Introduction

- Sickle Cell Disease (SCD) is the most common hereditary disease in the world and in Brazil (6-7% affected)
- 3, 500 babies are born with the disease, 200, 000 are born with Sickle Cell Trait each year
- Despite legislative advancements, critics argue that funding incentives and clinical diagnosis are hindered by pervasive racism in Brazilian society

Methods

- Review of data and publications in Brazil Ministry of Health and USP
- Expert interviews of policy makers, researchers, and health professionals conducted at Faculdade de Medicina and Centro de Saúde-Escola of USP

Results

History of SCD legislations
- Zumbi dos Palmares March Against Racism, for Equality and for Life in 1995 in Brasilia involved many SCD NGO’s and demanded national prioritization of SCD
- National Comprehensive Care Program for Persons with Sickle Cell Disease and Other Hemoglobinopathies incorporated into the Unified Health System in 2009
- Ministry of Health released manual clearly outline occupational hazards unique to SCD patients yet denounces discrimination against SCD patients in the workplace

Clinical classification of race
- Health providers and epidemiologists are required by law to ask people how they identify racially
- However, judgments and behaviours within public health field are largely influenced by the colour of one’s skin
- Many researchers criticize the validity of race as a foundation of policymaking given the high levels of admixture in the Brazilian gene pool

Accessibility to AfroBrazilian communities
- Various hemocentres are located across the country and SCD is included in the National Neonatal Screening Program
- Survey shows that the black population in São Paulo is over-represented in the peripheries, further from employment opportunities and likely from SCD centres
- Despite the existence of Black researcher committees AfroBrazilian researchers are extremely under-represented in SCD research

Discussion

- The scope of this research was limited by
  - Language barrier
  - Missing patient perspective and diversity of opinion
- Further investigations may address
  - Whether it is necessary to standardize the notion of “race” in medical and scientific contexts

Conclusions

- The tension between quests for scientific accuracy and racial equality may hinder clinical advancements
- There is a need to empower black voices in SCD scientific community and incentivize SCD research
- Continuing discussion on the intersections between race and public health, especially in the context of hereditary disease, calls to question the impact of social discourse has on the medical field and vice versa

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