any other perceived discrepancies in their care is broadly recognized
- Patients and physicians identified additional resources facilitate productive conversations
- Communication-based solutions to improve conversations about racism and intersectionality that prioritize racial healing.

Thank you

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Feedback

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