3<sup>rd</sup> Annual Hopkins Center For Health Disparities Solutions Symposium

Race And Racism In Research and the Community *April 12, 2021* 





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### **Building.Belonging.Becoming.**

### Potential Conflicts of Interest\*#

Atlantis NIH<sup>1</sup> HealthCare<sup>2</sup>

\* 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

## UNEQUAL TREATMENT

CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE

INSTITUTE OF MEDICINE





# 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 <u>scientifically accurate view</u> that there is a single human race and uses <u>ethnicity</u> to characterize different socio-cultural groups.
  - •Share traditions, ancestry, language, history, culture, nation, religion, and/or social treatment within a society



Marshall E. DNA studies challenge the meaning of race. *Science (New York, NY).* 1998;282(5389):654-655. Ethnicity and Health. Pan American Health Organization/World Health Organization.



# **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 <u>indirectly</u> (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

# Racism = What society does to you based on how it sees you



Jones CP. Confronting Institutionalized Racism. *Phylon.* 2002;50(1/2):7-22. Jones CP. Levels of racism: a theoretic framework and a gardener's tale. *Am J Public Health.* Aug 2000;90(8):1212-5.



### **Structural Racism in Action**

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

BY MEGHAN ROOS ON 4/16/20 AT 6:33 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 | @dylanlscott | dylan.scott@vox.com | Apr 17, 2020, 4:10pm EDT



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



#### The Makings of a Disparity



David Geffen School of Medicine 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



Nicholas SB, Kalantar-Zadeh K, Norris KC. Racial Disparities in Kidney Disease Outcomes. *Seminars in Nephrology*. 2013;33(5):409-415. Bailey ZD, et al. Structural racism and health inequities in the USA: evidence and interventions. *The Lancet*. 2017;389(10077):1453-1463



#### **Towards Achieving Equity and Justice to Eliminate Disparities**



# What About Race and Ethnicity in Research?





#### Conceptual Model of Race in Research



Latent (unobserved factor)

Manifest indicator (Skin Color)

Categorization into risk/behavior groups

**Risk Exposure** 

#### Health Outcome



Adapted 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





#### **Biological "Weathering"**

#### **Weathering**

"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"



The Aging of the President

(or maybe his hair turned grey early)



#### Arline Geronimus





#### **Black vs White Differences in Adult Adversity**





MIDUS - Courtesy Dr. Teresa Seeman



#### Differential Weathering in the MIDUS Cohort (ages 35-85)

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



Courtesy Dr. Teresa Seeman



**Poverty and Allostatic Load** 



Note. PIR = poverty income ratio.

### 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).



Geronimus AT, et al. "Weathering" and age patterns of allostatic load scores among blacks and whites in the United States. *Am J Public Health*. 2006;96(5):826-833.



#### Lifetime Discrimination & Inflammation Burden\*in Adults: Mid-Life in the US (MIDUS)





(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 populationlevel 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

 Mitchell UA, et al. Change in Cardiometabolic Risk Among Blacks, Whites, and Hispanics: Findings From the Health and Retirement Study. J Gerontol A Biol Sci Med Sci. 2019 Jan 16;74(2):240-246.

#### 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)
- Cadet T, et al. Timing of Immigration Effects Asset Change Among Hispanic Caregivers of Older Family Members. J Fam Econ Issues. 2020 Oct 6:1-12.





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



Kind AJ, et al. Neighborhood socioeconomic disadvantage and 30-day rehospitalization: An Analysis of Medicare Data. *Ann Intern Med*. 2014;161(11):765-774.



# 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**





#### **A Conceptual Model of Racism in a Research Paper**

#### **Racism, Racial Residential Segregation and Health**

Experience of discrimination



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?



Adapted from McNulty M,, et al. Implementation Research Methodologies for Achieving Scientific Equity and Health Equity. Ethnicity & Disease. 2019;29(Suppl 1):83-92.



#### **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 &  $16\% \ge 4$ 

 Females and several racial/ethnic minority groups were at greater risk for experiencing <u>></u> 4 ACEs.

- Persons who had experienced 
   <u>></u> 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





Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. Geneva, World Health Organization. 2008
 Schroeder S. Shattuck Lecture We Can Do Better — Improving the Health of

the American People. N Engl J Med 2007;357:1221-1228.



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

Support social needs screening in clinical settings	84%
Confident in their ability to address social needs	41%
Routinely screen for social needs currently	23%
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.



Schickedanz A, et al. Clinician Experiences and Attitudes Regarding Screening for Social Determinants of Health in a Large Integrated Health System. *Med Care*. 2019;57 Suppl 6 Suppl 2(Suppl 6 2):S197–S201









#### **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 academiccommunity 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





Del Pino HE, et al. Integrating Community Expertise into the Academy. South Los Age as' Community-Academic Model for Partnered Research. Prog Community Health Partnersh. 2016



#### **Community Faculty**



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



Del Pino HE, et al. Integrating Community Expertise into the Academy: South Los Angeles' Community-Academic Model for Partnered Research. Prog Community Heatth Intersh. 2016





Dehaene S, et al. A neuronal model of a global workspace in effortful cognitive tasks. PNAS. 1998 24;95(24):14529-34.



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



-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



David Geffen School of Medicine 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 Careful th Candidate Selection in Medical Education. ATS Scholar. 2020;1(3):211-7

## Empathy is

seeing with the eyes of another, listening with the ears of another, and feeling with the heart of another.

#### 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

;h



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



David Geffen School of Medicine Photo: From UCLA Health Care Workers Rally for Black Lives Matter – June 2020 DOM EDI- <a href="https://edi.med.ucla.edu">https://edi.med.ucla.edu</a> UCLA Health