

Race, genes, power

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... [T]he thing is, we treat racism in this country like it's a style that America went through. Like flared legs and lava lamps. *Oh, that crazy thing we did. We were hanging black people.* We treat it like a fad instead of a disease that eradicates millions of people. You've got to get it at a lab, and study it, and see its origins, and see what it's immune to and what breaks it down. (Chris Rock, interviewed by Frank Rich, *New York Magazine* 2014)

Race is sorting schema that is rarely neutral. It permits people to be classed, judged, included, excluded, normalized, pathologized and, at the extreme, killed. Racial death-dealing practices shift as our political sympathies and apathies change, as do the life-promoting technologies that racial thinking imbues with persuasive power today.

In the quote above Chris Rock is speaking to columnist Frank Rick about Ferguson, Missouri and the state of race in the USA at the end of 2014. A new attention to police racism, and death dealt to unarmed black men at the hands of white officers, has made daily headlines, inspired massive protests in most major US cities, and put hope for improved race relations at a periodic new low (Pew Research Center for People and the Press 2104). A real concern that black, human, male lives lost are seen as insignificant and disposable has spawned a social movement called '#Blacklivesmatter' that has also reached Europe. With the pain and quest to interrogate what racism is 'immune to', several bloggers, academics, leaders of the NAACP, and editorialists in both the USA and the UK have compared recent killings of black men in America to an earlier era where lynchings took place with impunity (Cheyney-Rice 2014; Grundlund 2014). Commenters point out the striking recurring similarities of blacks being murdered without due process during the Jim Crow era with underreported FBI data on the statistical frequency of today's killings of blacks at the hands of police (King 2014; Wilkerson 2014.) The sociologist Jerome Kerabel has widened the conversation on race, state power, and death: he makes the point that today's police killing of untried, innocent people is state capital punishment, albeit in a new form. It is one with much less oversight, yet with many more executions per year than the official kind (Karabel 2014).

In witnessing criminal justice and other institutional forms of race bias, we observe racism's immunity on a daily basis. But what breaks it down? And what might the site of the lab have to do with this? Is there a possibility that what breaks it down, also reinvigorates its immune system? The answer to the latter is yes, and it turns out that genetic and genomic science today prove to be key sites to explore how this happens.

Technologists often cite the concept of 'dual use' to describe how scientific advances and the tools that emerge from them can be used either for harm or good. The point I make here is that 'dual-use' thinking is severely limited regarding racial technologies of the sort that Troy Duster covers in his piece, 'A Post-Genomic Surprise' (2015). Rather, it is my view that when technologies are born of race sorting logics, then the resultant race problems and their proposed solutions contain the same disturbing seed elements. Racial logics have inhered in genetic research long before contemporary genomics projects, surely. What is significant about the latter, however, is that those at the helm of the Human Genome Project (HGP) confidently disavowed that racial differences had a genetic basis from the first highly publicized unveiling of the Human Genome Draft Map in 2000. The issues of race in US genome science – which might appear to be local, constrained by our census reporting, marred by our history, and cemented as biologically real by our health disparities – are related to larger global issues in their structure. At one level this manifests in the ways that US genetic research is more generally, in Donna Haraway's words, both 'death dealing' (linked to violence, alienation, and decisions about who lives and dies) and life-promoting (1990). Correspondingly, revisiting Michel Foucault's diagnostic that modern power both 'makes live' and 'lets die' (1990: 134–43) gives us similar language to explore the dynamic wherein racial logics gain immunity by the very forces that attempt to break them down. In essence, the use of continentally-based ancestry genetics, admixture mapping, and a focus on genes 'to make live' as a means to eradicate health disparities in black and brown populations in the USA run the risk of reinvigorating the dangerous idea that race is bio-genetic. There is an increased acceptance and routinization of racialized genetic ancestry tools to both assess disease risk and to determine phenotypes of race for police work. So far both efforts have mostly produced results that implicate black people, or people of African descent (Fullwiley 2014; David Reich, interview 2010). The idea that racializing the biology of minority groups in the USA and elsewhere might lead to anti-racist solutions to redress past medical neglect, poverty, and health disparities may be well-intentioned. Yet it overlooks the reality that when people believe that race is genetic they may not only feel that resolving societal inequalities is futile, they also feel little need to connect with others who are unlike them (Williams and Eberhardt 2008). A representative US survey showed that genetic admixture tests (DNA-based models that infer a subject could be, for example, 50 per cent African, 20 per cent Asian, and 30 per cent

European) reinvigorate beliefs in essential racial differences. The same study posited that such thinking can embolden racism (see Phelan et al. 2014: 18–19). Any or all of these effects can lead to less possibility for equal opportunities, for livelihood, freedom, quality of life and, ultimately, increased morbidity and mortality for minority populations.

Life and death in genome science

In detailing what he calls the unintended consequences of the HGP, Duster makes the critical point that the project was launched largely as a ‘health’ effort. His focus on the HGP’s spillover is largely in the civilian domain – race and admixture testing, misguided framings of minority health disparities, racialized forms of minority medical inclusion, and criminal justice tools based on admixture tests called ‘molecular photofitting’ or ‘DNA phenotyping’. These are areas that clearly warrant our attention if we want to understand the staying power of race as well as the potential for racism and new forms of subjectification it contains. Before discussing how these examples comprise a hybrid where genetic and genomic science that is seen as progressive or liberating contains the possibility for further racialization, it is worth outlining the larger structure of life and death dynamics that have powered US genome science.

In the mid-1980s the US Department of Energy (DOE) was one of two principal government agencies that financed the HGP along with the National Institutes of Health. DOE scientists hoped to understand disease fallout from the toxicity of modern warfare. The state’s interest centered largely on understanding the mutagenic (gene altering) effects of radiation given the rise in cancer rates in Hiroshima and Nagasaki after the US military dropped the atomic bomb on Japanese populations (Cook-Deegan 1996: 93–97). As Robert Cook-Deegan details in his book *The Gene Wars*, notably in the chapter entitled ‘Genes and the Bomb’, the laboratory life of genome science was, in part, co-articulated with state military power from its very inception. Similarly in their ethnography on the blistering skin condition *Epidermolysis bullosa* (EB), anthropologists Deborah Heath, Rayna Rapp and Karen-Sue Tausig report that the DOE funded basic research on this rare genetic disorder because ‘its wounds model those of both conventional and chemical warfare’ (2004: 160). These are some of the ways that the HGP was about ‘health’ – and death. In civil society, however, the leitmotif was, as Duster points out, that gene therapy would radically re-write people’s genetic endowment, and save countless lives from disease. The notion of disease here was that of ‘the accidental mishap’ – the quotidian ailment or condition. It was usually detached from war, in concept. In short, ‘disease’ concerned errors in the biological script of heredity, families, bodies, and fates as these would unfold in commonplace sites, such as homes, hospitals and in ordinary everyday life.

Death-dealing and life-promoting powers remain linked in other aspects of contemporary genetic science. One obvious pattern lies in the legacy effects of US state military expansion, usurpation of Indian territories and broken treaty agreements that have left many American Indians dispossessed of land, prior livelihoods and access to foods that they once cultivated. Like the case of the Pima that Duster reviews, the Havasupai in Arizona also have alarmingly high rates of diabetes and less than optimal living conditions. Researchers at Arizona State University offered them nutritional education and promised more interventions if they would participate in a genetic study on diabetes. An investigation into Havasupai involvement in this research in the early 1990s revealed a lack of proper informed consent and various violations of this marginalized group (Hart and Sobraske 2003). The treatment of the Havasupai also raised myriad questions concerning how racialized people are harmed or helped when researchers focus on their health disparities in stark genetic terms (Reardon and Tallbear 2012: S238–S240).

First is the topic of consent. One of the most common issues that deserve our attention is when people are enlisted in genetic research with the promise that it will ‘help’ future generations. This is sometimes worded in life-promoting terms regarding their own future offspring: that the research will stop the disease from spreading ‘to their grandchildren’ (Bommersbach 2008). Many consent forms for genetic research ask donors to give of their biological material for a wide range of vague uses, such as ‘behavioral disorders’, or ‘future research relating to’ the condition being studied at the time of consent. Given the increasing methodologies and capacity to data-mine genomes, the latter could manifest as an as of yet unknown number of potential linkages to innumerable traits (Lunshof et al. 2008). In the case of the Havasupai, more than 100 people donated blood samples after signing a broadly phrased consent form allowing ‘study [of] the causes of behavioral/medical disorders’. (Editorial, *Nature* 2010). The Havasupai initially collaborated with geneticists and anthropologists so that they might learn why so many in their tribe were now dying at higher rates from diabetes than in previous generations. After Carla Tilousi, a woman from the tribe, attended a doctoral dissertation defence at Arizona State University where she was a student, she realized that DNA from the diabetes study was in fact shared more broadly. Specifically, the doctoral student’s research used Havasupai DNA to assess whether tribe members had schizophrenia, and to inquire into their ancestral origins and migration history. The latter was especially upsetting because, as Tilousi gleaned from the presentation, the scientists who took and stored the DNA had sought to know whether the Havasupai had inbred. Pulitzer-prize winning journalist Amy Harmon reported on the case for the *New York Times* in 2010. A brief excerpt reads as follows:

Ms. Tilousi understood little of the technical aspect, but what she heard bore no resemblance to the diabetes research she had pictured when she had given her own blood sample years earlier.

‘Did you have permission’, she asked during the question period, ‘to use Havasupai blood for your research?’

The presentation was halted. Dr. Markow and the other members of the doctoral committee asked the student to redact that chapter from his dissertation.

But months later, tribe members learned more about the research when a university investigation discovered two dozen published articles based on the blood samples that Dr. Markow had collected. One reported a high degree of inbreeding, a measure that can correspond with a higher susceptibility to disease.

Ms. Tilousi found that offensive. ‘We say if you do that, a close relative of yours will die’. (Harmon 2010)

Carla Tilousi’s fear of death for a family member here is a notion that would likely not occur to most genetic researchers who want to help eradicate health disparities. Such an understanding, however, is key to being able to engage people with respect and to navigate their different conceptual terrains of life and death.

Despite a strange flurry of denials on the part of lead scientist Therese Markow that she herself did not publish anything on schizophrenia, it is clear that some of her earliest studies on the Havasupai indeed focused on inbreeding.¹ And those studies were published. The methodology and terminology used was that of ‘dermatoglyphic traits’, or patterns in hand and fingerprint swirls (Markow and Martin 1993). This collection of such data was likely not understood by the Havasupai to be about bio-indicators that would reveal tabooed consanguinity. A detailed chronicle of the events written by Jana Bommersbach in *Phoenix Magazine* relies on numerous interviews with Havasupai who gave blood for the study. The account is moreover interspersed with reminders that many people who contributed DNA and other morphological data, such as handprints, have since died of diabetes complications. The article is as much a reporting of genetic research gone awry as it is an obituary of both trust lost, and lives lost. It details hurt, violation, alienation, and death.

Survival

These dynamics extend beyond the USA and beyond contemporary genetic research. The Canadian anthropologist Lisa Stevenson powerfully details present-day public health campaigns in the Canadian Arctic where the suicide

rate among Inuit youth is now ten times the national average. Posters and billboards imperatively read: 'Inuit Pride, Stay Alive . . . Survive' (Stevenson 2014: 82). This is a complicated plea steeped in humanitarian care for marginalized and racialized bodies as a government health intervention. As Stevenson details the history of welfare colonialism in this region throughout the twentieth century, she recounts the massive removal of people from their land, the separation of families, and the killing of sled dogs as tuberculosis ravaged the population. All of these acts constituted health 'interventions' carried out by the state to save lives from TB. The people who were targeted for 'help' were thankful for the medical aspect of the care, but during their exiled hospital and sanatoria stays some wrote letters expressing how baffled they were at how officials could overlook the grave seriousness of removing them from their families, community, land, animals and way of life. One legacy effect of this string of violations, Stevenson argues, manifests as a new generation of young people who no longer see the point of living. It is they who are now being implored to 'survive'.

Stevenson argues that removing people from their land is a form of genocide. She and others concur that land is necessary for life, and that the wholesale appropriation of native lands corresponds to a logic of elimination that structured past dispossession and still structures colonial settler society today (Stevenson 2012: 598; Wolfe 2006: 387). To connect back to the sciences of admixture, anthropologist Circe Sturm documents how the calculus of blood quantum imposed by colonial federal policy in the nineteenth and twentieth centuries was *the* means by which Cherokee could be allotted small bits of land once their territory was taken. In part, this is how this group would survive as people but also as a political entity.

Today contention over such fractionations, and who does or does not belong to the Cherokee Nation, is based on some degree of 'biological possession' of 'blood' (Sturm 2002: 86). Race intersects with this logic in obvious and less obvious ways. On the one hand, Cherokee measurements of blood quanta have been much less than for many tribes, often allowing people to become citizens if they have up to 1/2048th of Cherokee blood. This openness has increased their numbers dramatically. On the other hand, however, this only applies to 'White Cherokees' in practice. Cherokee of African descent are continually battling to be allowed into the nation and recognized as citizens. In many ways the Cherokee Nation has articulated race and belonging based on US racial policies meant to dispossess them of land, while they have adopted aspects of US white supremacy and racism toward blacks (Sturm 2002: 169–70). The use of ancestry fractions that originate in US colonial policy and the new forms of racism that they engendered are clear in the case of the Black Cherokee as well as Seminole Freedmen who have recently appealed to geneticist Rick Kittles to possibly arbitrate their tribal belonging when tribal governments have rejected them (See Koerner 2005). Cases like

these are troubling on many levels, not the least of which is that the politics and science of admixture, as well as the legacy effect of fractionating bodies for citizenship rights and group survival, have now put marginalized Indian groups at odds with black US minorities. The latter, of course, have been systematically oppressed in different but no less damaging ways. In short, admixture politics steeped in race logics have engendered a troubling amount of racism on the part of non-black Cherokee leaders. This racism is immune to any obvious cure because it is perceived as justified. After all, the Cherokee have battled centuries of racist US state power that has consistently threatened their sovereignty. Today various other patterns of dispossession and group cohesions/exclusions mark many Native Americans targeted for genetic studies. Colonization and federal policies have largely structured Native identity, naming, and tribal affiliations, which should not be taken for granted as natural. As Kim Tallbear writes: 'The tribe is not strictly speaking a genetic population. It is at once a social, legal, and biological formation, with those respective parameters shifting in relation to one another' (Tallbear 2013: 83–4).

Eradicating health disparities and redressing medical neglect through genetic research

Drawing on his own interactions with scientists and the work of ethnographers who have gone to multiple laboratory sites to study these technologies, Duster shows that racial genetic admixture models are circular in their architecture. They rely on notions of continentally-based racial types as unacknowledged inputs, or priors, only to produce racialized 'ancestry' results as outputs in the form of precise genetic compositions (Fullwiley 2008: 700–1; Fullwiley 2014; Rajagopalan and Fujimura 2012). This happens no matter how laudable the scientists' professed anti-racist intentions are, and also despite certain professionals' refusals to use 'race' as a term at all (Roberts 2011; cf Fujimura and Rajagopalan 2011).

The larger point of his essay centres on what he has called the molecular re-inscription of race, which today happens largely through scientists' interests in problems like Native American diabetes and African-American prostate cancer: the dilemma of US minority health disparities. The solution of ancestry-based medical genetics to locate the causal factors involved has largely ignored the social determinants of both diseases and the long histories of dietary and health changes linked to loss of lands and economic possibilities (See also Montoya 2011). Here the quest to quash disease with the hope of 'health' presents a new danger. As I stated at the outset, it runs the risk of racializing the genetic make-up of Native Americans with diabetes and African-Americans with prostate cancer. This happens when people's odds of

developing these diseases are conceived of as linked to continentally-based, deep ‘ancestry’ through models that statistically frame the issue as if genetic answers were the only options. In my own ethnographic field stays, I’ve heard geneticists use terms like ‘stretches of African chromosomes’, ‘European loci’, ‘Native American genetic markers’. Others have argued that geneticists have all but re-conceptualized human chromosomes as racialized ‘genomic geographies’ (Fujimura and Rajagopalan 2011) Here ancestry inference techniques conceptually link DNA loci to continental landmasses, which have been tied to racial schemas for centuries. Furthermore, it is clear that when scientists of colour embark on racializing genetic research with the rationale to reduce health disparities, then things get more complicated. As members of minority groups themselves, certain very vocal geneticists articulate that science has always been political – and they now want to situate themselves within the field of genetics to make sure that minorities do not get left out of the genetic revolution (Fullwiley 2008). There are similarities to be drawn between minority scientists who research the genetics of health disparities that could biologize race and the leaders of the Cherokee Nation who find themselves in the position of deploying admixture fractions to politically exclude Cherokee of African descent. As the Cherokee leaders fight to assert their sovereignty within the US system, they simultaneously commit a racism that Black Cherokees experience as both damaging to who they think they are, and doubly dispossessing of their right to citizenship and nation. For the scientists I’ve studied, the bind is only slightly less complicated. None of them want to aid racism and they have taken some steps to distance themselves from situations where they fear racist consequences of their work. The African-American geneticist Rick Kittles stopped sharing DNA with scientists who were developing ancestry informative marker technology for the forensic tool of molecular photofitting. As he told me, ‘I don’t want to help them put more black people in jail’. Similarly, Esteban Gonzales-Burchard, a Mexican-American physician-scientist who works on Latino and African-American Asthma disparities, has disavowed the public praise that he received from the white supremacist David Duke for his research (Fullwiley 2008: 711–13). In each of these cases, it is clear that the problem of genomic, continentally-based admixture science – as well as the solutions that geneticists hope to advance in order to address current societal racial disparities – end up sharing the same deleterious base. Given this, if we really hope to code new futures we will be better off seeing ourselves as whole individuals connected to each other through shared social goals and a hope to better the broken societal structure that lets so many fall through its cracks. Fractionations of persons, and admixture that relies on putative notions of racial purity located in DNA, will keep us engrossed in an unhealthy circulatory system. It is one where the will to eradicate the ills of racism unwittingly boost its immunity. If we are not careful, it will also promote new forms of racist life

that we will increasingly experience as acceptable, rational, ordinary – where the stakes will be about health, sovereignty and a deeply desired, long-awaited, empowerment.

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Note

1. See Lewis 2013.

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