Racial Differences and Racial Disparities: The Distinction Matters

Running title: Taylor; Racial Differences in Heart Transplant

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Those who practice medicine in the United States are unavoidably confronted by the fact that health status, disease burden and lifespan vary by population groups – particularly the persistent reality that cardiovascular disease outcomes are poorer in African Americans compared to European Americans (the majority reference group), Asian Americans (those from China and Japan having best outcomes, those from South Asia having higher disease burden at younger ages) and Hispanic Americans (who experience better than expected outcomes despite having many risk factors). The causes for population variation in health outcomes are multifactorial and can include biologic, environmental (physical and social), genetic, epigenetic and social determinants, a mixture of disparities and differences.

In this issue of Circulation, Kilic et al\(^1\) have examined clinical characteristics, biologic features and one year post-transplant mortality using data from nearly 19,000 patients who have undergone orthotopic heart transplantation in the United States over a 10 year period. They compared clinical characteristics, immunological features and one-year post-transplant outcomes among three US racial/ethnic groups designated as black (African American), white and Hispanic. Significant differences were identified in one-year post transplant mortality and in several categories of variables which might impact post-transplant mortality, principally between African Americans and whites. Differences between whites and Hispanics were few. Variables included a few general social factors (highest level of education attained, insurance type); selected clinical features (renal function, time on the waiting list prior to transplant, etiology of heart failure, need for pre-transplant mechanical support, donor and recipient risk scores and post-transplant medication compliance); and a small number biologic features (degree of blood type and HLA matching, recipient gender, and donor recipient racial concordance).

The key finding was a significantly higher adjusted and unadjusted one-year post-
transplant mortality for African Americans compared to whites and Hispanics. Much of their analysis focused on the relationship between the performance status of the transplant center and the one year post-transplant mortality outcomes by race/ethnicity with the following principal findings: Firstly, African Americans were more likely to undergo transplantation at poorer performing centers; secondly, at those centers, African Americans had significantly increased risk adjusted mortality; thirdly, centers with worse performance status had higher proportions of African American patients than whites and Hispanics. However, the most interesting, unexpected and compelling finding in the study was that African Americans transplanted at excellently performing centers also had increased one year post-transplant mortality compared to whites (OR 1.42, 95% CI 0.99-2.02, p=0.06). It is startling that the ratio of mortality between whites and African Americans at excellently performing centers was worse (0.72) than at poorly performing centers (0.83) (p=0.03 for the difference in 1 year mortality between races at excellent centers, Table 3). They correctly identify the limitations of analysis of limited registry data.

Interestingly, however, the author’s discussion focused on what they described as “the propensity of blacks to be transplanted at worse performing heart transplant centers”. While they rightly conclude that simply shifting patients to higher performing centers would not fully resolve the higher mortality in African Americans, they have totally missed an opportunity to consider deeply what the meaning might be of the most unexpected and thought provoking finding of the study. Worse and perhaps recklessly, the conclusion that the cause of the difference could be attributed to a “propensity”, (defined by the Oxford English dictionary as a “natural inclination “) of African Americans to choose more poorly performing centers could actually discourage probing the meaning of their most novel finding.
At first glance, this is a paper that adds modestly to a longstanding literature enumerating racial/ethnic variation, frequently exclusively described as “racial/ethnic disparities” in the outcomes of solid organ transplantation, and confirms significantly poorer outcomes in African Americans than in other demographic groups in the US. However, upon further consideration, the paper highlights a more overarching contemporary issue in medicine that requires critical attention. That is how we conceptualize and, importantly, use language to describe variation among population groups. Because words carry both denotative and connotative meanings, the linguistics of population group differences will be highly influential as we advance the research and clinical care initiatives to personalize medical care.

“Health disparities” according to the Institute of Medicine Report “Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare” are “differences … that are the result of the operation of healthcare systems, legal and regulatory climate as well as discriminatory biases, stereotyping and uncertainty”. Thus in this instance, the greater use by African Americans of more poorly performing centers may, in fact, be an example of a true racial disparity driven by the social and system complexities that determine choices of residence, economics of access beyond income level and insurance type, healthcare system services to segments of the population, as well as the nature of the physician patient interaction. A sample of the significant literature exploring these factors might have informed the discussion. The conclusion that the reason for this finding is a “propensity of blacks to be transplanted at poorer performing sites” would suggest that this is a “natural inclination” of this population group. This linguistic frame discourages study of the complex reasons, well beyond what could be described as a “natural inclination”, why African Americans might choose such centers. Further, it shifts the blame for use of poorer centers to patients with limited choices as opposed to understanding
the multiple personal and system drivers of health care choices. This is an example of a counter productive and likely unintended use of language in reference to racial variation in health outcomes that, by its connotation, encourages a negative social view of African Americans in what should be a more carefully considered medical context.

In contrast to racial disparities, is the issue of “racial differences” as determinants of health status and disease. “Racial differences” should be defined as clinical, biologic, genetic or epigenetic factors associated with disease risk, outcome or treatments not caused by social factors that vary in prevalence in population groups. 14,15,16 “Racial differences” are, however, considerably more difficult to discuss because of the social construct that defines race. “Race” has been the traditional way to describe populations originating from different continents with similar superficial phenotypic characteristics. Social scientists correctly point out that there is only one human race and that the traditional concept of “race” is used in sociopolitical and economic contexts as a measure of overall difference, superiority and inferiority. Consequently, it is used as a rationale to devalue, demean, and debase specific population groups. It is this meaning of “race” that has been used historically by societies, individuals and sadly even, at times the medical establishment (in a time not distant enough to be erased from the memories of still living African Americans), to justify abuses, legalized crimes and atrocities. Within this context, social scientists rightly insist that the concept of “race” has no place in medicine. However, we are still left with “differences” sorting along traditionally defined “racial” population groups that have important impact on disease etiology, expression and treatment. Kilic et al.1 describe some of these differences in the clinical characteristics and immunologic features that sort along the boundaries of traditionally defined racial groups in their study. These differences require focused study to understand their causes, impact and mitigation. In this

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instance, “race” is important in medicine, but we are at a loss for a language about race that is unencumbered by and uncoupled from the shameful social history of “race”.

Personalized medicine has as its goal use of genetic data providing clues to specific disease risk, expression and therapeutic targets to optimize treatment for every individual, regardless of his/her “social race or ethnicity”. One excellent byproduct of this approach effort will be the ability to transcend concepts of race in medicine by the use of knowledge derived from extensive genomic analyses from large numbers of population groups applied to understanding and treating diseases in individuals.

Data will likely, at least initially, still be collected from groups defined by the conventional “racial” groupings, a prospect that generates substantial angst among minority populations who fear that “social racism” may pervade the study of genetic differences and result in “genetic racism”.

As this work moves forward, it is perhaps timely to strongly consider finding a language that permits definition of population “differences” without the stigma associated with the social construct of race, but a language that maintains the social construct of race where it is truly important – as the impetus for the very real health “disparities” that stubbornly persist in our society.

One final thought about the most compelling data point in the paper by Kilic et al, the fact that the “racial difference” in outcomes at the excellently performing centers was greater than at the poorly performing centers. The reasons for this finding should strongly drive further aggressive research in both “racial disparities” (i.e. could social factors still strongly influence care at excellent centers resulting in adverse outcomes for African Americans?) and “racial differences” (i.e. how do the biologic, immunologic or genetic factors drive the outcome
differences and are there as yet undefined factors) as well as interactions between disparities and differences. However, if we do not rigorously attend to the conceptual, contextual and linguistic challenges of “race” in medicine, we will remain mired in past centuries and sabotage the future of individually optimized medical care.

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