



2022 FORCE FOR GOOD ESSAY CONTEST WINNERS

Essay Question:

What is a health care practice related to genetics or genomics that disproportionately affects one group of people on the basis of race, ethnicity or other identifier, and how can we challenge this practice?

READ: [1ST PLACE](#) | [2ND PLACE](#) | [3RD PLACE](#)

1ST PLACE ESSAY: Lindsay McBride, Pennsylvania

Racial Disparities among Breast Cancer Patients: Breaking Down Physician Biases & Rebuilding Patient Trust

"I'm sorry," the primary physician said. "I don't think referring you to genetic counseling and testing would be an effective solution here."

The next patient entered the room, coincidentally with the same concerns and similar lab results as the prior patient. Having the time to conduct some preliminary research online, this woman entered the room with a greater degree of confidence. "Oh, I forgot to fill out the office paperwork," she lamented. "Let me do it real quick." Female: check. White: check. The woman marked large Xs in all the other boxes.

"Here's the name of our best genetic counselor," the primary physician said this time. "I think you'd be best suited to make an appointment to discuss your breast cancer – I always recommend him to patients like yourself."

According to a 2021 survey in the Journal of Clinical Oncology[1], physicians' attitudes might partly explain why less Black women with breast cancer are sent for genetic counseling and testing than white women. Whereas white patients are referred for genetic counseling 93% of the time, Black patients are only informed of this opportunity in less than 60% of cases. Why is this?

Perhaps the answer lies in that 55% of physicians believed that Black patients with breast cancer were more likely than white patients to experience heightened psychological distress from genetic testing, or that 26% believed Black patients would flat out refuse. Regardless of if a patient refuses genetic testing, since when do physicians offer treatment plans based on what they think the patient will like? Medicine involves information, which by nature cannot be

restricted. Patients have the unequivocal right to be informed of their options. Restricting them, especially based on race, perpetuates negative health outcomes and medical racism.

The research further indicated that Black women are more comfortable with doctors of their same race – but only ~3% of oncologists in the United States are Black, and not all are female.

It doesn't take a degree in statistics to notice that the odds are stacked against Black breast cancer patients.

The definition of an unconscious bias is self-explanatory. Yet, rather ironically, we are unable to explain or even recognize these hidden prejudices and thought patterns in ourselves. This is where the danger lies. Doctors, nurses, and other medical providers are among the worst people to be victims of unconscious biases because their opinions, however informed or misinformed, dictate the wellbeing of real, sentient patients. Patients who believe that their healthcare providers are highly knowledgeable and well-trained, so therefore the patient should heed all advice. But when a doctor believes a faulty stereotype about a racial group, and it influences their practice, patients unknowingly incorporate faulty advice into their wellness, just because their doctor supposedly received advanced training.

The choice to withhold a genetic testing referral because the patient will “probably refuse” might be the difference between life and death. It might be the difference between the patient's daughter getting a preventative mastectomy because she discovers she inherited the BRCA1 gene. It might be the difference between the patient's sister deciding to schedule a mammogram because she realizes as a result of genetic testing that she might have early risk. While patients can get second opinions, any medical opinion that is badly informed can poison the metaphorical well and send patients down a dangerous path. In the case of breast cancer, Black women are more likely to be harmed by misdirected physician advice. They have a higher incidence of early-age onset breast cancer before age 50, are twice as likely to be diagnosed with triple-negative breast cancer (an aggressive and difficult to treat form of breast cancer associated with a BRCA1 gene mutation), and have a 42% higher mortality rate from breast cancer compared to White women.[2]

By supporting prospective Black oncologists – aka Black medical students, premedical students, and even high school students – we can increase the 3% of current Black oncologists and thus create more opportunities for Black patients to connect with their doctors on a more comfortable level. Representation is critical on all fronts; creating more scenarios where patients feel a degree of trust with their physician is one way to help alleviate the disparities in genetic testing referrals. In the meantime, healthcare providers must understand their role in identifying individuals for genetic testing and ensuring that patients know their options (& if necessary, that they follow through with them) should be emphasized. From a scientific perspective, there must be a more directed effort to include Black participants in clinical trials to identify more effective drugs, and in genetic research studies to better represent populations and make results generalizable. But some patients are wary of participation – higher levels of medical mistrust have been linked to lower participation in genetic counseling and testing, and often research studies as well.[3]

Black women have historically been experimented on, subjected to ethical travesties, and forced to endure horrific treatment (often at the hands of white male physicians, who had incorrect

beliefs i.e. Black women do not feel as much pain). It's more than understandable why some patients are hesitant to offer blood samples and undergo genetic testing. These patients should not be marked down as "noncompliant". Rather, physicians should take the time to be transparent about all aspects of genetic testing and understand the social context behind a patient's perspective, especially because not all persons from a subgroup have the same level of medical mistrust. Trust is earned through action, and can't be fully established after one appointment.

Rachel, a 40-year-old female participant of a 2016 study, explained her concerns: "I figure if they can find a cure for polio, then they can find a cure. I think they don't really care because it's mostly attacking the black community, so they don't care. But if it attacks mostly the white community then it's a problem." [4]

Decreasing disparities in genetic testing means decreasing physician biases & increasing patient awareness of available options. By combining forces and including all opinions, we can move towards a healthier world.

Citations:

1] Ademuyiwa, Foluso O et al. Genetic Counseling and Testing in African American Patients with Breast Cancer: A Nationwide Survey of US Breast Oncologists. J Clin Oncol. 18 Oct. 2021, pubmed.ncbi.nlm.nih.gov/34662201/.

2] Jones, Tarsha et al. "Predictors of BRCA1/2 Genetic Testing among Black Women with Breast Cancer: a Population-Based Study." Cancer Medicine, 2017. [ncbi.nlm.nih.gov/pmc/articles/PMC5504315/](https://pubmed.ncbi.nlm.nih.gov/pmc/articles/PMC5504315/).

3] Sheppard, Vanessa B. et al. "Medical Mistrust and Self-efficacy Influence Black Women's Level of Engagement in BRCA1/2 Genetic Counseling and Testing." [ncbi.nlm.nih.gov/pmc/articles/PMC5504315/#cam41120-bib-0051](https://pubmed.ncbi.nlm.nih.gov/pmc/articles/PMC5504315/#cam41120-bib-0051).

4] Fillon, Mike. "Solutions To Reduce Racial Mistrust." Journal of the National Cancer Institute, 7 Jul. 2016, <https://academic.oup.com/jnci/article/108/7/djw180/2412983>.

2ND PLACE ESSAY: Sophia Dube, Oregon

Chronic Stress, Epigenetics, and the African American Community

Chronic stress syndrome is far more harmful than many people realize. The impact of stress over long periods of time can have psychological as well as physical implications for one's health. Many of the factors that contribute to chronic stress feel impossible to change. People of Color (POC), especially Black people, suffer from chronic stress due to systemic racism and microaggressions on a regular basis. The syndrome can manifest in a variety of symptoms, including but not limited to insomnia, low energy, emotional withdrawal, ache and pains, and increased alcohol and drug use (Yale Medicine, n.d.). In addition to directly related symptoms, researchers have seen a correlation between chronic stress and hypertension, depression, addiction, and anxiety disorders. For these reasons, microaggressions are more harmful than previously thought, akin to death by a thousand paper cuts.

One might wonder how this condition relates to genetics. For a long time, the medical industry has said African Americans have higher rates of hypertension, heart attacks, and strokes, with treatments tailored to those conditions with the assumption that Black people have 'poor' genetics. However, what research has shown is that chronic stress syndrome plays an important role for this population. Epigenetics, the study of how gene expression is affected by one's milieu. The impact of stress on an earlier generation can affect the development of the next generation. For example, pregnant women in areas of famine are not only more likely to have smaller offspring but their children are also at a higher risk of developing heart disease, schizophrenia, and Type 2 diabetes (Centers for Disease Control and Prevention, 2020). High stress changes the cellular environment, causing genes that would have remained dormant to be expressed during mitosis and meiosis. In larger terms, chronic stress can lead to metabolic interference, causing a plethora of diseases (Tamashiro et al., 2011). These diseases decrease the quality of life, creating a vicious cycle during which compounding stress leads to poorer health outcomes thus exacerbating the stress. Fortunately, there are some solutions to treat chronic stress syndrome and build trust between the medical field and the African American community.

Historically, the African American community has had a contentious relationship with the medical system. From the Tuskegee experiment to the story of Henrietta Lacks and the development of modern gynecology and contraceptive treatments, the oppressive force of racism has sown seeds of distrust, resulting in an unwillingness to seek medical care for a large portion of Black people in America. Part of educating this community about chronic stress comes with rebuilding confidence in medical providers. Community outreach and information would greatly benefit people who want to understand genetic predispositions as well as how their family history may currently be affecting them.

For younger people, the most effective outreach mechanism may mean sharing information across social media platforms such as TikTok, Instagram, or Snapchat. While mental health awareness has grown in the past few years, there is less conversation about how stress can change a person on a genetic level, not only affecting themselves but also the future lineage of their family.

For older people, social media like Twitter and Facebook also have the potential to serve as effective means of communication; however, in-person events are more effective tools in educating people about chronic stress. These events could take place at YMCAs, churches,

schools, or wherever people congregate. It is of the utmost importance that the information be community-specific and culturally sensitive. Topics could include the stress of gun violence, specifically police shootings or the effects of underestimation; there is even the possibility of addressing issues such as intersectionality for Black women. The medical community, especially physicians, needs to know about and consider chronic stress as a valid reason for health concerns.

Bibliography:

Centers for Disease Control and Prevention. (2020, August 30). Genomics & Precision Health : Epigenetics. CDC. Retrieved April 24, 2022, from <https://www.cdc.gov/genomics/disease/epigenetics.htm#:~:text=Epigenetics%20is%20the%20study%20of,body%20reads%20a%20DNA%20sequence.>

John Hopkins Medicine. (2010, September 15). Chronic Stress May Cause Long-Lasting Epigenetic Changes. Hopkins Medicine. Retrieved April 24, 2022, from https://www.hopkinsmedicine.org/news/media/releases/chronic_stress_may_cause_long_lasting_epigenetic_changes.

Tamashiro, K. L., Sakai, R. R., Shively, C. A., Karatsoreos, I. N., & Reagan, L.P. (2011). Chronic stress, metabolism, and metabolic syndrome. *Stress*, 14(5), 468-474. <https://doi.org/10.3109/10253890.2011.606341>.

Yale Medicine. (n.d.). Chronic stress. Yale Medicine. Retrieved April 24, 2022, from <https://www.yalemedicine.org/conditions/stress-disorder.>

3RD PLACE ESSAY: Arun-Singh Bal, Texas

Genetics and Race in the Medical Field

Imagine one day you are laying on the floor one day, watching the clouds as they float in the sky. You get up and it suddenly becomes night, stars start flying around, while the rest is enshrouded in darkness, and you feel sick. 'This must be time travel... right?' you ask yourself as you fall to the ground and you rush yourself to the doctor's office for a clue on what just happened. You tell the doctor what has happened, and one of two things may happen, both of which confirm that unfortunately, you did not suddenly cross to another dimension. If you are a non-African American, you will be met with a diagnosis of anemia, following paperwork to confirm the prognosis. You will soon be treated with iron supplements, while correctly addressing the issue. If you are African American, however, you will be suspected of sickle cell anemia, and when the paperwork comes back with a positive test on anemia, you will then be placed on a course for sickle cell anemia treatment. While the two are completely different disorders, it is more suspected in African American individuals, because sickle cell is said to be more common in African Americans[1].

While this is true to some extent, with 1 in 13 being seen as a carrier to sickle cell[2], this will not apply to everyone who is African American, because not only is the gene recessive[3], but there are many African Americans who are biracial, or multiethnic, and are less likely to be seen as a non-carrier of the gene. The trait is also very high in people who are in or come from a population in a malaria endemic area, and the defect increases survival.[4] Another reason why ancestry needs to be looked at is because sickle cell can also be confused with thalassemia, another blood disease with very similar effects, because both are caused by a defect in the hemoglobin S, which carries iron, and causes similar symptoms when it is defective.[5] This would most definitely prove that there would be more confusion, because discrimination in general is quite common among African Americans in general[6], doctors are more likely to lean towards sickle cell.

While sickle cell being confused with anemia and being a first diagnosis may be bad enough, there is also another sort of discrimination in people of color, primarily African Americans, that also bleeds into society. This is shown by the fact that there is very little study on African or Asian genetic genomes in the United States, and this underrepresentation can lead to misdiagnosed individuals and mistreatments. To combat this lack of information, medical practitioners must know about the fact that even though 1 in 13 African Americans lean towards sickle cell, anemia currently affects 5.6% of the US population [7], with African Americans having a 20% chance.[8] African American also have 26% to be on food stamps[9], which is a high number, and gives a greater chance of malnourishment and lack of access to proper foods. Given that many African Americans live in conditions that do not give proper access to foods, and that many are more likely rely on food stamps, it is crucial that medical communities take these following factors into consideration before deciding that any said symptom may be sickle cell anemia, doctors need to analyze the diet of the patient, as well as socioeconomic conditions that the patient may be under, such as poverty. This is also why it is crucial that doctors and geneticists establish connections with patients to prevent further misdiagnosis in the medical community. Doctors need to ask patients what their diet may consist of, what sort of support system they may be under, and other supplements they may be taking. Many medications such as aspirin, a common household product, can reduce the reuptake of iron in the GI tract[10], which can also lead to other more common symptoms of anemia and sickle cell, with internal bleeding

also being present if taken long term.

Genomes do vary on ancestry, however, with the increasing mixed race population, there needs to be science that is up to date with these individuals, such as with the LCT gene in mixed race individuals, specifically those mixed with European ancestry with individuals of Asian descent.[11] It is no secret that many Asian individuals have had this gene shut down after breastfeeding, because there was no need to consume lactose above a certain age in these cultures. In these cultures, there was less of a reliance on animal products in general, whereas Europe suffered from many famines and relied more heavily on animal products, such as lactose, which needed the gene to not shut down. Not many studies have been conducted on the genetic shutdown of the LCT gene, and how many lactase enzymes are present in mixed race individuals after the consumption of lactose. These studies may be crucial to understanding the behavior of certain genes and even gene regulation within people who have a mix of genetic codes. Understanding how genetic codes mix may not only bring great understanding to the needs of mixed race individuals, but also a deeper understanding of how genetics work when combining genes that shut on and off, and can even help with the study of diseases that may be caused by a number of genetic factors, such as cancers. These studies can be conducted by bringing mixed race individuals to ask about their experiences of lactose intolerance, and monitoring lactase after their consumption to fully understand how the gene can switch on and off.

Overall, these practices and studies will provide better overall experiences to many minority groups, and will bring the beginning to a newly advanced society which introduces the practices of studying genomes in racial minorities and mixed ones. These understandings on how these genes react can provide better care and reduce patient discrimination by doctors worldwide.

Citations:

1] <https://www.medicalnewstoday.com/articles/african-american-anemia#:~:text=People%20with%20one%20sickle%20cell,help%20protect%20against%20the%20disease.>

2] [https://theregoesmyhero.org/african-americans-affected-by-sickle-cell-and-multiple-myeloma/.](https://theregoesmyhero.org/african-americans-affected-by-sickle-cell-and-multiple-myeloma/)

3] <https://medlineplus.gov/genetics/condition/sickle-cell-disease/#inheritance>

4] [https://www.cancertherapyadvisor.com/home/decision-support-in-medicine/hematology/sickle-cell-syndromes/.](https://www.cancertherapyadvisor.com/home/decision-support-in-medicine/hematology/sickle-cell-syndromes/)

5] <https://www.nature.com/scitable/popular-students-page/113/#:~:text=Both%20thalassemia%20and%20sickle%20cell,caused%20by%20mutations%20in%20genes.>

6] <https://www.improvediagnosis.org/dxiq-column/why-the-color-of-your-skin-can-affect-the-quality-of-your-diagnosis/#:~:text=If%20you%20are%20a%20patient,diagnostic%20errors%20than%20they%20do.>

7] <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5112924/>

8] <https://www.aafp.org/afp/2007/0301/p671.html>

9] <https://frac.org/blog/new-usda-report-provides-picture-of-who-participates-in-snap>

10] <https://www.ijp-online.com/article.asp?issn=0253-7613;year=2004;volume=36;issue=4;page=226;epage=230;aulast=>

11] <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6308090>