

Race and health in post Civil Rights America

Interview with Alondra Nelson

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Do special health programs for Black people and practices such as genealogical ancestry testing represent a risk of regression to a medical Apartheid in today's America? For Alondra Nelson, health and science applied to Black bodies do not necessarily lead to the re-racialization of Black identity, they are also means of collective empowerment and can help to negotiate one's ethnic identity.

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Challenging Racial Formation on the Terrain of Health

Books & Ideas: According to what you call a “narrative of victimization”, Blacks have historically been the casualties of science and technology, and have accordingly shown a deep mistrust of all scientific authorities. Your research on both the Black Panthers’ health policies and on the use of genetic genealogy testing shows, on the contrary, that Blacks have resorted to science and technology as a way of self assertion, of personal and collective empowerment. According to you, what made this reversal possible?

Alondra Nelson: As a graduate student, I was trained with a whole generation of works explaining how science and medicine had created race, such as the work of Sander Gilman and many others. I was struck that these kinds of works, and even more recent

works like Harriet Washington's *Medical Apartheid*,¹ give you an overwhelming sense of the ways in which science and medicine subjugate racialized populations, but they always give you a top-down view. I explicitly started looking for spaces where black communities were challenging the process of racial formation in medicine and science. I looked at what the Black Panthers had done such as sickle-cell screening, the nutrition and education programs... One of the ways that racial discrimination has worked in the US on the plantation, during Jim Crow, and in the contemporary moment is on the terrain of health. So, health care has always been by necessity a place where civil rights activism has had to take place. In *Body and Soul*,² I place the Black Panthers in a genealogy of health activism. Starting with Marcus Garvey, even though one does not think much about Garveyism's health politics – however, one of the more memorable photos we have of the Garvey organization depicts the iconic Black Cross nurses walking in their white uniforms down on a broad avenue in Harlem. On the one hand, these nurses were seen as necessary to the nation-state in waiting that Garvey was interested in creating; on the other hand, we can understand the existence of this group as a critique of the inability of black women to be integrated into mainstream nursing at this time. During World War I, hospital wards were still segregated – black nurses and doctors attended black people.

I also place the Black Panthers in a genealogy with SNCC and Freedom Summer. Members of the Medical Committee for Human Rights, which was made up of doctors and nurses that came from the North, were the health care corps of the summer campaign. Several of those people would go on to help the Black Panthers set up their own clinics.

I show in my book that because medicine was a site where racist claims about black bodies were often made, health activists always had something to say about the racialization of black people in this area. The Black Panther Party is one of many voices across African-American history that has been speaking back to the top-down process of medical racialization.

¹ Harriet A. Washington, *Medical Apartheid. The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*, Doubleday, 2007.

² Alondra Nelson, *Body and Soul: The Black Panther Party and the Fight Against Medical Discrimination*, University of Minnesota Press, 2011.

The Panthers' Fight against Health Discriminations

Books & Ideas: To what extent did the Black Panthers resort to health as a way to remodel the group? Was theirs a project of social engineering?

Alondra Nelson: Their health activism is part of their critique of the civil rights movement. By 1966, when they created the Party, the Movement had not appreciably changed the lives of many black people, particularly in cities and ghettos. Their health politics was an instantiation of their critique of the moderation of the civil rights movement. The fact that the state did not care about the very bodies of their citizens showed the limits of what some people wanted to see as the revolutionary gains of the Movement. On the other hand, the Panthers developed the vision of a rich and meaningful social welfare state. They were pointing out ways in which the state was inconsistent in divvying out funds for research. In their sickle-cell anaemia research campaign, they highlighted the fact that various genetic diseases had various racial and ethnic “constituencies”. They compared the fact that the Nixon administration had given very little money towards research on sickle-cell anaemia that affected blacks disproportionately, with the amount of money that had been given to diseases like cystic fibrosis that affected white people disproportionately. Their critique was also a critique of what they called, following people like Barbara Ehrenreich, the “medical-industrial complex”. They had the sense that American health care was getting increasingly commodified and capitalized, and that this process was at its core a violation of human rights. The Black Panthers would say about the Vietnam War that “the spirit of the people is stronger than the Man’s technology”, which could apply to health as well. Yet they had an interesting complicated relationship to the system: they wanted anti-capitalist health care, anti-racist health care, and, at the same time, the benefits of health and medicine. Their complex view on health issues is shown in their campaign on sickle-cell anaemia. To promote the campaign, they created an origin myth of the disease. In order to do so, they looked at research by population geneticists showing which genetic diseases were adaptive or maladaptive to various environmental conditions. And they made a migration, evolutionary argument that was consistent with their political aims, in which the genocide

frame was very present: “Part of the reasons we have this disease is that we were taken from our home in Africa in the Middle Passage. We had this marker that help people combat malaria, where it had a sort of biological-ecological purpose. And we are now strangers in a strange land, and this strange land, this is killing us”. So they actually took up scientific explanations of the disease, but they rendered them through their political agenda.

Books & Ideas: So you would say that their health care project was more a response to health disparities, than a rupture with white medicine.

Alondra Nelson: The Panthers had some appreciation for the War on Poverty and some of its programs, but these programs were supposed to have a community control component, which they often did not have. When Huey P. Newton and Bobby Seale started the Panthers, they were working at one of these programs; it is partly out of dissatisfaction with the War on Poverty that they started the Black Party, out of a more general dissatisfaction with mainstream social welfare projects. The Panthers also defined themselves against what they saw as bourgeois African-American activists – with regard to sickle-cell anaemia, they were very critical of black organizations that were trying to raise awareness about the disease and money, but did not have a politicized frame to think about their action. They rejected both sides.

In the late 1960s, while the explicit science of racial discrimination had disappeared, tremendous health disparities still existed: for the Panthers, it was the proof that blacks had not had a great revolution in terms of race relations. The discourse about health inequalities was a relatively new discourse in American history, though the phenomenon of health disparities is an ongoing one. Sociologists and epidemiologists show that the statistics on mortality rate among African-Americans have hardly changed over the course of the 20th century. By highlighting health disparities, the Black Panther Party really brought to the fore the persistence of health inequality. I would argue that they were one of the first activist groups to identify the problem.

Books & Ideas: How was this concern for health articulated with their wider political and social program of racial equality and empowerment?

Alondra Nelson: Within Black Power, the Panthers distinguished themselves: they had a strong program for black communities but they were not separatists. Bobby Seale very early on ran, in 1968, ran on the Peace and Freedom Party presidential ticket. The BPP always favoured interracial collaborations, they were against homophobia, against antisemitism... they were fairly cosmopolitan for Black power activists. Most of the people who supported their health programs were white. In the 1960s and 1970s, the percentage of doctors who were African-American was around 3%, so the Panthers could not tap into a large pool of African-American nurses and doctors. They could not have created black-only clinics.

The Panthers had what I call a social health frame which worked on scalar level. For them, the health of the individual was always related to the health of the community and the health of the nation state. Since the black community could never be fully healthy, the US as a nation could never be fully healthy. They always understood health and politics to be articulated. This is why sickle-cell anaemia was a story about geopolitics, and not only a story about genes. This is why their health clinic network was about more than just opening a place where people could get immunizations and have their blood pressure measured; they wanted to create places where people could get organized, and get political education classes. Like the headquarter offices, clinics were important organizational spaces where they dealt with a lot of other kinds of social work, such as advocacy for employment... Their clinics were open part-time, they had a part-time staff, Panther volunteers and doctor volunteers. But they had allied doctors working in various places to whom they could refer people. They had a driver whose job was to take people to doctors; patients' advocate would help people get food, housing... They understood health to be more about more than the minute workings of the body.

There were between a dozen and fifteen clinics. People, inspired by the creation of the Party, started chapters which the headquarters then tried to convince to adopt its

national guidelines. These chapters were supposed to open a health clinic, start a breakfast program, and sell newspapers, among other things. In 1966, the Panthers' Ten point-platform mentions health in passing. By 1969, all the chapters were supposed to have opened a clinic, and by 1972, the revised Ten point-platform includes a new point Six, which is a statement about health care. Health acquires a greater importance in the political work that they are doing.

The Party mandated clinics, but many of them were independent projects. The Party leadership did not have the resources or staff to fund all the clinics. So it really was up to various chapters to get the clinics running. It often depended on what the local networks, local situation and local needs were. For example, in Portland, Oregon, a PhD in chemistry worked with the Black Panthers to set up a clinic. He was working at the time at a diagnostic laboratory and had affiliations with local hospitals. That clinic was run with a lot of help from local medical students and local medical colleges. Black communities were unduly subject to really poor health care at teaching colleges – the Black Panthers were critical of ill-trained medical students and black people having to be the guinea pigs of people who were barely out of medical schools. On the other hand, they understood that they needed to work with medical students. The Black Panthers played a mediating role between black communities and medical schools. The Party vetted health professionals and made sure that they were what I call “trusted experts”.

In Winston-Salem, the mainstream medicine was notoriously racist and had a discriminatory ambulance service, so this Black Panther chapter started its own service. There are also cases like Kansas City, Missouri, where a radical doctor was asked by the Panthers to help get a clinic off the ground. Malik Rahim who started the Common Ground Clinic in New Orleans after Hurricane Katrina was also a member of the Panthers in New Orleans. He said he was able to start this bare bone clinic because he had done it before with the Panthers. It is difficult to evaluate whether the Black Panthers' clinics were a success story or not but they did leave a legacy.

Negotiating one's Racial Identity

Books & Ideas: One could think that the use of genetic ancestry testing by Blacks in search of their family history would lead to validate the scientific theory of race, and invalidate all social science that has shown that race is a social construct. According to you, the understanding of race is not radically transformed by genetic testing. What prevents this return to the racist conception of race and the “geneticization” of identities in the use of genetic testing?

Alondra Nelson: This is a central question. When I started this research in 2003 I was curious to understand why black people who had been historically suspicious of medicine and health care policies resort to genetic genealogy testing. Why would they put their DNA in an envelope and mail it to a stranger? The question of geneticization and racialization is different in a criminal justice context – there is no negotiation, there is no flux. The negotiation that I saw with African-American consumers of genetic genealogy testing really suggested that people were doing something different. None of this people would tell me “I believe race is biological and I am doing this because I know I embody the biological essence of my race”.

In 1991, a controversy followed the discovery of the African Burial Ground next to Ground Zero. African-American activists saw a distinction between archaeological work that would do what they called “biological racing”, and archaeological work and interpretation that could restore their ethnicity to them. It is what is at stake for people. One of the scientists from Howard University who worked on that project, named Rick Kittles, went on to start the African Ancestry Company –which is the company that I write most about. Initially, the remains that they excavated were to be analyzed at a forensic lab of Lehman College, which is part of the City University of New York. People who train and work there are interested in crime scenes, and have a conjectural approach to corpses they analyze. In asking for the move of the remains from the Lehman forensic lab to the Howard Lab that activists were seeking a more holistic analysis of the remains. They were using techniques that would allow them to move from a general idea of race to the specificity of ethnicity. Historian Michael Gomez has shown that in the Middle Passage, over time, different African ethnicities have become race in the United

States, and blackness in a particular way. Part of what was at stake for the African American activists groups involved in the Burial Ground controversy was the reversal of that, the move of race to ethnicity. You see it very clearly in the contest about where the remains would be analyzed, and how they would be analyzed. It was this return to ethnicity that was at stake. This example shows that people are after something else than biologizing race when they think about genetics and black bodies. The difficulty with genetic genealogy testing is that it is a threshold for people who had never thought about a relationship between genetics and identity. In my interviews, people often talk about different forms of genetic testing to authorize or validate other forms. They would say things like “because I have done this genetic genealogy testing and have these results which are powerful to me, I now better understand what a genetic counsellor was saying to me about this cancer gene that runs in my family”. Or this woman would say to me “Because I work as a forensic lab technician, and I have seen black people exonerated using DNA evidence in a criminal justice setting, I am very trustful of genetic ancestry testing.” It plays a role in a larger process of geneticization. In the specific site of genetic genealogy testing, there is a discursive negotiation happening that may not be possible with other forms of genetic testing, like in a criminal justice setting, for example.

People have genealogical aspirations – family stories that they want to confirm, family mysteries that they want to solve. The power of genealogical aspirations is really born out in the way that people select particular tests to give them particular information. If people are interested in finding out if they have European or Native American ancestry, they would do the “Admixture test” which can yield that information. If they are interested in their African ethnicity, they would go to companies that can yield those types of results, using either Y chromosome DNA testing or mitochondrial DNA testing.

Books & Ideas: Do you think this resort to genetic testing is necessary for the assertion of a sense of diaspora-belonging? How does it play together with other diasporic resources (such as name changing, or the celebration of Kwanza)? How do you connect this use to the ideology of pan-Africanism?

Alondra Nelson: Most of the people I have interviewed are not pan-Africanist in an explicit political way. They are not Afrocentrist activists, even if they are interested in African politics and culture. But many people who do genetic testing try to forge relationships with African expatriates living in the US, based on their genetic results. People also travel to Africa after getting their test results. There is an economy linked to ancestry research. The African Ancestry company has a niche market because it claims to have the biggest database of contemporary African genetic samples, which in turn authenticates the identity of blacks in the US.

In another research project, I have looked at young African Americans who have used genetic genealogy testing and made videos on YouTube.com where they record and broadcast the process of DNA testing and/or they show the moment when they receive the results and their reaction to this information. There is an interesting demographic shift happening – in the US, genealogists tended to be older people, who had time and financial resources to do research. It used to take a lot of time to be genealogist in the years before internet databases existed. These videos that I call “roots revelations” show a new, younger generation of genealogists. They also help us think about diaspora in the way that they provoke responses from the audience, people who claim to be Africans who live in the diaspora, in the US or Europe, or Africans living in Africa. They speak back to the video-maker about what it means to be African. It is a place where the genetic tests stimulate a conversation about the limits and the possibilities of a pan-African identity. If the result is an African ethnicity, the general response tends to be “congratulations, welcome home, brothers and sisters, fantastic!” In a few other cases, commentators said things like “You are not African, you don’t have African cultural practices, you don’t have a commitment to the betterment of communities in Africa...”

Books & Ideas: You have forged the expression “Reconciliation Projects” to designate the use of genetic testing. Do you have in mind the reconciliation with the African past or the reconciliation with American society? Are not these projects antagonistic?

Alondra Nelson: I don't think they are contradictory, particularly if we think of W.E.B. Du Bois' idea of "double consciousness". Genetic testing does not resolve any controversy about Black people's history. What is at stake is a sense of reconciliation that perhaps cannot be provided by science. People are using these genetic tests because they want to inaugurate a process of acknowledgment and public airing. The Truth and Reconciliation Commission in South Africa and the 2005 Truth and Reconciliation Commission in Greensboro (South Carolina) have not been great success stories but they have done the work of publicly airing and allowing a public conversation around these things. I think this is the kind of acknowledgment that some users of these DNA tests seek—a form of recognition from U.S. society. In the use of genetic genealogy testing, there is also reconciliation with Africa, in the sense of a reunion of the diaspora.

Back to the Racialization of Health?

Books & Ideas: Your interest in the issue of race and science has also led you to discuss the use of racial categories in medical practice and research. You show that racial profiling in medical practice – used to define populations at risk, to make a proper diagnosis as well as propose an appropriate treatment – tends to conduct to neglecting social conditions and family histories. Is the debate here still along the lines of heredity vs. environment (as it was before, about the so-called dysfunctional black family, the controversy on IQ testing, etc.)? Or has the debate been renewed?

Alondra Nelson: There is now a post civil rights generation of doctors and medical researchers who, like me, are the beneficiaries of affirmative action in the US and who are now involved in the discussion about racialization in bioscience and medicine. It has significantly changed the discourse. Health disparities has been taken up in a kind of civil rights discourse. Let's take the example of BiDil, this heart failure medication that the US Food and Drug Administration approved only for African Americans people. Africans have the most genetic diversity and African Americans are multiracial, so how could this drug possibly work for all black people? What is interesting is that BiDil has been taken up by African American professional societies (like the Association of Black Cardiologists) and organizations such as the Congressional Black Caucus and the

National Association for the Advancement of Colored People (NAACP) that argue that the issue of health disparities is the terrain of the next civil rights struggle in the US. They want the federal government to get behind this drug that presumes the peculiarity of the black body. We've reached a point that the sociologist Steven Epstein has brilliantly conceptualized as the "inclusion and difference paradigm": on the one hand, American liberalism requires that you now include people more in the mainstream health care state, on the other hand, this inclusion is predicated on the identification of groups as being different from one another and having distinct needs, be they social needs or biological needs. I am glad that there is now an office at NIH (the National Institutes of Health) that is dedicated to minority healthcare issues, but I wonder what political concessions will we have to make as a black community in order to be able to demand adequate health care resources from the state? One could argue that creating an office of minority health is a type of segregated medicine. This potential is there, but this is obviously not the intent of this office. But we should bear in mind that the projects that are meant to combat health disparity might be unwittingly creating forms of segregation, of racialization. We have to understand the ambiguous genealogy between scientific racism and research on health disparity. It is the vexed claim around biological citizenship that gets created in the context of deprivation.

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