Racial profiling in medical research: What are we measuring?

Basset1 relates the story – probably apocryphal – of the American visitor to Haiti who, upon meeting Jean-Paul Duvalier, the legendary (if notorious) dictator popularly known as Papa Doc, asked him ‘So, how many whites live in your country?’ ‘Why, in Haiti, nearly everyone is white,’ Papa Doc replied confidently. Astonished, the visitor enquired ‘But how do you define white?’ The iron-fisted ruler thought for a moment, and then asked ‘How do you define black in the US?’ The American proceeded to explain the ‘one drop rule’ whereby anyone with black ancestry within four generations was classified as black. ‘Well, we use the same definition,’ Papa Doc retorted (many Haitians can trace white ancestry within four generations).

The story aptly illustrates the soft underbelly of ‘racial’ classification based on ancestry or physical attributes, something with which we in South Africa became all too familiar during the era of apartheid with its Population Registration Act (PRA) and other similar legislation. Sadly, our current population census forms and other public and private registrations still require South Africans to indicate their ‘race’ by ticking one of 4 boxes (the bureaucrats have determined that there are only 4 ‘races’ in the country). In the US, a country with a similar history of social and statutory racism, the census form provides for 5 ‘race’ categories, which are listed as white; black or African American; Eskimo and Native American; Hawaiian and Pacific Islander; and Asian. But, in a strange and telling twist, the respondent is allowed to tick more than one box.

The rationale given for continuing to collect statistics by ‘race’ in South Africa is so that post-apartheid transformation can be monitored, the theory being that such race-based vigilance will facilitate the redress of past deprivations. Plausible as this may sound, and while one may have some sympathy for the state’s dilemma, the practice runs the real risk of entrenching a ‘race’-based mindset and ‘race’-based attitudes. People are more likely to perceive the obligation to declare one’s ‘race’ on a form as an affirmation of the ‘race’ classification based on ancestry or physical attributes, something with which we in South Africa became all too familiar during the era of apartheid with its Population Registration Act (PRA) and other similar legislation. Sadly, our current population census forms and other public and private registrations still require South Africans to indicate their ‘race’ by ticking one of 4 boxes (the bureaucrats have determined that there are only 4 ‘races’ in the country). In the US, a country with a similar history of social and statutory racism, the census form provides for 5 ‘race’ categories, which are listed as white; black or African American; Eskimo and Native American; Hawaiian and Pacific Islander; and Asian. But, in a strange and telling twist, the respondent is allowed to tick more than one box.

The winds of change of the 1990s inspired a new editorial policy at the SAMJ not to publish papers making unwarranted reference to ‘race’. The policy evoked some anxiety and debate among activist epidemiologists who viewed the continued use of ‘race’-based analysis as still necessary to highlight residual health and health care inequities, and as a mechanism to monitor and press for post-apartheid redress.

Since that time, however, other peer-reviewed international journals have adopted a similar editorial policy. Wikipedia4 records that ‘In February, 2001, the editors of the medical journal Archives of Pediatrics and Adolescent Medicine asked authors to no longer use “race” as an explanatory variable and not to use obsolescent terms. Some other peer-reviewed journals, such as the New England Journal of Medicine and the American Journal of Public Health, have made similar endeavours.’ In their 2001 editorial, the editors of Archives of Pediatrics and Adolescent Medicine elaborated that ‘race and
ethnicity should not be used as explanatory variables, when the underlying constructs are variables that can, and should, be measured directly (e.g., educational level of subjects, household income of the families, single vs 2-parent households, employment of parents, owning vs renting one’s home, and other measures of socioeconomic status)\(^3\). More often than not, ‘race’ serves as a proxy or surrogate for the real causes of ill-health. Invoking ethnicity as a health determinant without further elaboration ‘leads to sloppy thinking about causation and confuses social, political, and cultural determinants with unproved genetic factors’.\(^4\) This does not render these social population groups biologically distinct ‘races’, nor are these disorders limited exclusively to them.

Health inequalities are rooted in our society, not in our genes

The point of this editorial is not to deny the reality of ethnicity, understood here to refer to social formations based on shared culture, values, language, descent, religion or other commonality, and which can be fluid and open-ended, so that one can be Ethiopian, African, and Jewish all at the same time. Nor is it to deny the reality of external differences based on skin colour or other physical characteristics.

In unequal societies with a history of institutionalised racism, particular health and medical problems have a particular prevalence in ethnic groups that are longstanding victims of material deprivation and health care inequities. In this context, research into health disparities of social groups that are victims of discrimination is both legitimate and important. However, the researcher should be quite clear as to what is being measured. The research should not lead to ‘social and economic variables [being] mixed up with, and confused with genetic determinants’\(^5\) in the mind of the researcher, and should not lead to the misperception that being black (for example) – rather than poverty, limited education, poor housing, lack of sanitation, poor nutrition and other deprivations – is the ‘explanation’ for ill health.

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