3rd Annual Hopkins Center For Health Disparities Solutions Symposium

Race And Racism In Research and the Community
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Potential Conflicts of Interest*

* Activities within the last year
  Grants: 1
  Consulting: 2

# None related to this talk

I believe in a society grounded in Equity & Justice
Major Race-Based Inequities Exist in Society & in Medicine that lead to Disparities and Undermine the Optimal Care for All
A Few Definitions
Race/Ethnicity

• Despite its official status in government, research and health professions, the term race is a misnomer.
  • There is only one race, the human race or Homo sapiens - the only extant human species.

• The Pan American Health Organization/WHO holds the scientifically accurate view that there is a single human race and uses ethnicity to characterize different socio-cultural groups.
  • Share traditions, ancestry, language, history, culture, nation, religion, and/or social treatment within a society.
Race – social interpretation of how one looks in a “race”-stratified society

• A socio-political construct to control power and marginalize people based on how they look (race)
  • *White supremacy ideology to justify and maintain Native American/American Indian genocide/oppression and Black American chattel slavery/oppression*
• Race is *indirectly* (not directly) related to ancestry
• As a research variable: race is a poor indicator of biology/genetics and a strong indicator of exposure to racism

Race = How society sees you and thinks of you
Racism: a system of structuring opportunity and assigning value based on race

Racism by design

1. Unfairly disadvantages some individuals/communities,
2. Unfairly advantages other individuals/communities, and
3. Saps the strength of the whole society through the waste of human resources.

• *Structural or Institutionalized racism; personally mediated, internalized*

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Structural Racism in Action

Communities of Color are 2-4 times more likely to have COVID-19 Infection, Hospitalization & Death

U.S. CORRECTIONAL FACILITIES REPORT STEEP RISE IN CORONAVIRUS INFECTION RATE

BY MEGHAN ROOS ON 4/16/20 AT 8:33 PM EDT

‘They’re Death Pits’: Virus Claims at Least 7,000 Lives in U.S. Nursing Homes

More than six weeks after the first coronavirus deaths in a nursing home, outbreaks unfold across the country. About a fifth of U.S. virus deaths are linked to nursing facilities.

COVID-19: a potential public health problem for homeless populations

Native American Deaths Rising at Alarming Rate from COVID-19

Covid-19’s devastating toll on black and Latino Americans, in one chart

The US health system has failed black and Latino populations for decades. Now they’re paying the price.

By Dylan Scott | @dylaniscott | dylan.scott@vox.com | Apr 17, 2020, 4:10pm EDT
The Makings of a Disparity

Structural Racism*
(e.g. residential segregation, underfunded school systems, poverty, chronic discrimination)

Increase Risk of Exposure
- Service Jobs
- Poor housing conditions
- Public Transportation

High Chronic Disease Burden
- DM/CKD
- HTN/CVD
- Asthma/COPD

Lack of Access to Quality Care
- Early testing shortage
- Poor preventative care
- Low quality hospitals

Every system is perfectly designed to achieve the results it gets - Don Berwick
Structural Racism

- Totality of ways in which societies foster racial discrimination through **mutually reinforcing systems** of housing, education, employment, earnings, benefits, credit, media, health care, criminal justice, etc.
- Unequal distribution in wealth, employment, residence, toxic environmental exposures, nutrition, education, and psychosocial stress, **quality of care, healthcare access**
- No one on this zoom owned an enslaved person or created structural racism. Everyone on this zoom can support structural racism (promote or do nothing) or help dismantle it.

*These patterns and practices reinforce discriminatory beliefs, values, and distribution of resources and strongly influence self reliance & personal responsibility*


Towards Achieving Equity and Justice to Eliminate Disparities

1. **EQUALITY imagines an equal world.**
   "I care about all students equally"

2. But the world ISN'T EQUAL.

3. And it has BIAS AND SYSTEMIC RACISM.

4. Within this same picture, a DIVERSITY lens focuses only on bringing more students into an unequal pathway.

5. In contrast, EQUITY redirects resources to the pathways with greatest need to fix barriers and intentionally provide support.

& Justice closes the hole and starts adding some boxes

Adapted from the USC Center for Urban Education
What About Race and Ethnicity in Research?
Conceptual Model of Race in Research

Race

Physiognomy

Societal

Culture/Ethnicity

External Risk Exposure

Health/Wellness Behavior

Risk Exposure

Health Outcome Differences by Race

Latent (unobserved factor)

Manifest indicator (Skin Color)

Categorization into risk/behavior groups

Reproduced from La Veist TA. Why we should continue to study race...but do a better job: an essay on race, racism and health. Ethnicity & Disease. 1996;6(1-2):21-9.
Considerations for Racial/Ethnic Disparities in Research

• Why and how are we examining race/ethnicity
• Substantial heterogeneity in each R/E group
• Understand the impact of structural racism
• Race/Ethnicity are not surrogates for SES
  • When we are examining race and control for SES we must recognize race/structural racism are not independent of SES
• Race/Ethnicity are associated with but are not risk factors for health conditions/outcomes

Race is a risk factor for racism

Exposure to racism is risk factor for health conditions/outcomes and health disparities
The Biology of Racism

Society ↔ Structural Racism
Inequity in resources and opportunities
Personal Experiences with discrimination and racism
Health inequities and subsequent impact
“Blacks experience early health deterioration as a consequence of the cumulative impact of repeated experience with social and/or economic adversity and political marginalization. On a physiological level, persistent, high-effort coping with acute and chronic stressors has a profound impact on health”

Arlene Geronimus
Black vs White Differences in Adult Adversity

- Major discrimination events: 2.9 (Blacks) vs 14.8 (Whites)
- Everyday discrimination: 3.2 (Blacks) vs 14.8 (Whites)
- Major life events: 4.1 (Blacks) vs 3.2 (Whites)

MIDUS - Courtesy Dr. Teresa Seeman
**Differential Weathering in the MIDUS Cohort**
*(ages 35-85)*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Black participants <em>(n=228; avg age=53)</em></th>
<th>White participants <em>(n=942; avg age=58)</em></th>
<th>Race Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fasting glucose (mg/dL)</td>
<td>111.1 ± 42.3</td>
<td>99.9 ± 23.4</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>HOMA-IR</td>
<td>1.5 ± 0.64</td>
<td>1.3 ± 0.55</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>CRP (ug/dL)</td>
<td>1.34 ± 0.80</td>
<td>1.0 ± 0.68</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>IL-6 (pg/mL)</td>
<td>1.5 ± 0.54</td>
<td>1.2 ± 0.51</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>E-selectin (ng/mL)</td>
<td>52.1 ± 28.9</td>
<td>41.3 ± 20.6</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Waist</td>
<td>101.4 ± 18.1</td>
<td>96.5 ± 15.7</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>BMI</td>
<td>32.8 ± 8.6</td>
<td>29.0 ± 5.9</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

Courtesy Dr. Teresa Seeman
Poverty and Allostatic Load


**FIGURE 2**—Probability of having an allostatic load of 4 or higher, as predicted by poverty income ratio (a) and poverty income ratio and race (b).

*Note. PIR = poverty income ratio.*
Lifetime Discrimination & Inflammation Burden in Adults: Mid-Life in the US (MIDUS)

Sum top 25%: CRP, IL-6, fibrinogen, E-selectin, intracellular adhesion molecule-1 (ICAM-1)

(Ong et al, 2019)
Let’s get Back to Race and Ethnicity in Research?
Use of Race and Ethnicity in Medicine

• Race is a complex population-level social variable

• Research data on R/E is critical for population-level assessments that inform public health and community messaging, screening, monitoring progress in addressing disparities, modifying systems, creating policy recommendations, etc.
Health Disparities research

• Comparing Racial and Ethnic Groups


• Minority health research

• Analyses Within a Racial and Ethnic Group

• Thorpe RJ et al. The Association Between Depressive Symptoms and Accumulation of Stress Among Black Men in the Health and Retirement Study. Innov Aging. 2020 Sep 29;4(5). (accumulation of stress using allostatic load)

Considerations for Racial/Ethnic Disparities Research

• Qualitative research, **including community engaged research**, to better contextualize findings

• Historically greater likelihood of R/E minorities to be uninsured (may still be underinsured) than their White peers - attenuated with the ACA (2010)
  
  • Insurance does **not** = access to care
  
  • Insurance = potential access to care
    
    • Narrow networks, historical mistreatment, job, transportation, etc. still impact actual access to care
Considerations for R/E Disparities in Aging Research

• Medicare analyses (mostly >65): at least recent “equity” in access to care
  • survivor bias, consider controlling for allostatic load/weathering
• Medicaid analyses: represents potential “equity” in access for low-income older populations (and children)
• Closed health system - Kaiser, VA (intrinsic biases in the mix of patients and > equity in care)
• Open health systems – large EHR data; more generalizable
• Large Observational Datasets:
  • National Health and Nutrition Examination Survey (NHANES), National Health Interview Survey (NHIS), National Inpatient Sample (NIS), Medical Expenditure Panel Survey (MEPS), Health and Retirement Study (HRS)
Often we control for Social Disadvantage to better understand “Race/Ethnicity”, but we are really better understanding the role of other pathways of structural racism

- Educational attainment
- Unemployment
- employed white-collar jobs
- Median family income
- Income disparity
- home value
- gross rent
- monthly mortgagee
- home ownership

- % families < poverty level
- % population <150% FPL
- % single-parent households
- % occupied housing units without
  - a motor vehicle
  - a telephone
  - complete plumbing
- % occupied housing units with > one person/room

How not to use race/ethnicity in medicine?
How not to use race/ethnicity in medicine

• For Diabetes let’s say the Hispanic community has a 1.5 times the rate of diabetes and let’s say they have an average HbA1c that is 0.5% higher
• You cannot create a formula to get a number (e.g. 0.5%) and subtract 0.5% from each Hispanic patients HbA1c
  • The risk of diabetes is due to structural racism and not race/ethnicity. While a marginalized group may in general experience structural racism somewhat similarly it varies tremendously for each individual.
Use of race/ethnicity in clinical formulae or algorithms?

Generating and assigning a specific value (e.g. modifier, coefficient) to each individual patient in a “minoritized” group:
1. Treats race as a fixed biologic variable, thereby denying it is not a biologic variable
2. Ignores large genetic and social heterogeneity within groups
3. Reinforces racist stereotypes
4. Obscures the mechanisms linking racism to health disparities
5. Assumes each individual is exposed equally to the myriad of elements through which racism operates
6. Lacks understanding that race is a risk factor for racism not health, so it has a very imprecise association
7. Generally lacks scientific rigor (e.g., ecologic fallacy and substantial aggregation bias)
Conducting our Research
High levels of residential dissimilarity signify that Blacks and Whites have little common area of residence within the core-based statistical area (CBSA), and, the more spatially separated Blacks and Whites are within a CBSA, the more likely they are to lead separate lives in neighborhoods increasingly different in quality and in access to influence and resources.
A Way Forward
Preparing our research

1. Do we understand what race or ethnicity means to us in the study?
   - Is there an intersectional lens (sex, linguistic background, sexual orientation, SES, other?)

2. Do we have the right partners?
   - Who is not at the table?

3. Have we thought through the impact of structural racism in the translation to providers, health systems, etc. and how it manifests in heterogeneous populations and diverse communities?

Adverse Childhood Experience Questionnaire for Adults

1. Did you feel that you didn’t have enough to eat, had to wear dirty clothes, or had no one to protect or take care of you?

2. Did you lose a parent through divorce, abandonment, death, or other reason?

3. Did you live with anyone who was depressed, mentally ill, or attempted suicide?

4. Did you live with anyone who had a problem with drinking or using drugs, including prescription drugs?

5. Did your parents or adults in your home ever hit, punch, beat, or threaten to harm each other?

6. Did you live with anyone who went to jail or prison?

7. Did a parent or adult in your home ever swear at you, insult you, or put you down?

8. Did a parent or adult in your home ever hit, beat, kick, or physically hurt you in any way?

9. Did you feel that no one in your family loved you or thought you were special?

10. Did you experience unwanted sexual contact (such as fondling or oral/anal/vaginal intercourse/penetration)?
Adverse Childhood Experience Questionnaire for Adults

• 61% of adults had at least one ACE & 16% > 4
  • Females and several racial/ethnic minority groups were at greater risk for experiencing > 4 ACEs.

• Persons who had experienced > 4 ACE compared to those who experienced none had:
  • 2-5 fold increase in obesity, cancer, diabetes, heart disease, drug abuse, depression, and suicide attempt independent of race/ethnicity, sex, and age

It’s not what’s wrong with you or them it’s what happened to you or to them
WHO and Improving Global Health – Include the US

• Improve conditions of daily life

• Tackle the inequitable distribution of power, money, and resources – the structural drivers of those conditions of daily life – globally, nationally, and locally

• Develop a workforce trained in the social determinants of health, & raise public awareness about the social determinants of health

Clinic

### Clinician Experiences and Attitudes Regarding Screening for Social Determinants of Health

<table>
<thead>
<tr>
<th>Support social needs screening in clinical settings</th>
<th>84%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confident in their ability to address social needs</td>
<td>41%</td>
</tr>
<tr>
<td>Routinely screen for social needs currently</td>
<td>23%</td>
</tr>
</tbody>
</table>

**Most significant barriers**

| Lack of time to ask / Lack of resources | 60% / 50% |

258 clinicians including primarily physicians, social workers, nurses, and pharmacists from a large integrated health system in Southern California.

Narratives on Beliefs and Preferences

• White supremacy ideology and narrative of racial difference

• There are narratives that beliefs and preferences are individual choices, independent from racism, but the weight of life circumstances may be powerful forces.

• We are conditioned to say a person’s situation is an individual choice to reinforce inferior people are making poor choices of free will within our “meritocracy”.

• A “non-adherent” mother may “choose” not to refill her meds, but because she “chose” to buy food for her kids. In many instances beliefs and behaviors can be due to unfair/unjust circumstances and are in fact disparities
Workforce Innovations to Address Social Determinants: Community Faculty

- A novel and innovative pedagogic approach to academic-community partnership that recruits local resident community experts as university faculty members
- Analogous to a Clinical Faculty Track
  - Clinical Faculty provide non-academic based, clinical care training and mentoring
  - Community faculty bring the unique experience of knowledge about the community and social determinants of health that lends itself to the best training, research and practice

Community Faculty

• Prepare students and faculty to provide quality care that includes an integration of the role of social determinants of health and the leadership skills to transform the health of low resource communities
  - Education, Employment, Safety, Housing, Health
  - Stress/Depression, Violence, Social Justice, Environment
• Uniquely prepare students and faculty to conduct research with the community
• Foster the development of necessary skills to facilitate the translation of knowledge into the community setting

Structural Racism: Poverty/Discrimination/More

Psychosocial Stress  Poor Cognitive Processing

Stress (to survive) leads to realignment of workspaces that limits cognitive processing

What might happen if/when an “under-resourced/marginalized” patient makes it to their visit & then goes home?

Inability to remember

Suboptimal Clinical Outcomes

Cost of food, housing, more

Inability to implement

Mistrust and Stress from social injustices (-isms)

Small margin for unforeseen events

Fear, anxiety apprehension

Which ball(s) are your under-resourced/marginalized and disproportionately minority patients likely to drop
-Rent, food, electricity, childcare, elder care or
-Provider recommendations, f/u visit, meds/other?
For Countering Bias & Racism

• Overcoming Unconscious or Implicit Bias
  • Recognize it could be you
  • Focus on treating patients/peers/staff as individuals and not as a category.
  • Practice Empathy, Caring, Respect

• Unraveling the Institutionalization of Racism
  • Revise health system policies
  • Recognize your role as a community resource and/or leader for health – Help change laws/policies that promote inequity and adverse social determinants of health

• Passivity is a choice – it is choosing to perpetuate structural racism and health disparities

Adapted from Masters C, et al. Addressing Biases in Patient Care with The 5Rs of Cultural Humility, a Clinician Coaching Tool. JGIM 2019;34(4):627-630
Capers Q. How Clinicians and Educators Can Mitigate Implicit Bias in Patient Care and Candidate Selection in Medical Education. ATS Scholar. 2020;1(3):211-7
Caring for Marginalized Patients

What many “Marginalized” Patients have

• Discriminated Group
• Limited Income
• Under and Un-Insured
• Low Educational Attainment
• Limited Access to Care
• Impaired Cognitive Processing
• Adverse biologic profile
• Multimorbidity

What many “Marginalized” Patients need

• High Quality Care
• Treated with Respect
• Our Empathy
• Our Compassion
• Our Support
• To be given Hope
• Judgement
• Ire
• Lecture

Tell your patients that you treat them like family
And then do it!

And remember: It’s not what’s wrong with them
it’s what did we do to them
The truth is that there is nothing noble in being superior to somebody else. The only real nobility is in being superior to your former self. – Whitney Young, Jr. adapted from Hemingway

Photo: From UCLA Health Care Workers Rally for Black Lives Matter – June 2020
DOM EDI- https://edi.med.ucla.edu

David Geffen School of Medicine
UCLA Health