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Lessons in our faults: Fault lines on race and research ethics

Addressing the question of race in scientific research

Since the publication of the now infamous paper 'Age- and education-related effects on cognitive functioning in Colored South African women' by Nieuwoudt and colleagues where they claim the cognitive functioning of coloured women is defective in some ways,[1] there has been renewed doubts about the legitimacy of race in research at Stellenbosch University and the controversy has become a matter of concern for universities and research ethics boards across the country. Because of the harms the Nieuwoudt paper has caused, the question of the use of race in research has re-emerged as a central concern. What researchers want to know is how to assess whether race is relevant to some question(s), how to use racial classifications if race is relevant, and when to leave race out.

The attention which this paper has received is perhaps related to how it is a caricature of a more common and mundane problem about the status of race in research. Considered responses to the paper have centred on the question of how we are to use race in academic settings if at all. The Nieuwoudt paper is a caricature of the problem because the study it presented was fundamentally misguided, it relied on racist stereotypes in a quite explicit fashion, its claims about the homogeneity of the group it studied are patently false (to bolster their claim, they cited a paper that actually makes the opposite claim), and it did not meet basic scientific standards in both its claims and their assessment.[2] Because of its basic scientific failings, some academics have asked how the Nieuwoudt paper managed to pass peer review and how the research protocol managed to attain ethics approval in the first place.[3] A speculative conjecture in this regard is that the reviewers themselves may have held uncritical beliefs about race that made them overlook what, for many researchers and concerned South Africans, were glaringly dubious and problematic claims about race.[3] After a year-long investigation at Stellenbosch University, it was finally announced that 'the article was not aligned with the Research Ethics Committee (REC) approved protocol', meaning that it is arguable that this research did not follow the recommendations of the REC.[4] That the article was soon retracted by the journal for its lack of scientific merit suggests that there was a failure of quality control at the level of the peer review that the journal recognised on a second assessment.[5]

The more general and mundane problem this points to, both locally and internationally (the paper was published in an international journal of good standing), is that this publication may be indicative of a lack of understanding about how to manage the variable of race and its possible uses. It is for this reason that the Nieuwoudt paper inspired numerous symposia and workshops about race and research on the various campuses of Stellenbosch University. Notable are the events held by the University Senate, the Department of Psychology, and the Medical Faculty. Out of the event held by the Medical Faculty came an edited collection, *Fault Lines*.[6] This edited collection aims to tackle the problem of race in research head-on.

The book is a welcome beginning to treatments of race in research and opens the door to more critical discussions about the issues it explores. A glaring gap and fundamental weakness of the collection is the absence of dealing with the material and economic aspects of race and racism despite its historical lens. The book has very little to say about the point of white supremacist ideology through colonialism and apartheid being used to justify dispossession and to ensure the material racial domination and material inequality from which the country still suffers. This may make it seem as if the problem of the continued production of racist research is disconnected from the problem of the continued reproduction of a systemically racist society in not only the academy but in the economic domain as well. Addressing the issues of the material bases of race and racism directly would have gone a long way to further contextualising and illuminating the conditions which produce or afford these research products and the broader social power relations to which they belong and from which they manifest.

The resultant scope and strength of this collection is how it gives some historical context to the use and abuse of race in different research settings, especially in how research ethics have been contravened in respect to race around the world. Importantly, this book provides specific guidelines on the use of race in research in the South African setting. Given that the aim of the book is to help us understand race in research, the collection feels incomplete as it leaves out a central aspect to understanding race – the material and economic – and how that then plays out in our research activities. Nevertheless, this collection is a useful introduction to the debate that can be supplemented with works about the material bases of and incentives for the continuation of racism in South Africa.

Not all contributions in the book endorse racial classification or its use. Some contributors outline an orientation that challenges 'race thinking' and its place in academics, politics, and in social and personal identity. It is unclear how the tensions between the problematic nature of race and race's employment in research is to be resolved under those considerations, but they do open up a space to explore many interesting questions.

Other contributions in the collection argue for critical uses of race, which often accompany an understanding of race as real and having a justifiable place in research. One of the editors of the collection, Johnathan Jansen, puts the case like this:

> *Not all studies of race are socially regressive. Put differently, there are critical studies of race that should not be denied ethical clearance simply because the study is about race. The point of departure for such critical studies of race is not that race is real in the sense of it being a biological or cultural essence; rather, the starting point for such studies is that race is a social category whose functions need to be unmasked.*[7]

I will further comment on three chapters in the collection that I believe hold some important lessons for the use of race as a variable in research – both in terms of thinking about what race is in general and in thinking about if race is relevant to specific scientific studies.

From genetics to race and ethnicity in the human sciences

After an introductory overview, the first chapter of the book takes us through the basics of human genetics and human biological diversity. This chapter, 'The Role of Genetics in Racial Categorisation of Humans'[8], addresses the question of whether race is biologically real. This chapter is penned by two geneticists, Soraya Bardien-Kruger and Amica Müller-Nedebock, from Stellenbosch University.

They make the case that race is not biologically real, and recount the standard reasons related to the apportionment of genetic diversity across our species and how genetically similar people are to one another. Much attention in this contribution is paid to sketching the basics of human genetic diversity and the current consensus about individual- and population-level differences between humans. This makes this chapter especially useful as an introduction to the relationship between race and biology. The authors make their case by explaining why race is not a valid taxonomic category, why race does not represent human genetic diversity well, and why race can sometimes correlate with some clinically or medically relevant information despite race not being biological. The authors do this in a lucid non-technical style that makes it easy to follow even if you do not have a background in genetics.

One reservation I had with this chapter is its treatment of ethnic groups as biological categories. Although ethnic groups may be more reliable in a number of respects in clinical settings and generally have a closer relationship with genetic ancestry than races do, ethnic groups are still social groups and are not biological categories.[9,10] The use of ethnic groups is one way approximations to biogeographical or genetic ancestry are made, as the authors describe, but ethnic groups are not themselves units of ancestry – ethnic groups are not ancestry groups at any level of biological population. This means that ethnicity is separate from genetic ancestry.

All that one needs to do to understand why ethnicity and genetic ancestry are separate is to think about how ethnic classifications operate. Consider the case of 'trans-ethnic' adoption between, say, English parents and an Afrikaner or French child, or a Tsonga family and a Zulu or Shona child. The child's ethnic group can change, yet their genetics remains the same. Even as an adult, the ethnic group someone is said to belong to is heavily dependent on the aspects of their heritage or acquired culture with which they are associated, and this heritage or culture is not strictly tied to specific relations of a biological nature. Ethnic classifications, like racial classifications, are social categories, despite any correlations they may have in some clinical and medical research settings.[11] Racial and ethnic categories, along with all of their surrogates, should not be used uncritically as uncritical uses of these categories can be misleading and have dire consequences that can be quite direct for patients in clinical contexts.

This difference between race, ethnicity and genetic ancestry is made clear by Jimmy Volmink, Lynn Hendricks, Lindokuhle Mazibuko and Leslie Swartz in their contribution 'Race and Health: Dilemmas of the South African health researcher'.[12] They distinguish genetic ancestry from social classifications like race and ethnicity and explain how they operate differently. They explain:

> *Unlike race or ethnicity, which is concerned with how a person fits into a particular group, genetic ancestry focuses on how an individual's history has unfolded – essentially, how his or her ancestors moved and mated. Someone's self-identified or assigned race or ethnicity may therefore differ considerably from data computed using AIMs [*ancestry informative markers*], and may also reflect multiple ancestral origins.*[12]

The concern in this chapter is with the understanding and use of race in health and clinical research settings. The authors make a case for a nuanced approach to the use of racial terminology that takes into account the various environmental and genetic influences that could be at play in any particular health setting. In the same breath, they warn of the dangers of 'clinical racial profiling' and the dangers inherent in profiling in health-care settings more generally. Because the use of race and ethnicity as markers of biological variation is misleading, they discourage their use as guides to such variation, especially as it could undermine patients' quality of care and afford the neglect of investigating or identifying structural pathways to certain health outcomes. It is in light of these considerations that the chapter looks at the use of racial, ethnic, and ancestry related terminology in a year's worth of publications from the medical faculty at Stellenbosch University. In this, they debate the need to keep to international standards in the use of classifications whilst taking the local context and the particular history of racial terminology in South Africa into account.

The last contribution I will discuss, which is also the final chapter of the book, brings the collection to a close in answering the central question of the book: the relationship between race and research ethics. That question is whether or not the use of race in research is ethically justified. This is the topic of Keymanthri Moodley's contribution, 'Science, Race and Ethics'.[13]

In the context of research ethics, justification must incorporate both social and scientific reasons that show the benefits of undertaking research in one particular fashion rather than another. Ethical research, Moodley suggests, weighs the relative costs and benefits of research. The eight criteria Moodley offers for undertaking ethical research are meant to help decision-makers make a cost–benefit assessment. These eight criteria are: (1) establishing collaborative partnerships, (2) considering the social value of a study, (3) ensuring its scientific validity, (4) ensuring the fair selection of participants, (5) assessing the risk–benefit ratio of a study, (6) going through an independent ethics review, (7) having informed consent, and (8) ensuring respect for participants. These are practical criteria that can be used as a guideline in considering the ethics of a study.

Moodley's chapter begins with an overview of instances of scientific malpractice and unethical scientific experimentation on human subjects. Local examples she touches on are the infamous experiments of South Africa's Project Coast led by Wouter Basson to the Bezwoda case, and some of her international examples are the eugenics programmes of the 20th century and the US Tuskegee syphilis study. Different lessons can be drawn from the lack of research ethics in each case, specifically in respect to the blatant disregard of the human rights of the people experimented on in each of these cases. The cases explored are woven together by their racist ideological underpinnings that enabled justifications for targeting particular demographics for unethical treatment in scientific settings. The scientific merits for undertaking many of these studies were in themselves fundamentally questionable beyond their more general ethical failings.

As a precondition for research being ethical, Moodley posits that the research must be scientifically sound. As the methodology of the Nieuwoudt study was not scientifically sound, it should not have passed ethics review (note: the protocol used in the Nieuwoudt study was found not to match the protocol approved by the REC).[4] It is under such a framing that Moodley says 'this study is regarded as unscientific and therefore unethical'[13]. Her point is that expertise is central to the ability of researchers to be able to carry out ethical research. In this regard, the question arises as to why cognitive function was a topic seen fit to be explored by sport scientists as well as if any of them had the relevant expertise to undertake such a study. Addressing these questions may have led the researchers to make better decisions about this study, if to undertake it at all.

Researchers may not always have a fair idea of their own abilities or limitations. This is where the role of peer review and academic checks and balances have a role to play. Checks and balances present an opportunity to interrogate the assumptions researchers may have and to test the social and scientific viability of their studies. This is the role of a REC, and it is critically important when considering difficult topics. In this regard, Moodley suggests that:

> *Given our history, any study that attempts to link race with cognitive function must be carefully considered by a REC. This is why the National Health Research Ethics Council (NHREC) in South Africa has guidelines for who should serve on a REC. Members should represent the demographic profile of the country to ensure sensitivity to local context in order for a proper risk assessment to be made.*[13]

This is perhaps challenging to do at universities like Stellenbosch University which remain predominantly white in both academic staff and student demographics. Because many South African universities remain untransformed in similar ways, universities struggle to meet these conditions. Thus, oversights on certain issues may be a direct result of these more institutional issues and the institutional culture under which research is assessed and produced. The institutional orientation and demographics of the University itself may be structurally biased towards the poor outcomes manifest in caricature in the Nieuwoudt paper. Moving forward, my hope is that the Nieuwoudt paper could bring urgency to calls for transformation and spur on efforts to undertake some fundamental change in our universities' structural orientations, pedagogy and research traditions.

An important lesson to come out of the Nieuwoudt experience that has been somewhat overlooked is the importance of research ethics for researchers themselves. If the details of the Nieuwoudt study are significantly different from what was approved by the REC,[4] then the researchers missed the opportunity to subject their work to quality control checks from which they could have benefitted. Nevertheless, as many of the contributions in *Fault Lines* suggest, the problems of race and research run far deeper than the operation of RECs. So long as those problems are not resolved, we can expect the production of racist research to be recurrent.

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