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# Biocultural citizenship and embodying exceptionalism: Biopolitics for sickle cell disease in Brazil

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## ABSTRACT

In 2006, the committee that developed the National Health Policy for the Black Population (NHPBP) chose sickle cell disease as their “flag to demand health rights.” The drafting of this policy was official recognition from the Ministry of Health for racial differences of its citizens in order to address certain inequalities in the form of racial health reparations. Through an ethnographic study which consisted of participant observation, life-story and semi-structured interviews, and surveys in the urban centers of Rio de Janeiro, São Paulo, Salvador, Belo Horizonte, and Brasília between November 2013 and November 2014, I introduce a new conceptual approach called biocultural citizenship. It is a flexible mode of enacting belonging that varies depending on disease status, skin color, social class, recognition of African lineage, and other identifiers. Using empirical evidence, this article explores how people living with sickle cell disease (SCD), civil society, and the Brazilian government—at state and federal levels—have contributed to the discourse on SCD as a “black” disease, despite a prevailing cultural ideology of racial mixture. Specifically, I demonstrate that the SCD movement strategically uses Blackness to make claims for health rights. Biocultural citizenship is dependent on the idea of biological and cultural difference that is coproduced by the State and Afro-Brazilian citizens. The use of biology to help legitimate cultural claims, especially in the Black Atlantic, contributes a new and distinct way to think about how race and skin color are used as tools of agency for diasporic communities.

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## 1. Introduction

In 2006, the *Política Nacional de Saúde Integral da População Negra* or National Health Policy for the Black Population (NHPBP) was approved by the National Health Council in Brazil to bring attention to a package of diseases thought to disproportionately affect Afro-Brazilians. It was the first piece of legislation from the Ministry of Health that officially recognized Black Brazilians as a vulnerable population warranting separate consideration. This is remarkable because embedded in this recognition of vulnerability is the promotion of a biologically and culturally distinct Black population in a nation known for racial ambiguity and fluidity (Freyre, 1933; Harris, 1970; Telles, 2004). Brazil's racial classification has been studied extensively and will be covered in more length below. As noted by Pagano (2011), the NHPBP “challenges national ideologies of racial and cultural unity by affirming the existence of an essential black body with specific health concerns, as well as an

essential Afro-Brazilian culture that materializes in recommendations for culturally competent health care” (xiv). When the Brazilian government implemented NHPBP, it added health to the cadre of programs—most notably, educational affirmative action programs—that formalized citizens' racial and ethnic differences in order to address inequalities among them.

Sickle Cell Disease (SCD) is an important political site in which race, citizenship, biological determinism, ancestry, and health are contested. Historically associated with Blackness (Tapper, 1999; Wailoo, 2001), SCD was chosen by activists as the quintessential representation of a disease that set Black Brazilians apart both biologically and culturally. These distinctions were mediated by African heritage. I interviewed Rui Leandro da Silva Santos, the then General Coordinator (the equivalent to a Program Manager) of Support for Popular Education and Social Mobilization, within the Department of Strategic and Participatory Management of the Ministry of Health, and asked him what he knew about SCD. In this role, Rui was instrumental in the operationalization of the cadre of health policies designed to address the needs of the marginal populations the NHPBP targeted, yet he admitted he knew very

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little about SCD:

... it's been very important for me—politically very important. Because it's what made space for the Black movement in health... there was a universal healthcare system, but the [Black] movement was saying “look, there are specific issues for Blacks”... SCD was like our flag to demand our health rights... these issues are specific to the Black race... genetically. Even though we have blondes with blue eyes who have SCD... the origin was from Africa.

In this statement we can find several assertions. We are alerted to the use of a disease, often associated with Blackness, strategically being used as a vessel to capitalize on the “right to health” discourse created by the 1988 Constitution, which required the State to obligate itself to every citizen in the creation of a healthcare system, distribution of pharmaceutical drugs, and regulation of healthcare services for all. This statement also highlights the tension between the notion of universality and equality offered to each citizen by virtue of birthright and the realities of the marginalized citizens who compete for state resources. Finally, Rui's statement exemplifies a linkage between biology and Blackness. Despite the biological evidence that describes SCD as an evolutionary response to malaria, Rui is just one of many actors in Brazil who have constructed sickle cell to have direct ties to African ancestry and the Black Brazilian body.

## 2. Sickle cell disease and biocultural citizenship

SCD is the most common hereditary hematologic disorder in Brazil and throughout the world (Cançado and Jesus, 2007). In 2010, it was estimated that 200,000 infants are born annually with the disease in Brazil (Jesus, 2010). Although SCD is not a biological marker for race, it can be considered a marker for ancestry from a geographic location where malaria is or was prevalent. Given that the biology of sickle cell stems from the endemicity of malaria and the subsequent protective and genetic response, and as a result is not attached to any one ancestral or racial group, it *could* be a disease that represents the Brazilian lore of a geographically, culturally, and racially diverse and integrative nation (Bala, 2009; Lima, 2007; Peard, 1997; Stepan, 1976). Instead, the Brazilian state has assigned SCD almost exclusively to Afro-Brazilians.

As exemplified in Rui's statement above, arguments used by the Brazilian state to justify the inclusion of sickle cell disease within the NHPBP directly link race, culture, and genetics. This linkage, at least between race and genetics, has long been made in the case of sickle cell disease; historically SCD was believed to only manifest itself in Africans and those of African descent and only later became understood as a molecular disease. As El-Haj (2007) posits, the “commitment to race as a molecular attribute” (287) can be observed in the actions of the State. This typological thought process harkens to the racial science of the nineteenth and early twentieth century. The policies from nation-states that stemmed from this time period were created to control “the boundaries of inclusion and citizenship” (286), often of those considered non-White (El-Haj, 2007). I argue that the Brazilian State uses these potentially problematic classifications to *create* routes of access and citizenship, specific to its Afro-Brazilian citizens.

In addition to cultural ties, biology thought to be inherited directly from Africa has led to successful claim-making by some citizens with SCD. This deep entanglement of biology and culture—as shown through Brazilian actors who attempt to gain access to fuller citizenship—is what I call *biocultural citizenship*. Examining the experiences of several of my research participants who draw upon the sickle gene and/or African heritage to make

competing claims upon the State, as well as legitimize their belonging to a social group, can provide us with viewpoints in which we can begin to interrogate how skin color, ancestry, identity, and citizenship are intertwined in claims-making. Biocultural citizenship, then, (a) encompasses the strategies used by people living with SCD to make or avoid claims-making as well as (b) interrogates the ways in which the State creates new subjects by linking ancestry, race, and disease in new ways.

Annemarie Mol's (2002) idea of mutual inclusion is helpful here. Mutual inclusion helps explain how biology or nature and culture are, in fact, in “coexistence side by side” (150). This notion that “what is ‘other’ is also within” (Mol, 1999, 85) has been explored extensively and across disciplines (Fausto-Sterling, 2012; Frost, 2016; Fullwiley, 2015; Inda, 2014; Schell et al., 2005; Tallbear, 2013). Further, Wade et al. (2014) contends that in a Latin American context, “it is important to recognize that, in general, culture and biology—or culture and nature—are always intertwined in racial thinking, so it is misleading to think in terms of a simple temporal transition from one to the other” (18). I account for the “bio” in biocultural citizenship via the S allele in my study participants, as represented by sickle cell trait (AS), homozygous sickle cell disease (HbSS), sickle cell SC (HbSC), and sickle cell beta-thalassemia (HbSβ-Thal). Ethnography and interviews, in addition to a geo-historical understanding of Brazil that allows for the S allele to interact with a number of cultural variables (race/skin color, ancestry, geographic location, activism, gender, appearance, and kinship), accounts for my understanding of culture.

Interwoven into the fabric of the nature–culture dynamic, race is inscribed on the body in ways that translate to—and, perhaps simultaneously arise from—the biological. Some public health scholars (Baer et al., 2013; Krieger, 2014) suggest we seek to explain how “race becomes biology” (Gravlee, 2009, 47) rather than wholly discounting the biological aspects of race when discussing the health disparities found in different populations. My intent is not to purely demonstrate “how experience gets written on the body in terms of measurable physiological, psychological and even morphological outcomes” (Dressler, 2005, 24). Rather, I assert that these processes of embodiment are occurring and are emboldening study participants to use these biocultural processes to their advantage in the claiming of health rights.

## 3. Mixed qualitative methods

Between November 2013 and November 2014, I conducted an ethnography, which consisted of participant observation, life-story interviews, and semi-structured interviews in the urban centers of Rio de Janeiro, São Paulo, Salvador, Belo Horizonte, and Brasília. A challenge of ethnography in public health and health policy research is its time-consuming nature, but I found it crucial to conduct ethnography due to the nuanced and experience-based nature of race in Brazil. I explored the implementation and implications of the NHPBP. The utilization of ethnography (observations and interviews) helped elucidate how certain communities played a role in policy development, how they continue to interact with the legislation, and how the SCD policy was embodied. I also distributed a questionnaire to collect basic demographic information (age, race/color, gender, religion, occupation, marital status, etc.).

### 3.1. Interview procedures

I collected 50 formal oral histories from a cross-section of racial, class, professional, and educational categories (see Table 1). I used the following techniques to collect oral histories: (a) questions were open-ended and person- and experience-centered; and (b)

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