THE EUROPEAN SOCIETY OF MEDICINE
Medical Research Archives, Volume 13 Issue 7

RESEARCH ARTICLE

# Between desire and fear: Women with sickle cell disease and the pursuit of motherhood in Brazil

**Ana Cláudia Rodrigues da Silva**

Federal University of Pernambuco, Anthropology and Museology.

acrodriguess@gmail.com

OPEN ACCESS

**PUBLISHED**
31 July 2025

**CITATION**
Silva, ACR., 2025. Between desire and fear: Women with sickle cell disease and the pursuit of motherhood in Brazil. Medical Research Archives, [online] 13(7). https://doi.org/10.18103/mra.v13i7.6860



**DOI**
https://doi.org/10.18103/mra.v13i7.6860

**ISSN**
2375-1924

## ABSTRACT

**Background:** The article seeks to explore motherhood experiences of women with sickle cell disease (SCD) and sickle cell trait in Brazil, highlighting intersections between race, gender, and health. The study aims to understand how these women experience motherhood, the challenges they face, and the care strategies they develop.

**Methods:** The research was qualitative and used the ethnographic method, with fieldwork conducted at a Hemocenter and a Polyclinic in the state of Pernambuco, in addition to semi-structured interviews with 13 women with Sickle Cell Disease.

**Results:** Identification of the challenges faced by women with Sickle Cell Disease and Trait who wish to become mothers. Description of public policies for the assistance of women with sickle cell disease in Brazil. Identification of racism as one of the main obstacles they face in accessing care during pregnancy and living with a chronic illness.

**Discussion:** Motherhood for women with Sickle Cell Disease and sickle cell trait is marked by additional challenges due to the genetic condition. Mothers of children with Sickle Cell Disease face greater social pressure and need to reorganize their lives to meet their children's health needs. The research highlights neglect and institutional racism present in health services, which negatively impact access to adequate treatments and increase risks during the pregnancy of women with SCD.

**Conclusion:** Motherhood experienced by women with sickle cell disease and mothers of people with sickle cell disease is intertwined with aspects of racial and gender inequality in Brazil. These women's experiences reveal the need for an intersectional approach to understand the multiple forms of motherhood. The lack of adequate assistance policies and institutional racism are significant obstacles these women face. The research suggests that, with proper follow-up, it is possible for women with SCD to be mothers, but it is necessary to ensure access to quality information and care.

## Introduction

Sickle cell disease (SCD) is the most prevalent genetic disease in Brazil, affecting an estimated 60,000 to 100,000 people. Annually, around 200,000 children are born with the sickle cell trait and 3,500 children with sickle cell disease, resulting in an average incidence of 1:2500 live births. Despite its high prevalence, SCD is an invisible disease, especially due to its predominance in the black population (black and Pardo individuals). The historical, political, and economic contexts that mark structural inequalities in a country with a history of colonization and slavery contribute to this invisibility[1-4]. Racism in Brazil operates as a device of raciality[5], inserting racialized bodies into the sign of death and being responsible for the worst health indicators of the black population.

Sickle Cell Disease is characterized by the presence of the hemoglobin S gene or sickle cell gene (Hb S), inherited from the parents. It can occur in the homozygous SS form, when inherited from both parents, or heterozygous AS, when inherited from only one parent. The latter is known as sickle cell trait, which is not a disease but a genetic characteristic. As a genetic disease, SCD has been included in the National Neonatal Screening Program (Heel Prick Test) since 2001. Given its prevalence, it has a specific public policy, the National Policy for Comprehensive Care for People with Sickle Cell Disease and other Hemoglobinopathies, established and implemented in 2005, during a period of intense discussions about affirmative policies for the black population. SCD enters a political scenario where various actors operate, including black social movements, doctors, scientists, geneticists, associations of people with sickle cell disease, and the Brazilian state. The relationship between race and sickle cell disease is observed in other countries such as the USA and Cuba, which also have a significant presence of descendants of enslaved Africans[6-8].

The national policy for care for people with sickle cell disease was a demand from the movement of entities of people with SCD, organized in the National Federation of Associations of People with Sickle Cell Disease (FENAFAL). This policy is related to the National Policy for Comprehensive Women's Health Care and the National Policy for Comprehensive Health Care for the Black Population. Although it involves discussions about reproductive rights linked to women's health, the racial factor places black women as the main ones implicated in the developments of living with a chronic disease or as caregivers of people with SCD in a country where the intersection between race and gender shapes specific situations in living and dying. According to the maternal death monitoring panel, in 2024 the country recorded 65,549 deaths, of which 38,062 occurred with black women[9]. It is worth noting that maternal mortality is an indicator of social equity.

Black women have the worst indicators in education, access to the labor market, and goods and services. Considering the complications arising from SCD, Altair Lira, a researcher and member of FENAFAL and father of a child with SCD, points out: "due to the high susceptibility to infections that people with sickle cell disease present, housing, hygiene, and nutrition conditions become predominant factors for the evolution of the clinical picture"[10].

Pregnancy is not contraindicated for women with SCD, but it is considered high risk, requiring differentiated attention. It is not just a clinical issue, but one that affects the emotions of those who already live with a chronic disease[11]. A period that for many women is one of joy and positive expectations becomes marked by the fear that their children will be born with SCD and not survive, as most deaths occur among children up to 2 years of age. Pregnancy can worsen SCD, increasing the number and severity of painful crises and infections. The risks include an increase in vaso-occlusive crises before and after childbirth, urinary tract infections, pulmonary complications, anemia, pre-eclampsia, and even death and premature births[12].

The recommendations of the Ministry of Health indicate that pregnant women with SCD should

have prenatal consultations every two weeks until the 26th week, and after that period, consultations should be weekly. It is also important that they are attended by a multidisciplinary team trained with knowledge about SCD, to ensure that all aspects of pregnancy are covered. Late diagnosis is common among women of reproductive age with SCD, many only discover they have the disease or trait during pregnancy. In this sense, the Hemoglobin Electrophoresis test was included as one of the necessary exams during prenatal care for all pregnant women, in addition to protocols for pregnancy and childbirth. When detected, they are referred to institutions focused on high-risk pregnancy[13]. According to research developed by Ana Claudia Silva, the fact that the heel prick test was only mandatory in 2001 left uncovered a range of women who did not benefit from the service and had their diagnosis late. Silva presents the case of a black woman who was only diagnosed at the age of 50.

This article presents data from the ethnographic study of the doctoral research entitled "Sharing genes and identities: genetic counseling, race, and health policies for people with sickle cell disease and trait in Pernambuco," conducted in 2013 in the Graduate Program in Anthropology at the Federal University of Pernambuco. After 12 years of conducting the research, the literature review shows that the data and contexts presented have undergone few modifications, placing sickle cell disease (SCD) in the field of neglected diseases, despite its high prevalence[14].

The experiences of motherhood will be presented from two perspectives: women with sickle cell trait who had or have children with sickle cell disease and women with sickle cell disease and their journeys in pursuit of the right to motherhood. The first perspective addresses mothers who, upon discovering their children's genetic condition, face additional challenges in raising and caring for them, often needing to reorganize their lives and routines to meet their children's specific health needs. The second perspective focuses on women who, in addition to dealing with their own health condition, face barriers and prejudices in seeking to fulfill their desire to be mothers, often requiring specialized medical care and facing additional risks during pregnancy.

## Methods

To approach the experiences of women with sickle cell disease and trait, the ethnographic method was used, based on immersive fieldwork sensitive to the aspects experienced by the subjects of the research. The ethnographic research conducted in Pernambuco took place at a Hemocenter, a polyclinic, the Associação Pernambucana de Portadores de Anemia Hereditárias (APPAH – Pernambuco Association of Carriers of Hereditary Anemias), and the Gerência de Atenção à Saúde da População Negra da Prefeitura do Recife (Office for Black Population Health in the City of Recife), during the years 2010 to 2012. For the present discussion, I mainly use the data from the ethnographic research at the Hemocenter, a regional reference in the care of people with sickle cell disease, and the Polyclinic, responsible for the care of children born with sickle cell trait and their parents.

Hemope Foundation is a scientific, educational, and assistance institution linked to the Secretaria de Saúde do Governo do Estado de Pernambuco (Department of Health of the Government of the State of Pernambuco). It operates in the segments of Hemotherapy and Hematology. It has a hospital for activities related to hematological treatment, providing outpatient services, emergency care, day hospital, dental care, and physiotherapy and psychological follow-up. Located in the central region of Recife, the institution receives patients from the interior of the state and neighboring states. The research was conducted in the outpatient clinic, which at the time had five consulting rooms, a pantry, bathrooms, a reception, and a space for children. The research strategy used was to accompany the patients still in the waiting room, as they arrive very early at the Hemocenter for exams and are only seen by doctors afterward. Appointments are scheduled and generally held every six months, unless there are complications.

I arrived early in the waiting room, observed the movements, and at an opportune moment, established contact with people, introduced myself as a researcher, showed the documentation of permission for research, and asked if I could accompany their consultation. I had almost no refusals. As for the professionals, they all knew of my presence, but I always had to explain what the research was, as the Hemocenter receives many students in training. For three months, I was in the outpatient clinic on Tuesdays and Wednesdays. I accompanied 50 consultations, of which 38 were with women of different age groups. Observations were noted in field diaries. Patients were already accustomed to the presence of students and residents in the consulting room, and my presence did not seem to bother them. Of the 38 observations with women, 10 were conducted with mothers of children who tested positive for sickle cell disease in the Neonatal Screening. All children with sickle cell disease are referred for orientation consultations at the Hemocenter, where parents receive the first information about their child's condition. Generally, they arrive at the hospital full of doubts and uncertainties. After the consultation, they are referred to retake the test in six months and return to the unit.

In addition to observation, I conducted semi-structured interviews with 13 women, which took place before or after the consultations, depending on their availability. Of the interviewees, eight had completed high school and five had incomplete elementary education. Eleven lived in the metropolitan region of Recife and two in the countryside of the state of Pernambuco. Ages ranged from 20 to 55 years. Nine received the government's Continuous Benefit Provision and only four were employed as public servants. Regarding race/color, all self-identified as black (Pardo and black). Six were married or in a stable union, one was widowed, and five were single. Only three women were mothers and one was pregnant.

The Polyclinic Albert Sabin health unit is located in a neighborhood in the northern zone of Recife. It is a medium-complexity unit with spontaneous and referred demand. It has several specialties, including hematology and genetic counseling services for people with sickle cell trait referred from maternity hospitals after a positive result for sickle cell trait in neonatal screening. At the unit, I also accompanied orientation consultations for two months. Unlike Hemope, where there are specific days for the care of people with sickle cell disease, the polyclinic did not have this planning. I went to the unit every Wednesday in the hope of having a child referred from screening. The maximum number of patients observed per day was three. Generally, children are brought by their mothers or another woman, like a grandmother. I only accompanied two fathers during the research.

In genetic counseling, the geneticist explains to the guardians what sickle cell trait is and the implications of the genetic condition. Although emphasizing that it is not a disease, mothers always become very apprehensive because, generally, they are unaware of the genetic condition and want to know if their children will have a normal life or if they are at risk. I observed 20 consultations, and in only one, the couple knew what the trait was and the difference from sickle cell disease. The counseling provided by the geneticist is more focused on passing information to the parents. Hemoglobin electrophoresis tests are requested for the parents, siblings, and grandparents of the child. The most emphasized issue is the care for future pregnancies in case the parents test positive for the trait, as it is possible for a child with sickle cell disease to be born. There is also guidance for the future relationships of the child, in case they have children with partners who have the trait. This is a moment when, even hearing the doctor's explanations, mothers showed a lot of fear and some expressed the decision not to have more children, especially when the partner also had the trait.

The genetic counseling service in the Sistema Único de Saúde (SUS – National Unified Health System) is precarious, with few specialized professionals. In this sense, considering the profile

of people with sickle cell trait and disease in Brazil, generally low-income and with little education, misinformation is a constant. People are deprived of genetic information, and the country is far from ensuring genetic justice or genetic citizenship.[15-17] At this unit, I did not conduct semi-structured interviews with the mothers, only accompanied the consultations, and we had many conversations in the corridors and waiting rooms, as the doctor almost always arrived late and they waited a long time for the consultations. Observations were recorded in a field diary.

The treatment of the material followed this order: writing in the field diary, transcriptions of interviews, and systematization of data. For the interviews, content analysis was employed based on specific themes, including motherhood and reproduction. The thematic content was organized into specific tables for each interviewee and to compose a general framework of the dissertation. All content was analyzed based on the theoretical framework of the dissertation.

## Results:

The main results identified were: identification of the challenges faced by women with sickle cell disease and trait who wish to become mothers; a surve of existent public policies for assisting women with sickle cell disease in Brazil; and the identification of racism as one of the main obstacles they face in accessing care during pregnancy and living with a chronic illness.

Black women occupy the lowest positions in the social pyramid. Despite being the majority as users of public health services (SUS), they also top the statistics for maternal mortality, breast cancer deaths, hypertension, and diabetes, all avoidable diseases. The research Mortality Ratio for Maternal Causes by Race/Color Groups, Brazil - 2019 to 2022 indicates that Black women are twice as likely to die from abortion compared to white women and 1.7 times more likely to die from hemorrhage and 2.8 times more likely from hypertensive syndromes.[18] If these numbers are alarming when intersected with morbidity and mortality rates in women with sickle cell disease, the problem becomes even more pronounced.

The lives of women with sickle cell disease are marked by a journey of neglect and structural, political, social, economic, and cultural obstacles. These journeys are underpinned by institutional racism, which directly impacts access to public health policies and appropriate treatments, exacerbating pain and making living with sickle cell disease a dilemma.

## Discussion

The anthropological literature understands motherhood as a sociocultural construction that goes beyond biological aspects. In this sense, motherhood is constructed in various ways and assumes a multiplicity of meanings, that is, it is constituted in the experiences of women. According to Parry Scott, the practical and symbolic construction of motherhood is made from the multiplicity of meanings, but also by the obligation of the responsibility of care marked by suffering and sacralization. Addressing the context of mothers of children with Congenital Zika Virus Syndrome, the author demonstrates how the reality of these mothers is linked to the search for causal explanations and various therapeutic responses to their children's condition[19]. This sense is also observed in mothers of people with SCD.

Regarding mothers with sickle cell trait who had children diagnosed with SCD, Uliana Silva demonstrates how these mothers are generically charged as women and specifically as mothers of children with a chronic disease. They are assigned a "double care" for their children, a social charge even greater in the eyes of society that understands that these mothers need to live solely and exclusively for the care of their children. In her research with mothers in the state of Paraíba, she reports:

> All the mothers participating in this research were unaware of the disease until they were informed about the possibility of their

> children being affected. All the women who allowed themselves to be part of this research reported how they became mothers of children affected by a genetic alteration – women who discover they have the sickle cell trait, who need to abandon their jobs to be able to accompany their children's treatment. They need to change their routines, as they are invited to establish a new daily life with medical appointments, seeking rights, and knowledge, recognition, and respect[20].

Mothers of children with SCD become mothers with each experience based on their children's needs. In their daily experience, they create and recreate care strategies for each situation, taking into account their subjectivity and that of each child. The journey to becoming a mother of children with SCD is a path full of challenges, learning, and affections. They go through the entire pregnancy without knowing that their children have any illness, arrive at childbirth like other women full of expectations, joy, and hope. The moment of change in becoming a mother of SCD occurs when they receive a call to go to the maternity hospital because their child's test showed some alteration. At that moment, according to the mothers, an abyss is created and fear invades their lives. They think, "how come, my child is fine, has nothing, is normal". In this first communication, depending on the professional who conveys the information, fear can be intensified. Some hear that their child has an incurable disease, that they have a blood problem. Until they reach a consultation at a reference center and receive the first clinical information, women experience a dark period full of uncertainties. At that moment, there are many opinions from third parties, information not always reliable on the internet, or silence. After all, not every mother makes her child's condition public, partly due to prejudice against a disease that is unknown to much of the population. These women need to reorganize their lives in various aspects. Some abandon their studies, jobs, and start living a life dedicated to motherhood marked by integral care, especially in childhood[21-22].

Uliana Silva refers to this reorganization as an adaptation that ranges from family arrangements and help, generally from other women, to professional aspects. When they do not definitively leave their jobs, they need to perform some remunerated home office activity to be able to stay close to their children. All these adaptations, constant visits to hospitals, daily care, attention to crisis signs, specific diet, make the mothers' routine exhausting. They are care itineraries with the child in public and domestic spaces and involve not only physical issues but emotional and structural issues due to being a mother in a society that delegates care to women.

If for women who have the sickle cell trait and children with SCD, motherhood is a challenge and requires adaptations, for women who have sickle cell disease and want to be mothers, the process is reversed with other issues. Many women discover they have sickle cell disease during pregnancy, others know their condition and choose to become pregnant aware of their clinical condition. After all, as I have already mentioned, pregnancy is not contraindicated, but requires specific care. If being a mother should be a conscious and guided choice, for mothers with SCD, choices are based on conditions mediated by desire and fear[23-24].

The late discovery of the disease condition puts women at risk of spontaneous abortions and even death due to disease complications. The case of Onix is exemplary[25]. A black woman who at the time of the research was 55 years old, retired, had worked as a domestic worker since the age of 9. She has the Hemoglobin SC gene.It is included among sickle cell diseases, has symptoms similar to SS such as acute chest syndrome, retinal hemorrhages, femur necrosis, and chronic pain. She went through successive medical appointments where she was diagnosed with

rheumatism. Onix had three children from different fathers who were not born with the disease. The children never showed symptoms, but never had any tests to know their genetic condition. She reports having had several spontaneous abortions, thought she would never be able to be a mother, but did not know the cause. Sometimes she did not even seek health services because the abortions were early in pregnancy. The lack of diagnosis put Onix's life at risk. As she herself says, "thankfully nothing serious happened, but it could have and I didn't even know, right!". The three pregnancies, according to her, were difficult. She felt a lot of pain, weakness, but the doctors said it was normal during pregnancy. She had a normal delivery and did not attend all prenatal consultations. She only discovered at the age of 50 what she really had and after starting appropriate treatment, she reports having improved her quality of life because she controls joint pain that previously prevented her from making simple movements. Onix was a domestic worker and took care of her children and her employer's children. We can imagine how difficult it was to reconcile everything with pain crises. She says she loves her children very much, always wanted to be a mother, but emphasizes that if she knew her condition, she might not have had children because she still suffers from the expectation that one of her children might develop the disease. Onix is part of generations of women who did not benefit from neonatal screening policies. One of the worst things for her was feeling pain and seeing people and health professionals distrust her, especially during childbirth.

Pain crises, the first manifestation of the disease, are caused by the obstruction of blood flow by sickle cells. Pain is present in the daily life of many people with sickle cell disease and is responsible for a large part of hospitalizations. Onix reports that as a child she fainted from so much pain. The first manifestations occur in childhood, persisting throughout life. Crises last around 4 to 6 days. Factors that trigger painful crises are: exposure to cold, trauma, physical exertion, dehydration, infections, and hypoxia. Painful crises cause a lot of suffering for people. In many cases, there is disregard by health professionals who do not believe in the person's pain. When Onix points out the pain during childbirth, it leads us to think about the dimension of racism in Brazil that naturalizes pain in black bodies, bodies that endure pain, especially black women. Discussions about obstetric racism help us understand why these women are subjected to pain without analgesia. According to Santana et al:

> Obstetric violence affects women in different ways, however, black women are the ones who suffer the most from this type of violence in the country, as indicated by data from the population-based study "Nascer no Brasil". This research showed that black women have a 62% higher chance of inadequate prenatal care, 23% lack of linkage to maternity, 67% absence of a companion during childbirth, and 33% antepartum pilgrimage[26].

Institutional racism is also an obstacle present in health services aimed at people with sickle cell disease, resulting in negligence and invisibility of these people's pain. Uliana Silva refers to social pain marked by a path of negligence that ranges from poorly guided phone calls, pilgrimage through health units, and lack of adequate treatment. Asking why a person takes 50 years to get a diagnosis of a disease that should be widely identified in the medical field leads us to ask which bodies are neglected. With appropriate treatment and quality of life, a woman with SCD can plan her pregnancy and fulfill her desire to be a mother if she wants. The unequal conditions assigned to black bodies increase the risks during pregnancy.

The case of Pérola was the one that most marked me during the research and I will dwell a little more on it. A black woman who at the time of the research was 34 years old, was diagnosed with SCD at birth. She and her twin brother were born with the disease, but the brother died at the age of 15.

In the family, there are several cases of SCD, including her deceased father. Pérola had a different routine from other children from a very young age with many restrictions and many visits to health services. She considered herself a person who took care of herself, tried to follow medical guidelines.

Her first pregnancy was at the age of 21. She was monitored by a hematologist, was referred to a high-risk maternity hospital, followed medical instructions, but her child was born dead. According to Pérola, her case was indicated for surgery, but it did not happen. She stayed in the maternity hospital waiting for a normal delivery even informing the medical team of her condition. The surgery was only performed after a cardiologist identified that the baby had no heartbeat. Pérola had complications and went into a coma. In her words: "I went into a coma for a day and my mother was accompanying me and the doctors only said this, look at that little machine, if it stops working, your daughter died. Then my mother would lose a grandson and me, right! Due to negligence".

This episode marked Pérola's life and ledto separation, but the desire to be a mother encouraged her to try again. With a new partner, she became pregnant three times and had three abortions despite medical monitoring. After the last abortion, the doctor who accompanied her advised her to give up because she could have serious complications and put her life at risk. Pérola was always advised to try since her partner did not have the sickle cell trait. After the failed attempts, her husband abandoned her and only returned after she decided to adopt a child.

In the words of Pérola:

> Because when I lost those babies, my husband left, left me alone, then we talked a lot, and he came back and we adopted this baby and we are super happy. [...] When I had a relationship and said I couldn't give them children, they were kind of like that and then it didn't work out until this one did, it's been 10 years, the others didn't because I couldn't give them children. My cousin who has anemia recently separated from her husband because he wanted children and she couldn't, and he didn't want to adopt either. Because this bothers men a lot. Because women, in my case and hers, we are afraid.

The fear that permeates the lives of women with sickle cell disease is not only in the risks of pregnancy, abortion, complications in their health, but also in the fact of not corresponding to the sociocultural role of being a woman and mother. There is a rejection of this body that cannot gestate and for those who have children with some disability or chronic disease, this is intensified. As Parry Scott observed for mothers of Zika, many women were abandoned by their husbands and had to bear the care alone or with the help of another woman in the family. Research in Brazil points to the loneliness of black women who have fewer chances of establishing relationships than white women[27].

The desire to be a mother for women with sickle cell disease or trait faces some barriers. One of them is the lack of adequate assistance policies, leading them to a path of abandonment and negligence. They need to break racial and gender prejudices in search of motherhood that is experienced with each crisis of their children or their own crises. As Uliana Silva points out, mothers of people with SCD:

> They create strategies in the face of illness symptoms. Care can be perceived in the mothers' speech when they present how they usually take care of their child, when they talk about medication at the right time, dietary restrictions, sun exposure, not letting people who apparently seem sick approach their children, not letting them shake the child's hand, all these are elements that refer to care strategies that they develop daily[28].

Pregnancy in women with sickle cell disease presents a mix of fear and desire, as can be seen in the following narratives[4].

In the words of Jade (28 years old):

> When I found out I had anemia, I was about 13 years old. The doctor who attended me said right away; you have sickle cell anemia and you will never be able to get pregnant. I was devastated and for a long time, I thought it was really like that. But then with treatment at HEMOPE, listening to lectures, I saw that it wasn't like that, and that I could have children. [...] So, I got married and did everything right, my husband took the test, he didn't have the trait, but there is always a risk, and I was worried throughout the pregnancy until the child was born because there was a risk of eclampsia, but thank God, everything went well, and my child doesn't have the disease.

In the words of Ametista (22 years old):

> The doctor told us, if we marry someone who has the trait or the disease, we can transmit it, but if the person doesn't have [the trait], the child can be born healthy or only with the trait and rarely, they can be born with sickle cell disease. Now, to have children, I don't want to because my sister has sickle cell disease and she had a child and she almost died, she had fluid in her lungs, thrombosis, heart problems, she had a lot of things, she almost died and she was never the same again, my mother stayed with her in the ICU at IMIP. But she had it because she wanted to, because everyone warned her, the doctor herself told her it was a high-risk pregnancy, especially because when she got pregnant, she didn't know if the father had the sickle cell trait and that the child could be born, but thank God, he wasn't born with anything. I mean, we don't know because he is already two years old and we never received the heel prick test; they said they lost it and he will have to do other tests.

To conclude this topic, I bring the testimony of a young woman with SCD given at the VI Brazilian Symposium on Sickle Cell Disease:

> During pregnancy, a woman with SCD should be accompanied by a good obstetrician, competent, with prenatal consultations to ensure a safer pregnancy for the mother and baby, a high-risk prenatal. We must have all the support to receive the best possible treatment. It is perfectly possible, with proper monitoring, to be a mother and have a normal life. [...] We have the right to choose, every woman with SCD should be informed of the risks that exist, but also of the possibilities of being a mother, because many times they say, you cannot be a mother. But you can. So, we should be informed of the care.

## Conclusion

Motherhood experienced by women with sickle cell disease (SCD) and mothers of people with SCD is intertwined with aspects of racial and gender inequality in Brazil. From their experiences in the process of becoming mothers, we can understand that there are multiple forms of motherhood, a fact supported by scientific literature. For the case of black mothers with SCD and sickle cell trait (SCT), motherhood needs to be viewed through an intersectional lens. The imbrications of racism and their clinical condition shape how they experience motherhood, oscillating between fear and desire.

According to data from the Ministry of Health, the lethality rate in pregnant women with untreated SCD is between 20 and 50%, while if treated, this rate is reduced to 2%. As observed in the narratives of the women, the greatest risk lies in negligence and abandonment, in the lack of adequate assistance. Carriers of a genetic condition or disease, women with SCD and SCT should have access to what the literature calls genetic citizenship, where they could have adequate professional conditions and guidance to make conscious and safe choices. However, how can these rights be ensured in a country where the body of a black woman is worth less? In this sense, motherhood is still a challenge for black women with SCD.

## Conflict of Interest Statement:

The authors have no conflicts of interest to declare.

## Funding Statement:

None.

## Acknowledgements:

None.

## Link:

([http://lattes.cnpq.br/4177993008562757]

## Orcid ID:

Ana Cláudia Rodrigues da Silva: 0000-0002-0965-3193

## Biography:

Adjunct professor in the Department of Anthropology and Museology at the Universidade Federal de Pernambuco (UFPE) and the Graduate Program in Anthropology at UFPE. Coordinator of the AYÉ Research Group: interdisciplinary laboratory of nature, culture, and technique, and member of the Family, Gender, and Sexuality Center (FAGES/UFPE). Holds a PhD in anthropology and a post-doctorate in Public Health from UFPE. Works with the intersections of racialities, gender, health, and black epistemologies. Currently coordinates the project "Enegrecendo Currículos: racial relations in the medical courses of public universities in Pernambuco/Brazil.

## References:


1-Silva ACR, Lemos AC. Race and health: black female healthcare providers in the COVID-19 pandemic. *Saúde Soc*. 2024;33(3):e240356pt. https://doi.org/10.1590/S0104-12902024240356en

2-Silva UG. *Doença que não tem cura, é para o resto da vida: etnografando a experiência de mulheres mães de crianças com doença falciforme no estado da Paraíba.* MA Thesis. Universidade Federal da Paraíba; 2018.

3-Lira AS. *Análise da assistência ofertada às gestantes com doença falciforme, em Salvador/BA: o racismo nas tramas e enredos das redes do SUS.* MA Thesis. Universidade Federal da Bahia, Instituto de Saúde Coletiva; 2015.

4-Silva ACR. *Compartilhando genes e identidades: orientação genética, raça e políticas de saúde para pessoas com doença e traço falciforme em Pernambuco.* PHD Dissertation. Universidade Federal de Pernambuco; 2013.

5-Carneiro S. *Dispositivo de racialidade: a construção do outro como não ser como fundamento do ser.* Zahar;2023.

6-Tapper M. *In the Blood: Sickle Cell Anemia and the Politics of Race*. University of Pennsylvania Press; 1999.

7-Creary M, Williamson D, Kulkarni R. Sickle cell disease: current activities, public health implications, and future directions. *J Womens Health*. 2007; 16(5):575-582.

8-Lira AS. *Análise da assistência ofertada às gestantes com Doença Falciforme, em Salvador/BA: o Racismo nas Tramas e Enredos das Redes do SUS.* MA Thesis. Universidade Federal da Bahia, Instituto de Saúde Coletiva; 2015.

9-Painel de Monitoramento da Mortalidade Materna. Accessed 10 May 2025 http://plataforma.saude.gov.br/mortalidade/materna/

10- Fleischer S, Franch M. Uma dor que não passa: aportes teórico-metodológicos de uma antropologia das doenças compridas. *Política & Trabalho: Revista De Ciências Sociais*. 2015;1(42). Accessed May 15, 2025. https://periodicos.ufpb.br/index.php/politicaetrabalho/article/view/25251.

11- Xavier ASG, Ferreira SC, Carvalho ESS, Araujo EM, Cordeiro RC. Percepção de mulheres com anemia falciforme sobre a gestação: estudo exploratório. *Online Braz J Nurs.* 2013 Dec;12(4): 834-43. Accessed May 15, 2025. http://www.objnursing.uff.br/index.php/nursing/article/view/4289. http://dx.doi.org/10.5935/1676-4285.20134289.

12- Fundação Oswaldo Cruz. Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira. Portal de Boas Práticas em Saúde da Mulher, da Criança e do Adolescente. Postagens: Principais Questões sobre Gestação na Doença Falciforme. Rio de Janeiro; 2022 Nov 4. Accessed May 16, 2025. https://portaldeboaspraticas.iff.fiocruz.br/atencao-mulher/principais-questoes-sobre-gestacao-na-doenca-falciforme/).

13- Silva UG. *Minha companheira de vida: uma análise etnográfica sobre as estratégias de cuidado das pessoas com doença falciforme no estado da Paraíba"*. PhD Dissertation. Universidade Federal da Paraíba; 2024. Accessed May 20, 2025. https://sigaa.ufpb.br/sigaa/public/programa/defesas.jsf?lc=pt_BR&id=1918.

14- Silva ACR. *Compartilhando genes e identidades: orientação genética, raça e políticas de saúde para pessoas com doença e traço falciforme em Pernambuco.* PhD Dissertation. Universidade Federal de Pernambuco; 2013.

15- Brodwin P. Genetics, identity, and the anthropology of essentialism. *Anthropological Quarterly.* 2000;75:444-461.

16- Buchanan A, Brock DW, Daniels N, Wikler D. *Genética y Justicia.* Cambrigde University Press; 2002.

17- Rabinow P, Rose N. O conceito de biopoder hoje. Política e Trabalho, *Revista de Ciências*. 2006;24:27-57.

18- Carvalho D., Meirinho D. O quesito cor/raça: desafios dos indicadores raciais de mortalidade materna como subsídio ao planejamento de

políticas públicas em saúde. *RECIIS.* 2020;14(3). https://doi.org/10.29397/reciis.v14i3.1905

19- Scott RP, Lira LC, Matos SS, Souza FM, Silva ACR, Quadros MT. Therapeutic paths, care and assistance in the construction of ideas about maternity and childhood in the context of the Zika virus. *Interface (Botucatu).* 2018;22(66):673-84. doi:10.1590/180757622017.0425.

20- Silva UG. *Doença que não tem cura, é para o resto da vida: etnografando a experiência de mulheres mães de crianças com doença falciforme no estado da Paraíba.* MA Thesis. Universidade Federal da Paraíba; 2018.

21- Leonard C, Childs B. Genetic counseling: a consumer's view. *The New England Journal of Medicine.* 1972;287(9):433-439.

22- Lippman A. Prenatal genetic testing and screening: constructing needs and reinforcing inequities. *American Journal of Law and Medicine.* 1991;17:15-50.

23- Heath D, Rapp R, Taussig KS. Geneetic Citisenship. In: Nugent D, Vicent J. *A companion to the anthropology of politics.* Blackwel Publishing; 2007.

24- Hecht F, Hilmes LB. What we don't know about genetic counseling. *The New England Journal of Medicine.* 1972;287(9):464-465.

25- The names of the interviewees were replaced with the names of gemstones.

26- Santana AT, Couto TM, Lima KTRS, et al. Obstetric racism, a debate under construction in Brazil: perceptions of black women on obstetric violence. *Cien Saude Colet*. 2024;29(9):e09952023. doi:10.1590/1413-81232024299.09952023EN.

27- Oliveira P, Oliveira JR. E a solidão das mulheres negras, cumé que fica? *Rev Praia Vermelha.* 2024;34(2):393-422. Accessed May 15, 2025. https://revistas.ufrj.br/index.php/praiavermelha/article/view/54946/42758

28- Silva UG. *Doença que não tem cura, é para o resto da vida: etnografando a experiência de mulheres mães de crianças com doença falciforme no estado da Paraíba.* MA Thesis. Universidade Federal da Paraíba; 2018.

 