Categorizing Race and Ethnicity in Medical Research

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By the year 2050, racial and ethnic minorities will make up 47.5% of the total U.S. population

- In 2010, African Americans comprised 12.6% of the U.S. population, up from 12.3% in 2000
- In 2010, Hispanics comprised 16.3% of the total U.S. population
- Between 2000 and 2010, the Hispanic population grew by 43%
Assumptions about Race and Ethnicity

“Race” and “Ethnicity” and specific group designations are consistently defined
What Is Race?
When we talk about the concept of race, most people believe that they know it when they see it but arrive at nothing short of confusion when pressed to define it.

Evelyn Brooks Higginbotham
Genetics and Race

- No racial group possesses a completely discrete set of genetic characteristics.

- Definite biologic links between racial group and disease have rarely been found.
The variation in gene frequency is about 93%-95% within racial group, and about 3%-5% between racial groups.
Genetics and Race

- All individuals are 99.5%-99.0% identical at the DNA level

- Frequencies of particular variants will differ between populations

Genetic Diversity of Africa

Genetics and Race

- Genetic boundaries around population groups are not precise

- Differences in disease prevalence between groups may be due to:
  - Genetic differences
  - Dietary, cultural, environmental, socioeconomic factors
  - A mixture of both

Cancer Genetics and Race

- Prostate Cancer
  - African American men have higher risk of developing prostate cancer and higher mortality rate from this disease than European American men
  - The expression of current diagnostic and prognostic genetic markers is not significantly different between African American and European American men

Prostate Cancer

- Several genes related to metastasis or immune pathways are more highly expressed in African American men’s tumors.
- A two-gene tumor signature has been found to accurately predict whether a tumor was from African American or European American men.

Higher expression of AMFR, CXCR4, and MMP9 in tumors in African American men

CXCR4 and MMP9 are linked to metastasis

Cancer Genetics and Race (continued)

Cancer Genetics and Race (continued)

- Breast Cancer
  - The incidence of breast cancer is lower for African Americans than Caucasians
  - The age of onset is much younger for African American women

Breast Cancer
- The mortality rate of African American women <50 years of age with breast cancer is 77% higher than for Caucasian women in the same age group
- Cause believed to be multifactorial
Breast Cancer and Race

- Basal-like breast cancers (triple negative)
  - More common in premenopausal African American women
  - Hormone-receptor negative, HER-2 negative
    - ER-negative; PR-negative
  - High-grade, highly proliferative
  - High frequency in study of breast cancer patients in Nigeria

Other factors appear to influence the high breast cancer mortality rate among African American women

Race as a Social Construct: Racial Identification

- The variable “race” only approximates socioeconomic status, culture, and genetic history.

- “Race” significantly impacts daily life experiences.
Race as a Social Construct Underlies Health Disparities

- Racial Identification
  - Leads to differential levels of access, based on race, to services and opportunities
  - Negatively affects educational achievement, employment opportunities, and achievement of higher SES
Race as a Social Construct Underlies Health Disparities (continued)

- Within this conceptual framework, race is viewed as a factor on which access to health care, adequate housing, education, and nutrition are based, with resulting health effects.

- Race may be viewed as social psychological:
  - A social construct influenced by social and political factors.

Race as a Social Construct Underlies Health Disparities (continued)

- Race appears to be a predictor of exposure to external health risks, with resultant racial differences in health outcomes
Race as a Social Construct Underlies Health Disparities (continued)

- Phenotypic genetic expressions of race affect social interactions and health outcomes

Social-Environmental Factors

Susceptibility to Disease

Access to Health Care

Health Disparities
Relationships among Structural Life Inequalities, Chronic Stress, Negative Behaviors, and Physical and Psychiatric Health Disparities
Possible Interrelationships Among Environment, Stressors, Negative Health Behaviors and Physical and Mental Health Disorders

**ENVIRONMENT**
(neighborhood effects, noise, urban areas)

**STRESSORS**
(job, family, financial, relationships)

**POOR HEALTH BEHAVIORS**
(smoking, drinking, using alcohol and drugs, overeating)

**CHRONIC ACTIVATION OF HPA* AXIS**
(down regulation of immune system, outcomes associated with negative health behaviors)

**PHYSICAL HEALTH DISORDERS**
(diabetes, cancer, organ damage, etc.)

**PSYCHIATRIC HEALTH DISORDERS**
(major depression, anxiety, PTSD)
Racial Differences in Health Outcomes as a Combination of Socio-Cultural and Genetic Factors

Socio-Cultural Factors:
- Diet
- Physical Activity
- Environmental Exposure
- Psychosocial Stress

Genetic Factors:
- Genetic Variants

Ethnicity

- Personal identity
- Group identity
- A social-political construct
Ethnic identity, ethnic classification systems are specific to place, time and context

- Ethnic identity is fluid over the life course. A person may have no sense of ethnic identity in childhood but a strong identification later in life.
- A person may identify as Hispanic at work, Mexican at home and American when visiting Mexico.
Ethnicity (continued)

- Sharing a common culture, including shared origin
- Shared language
- Shared cultural traditions
Critical point: Ethnic boundaries are not precise and may be fluid

The term “ethnicity” is not always understood by study respondents

Disagreement in the literature over the use of “Hispanic”, “Latino”, and “Spanish American”
Ethnicity (continued)

- Two dimensions
  - Attributional dimension
    - Describes unique sociocultural characteristics (e.g., culture, diet)
  - Relational dimension
    - Describes characteristics of the relationship between an ethnically defined group and the society in which it is situated

Ethnicity
(continued)

- Attributional Dimension
  - Shared culture and way of life
    - Reflected in language, folkways, religious and other institutional forms, material culture such as clothing and food, and cultural products such as music, literature and art
Ethnicity (continued)

- **Relational Dimension**
  - Social stratification and social exposures may be related to the group’s relationship to the broader society
    - E.g., young age at first birth may be related to social isolation from youth development resources
Emerging evidence suggests that improving understanding of ethnicity is fundamental to achieving health equity for all.
Ethnic Group Membership Criteria

- Group membership is self-identified
- Group members share a common history, behaviors, and values
Ethnicity may influence health beliefs

- Symptom expression
- Physical functioning
- Entry into health service delivery systems
- Medical processes/treatments
Acculturation

Acculturation: the extent to which members of an ethnic group have adopted the beliefs and practices of another ethnic group

Relationship between ethnicity and health outcomes may be influenced by acculturation
Federal data collection guidelines dictate the procedures and categories to use when collecting ethnicity data.
ISSUE: Different Agencies Use Different Coding Schemes

- Example: National Center for Health Statistics combine ethnic groups when respondent numbers are low.

- This makes it difficult to compare data across different surveys.
Directive Number 15 of the Office of Management and Budget

- Hispanic or Latino origin is defined as a person of Cuban, Mexican, Puerto Rican, South or Central American or other Spanish culture or origin regardless of race.
Race is defined as:
- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander
- New Category: Some Other Race
Directive Number 15 of the Office of Management and Budget

- These federal standards mandate that:
  - Race and Hispanic origin (ethnicity) are separate and distinct concepts
  - When collecting these data via self-identification, two different questions must be used
1997 Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity

These federal Standards mandate that race and Hispanic origin are asked as separate items.
Directive Number 15 of the Office of Management and Budget

- Stipulates that federal agencies collect data on four racial groups and one ethnic group
  - American Indians or Alaskan Natives, Asian or Pacific Islanders, Black, Whites, and Hispanics

- Presents rules for classifying people into racial or ethnic categories
  - Two alternatives for identifying Hispanic ethnicity
Why Is the OMB Interested in Categorizing Race and Ethnicity?

Census data are used to:

- Plan and implement education, housing, health and other programs that address needs of different population groups
- Highlight regions for screening for diseases such as hypertension or diabetes
- Provide a rationale for implementing research interventions to improve health outcomes
Why Is the OMB Interested in Categorizing Race and Ethnicity?

- All levels of government use data on race and ethnicity to implement and evaluate programs:
  - The Civil Rights Act
  - Voting Rights Act
  - Fair Housing Act
  - Equal Employment Opportunity Act
  - 2010 Census Redistricting Data Program
stand up and be counted!
The Census Bureau

- Now obtains information on race through self-identification

- Issue associated with self-identification
  - Person’s self-concept regarding their race and ethnicity may change over time
Race and ethnicity were presented as separate items

Items allowed self-selection of multiple racial groups
NOTE: Please answer BOTH Questions 5 and 6.

5 Are you Spanish/Hispanic/Latino? Mark \( \checkmark \) the "No" box if not Spanish/Hispanic/Latino.
- No, not Spanish/Hispanic/Latino
- Yes, Mexican, Mexican Am., Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, other Spanish/Hispanic/Latino — Print group.

6 What is your race? Mark \( \checkmark \) one or more races to indicate what you consider yourself to be.
- White
- Black, African Am., or Negro
- American Indian or Alaska Native — Print name of enrolled or principal tribe.
- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Other Asian — Print race.
- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Other Pacific Islander — Print race.
- Some other race — Print race.
Reproduction of the Questions on Hispanic Origin and Race From the 2010 Census

→ NOTE: Please answer BOTH Question 5 about Hispanic origin and Question 6 about race. For this census, Hispanic origins are not races.

5. Is this person of Hispanic, Latino, or Spanish origin?
   - No, not of Hispanic, Latino, or Spanish origin
   - Yes, Mexican, Mexican Am., Chicano
   - Yes, Puerto Rican
   - Yes, Cuban
   - Yes, another Hispanic, Latino, or Spanish origin — Print origin, for example, Argentinean, Colombian, Dominican, Nicaraguan, Salvadoran, Spaniard, and so on.

6. What is this person’s race? Mark one or more boxes.
   - White
   - Black, African Am., or Negro
   - American Indian or Alaska Native — Print name of enrolled or principal tribe.
   - Asian Indian
   - Chinese
   - Filipino
   - Other Asian — Print race, for example, Hmong, Laotian, Thai, Pakistani, Cambodian, and so on.
   - Japanese
   - Korean
   - Vietnamese
   - Native Hawaiian
   - Guamanian or Chamorro
   - Samoan
   - Other Pacific Islander — Print race, for example, Fijian, Tongan, and so on.
   - Some other race — Print race.

Source: U.S. Census Bureau, 2010 Census questionnaire.
Percentage of Major Race Groups Reporting Multiple Races: 2010

(For more information on confidentiality protection, nonsampling error, and definitions, see www.census.gov/prod/cen2010/doc/pl94-171.pdf)

Note: Specified race group refers to the alone or in-combination population.
Source: U.S. Census Bureau, 2010 Census Redistricting Data (Public Law 94-171) Summary File, Table P1.
Assigns newborns the race and ethnicity of the babies’ birth mothers, although data on the fathers’ race and ethnicity are also collected.
Combines race and ethnicity into a single item

Replaced “other race” category with:

– Asian
– Asian American or Pacific Islander
– Hispanic
– Northern American Indian or Alaskan Native
Steps to Improve the System of Health Statistics in Medical Research

- Clearly define, operationalize, and standardize the meaning and measurement of race and ethnicity

- Comprehensively assess and incorporate into survey designs the way in which different segments of the population identify themselves by race, ethnicity, and other characteristics
Data on Race and Ethnicity in Health Care

- Data are used to:
  - Allocate resources
  - Develop interventions
  - Develop marketing plans
  - Create descriptive variables
  - Create covariates
Requirements of Instruments Assessing Race and Ethnicity

- Instruments should:
  - Produce consistent data over time
  - Allow comparability across populations and surveys
  - Use terms understood by the groups completing the instruments
A rationale for collecting racial/ethnic data should be held by researchers.
Summary

- Health disparities are real
- Resolving the issues should be a major concern to all public health and medical professionals
- Research studies could address racial and ethnic issues while highlighting prevalent environmental and genetic risk factors
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