## It's not just Black and White anymore: Incorporating health equity and social justice lenses in clinical research and health care to explain and address health disparities



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## Abstract

In medical research, researchers have long used the social categories of "race/ethnicity" and "socioeconomic status" to evaluate health and measure health differences/disparities that appear as groups of study subjects are compared. Often these research findings are incorporated into medical practice and beliefs. However, we now have learned that these social categories are instead proxies to the true underlying causes of disease and disparities: social determinants of health and structural racism. By applying new lenses to our clinical medical research, we can uncover true causes of health disparities that are hidden under the social labels of "race/ethnicity" and "socioeconomic status."

In medical research, researchers compare groups of study subjects by race, ethnicity, and socioeconomic status and find disparities in how health outcomes occur in these groups. Often, these findings get incorporated into medical practice and beliefs. For example, when looking at how a specific virus spreads in humans, the authors of a 2013 study used "race/ethnicity" and "socio-economic status" as markers that medical researchers have long used to make comparisons. The study authors noted "... substantial socioeconomic and race/ethnicity differences...," and they concluded, "These estimates can help researchers and clinicians identify groups most at risk [of infection with the virus]" [1]. Do these oversimplifications ignore other factors behind these differences? Instead of attributing racial disparities to underlying biological processes, we need to look at the social processes that cause health outcomes to vary by race. By using a lens that focuses on social determinants of health, medical researchers will be better positioned to identify and address the real causes of health disparities - factors that may run alongside the social labels of "race/ethnicity" and "socioeconomic status" that are so routinely used in medical research.

Individuals' choices and behaviors have traditionally been considered the target of focus by medical research's attempts to identify the causes of poor health outcomes [2]. However, in 2008, a World Health Organization (WHO) report showed that causes of negative health outcomes mostly lie outside of an individual's control [3]. Instead, social determinants of health (SDOH) broadly impact our health. Living with negative SDOH — from discrimination and racism to a lack of safe neighborhoods, nearby groceries stores, accessible quality health care, education and jobs with living wages —leads to poor health outcomes and health disparities [4].

Many people mix up "race" categories and "racism" and use the variables interchangeably [5], although they are different. Everyday Americans self-identify race and ethnicity in surveys, medical forms, and research studies. The U.S. Census Bureau notes that categories of race and ethnicity describe social or sociocultural groups, and they do not describe genetics [6]. Dr. Camara Jones, a physician and anti-racism advocate, clarifies race is "a social classification based on phenotype," and agrees it is "the societal box into which others put you based on your physical features" [7]. Unfortunately, throughout history, use of physical features and social categories "...unfairly disadvantages some individuals and communities, and unfairly advantages other[s]" [8]; it creates structural racism, a particularly insidious negative SDOH.

One example of obsolete language use is a major U.S. cancer center's website post from 2010 entitled: "Race and ethnicity as cancer risk factors" [9]. It highlights old beliefs that blamed individual "lifestyle behaviors" for causing cancer, mistakenly attributed "cultural factors" instead of "historical trauma" [10] as causes of mistrust by certain communities toward health care systems and revealed a racist bent when describing "extenuating factors associated with the different racial and ethnic groups" [11]. We must stop perpetuating racist beliefs that both cause health disparities and obscure actual causes. In 2016, Dr. Rachel Hardeman, director of the University of Minnesota's Center for Antiracism Research for Health Equity, called on all to start "[r]ecognizing and naming racism, in our work, our writing, our research and in our

interactions with patients and colleagues...[to] advance understanding of the distinction between race and racism, and allow for efforts to combat racism" [12].

An example of applying an antiracist lens to health disparities is the re-analysis of my research team's studies from 2011-2018 on Epstein-Barr virus (EBV) [13, 14]. We, too, used "race/ethnicity" and "socioeconomic status" categories as we studied EBV, which leads to several kinds of cancer [15]. EBV typically causes "infectious mononucleosis," also known more commonly as "mono" or "kissing disease." After the initial infection, EBV stays in the body and later can cause serious illnesses, including

1.5% of human cancers [16]. To prevent initial infections and future EBV-associated cancers, the team is developing a vaccine. To determine when that vaccine should be administered, we evaluated 782 children with blood tests to see when children get infected. Race/ethnicity of children was tracked, and the results were surprising. Children whose parents identified them as Black and multiracial caught EBV much earlier than those identified as White [17], as you can see in the graph labeled "Table 3" that shows EBV antibody prevalence (past infection) by age group and race/ethnicity groups.





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Condon, LM, et al. Age-Specific Prevalence of Epstein-Barr Virus Infection Among Minnesota Children: Effect of Race/Ethnicity and Family Environment. Clin Infect Dis, Volume 59, Issue 4. 15 August 2014, Pages 501-508, by permission of Oxford University Press.

Condon et al. (2014), did not find socioeconomic differences, but found significant race/ethnicity differences and greater "family education" levels in White parents. It was suspected that other "family environment" factors were possible causes of the disparities [18]. Today, we can recontextualize the finding of differences in parental educational opportunity — and its relation to past advantages and disadvantages — through a SDOH lens,

and now the infection "differences" that we detected by "race/ethnicity" can today be understood as effects of SDOH. Back then, we did not recognize them as such. Instead, we recommended EBV immunization at age 15 to 24 months and suggested further research [19]. Our team also speculated that the children's EBV health disparity was due to possible genetic risks, which are difficult to study, and instead focused next on "family environment" factors, or the "sharing environment" [20].

Approximately 90% of American adults have past EBV infection, and at any one time 22-90% shed EBV in their saliva [21]. To see how many parents were shedding and possibly "sharing" EBV with their kids, our second study evaluated saliva from 800 parents, who self-identified themselves with standard "race/ethnicity" categories [22].

Parents who self-identified with Black and multi-racial social groups had much higher rates of EBV shedding — and higher amounts of viral DNA in their saliva — compared to rates in the White social group [23], as one can see in the graph labeled "Figure 1" that shows EBV in oral secretions of parents by race/ethnicity groups.



**Figure 1.** Epstein-Barr virus (EBV) oral DNA by race/ethnicity; 1-way analysis of variance test for difference in prevalence across race/ethnic groups (P = .0015). Difference in mean EBV copies/mL was not statistically significant (P = .09).

Cederberg, LE, et al. Epstein-Barr Virus DNA in Parental Oral Secretions: A Potential Source of Infection for Their Young Children. Clin Infect Dis, Volume 68, Issue 2. 15 January 2019, Pages 306-12, by permission of Oxford University Press. <a href="https://academic.oup.com/cid/article/68/2/306/5017239?login=true">https://academic.oup.com/cid/article/68/2/306/5017239?login=true</a>

Why do parents in Black and multi-racial social groups shed more? Why do kids in those social groups get EBV earlier? Our study discusses evidence that earlier infection leads to higher risks for EBV-associated diseases [24]. These health disparities may lead to higher rates of cancer.

Black, Latinx, American Indian and Alaska Native social groups historically have higher rates of diabetes, hypertension, obesity [25], and Blacks have the highest rates of cancer [26]. The 1985 Heckler Report "rais[ed] awareness of the disproportionate burden of poor health among black, Hispanic, Native American, and Asian...groups" [26]. Obasogie et al. provide a long list of Black and White health disparities and note: "Minority groups continue to live sicker and die younger" [28]. The American Cancer Society's 2019-21 report confirms: "[B]lacks have the highest death rate and shortest survival of any racial/ethnic group in the US for most cancers." [29]

Our research team observed health disparities in children whose families were more likely affected by negative SDOH, including systemic racism. We suspect that many of these children "caught" EBV at younger ages from their parents, who are impacted by these same stressful negative SDOH. We researchers must dig deeper and design ways to evaluate actual risks for certain health conditions by inquiring specifically about ZIP code, food, housing, income stability, safety in one's neighborhood, access to health care and education, and exposure to racism.

We need to educate the public, health care providers and researchers about SDOH, identify and address negative SDOH, support "Health in All Policies" [30], and advocate for improved health outcomes by recognizing and naming race and racism [31]. Only then will we find true causes of health disparities and effectively address them to achieve health equity.

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