



# 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)

**Table 1**  
Participant demographic information.

| Respondent Demographic Table | N (%)     |
|------------------------------|-----------|
| <b>Genotype</b>              |           |
| HbSS                         | 18 (67)   |
| HbSC                         | 3 (11)    |
| HbSβThal                     | 2 (7)     |
| Sickle Cell Trait            | 4 (15)    |
| <b>Race/Color</b>            |           |
| Negro                        | 12 (44)   |
| Pardo                        | 6 (22)    |
| Preto                        | 4 (15)    |
| Branco                       | 3 (11)    |
| Moreno                       | 1 (4)     |
| Mulata                       | 1 (4)     |
| <b>Age</b>                   |           |
| 18–30                        | 8 (30)    |
| 31–40                        | 6 (22)    |
| 41–50                        | 9 (33)    |
| Over                         | 50 3 (11) |
| Missing                      | 1 (4)     |
| <b>Gender</b>                |           |
| Male                         | 12 (44)   |
| Female                       | 15 (56)   |
| <b>State</b>                 |           |
| Bahia                        | 7 (26)    |
| Minas Gerais                 | 4 (15)    |
| Rio de Janeiro               | 6 (22)    |
| São Paulo                    | 8 (30)    |
| Distrito Federal             | 2 (7)     |

the questions aimed to elicit rich detail on the topic being studied and involved active listening. Opening questions were extremely general and open-ended, leaving it to the interviewee to direct the interview. I relied on a discussion guide to help consistently probe for specific themes when appropriate. In accordance with the principles and best practices for oral history, I used identifiable names, except when anonymity was appropriate or had been requested. Of the 50 formal interviews, five were conducted in English and four were conducted in a combination of Brazilian Portuguese and English; the remaining ones were conducted in Brazilian Portuguese. I have advanced comprehension and intermediate level of speaking of Brazilian Portuguese and conducted each interview. At times, assistants were utilized to provide interpretation and translation support. All interviews were digitally recorded, translated, and transcribed. In addition to interviews and conversations, I observed narrators in various aspects of their personal and professional lives. Very often these two realms blended and overlapped. This project was approved by the Institutional Review Board of Emory University. Oral consent was obtained before every interview after a research participant information sheet was reviewed. A copy was left with each interviewee.

### 3.2. Selection of narrators

In this study narrators varied by class, gender, regional representation, and phenotype. This study had three main categories of narrators: (a) persons who live with sickle cell disease; (b) public health practitioners or managers (*gestores*); and (c) civil society (non-governmental organization) leaders. Due to the nature of the sickle cell community, several people fit in more than one of the categories. Each of the respondents was over 18 years of age. Of the 50 study narrators, 27 people had SCD or SCT. I offered a questionnaire to only those who had at least one sickle allele. Thus, the data below represent only those with some variant of SCD or SCT. Data collected included age, gender, race/color, religion, education, occupation, marital status, and data specific to the diagnosis of SCD.

### 3.3. Recruitment

Primary sites of recruitment for persons who live with sickle cell (PLWS), public health practitioners, and civil society leaders included national, regional, and local conferences and meetings, office spaces of SCD organizations, and clinical sites such as blood banks and clinics. Points of contact with people living with sickle cell were either direct (via personal contact or social media) or mediated through my network of health officials, medical providers, or civil society leaders. Using snowball sampling, I expanded my network of potential narrators, as well as persons whom I could informally observe or converse. Eligibility requirements for those in the PLWS participant pool included a diagnosis of some genotype of SCD (HbSS, HbSC, HbS-Beta Thal).

### 3.4. Analysis

I conducted both thematic and interactional analysis. Both a priori and emergent or inductive coding were developed. As new codes emerged in subsequent interviews/oral histories, I used Glaser's (1965) constant comparative method to review previously coded interviews for indicators of newly developed codes. Throughout the open-coding process, I constantly compared previous excerpts of codes to newer excerpts to validate the meaning of the code. I managed all qualitative data in NVivo. In addition to the data that I gathered from interviews and observations, I also relied on a broad array of secondary material and sources including YouTube videos, pamphlets and other program products generated by SCD organizations, blood bank newsletters, prevalence data, and personal correspondence.

## 4. Brazilian classification and conceptions of race

Historically, Brazilian scientific and political elites used racial policies and measurement to invent identities, categorize individuals, and create a vision for a nation based on racial improvement (Schwarcz, 2006; Peard, 1999; Santos, 2004; Skidmore, 1993; Stepan, 1991). In the 1930s, Gilberto Freyre helped usher in a paradigm shift from the valorization of "whitening" to the celebrated acceptance of cultural heterogeneity. In his 1933 *Casa-grande e senzala (The Masters and the Slaves)*, Freyre popularized the idea of a *mestiço* (racially and culturally mixed) nation, constructing a vision of Brazil free of racism. Freyre and other Brazilian intellectuals of his time embraced the cultural union of these two populations, arguing that pacifistic race-mixing had forged a new national identity. This view was soon sanctioned by the State under the rule of Getúlio Vargas (Alberto, 2011; Dávila, 2010). Vargas incorporated Freyrean notions into his projects of federal unification, adopting symbols of African culture and reinventing them as Brazilian, all the while claiming *democracia racial* (racial democracy) (Alberto, 2011; Butler, 1998; Skidmore, 1993).

The historical racial and national constructions of Brazil are based on a racial classification system distinct from the United States and Europe. Unlike U.S. conceptions of race, which rely on the idea of the one-drop rule or hypodescent, Brazilians often use color (*côr*) terms instead of racial ones to describe themselves. Vital here is that different state actors utilize different racial classification systems. Since 1991, the Brazilian census has employed the categories white (*branco*), brown (*pardo*), black (*preto*), Asian (*amarelo*), and indigenous (*indígena*). *Pardo*, as both a color and category captures almost everyone in the phenotypic continuum between *branco* and *preto*. Created by the State, and shifting significantly over the course of the nineteenth and twentieth centuries, the above are the formalized categories used to measure race in early twenty-first century Brazil (Telles, 2004).

In addition to the formal system, there are a multitude of informal terms and categories. Harris (1964) makes early mention of the ambiguous nature of racial identity, citing 40 different terms of *côr* (color) in his study in which he provided nine portrait drawings and asked 100 individuals how they would be racially described. In 2003, the number of color classifications grew to 136 as listed by Schwarcz (2003). These terms were collected from a survey administered by the *Instituto Brasileiro de Geografia e Estatística* (IBGE). *Côr* refers to both phenotype (skin color, hair type, nose shape, lip shape, and more) and social position (Nobles, 2000; Parra et al., 2003; Telles, 2004; Travassos and Williams, 2004). The effect that socioeconomic status have on racial categories, an idea coined as “social race” by Wagley (1952), suggests the many ways in which racial fluidity can be influenced. The observation of this fluidity is prominent even in state-produced documents. In accompaniment to this fluidity of racial categories, is the great importance of racial hierarchy. Racial hierarchies often rank highest for those phenotypes that most closely resemble whiteness. In some cases, some phenotypic characteristics, such as hair type, carry more importance than skin color for determining *côr* (Gilliam and Gilliam, 1999; Hordge-Freeman, 2015).

In addition to the essentialized categories captured by the census and the informal classifications that take place in everyday life, there is one other recognized classification system. Important to the story of the NHPBP, the *Movimento Negro* (Black Movement) created and promoted its own racial classification system. This system uses only two terms, *branco* and *negro*—collapsing the terms *preto* and *pardo* into the *negro* category. The adoption of this bifurcated system as a tool of social organization explains why the Movement called for health policies to take a binary approach to race. The collapsing of these racial categories has substantial ramifications, both in terms of how “Black” health policy is produced and also regarding the interface between how people had long defined (and continued to define) themselves and their own racial identity.

## 5. Conceptual framework of biocultural citizenship

### 5.1. Background

Racialized health policy for Brazil is a relatively new phenomenon, though it is based on contemporary race-based social policies for education. These policies laid the groundwork for health regulations from the State in an attempt to address inequalities (Fry, 2005; Oliveira, 2003). For Brazil in particular, the rise of affirmative action education and health-related policies has often brought into question who has the right to make claims to the benefits bestowed to certain citizens by the government based on race or color. When the Brazilian government implemented NHPBP, it added health to the cadre of programs that formalize citizens' racial and ethnic differences in order to address inequalities. Unlike affirmative action for jobs or education, however, the health policies introduced for the *população negra* (Black population) rely not on the reallocation of resources for a specific population, but on the recognition of *being* biologically and culturally different. Due to the historical and systematic experiences of racism and exclusion shared by many Afro-Brazilians, claiming sickle cell disease as a *doença de negro* or Black person's disease allowed the *Movimento Negro* to capitalize on the equalizing narrative found in 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 study is informed by the embodied practice of individuals in both the medical and political sphere. The notion of biopower is imagined as practices embedded into the nation by the government

that can be used as tools of resistance (Foucault, 1979a, 1979b). The State distributes health rights to the “black political subject” (Paschel, 2016) via political processes that recognize both the multicultural and biological character of the political community. These political subjects with SCD are formed at the nexus of multicultural constitutionalism (Van Cott, 2000) and bioconstitutionalism (Jasanoff, 2011). Van Cott describes multicultural constitutionalism as a political process that occurred in Latin America during the 1980s. As part of these constitutional reforms, mostly Indigenous groups were recognized as part of a “multiethnic state” and given a platform to use their ethnic status as a way to make claims to the government to correct perceived injustices. While many Blacks in some Latin American countries sought equality rather than recognition for distinctiveness, in the countries that did include Blacks in this multicultural reframing, cultural difference was also highlighted to frame rights distribution.

Farfán-Santos (2015) describes how cultural recognition and rights are obtained for Afro-Brazilians in the case of *quilombo* land ownership. *Quilombos* are historically known as runaway slave communities; in contemporary times the descendants of those who originally inhabited the space (*quilombolas*) are contested by the State who want to make claim to their land. “The politics of cultural recognition requires that blacks assert an ethnic or culturally distinct group identity in order to obtain collective rights,” (Farfán-Santos, 2015, 112). Like two sides of a coin, this assertion is often in tandem with notions of strong national identity. The collective cultural ties to African ancestry are employed as strategy for claims-making for obtaining land rights, as well as equitable health outcomes.

The 1988 Constitution, which stated that health was a universal right for every citizen, allowed the actors to hold the newly democratic State accountable for its health-related grievances. By inserting this obligation to its citizens, the State made itself accountable for the biological underpinnings of Brazilian livelihood. After a harsh dictatorship, Black health activists were given space to be vocal about racial discrimination in public health services, invasive sterilization practices, and higher rates of mortality (Pagano, 2011). If bioconstitutionalism “displays the power of human subjects to articulate new claims vis-à-vis governing institutions,” activists living with SCD were given further permission by the NHPBP to make these claims. Through these biopolitical processes, the Brazilian narrators in my study have managed to reconfigure their relationship with the State.

### 5.2. Navigating citizenship: diasporic membership in hegemonic spaces

Health inequalities that exist between racialized groups has been discussed by Brazilian researchers, but only for the last 20 years or so. Prior to this, race data was not recorded within the medical/public health system. According to Pagano (2011), “once the Ministry of Health started to mandate the collection of race-based data during the late 1990s, researchers were able to demonstrate that black Brazilians die in greater numbers than whites from HIV/AIDS, homicide, alcoholism and mental illness, stroke, diabetes, and tuberculosis” (2). The rise in attention for *saude da população negra* grew after the administration of President Frederique Cardoso began to examine social exclusion of the poor and Afro-Brazilians and to implement policies and programs to promote social inclusion for those groups. In 2001, the Ministry of Health (MOH) published a “Manual of Diseases Most Important, for Ethnic Reasons, to the Brazilian Population of African Descent” and “National Health Policy of the Black Population: A Question of Equity.” SCD was featured in both documents. For those living with SCD, lack of awareness can often lead to dire health outcomes. Even

though the State created a universal public healthcare system under the premise that it provides care and treatment to all, many have reported discrepancies in how marginalized groups are treated within the system (Costa and Lionço, 2006; Falu, 2015; Kalckmann et al., 2007). How do people living with SCD, in response to neglect, set themselves apart in the attainment of better health?

It is helpful to introduce the claims-making strategies of Afro-Brazilians with SCD with some varied and overlapping influences of citizenship. The concept of differentiated citizenship orients us. In Holston's (2008) description, "citizenship is a measure of differences and a means of distancing people from each other" (5). When a minority group perceives that their cultural differences are being ignored by a nation-state that values national identity over any sub-identities, their survival is threatened (Holston, 2008). This represents the tension beneath the contemporary Brazilian conceptualization of citizenship: How does one form a heterogeneous identity in the hegemonic universality of being a Brazilian citizen? Purvis and Hunt (1999) suggest that the reality of marginalized groups is contested with the rhetoric of equality—demanding space in which some seek recognition for their specificity.

For some, that specificity, gets narrowed down to their genetic profile. Genetic citizenship (Heath et al., 2007) points to the ways in which molecular-based identities contest for power and a reframing of knowledge in a governmental context. Biocultural citizenship takes us a step beyond when considering how race or *côr* and culture may problematize "activism at the intersection between legislative politics and embodied experience" (154).

Here the theoretical tool of biological citizenship (Petryna, 2003) is also helpful to make sense of how people living with SCD make claims on the State. Adriana Petryna's study documents how Ukrainian citizens demanded recognition and redistribution of resources, in the context of long-term health problems following the Chernobyl reactor explosion, and the aftermath of the dissolution of socialism. Petryna's biological citizenship is a special status or practice that arises in a "subsystem of the state's public health and welfare infrastructure where increasingly poor citizens ... mobilize around their claims ... of injury" (Petryna, 2003, 5). This concept serves as the classic model to explain how some Brazilian citizens with a genetic point mutation can take action in requesting, né demanding, better care and service from the State. Petryna's subjects utilized their exposure from a particular event to make claims. Biocultural citizenship offers a temporal distinction that allows people to make contemporary claims based on biology and predicated on events that took place generations before the claimants were even born. Ultimately, slavery's cultural trauma compels Afro-Brazilians to action.

Furthermore, as Caldwell (2007) states in her study on Black Brazilian women, "The concept of cultural citizenship privileges the voices and experiences of marginalized communities by examining their vernacular definitions of citizenship and belonging" (3). Cultural citizenship is a means of enabling identities, affiliations, and belonging (Mercer, 2002), and can transcend traditional liberal and historical conceptions. Cultural citizenship "operates in an uneven field of structural inequalities" and has a role in "a process of constructing, establishing, and asserting human, social and cultural rights" (Rosaldo, 1997, 12, 37). Cultural citizenship is also a "dual process of self-making and being-made within the webs of power linked to the nation-state and civil society" (Ong et al., 1996, 738.) Members of the SCD Movement are being reconfigured in their biocultural claims in their attempt to be equal citizens. The cultural practices and beliefs associated with being Afro-Brazilian have been historically negotiated with the State for recognition (i.e., samba, *capoeira*, and *Candomblé*) and take modern form in the

NHPBP and "establish the criteria of belonging within a national population and territory" (Ong, 1999, 264). This negotiation is often through "ambivalent and contested" processes "with the state and its hegemonic forms" (Ong, 1999, 264). While each of these aforementioned iterations of citizenship is a rigorous concept, each fails to accurately describe the constellation of cultural, genetic, historic, and sociopolitical tensions needed to inform claims-making for those living with SCD in Brazil. For this reason, I employ the concept of biocultural citizenship in the case of SCD activists and their claims-making practices.

## 6. Color, class, and claims: narratives of biocultural citizenship

Biocultural citizenship is more than just a melding of concepts. If, as Lock (1993) suggests, "we must contextualize interpretations about the body not only as products of local histories, knowledge, and politics, but also as local biologies" (39), then we also must recognize how culture becomes biologized. As I define it, biocultural citizenship is a flexible mode of enacting belonging that varies depending on disease status, skin color, social class, recognition of African lineage, and other identifiers. It is dependent on the idea that biological and cultural difference is coproduced by the State and Afro-Brazilian citizens. I argue that the intricate ways in which skin color, race, ancestry, geographic location, and notions of kinship interact with SCD disease status (HbSS, HbSC, HbβThal, Sickle Trait) are influenced by external societal factors. While each actor with a sickle allele draws upon different cultural factors at any given time, they do so while interacting within Brazilian society; in turn, they are simultaneously vying for universal inclusion and distinctness. These societal factors overlap with social determinants of health and include racism, discrimination, social class, cultural and social capital, access to healthcare, income, and education. Layers of biology, culture, and society are interwoven with each other, drawn upon in different ways for each person, and affect the relationship that study participants have with their disease and the SCD policy. For these reasons, biocultural citizenship is vital to the analysis of race-based health policy.

As noted by Clarke (2013), scholars have "suggested that despite assumptions of membership and rights in relation to citizenship, the reality is that there are multiple layers of engagement and claim-making and that various other ethnic, cultural, and linguistic differences are at play" (465). Biocultural citizenship situates itself in the past, present, and future. The embodiment of identity for those who enact this process of citizenship is beyond geography, and even biology—it is intertwined with socio-historical experience, political economy, and colonialism.

At the end of my fieldwork period, I traveled to Rio de Janeiro for the third conference of the Worldwide Initiative on the Social Studies of Hemoglobinopathies (WISSH) that was held in conjunction with the Second Global Congress on Sickle Cell. These meetings brought together leading clinical and social scientists, public health officials, advocacy groups, people with sickle cell disease, and their families. Participants traveled from the Brazil, Benin, United States, France, United Kingdom, Ghana, Nigeria, India, and Italy to attend a four-day meeting that covered the state of science, policy updates, evidence-based practice, and social science research for SCD. On the last day for the closing plenary, conference participants filled a small room to hear about the plans for the development of a new organization: Sickle Cell World Federation. Plans were laid out to organize a global movement to garner the recognition and potential power akin to the World Hemophilia Federation. During the discussion period, a French national spoke of framing SCD as a "geographic disease." She suggested a strategy that should be approached due to the racial discrimination and

neglect that stems from racism attached to the disease. Most of the room, full of many Brazilians, gasped aloud at the thought. Soon after, Joice Aragão de Jesus, the then director of the National Sickle Cell Program for the Ministry of Health, took the microphone and addressed the woman. Joice explained that the Brazilian government had an obligation to people living with sickle cell, an obligation to the descendants of Africa. Once her mini-soliloquy was over, the room erupted with applause.

Biocultural citizenship recognizes that in Brazil, SCD is both a biological phenomenon and an urgent cultural issue that is legitimized by its African origins. To many in that conference room, SCD would not exist in Brazil had it not been for the forced migration of Africans who carried the S allele. As Ruha Benjamin (2015) points out, “what the state owes particular groups is connected to scientific definitions of what constitutes a group in the first place”. In the case of SCD in Brazil, health reparations in the form of policy, is also based on cultural definitions. Perhaps not all government officials would have responded as such, but Joice, a self-identified *negra*, was not only a physician and health official, but a known advocate for SCD within and external to the governmental sphere. She deeply acknowledged her African ancestry, practiced *Candomblé*—a religion strongly influenced by African culture—and displayed material artifacts throughout her house that signified links to Afro-Brazilian culture. When I expressed my gratitude for allowing me to live with her for part of my fieldwork, she told me, “The African way is to take care of everyone’s child” (Joice, personal communication, November 14, 2013). Perhaps it is of no surprise that Joice, as proxy of the state, recognized the biocultural maneuverings of the SCD Movement and worked to reward them with health reparations.

While SCD was an important focus of Black health activists in the 1990s—primarily as the quintessential disease to disproportionately affect Afro-Brazilians—many of these activists did not carry or were related to someone with the S allele. The Black Health Movement stemmed from the larger *Movimento Negro* (Caldwell, 2016). When I refer to the SCD Movement, I refer to those embedded in the activist communities concerned almost solely for the rights for those living with SCD. Indeed, those in the greater Black health movement often highlighted the need to bring other race-related health issues to the forefront. Taking advantage of this position, the SCD Movement often emphasized its connection to Africa and Blackness. In a slide set from the *Associação Baiana de Pessoas com Doença Falciforme* (Bahian Association for People with SCD) titled “incidence data for SCD in Brazil,” the third introductory slide to explain the disease’s origins reads: “[SCD] was not ‘brought’ from Africa by enslaved Blacks, it is a consequence of criminal uprooting. Ignorance and disregard for this disease result from the process of colonization, segregation and racism in Brazil and the Americas.” Those inserted in the SCD Movement are keenly aware of the ways in which biology, culture, and society are intertwined. Though this presentation is about data, they demonstrate a biocultural positioning by usurping how epidemiology is framed.

### 6.1. Perspectives of Brazilians with SCD

I met Barbara—42 years old, with HbSS, and self-identified as *preta*—for an interview at the blood bank and hospital in Rio de Janeiro, aptly named *HemoRio*. As the inaugural president of *Associação de Mulheres com Doença Falciforme do Estado do Rio de Janeiro* (Association of Women with SCD in the State of Rio de Janeiro), she was full of pride—“It’s the first of its kind in the world,” she told me. When we sat down for our interview, Barbara was concerned about the attention she perceived HIV/AIDS to have received specifically within the Black Brazilian population.

The true “Black health” related disease is sickle cell disease, not AIDS, as they’ve made it out to be. AIDS is infectious; our disease is hereditary. It’s different. It’s one thing for you to contract a disease, it’s another thing for you to get the disease from ancestors. (Barbara, personal communication, January 23, 2014)

Barbara goes beyond the biological pattern of inheritance, in which the S allele is inherited from either parent, and places her inheritance in the hands of her ancestors. Not knowing how far back she assigns the lineage of her ancestors, one might still assume that her intention is to evoke an ancestral imagery that brings us to the continent of Africa. This linkage to Africa usurps any prior messaging that deems AIDS the Black health cause de rigueur. The “true” Black health disease is the one authenticated by the African continent.

Due to the historic narrative that draws Brazilians’ ancestry from the Portuguese colonizers, enslaved people of Africa, and indigenous Amerindians, many Brazilians of all races believe themselves to have an African ancestor (Parra et al., 2003). This belief gets legitimized with the presence of SCD. Like the medical practitioners of the early twentieth century, Brazilian citizens who are phenotypically White link their disease status to an ancestor who was undoubtedly African. In a country like Brazil, where actors work especially hard to cement the association of Blackness with SCD, it is no wonder Flávio, 37 years old, from São Paulo, and a phenotypically White man (*Branco*) with homozygous sickle cell disease (HbSS), may feel contestation with himself:

My race, my skin color is White. But I have a problem that ancestrally speaking, I am considered of Black origin. I see that the disease is viewed as a Black disease. That excludes me when thinking about what group I pertain to, because I can’t say that I’m White. The little that I know about my genealogy and where the sickle cell anemia came from in my family, the disease probably came from my great-great grandfather who, according to my great-grandparents and grandparents and my parents, was Black.

(Flávio, personal communication, November 21, 2013)

Perhaps not surprisingly, race-based data is not available to help describe the epidemiology of SCD. Due to the construction of SCD as a disease almost exclusive to Afro-Brazilians—though it should be noted that SCD-related healthcare is universal—the numbers we do have access to are explained based on racial migration patterns. For instance, the prevalence for SCD in Bahia is 1:650 versus in Rio Grande do Sul where it is reported to be 1:10,000. Consistent justification for these statistics in Brazil-based literature has cited the numerous inhabitants of *afro-descendentes* (afro-descendant) in the northeast of the country and the lack thereof in the south.

Similarly, in addition to asserting a mixed-race national identity, Brazilians have traditionally constructed racial identity based on *côr* (color) as a malleable condition rather than an essential one. What remains is a complicated narrative that rests simultaneously on racial admixture and the oppositional principle of hypodescent, or the “one-drop rule.” As suggested by Kent et al. (2014), Brazil evokes simultaneous “genetic imaginaries” based on nation, race, region, and diaspora. Despite this understanding, we might understand how the presence of SCD disrupts one’s “social race” (Wagley, 1952), especially for Whites in Brazil on the phenotypic continuum.

Flávio’s phenotypic Whiteness delegitimizes his disease status and alters the identity that society has assigned. He simultaneously exists in São Paulo as a hegemonic entity while also navigating the

marginal spaces that a White person with SCD must traverse. He explained to me the differences among Black, Brazilian, and African that separate color from race:

When I say *negro* (black), the image that comes to mind is someone that is *bem escuro* (very dark)... the COLOR is *negro*, RACE is not *negro*... [race] is associated with ancestry and I respect that. Ancestry exists, yes. I don't ignore the merit given to the person that came from slavery. They could say, "Eu sou negro" (I am Black), but they don't have the same tradition that the *negro* has; they have traditions from Brazil that is another culture and another way of living.

By assigning the term *negro* to only those of the darkest hue, Flávio discursively negates the influence of any policy or program document which applies that term to those who do not fit that phenotypic profile. Flávio's statements are emblematic of not only the cultural weight put on color, but also of how easy it is to slip back and forth between the two constructs. The formation of identities, moreover, influences how each narrator operates in relationship to their own disease and ultimately to the relevant healthcare and governmental policies.

In the social world he lives in, the presence of the S allele equates to blackness. Flávio in his identity crisis, needs to create distance. This is evident in the above narrative. In addition, he has inserted himself in a discourse in which the racial purity associated with slavery is a thing of the past, while mixture is viewed as a phenomenon of the present. Kent and Wade (2015) have recognized "markers of a distinctive black culture" as a way to define Blackness in Brazil when genetic arguments were used to deny the definition. In this case, Blackness was also defined by African descent, which was mostly framed in spiritual, religious and cultural terms, as opposed to a biological one.

Furthermore, skin color and appearance played roles as well in the definition. Biocultural citizenship allows for some Brazilians to call on both biology and culture in the ways in which they make claims to the State. It also explains how some may feel less compelled to draw their rights from policy that positions Blackness as exceptional. For Flávio and other White narrators with SCD in the study, their Whiteness shifts how they engage with the State as a biocultural citizen. In the absence of any societal markers of blackness, these participants occupied a diminished role in pursuing the government's offerings in relation to SCD. In other words, the fight for policies and other political machinations held little interest to many I spoke with. Flávio demonstrates a cultural distancing from Africa. He understands Afro-Brazilians to have a distinctively separate culture from their African ancestors—even if Afro-Brazilians disagree. Further, how he and other White narrators with SCD engaged with society aptly demonstrated the notion of differentiated citizenship. There is less vulnerability for Whites living with SCD in Brazil and less resistance to a perceived lack of power and rights. Through these firsthand perspectives, the societal, material, and political dimensions of inclusion expose whiteness as capital (Reiter, 2009). Biocultural citizenship works as a sliding scale and demonstrates how the buttressing of Whiteness and distancing from Blackness can affect claims-making. The case of Flávio is useful to build on the work of Gravlee (2009) to further demonstrate the dangers of reductionism when creating health-based policy. His social experience of race is in constant tension with the biological framing from the state which ascribes an undeniable blackness.

## 6.2. Negotiating belonging among a national collective

For those living with SCD, attempts to create space in a

hegemonic reality of normalized and able-bodied Whiteness are enacted by the negotiation of belonging within the larger national collective. Many actors, especially those who identified as Black (*preto* or *negro*) with SCD, use the cultural and ancestral connection to Africa as well as the presence of a sickle allele as a way to make preexisting structural boundaries of society more flexible. These preexisting conditions should not be thought of as a medical condition that existed before one's insurance took effect, but instead as a societal condition that many of my respondents were born into or lived in. Better thought of as social determinants of health—occupation, education, access to adequate healthcare, and racism—these indicators are known to impact the health of individuals and populations. Study participants often spoke of the discursive ways in which they negotiated their belonging within societal constraints.

Gilberto, was 49 years old when I interviewed him and lived with the most severe form of SCD (HbSS). He grew up in *Vigário Geral*, a neighborhood in the North Zone of Rio de Janeiro most notable for the massacre that took place in its large *favela* in 1993. He beamed with pride when recounting his childhood there, "I am a resident of a family of seven children, a humble, poor family with a lot of difficulty raising us... I am proud that I was born in that poor family and was a resident of *Vigário Geral*" (Gilberto, personal communication, November 18, 2014). Of his seven siblings, three had SCD and all three have died. Gilberto died in March 2013 from complications of SCD; I interviewed Gilberto four months before his death. He recounted the origins of the national SCD organization, *Federação Nacional das Associações de Doença Falciforme* (National Federation of Sickle Cell Disease Associations), of which he was President for about a decade:

There was a meeting of another NGO, and they were more or less putting pressure on us. They proposed at this meeting that they wanted to represent us. In fact, they wanted to represent all the hematological diseases, but the folks with Thalassemia advised me to say no, and to not agree because they had already given a response of "no." "How were we going to let others that don't have anything to do with our movement or our pathology represent us?" someone asked. So we said no.

For Gilberto and many others, it was through the *Movimento Negro* that actors both with and without SCD were able to negotiate belonging in other spaces. Rabinow (1996) predicted both the usefulness and potential negative outcomes related to "a 'new genetics' [that is] embedded throughout social fabric at the microlevel by a variety of biopolitical practices and discourses" (186). "New genetics" emphasizes empowerment, choice, and benefits (Bunton and Petersen, 2002).

"New genetics" is conjoined with activism in Gilberto's narrative above in that genetic differences are embodied in distinct, disease-based social movements. Their specific pathologies allow for the patients within these groups to embody genetic citizenship, as referenced above. However, the thalassemia and sickle cell groups refer to specific geographic ancestry and the cultural frameworks of the posh Mediterranean (*anemia do Mediterrâneo*) and an impoverished dark continent evoke different imaginaries.

Those in my study who identified as *pardo* or *branco* and also claimed space within the SCD Movement recognized the Black Movement, albeit while also acknowledging their absence from its membership. Elvis, who was 47, from Brasília, identified as *pardo*, and had HbSS, was genuinely committed to the SCD movement. In our conversations, though, Elvis was careful to make the distinction between it and the Black Movement. Like many of my narrators who did not identify as *preto* or *negro* with sickle cell disease, they recognized a need for the State to acknowledge and act for the Black

population and believed the racialized policies recently implemented were justified.

I think that the debt the world has to sickle cell is very big. I don't know if it's even possible to pay. The debt that Brazil has to sickle cell is enormous and the debt that Brasilia has with sickle cell is very big too. But we see people wanting to pay back, and change this story, and I am happy about that. (Elvis, personal communication, November 11, 2013)

Though Brazil's Constitution of 1988 made its citizens able to hold the State culpable for their health, this particular idea of debt and neglect reflects the deep-seated historical memory of slavery, simultaneously far removed from the contemporary SCD Movement, but also ever-present in the minds of those involved. Advocacy surrounding SCD is based not solely on the biological condition of the genetic inheritance of the S allele, but also the historically and culturally constituted experience of diaspora and racialized identity in Brazil.

## 7. Conclusion

As I have suggested early in this paper, racialized experience is imbricated in biological consequences, and the Brazilian interpretation of race (*cô*r) cannot be interpreted without culture. Thus SCD, with its myriad cultural and biological nuances, will be inherently influenced in expression & experience by the particular context of Brazil, much as historical and social experience of race shapes health in discrete geographical contexts (c.f. Gravlee et al., 2005).

The formalization of racial identities via the utilization of a binary system, is striking in once sense considering how fluid Brazil's notion of race is; but understandable in that the Black Movement has adopted this bifurcated system as a tool of social organization. Despite this, race based health policy in Brazil cannot be a model for race-based health policy in the U.S. or elsewhere, due to the different ways in which race emerges from a geopolitical history. Biocultural citizenship as enacted by Afro-Brazilians with SCD, offers a way in which to understand health disparities in a disease that is not race limited, yet is associated with differential treatment and investment.

The use of biology to help legitimize 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. Though Duster (1990) and others have warned against new genetic technologies that may open the space for screening, treatment, and therapies that would introduce a “back door” eugenics, the participants who clamored for their rights in the production of these technologies are less concerned. Even as it reifies a biological notion of race, linking genetics to race aligns with individual and population health interests in this case. Those in the SCD Movement may not be worrying about this, and rather are glad to receive the relatively small (yet realistically quite meaningful) benefits that the NHPBP distributes. This is not incommensurable with their awareness that these benefits are microscopic in comparison to the larger scope of civil rights that ought to be afforded to them as Brazilian citizens.

For this study we can see how certain actors with SCD—usually those with darker skin color—choose to locate their site of negotiation in both their genotype and access to the African continent, in turn drawing on both biology and culture to help authenticate their claims to the State. Further, those who cannot fit firmly into either of these biological or cultural constructs often find themselves in contestation with themselves and less legitimized by the State and others, at least for SCD related purposes. In life external to SCD, particularly for actors who may find themselves outside of or

interstitially located in SCD membership, other forms of belonging, recognition, and respect take place in general Brazilian society. Often the exclusion that these (typically lighter-skinned) actors may feel from full membership in the SCD community is counteracted by affirmations of inclusion in other aspects of their lives. These affirmations take shape in the form of access to healthcare and education, better employment opportunities, less societal discrimination, and upward mobility. In essence, I found that being darker-skinned was associated with more reliance on the state-sponsored health policy to help legitimize one's citizenship. Those who were lighter-skinned acknowledged, but were indifferent to the policy. This lack of engagement, moreover, is yet another mode of enacting biocultural citizenship; the absence of claims-making for SCD demonstrates how whiteness ushers belonging. Hughey (2012) frames a collective narrative of belonging in a U.S. context by highlighting and contributing to a body of work that demonstrates “how racial discourse mystifies racial inequality and constructs white racial identity as a synonym for ‘citizen’ (165). So too, does the Brazilian configuration of citizenship (Nobles, 2000; Caldwell, 2007; Holston, 2008; Reiter, 2009).

The use of identity politics to achieve recognition is no new approach. Current thinking situates the biological as something that inherently breeds solidarity. Biocultural citizenship shows us that biology is still stratified along cultural lines. Furthermore, a commonality is formed only when we take into account the stratification of embodied suffering and the limits of existing political will to attend to that suffering. The recent resurgence of the Right in Brazilian politics may upend many of the efforts made by civil societies who frame their claims making around identities. As a result, the State's past emphasis on redressing past social and cultural injustices could come to an end. For now, as a political and scientific strategy, Afro-Brazilians have positioned their bodies as exceptional and in doing so have forced the state to respond to their claims.

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