ORIGINAL RESEARCH

Subjectively-assigned race versus self-reported race and ethnicity in US healthcare

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Abstract

Documenting patient "race" descriptors in clinical medicine, epidemiology, and public health data and analysis has been routine in the US. However, patient race has historically been and is still most often subjectively-assigned rather than self-identified. Even when self-identification is allowed, persons must often self-deny parts of their ancestry by adhering to restrictive race categories. In contrast, most other countries ignore so-called race and may use other ancestral background information including family and geographical histories, language(s) and/or ethnic group(s) membership.

We performed two studies involving 160 patients to investigate subjectively-assigned versus self-reported race using a verbal questionnaire in a New Orleans medical clinic. Results revealed that the subjectively-assigned race recorded by the hospital administration/physician was incomplete and therefore inaccurate.

Clinicians and researchers must make more accurate and respectful ancestral inquiries in order to derive useful information about individual and population health risks and disease conditions, while also being mindful of potentially erroneous race data previously gathered and conclusions inferred in healthcare literature.

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Introduction

The US's exceptional history in dealing with its human diversity has included numerous massacres of indigenous peoples; incorporation of chattel slavery in the 1789 US Constitution, which continued until the passage of the 13th Amendment to the U.S. Constitution in 1865, de facto (1865-1877) and then systematic (1877-1964) "Jim Crow" economic and human rights violations in effect from 1865 until 1964; miscegenation laws until 1967; and massive economic inequities existing today because of lack of restitution for centuries of official government oppression. Because of and despite this exceptional history, modern US society still primarily examines its population diversity through the concept of "race," a social construct abandoned by anthropology, the academic discipline most responsible for human evolutionary research.[1] "Race" in this article refers to the categories specified by the US government in Office of Management and the Budget (OMB) Directive 15.[2]

Although healthcare workers are obliged to be more accurate than general society, a subjectively-assigned (without input from the patient) race descriptor is still widely employed in the US medical, epidemiology, and public health (MEPH) professions.[3] However, the accuracy of patient race-labeling has been assumed rather than critically examined. In contrast, other countries use more accurate ancestral background information derived from patient geographical and family histories and/or ethnic group membership(s), while others do not use ancestral patient descriptors beyond a family history.

When a patient race descriptor is to be elicited in a US healthcare setting, patients can either be (1) race-labeled by healthcare workers (hospital administrative staff and physicians in our study) without

their knowledge, or (2) empowered to provide zero, one, or more races.[4] To determine the accuracy and judge the validity of race usage in US healthcare, we studied subjective race-labeling of patients by hospital administrators and physicians versus self-reported patient identification of race and ethnicity in two studies in New Orleans.

Methods

Two studies were designed to document and analyze if race identification differed between healthcare administrative staff (HA), physicians (MD), and patient self-report. Each study recruited 80 patients from a Tulane infectious diseases clinic in New Orleans. All patients had their HA and MD race assignment cataloged by collecting the information from patient "face sheets" (completed by HAs) and from clinical notes (written by MDs). Twenty-two patients in the first study and all patients in the second study were then asked about their ancestry including ethnic group membership(s) back to their grandparental level. Results were entered into a database. No additional variables were collected. The studies were approved as exempt research by the Tulane University Institutional Review Board.

The first study, titled the Selected Inquiry Race/Ancestry Study (SIRS), cataloged HA and MD subjective race-assignment for 80 consecutive patients. We further queried 22 selected patients who appeared multiracial to the investigating team (RW) in order to test the accuracy of investigator subjective race-labeling versus the patient's declared ancestry. The remaining 58 patients had only the HA and MD race data collected. The second study, titled the All Inquiry Race/Ancestry Study (AIRS), entered a separate cohort of 80 consecutive patients. All 80 patients in this study had their HA/MD race assignment compared to self-reported ancestries. Patients who were queried (22 in the SIRS and 80 in the AIRS) were asked about their ancestry back to at least their grandparents in the context of a Performance Improvement Module to improve patient care in the clinic. The topic was introduced verbally to patients: "This month we are doing a Performance Improvement Module to improve patient care in the clinic and would like to give you the opportunity to tell us about your and your family's ancestry in detail, starting with your parents and grandparents. Would you like to participate?" All patients agreed to participate and gave verbal consent.

Patient self-reported race and ethnicity was taken as the gold standard in these studies. All patients directly queried about their ancestry (22 in SIRS and 80 in AIRS) were specifically asked about African, Asian, European, Latino (South or Central American), Native American, and Cajun and Creole ancestry. In New Orleans and Louisiana, "Cajun" refers to persons of French heritage who were forced to emigrate from Canada to Southern Louisiana in the mid-18th century. While in the past "Creole" could designate a linguistic heritage of spoken French (and more distantly Spanish), in current times it is understood to be of French colonial ancestry, i.e., ancestry directly descended from French immigrants rather than those of French-Canadians exiled to Louisiana (Cajuns). Cajun and Creole heritages are therefore ultimately included in the European category. Patients were also queried whether they had Native American (also asked as "American Indian" in colloquial usage) heritage, and if so, were asked to specify which group(s) they belonged to, if known. Patients were also informed that they were free to volunteer any other category not presented.

The frequencies of multiracial (more than one race identified) patients determined by subjective HA/MD race-labeling versus patient self-identification of ancestry were compared by Fisher Exact testing.

Results

SIRS – Selected Inquiry Race/Ancestry Study

Of 80 consecutive patients, 28 were labeled "white" (European heritage) and 51 "black" (African heritage) by both HAs and MDs; one individual was labeled black by the HA and white by the MD (he was actually neither; see below).

On investigator query of 22 presumed multiracial individuals, 21 (95%) stated an additional different race ancestry than that documented on their medical records. Four patients labeled as mono-racial white by HA or MD had Native American heritages and described their ancestries as Blackfoot/German, Cherokee/European, Coushatta/European, and Cre-

ole/Mexican/Native American.* Sixteen of the 17 (94%) patients subjectively labeled as mono-racial black by both HAs and MDs but multiracial by study investigators were self-declared to be multiracial. Patient ancestries were:

13: African and European [Creole (10), Creole/Cajun (2), Honduran mestizo (1)]
2: African and European [Creole (2)] and Native American [Choctaw (2)]
1: African and Native American [Honduran Garifuna (1)]

One male of medium complexion whose biological mother could "pass" for European was designated as black by HA/MD and he denied multiethnic/multi-racial ancestry, stating he was of African heritage only. One male registered as black by the HA and white by the MD was actually neither, but a Lakota Native American ("Sioux Indian").

When an investigator suspected a patient was multiracial, this was confirmed in 91% (20/22) of patients when an ancestral history was performed. HA/MD race data correctly identified the race of one of two monoracial patients (1/22). The difference between these two methods is highly significant in our patient population (χ^2: $p < .01$). Despite the limited ancestral inquiry of only selected individuals who appeared multiracial in this study, 25% of the complete group (20 of 80) was found to be multiracial versus 0% by the HAs/MDs; this difference in the aggregated population was also statistically significant. Finally, one patient was race-labeled differently and erroneously by both the HA and MD, and was neither black nor white, but Native American.

AIRS – All-Inquiry Race/Ancestry Study

Of 80 consecutive patients, HAs labeled 78 of 80 patients (20 as white; 58 as black), and MDs labeled 66 of 80 patients (17 as white, 49 as black); all were assigned a single race. All but one of 65 dually HA/MD labeled patients were given same race. This individual was labeled by the HA as white and the MD as black, but he self-identified as African/European [Creole]/Native American/Latino. Only one of the 80 patients had neither a HA nor MD racial assignation; he self-identified as Nicaraguan-Latino. None of the patients in this study participated in the previous inquiry.

A majority (47/80, 59%) provided an additional race ancestry other than that documented on their medical records by either HA or MD.

Eight of the 20 (40%) labeled as white by HAs and/or MDs stated their ancestries as multiracial. They were:

7: European and Native American [Choctaw (2), Cherokee (1), Coushatta (1), Mohawk (1), unknown (2)]
1: African and European and Native American

Thirty-nine of 59 (66%) labeled as black by HAs and/or MDs stated their ancestries as multiracial. They were:

14: African and European [Creole (9), Cajun (1), Cajun/Creole (1), unknown (3)] and Native American [Cherokee (3), Blackfoot (1), unknown (10)]
13: African and Native American [Cherokee (3), Blackfoot (1), Choctaw (1), unknown (8)]
10: African and European [Creole (8), Creole/Cajun (1), unknown (1)]
2: African and European [Creole (1), unknown (1)] and Native American (unknown) and Latino (Honduras)

Native American heritage was claimed by 38 of 80 (46%) patients, with 14 of 38 (37%) naming a specific group. Native American heritage was evenly spread amongst those labeled white and black: 8 of 20 (40%) of those exclusively labeled white and 29 of 59 (49%) exclusively labeled black.

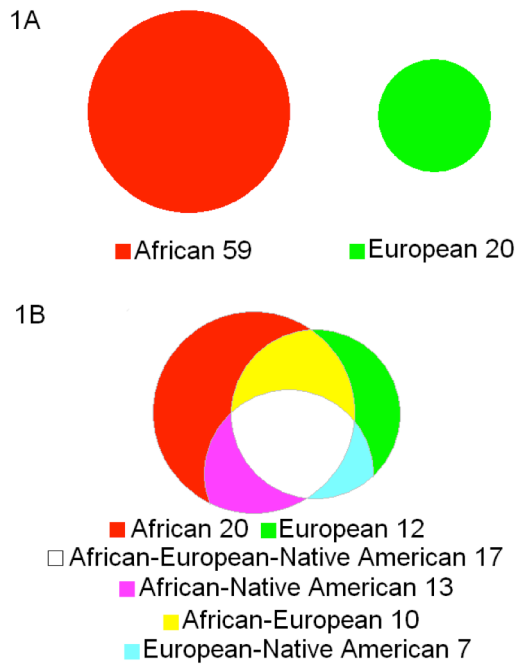
Taking an ancestral history on all patients resulted in correctly identifying far more patients as multiracial (47/79, 59%) than relying on subjective HA/MD race data (0/79, 0%). Figures 1A and 1B provide a striking Venn diagram visual dichotomy of perceived human diversity using the AIRS study data.

SIRS versus AIRS Study Results

When the two study populations were compared there was a significant difference between taking a patient ancestry history only when one suspects a

* All "multiracial" individual contributions are noted in alphabetical order in this paper

Figure 1. AIRS study: Comparative Venn diagrams of HA/MD subjective-assigned race (1A) and self-reported race and ethnicity (1B).



patient to be multiracial (SIRS study 25%: 20 of 80 "multiracial") versus taking an ancestral history for every patient (AIRS study 59%: 47 of 80 "multiracial"). Comparison of two separate cohorts – even if from the same community – does weaken this analysis. However, it is intuitive that full and accurate patient and population ancestral information cannot be obtained by selective patient query alone, i.e., by questioning only patients that appeared to be multiracial. Instead, query of all patients is necessary to obtain a more complete picture of individual and population diversity.

Discussion

These studies demonstrate that the subjectively-assigned race given by healthcare administrators and physicians misclassified 47 out of 80 (59%) patients, ascribing to them a single race when in fact they self-identified as multi-racial according to OMB Directive 15. However, this experience in the historically diverse "human gumbo" of New Orleans may not be typical of other areas of the US; some areas may be more diverse, others less so.

By querying patient ancestries, the investigations empowered patients to freely express their multiple ethnic group and "race" contributions. We subsequently aggregated patient ethnicities (such as Cajun versus Creole or specific Native American group) into the government race categories only for the specific purpose of demonstrating the gross inadequacy of subjectively race-labeling.

Although the studies asked patients about race and ethnicity, it is important to note that our patient-declared ancestry of 59% multiracial was in US government terminology a true "race" difference rather than an ethnic group difference. Race is by definition a much larger aggregated grouping made up of smaller distinct units such as ethnic groups. Therefore, our findings make the HA/MD ancestry error that much more striking.

The studies' results have reinforced our teaching and practice of never subjectively labeling "race" or ethnicity or any other patient ancestral characteristic. Patients must be asked directly and empowered to answer completely.[4] In an earlier work, the use of "race" was discouraged, and health workers were encouraged to accurately seek ethnic group and familial ancestral information when clinically indicated.[3]

In addition, we discourage the use of colors to describe human beings because they are overly simplistic and scientifically inaccurate. Human skin tones do not follow a primary color scheme. It has been generations since the yellow and red primary colors were inappropriately used to race-label East Asian or Native Americans. However, we acknowledge that white and black race-labels are still in wide use in the US for complex social and policy reasons beyond the scope of this paper. Similarly, the term "Caucasian" also provokes confusion as it represents an "ideal" human type from the Caucasus Mountains that is not representative of the geographic term "European."[5] Therefore, for all persons we encourage the use of their more precise ancestral and geographical terms that are ideally self-reported.

We believe these studies show that "race" (and to a much lesser extent ethnicity) is a continuous population variable that cannot be readily converted into a discrete variable (e.g., black, white, yellow, red,

brown). As a descriptor race provides vastly more information on social construction than on scientifically derived biological difference. That being said, it is intuitive that smaller ancestral groupings, voluntarily elicited from patients (such as ethnic, tribal, clan, and/or family groupings), provide more accurate social and genetic information. Although this clinical acumen is not yet widely accepted in US healthcare, it has been for some time the foundation of the major works of human medical[6] and evolutionary and population genetics.[7]

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