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The sickle cell illness experience under the qualitative lens

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Abstract *This article aims to analyze the content of the qualitative production (2000-2023) on sickle cell disease to support the analytical category – the sickle cell disease experience. Methodologically, we conducted a qualitative, bibliographical study with a thematic content analysis anchored in the dialogue between the revised collection and the adopted theoretical-conceptual references. The thematic content analysis triggered eight interpretative dimensions: daily life and itineraries, care, reproductive decisions, stigma and its expressions, gender, participation, ethnicity, and religiosity. The sickle cell experience emerges and is related to exclusion, devaluation, ignorance, and invisibility, strongly allied to race components in nuances that distance it from the generic illness experience.*

Key words *Sickle cell disease, Experience, Chronic disease, Qualitative research, Bibliographic study*

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Introduction

Initially, we emphasize that we consider the "sickle cell illness experience" as another expression of people living with it, embodied in their social places. This consideration's starting point is not a pathophysiological essentialization of Sickle Cell Disease (SCD).

We also stress that we focus here on the understanding that we perpetrate to the analytical construct – sickle cell illness experience – and how it differs from a generic chronic illness experience. Besides the rapprochements becoming chronicity, the racial and social dimensions inferred in the concept and all the different aspects that racism in Brazilian society infringes on the life and experience of Black people distance these two concepts. The terrible alliance between the impacts of racism on individuals and stigma, which is still directed at SCD, operates and marks the trajectory of those with this chronic illness.

We argue that the qualitatively-based academic literature – on the boundaries of human and social sciences identified with public health – justifies the review of this conceptual set called *sickle cell disease experience*. To this end, we need to resort – before triggering this literature that has interpretations about "sickle cell disease" and its derivations – to the encounter with the concepts of experience, dialogued with chronicity, and the person, dialogued with the contemporary expression of activism and associative organization.

We first turn to Schutz[1,2] to define experience as a biographical stock. This sociologist argues that individuals build their world based on established relationships[1]. An experience is always a place conjugated by the people in their social places and encounters[3]. Supported by phenomenological sociology, when thematizing the experience, one must focus on the subject who infers in the social interactions in which he is immersed as something that touches him/her, awakens passion, availability, interest, something singular, and not merely as an event.

Situating the origin of the disease in the territories of the African continent ended up enclosing it within the concept of "Blacks' disease", annihilated by stigma, marginalization, and invisibility of people with this diagnosis[4]. Even with our genetic heterogeneity in Brazil, SCD is still more prevalent in the Black population.

We need more than the set of digressions on SCD located by biomedicine. We are interested in the sickle cell disease experience, illuminating stigma at the intersections between race, class, and provision of care, with the burden generated by these processes. It is necessary to resort to the Social and Human Sciences in the Public Health lens to achieve these aspects and broaden the ethical and political interfaces, mobilizing several stakeholders linked to the theme, such as health teams, the Black movement, and associations of people living with SCD[5].

We assume the racial component of the disease, not as a clinical, descriptive variable but a social marker of difference, a social and political category intrinsically related to oppression, power hierarchies, and classifications that generate inequalities and discrimination per what Almeida[6] and Munanga[7] underscore when working with race as a political category.

The possibility of reconstructing the experience of chronic illness in its public presentation – through racial activism or collective associative organization – is intrinsically anchored in this dialogue of people's locations and interdependencies. However, we will move away from a Westernized discussion – conducted by Duarte and Giumbelli[8] and Duarte[9] – about the individual's public presentation, and we will approach another cosmology, as proposed by Oyěwùmí[10], who provokes us to deconstruct from the perspective of African Studies, in the knowledge undertaken in the Yoruba culture. As the author guides us: "[...] western science and history, [are] a history rooted in philosophical discourses about the distinctions between body, mind, and soul, in ideas about biological determinism and connections between the body and the 'social'"[10](p.20).

These binary and dichotomous distinctions also guide a certain academic view of chronic health conditions. At the same time, they are in crisis due to the health needs of specific groups, for whom living with a chronic health condition can mean other expressions of life and understanding. In the case of SCD, this biomedical definition can come into conflict with strong social stereotypes well beyond anatomophysiology and etiology to reach the political space of negotiations with racial discrimination, of models of being and behaving in public spaces, where individuals with SCD experience non-recognition of their pain and interruption of common routines.

Affirming, among the myriad of illness experiences marked by chronicity and long-term illness studied by other authors (Barsaglini[11], Canesqui[12], Castellanos[13], Fleischer[14], and Moreira[15]), the experience of sickle cell illness means recognizing race-related discrimination and con-

frontations rooted in Brazilian society. As Souza[16] points out:

Knowing oneself black is living the experience of having been massacred in one's identity, confused in one's perspectives, subjected to demands, compelled to alienated expectations. It is also, and above all, the experience of committing to recovering its history and recreating its potential[16](p.18).

The recognition of Black identity, also in its community, guides meanings that traverse how people live and get sick and how health can be produced. With this expressed, we justify the attempt to reach the dimension of the experience of sickle cell illness in its various axes and implications beyond the hegemonic Eurocentric theories.

To think about the definitions, we guided the "Afro-Brazilian Civilizing Values" by Azoilda Loretto da Trindade[17], which points to the importance of Cooperativism/Communitarianism. According to the author, accompanied by bell hooks[18], Sueli Carneiro[19], Angela Davis[20], and many others, the collective dimension is crucial for defining the Black person's identity. In this sense, we indicate the community as a strong unit in establishing and defining the SCD illness experience, whether in building one's identity and constitution or by the community involved in the illness.

We summon a parallel between the concept of stock of knowledge in Schutz[2] and the "passion of experience" by bell hooks[18], which points to the meanings, as a Black woman, of a body marked by suffering, which becomes, beyond an experience, the foundation for building knowledge and expertise. Again, with bell hooks[18], we agree with the caution of presenting an essentializing experience for people living with SCD. We underscore, according to hooks[18], how essentialization can also oppress marginalized bodies, which does not allow space for specificities. As a result, we direct attention to the fluidity this sickle cell illness experience can assume in alliance with the social markers of difference.

This situated and interactional articulation appears in Lopes and Gomes[21], expressing "living with SCD". The interactional and experiential dimension is justified in this overflow in the family environment, including the person identified with the diagnosis and those identified as direct and indirect caregivers, family, and support networks in the environment of relationships.

With this theoretical introduction, this article proposes to analyze the content of qualitative production, according to our predefined criteria situated around the construct "sickle cell disease" between 2000 and 2022 to substantiate the analytical category of sickle cell illness experience.

Methods

We undertook a bibliographical study with a qualitative approach, not limiting ourselves only to extracting and synthesizing the consulted sources. The discussions about the sources were analyzed to apprehend elements that would support us in defining the sickle cell illness experience.

In sequential terms, we searched for published articles, including sickle cell disease and qualitative research and experience, published between 2000 and 2022 in the Virtual Health Library (BVS) and the Fiocruz Institutional Repository (ARCA). The BVS was selected because it gathers databases of great relevance in academic spaces on the national and international scene, such as SciELO, PubMed, and LILACS. The ARCA Repository gathers Fiocruz productions. It was included due to the Institution's strategic place in scientific production in public health.

The definition of the keywords undertaken in the search for this research raises issues that brought a first analytical effort. The search results under the terms – sickle cell disease and race – under the same inclusion criteria addressed returned only eight documents. We also highlight that when the term "race" was inserted in the search platforms, the results mostly focused on the biomedical dimensions, where race was read as a clinical and biological variable. Thus, we believe that by the chosen descriptors – sickle cell disease, qualitative research, and experience – the results broadly considered the chronic illness due to SCD experience.

A search was conducted in September 2021 on both platforms under the criteria of full-text availability in Portuguese, English, and Spanish, in the proposed time bracket, with a qualitative approach, under the terms "SCD *and* qualitative research". A new search was performed in February and March 2023 with the same descriptors and the terms "SCD *and* experience" to add references produced in the last year to complement this review.

The search "SCD *and* qualitative research" in the BVS, with the stipulated selection criteria, returned 121 results. Fifty-eight articles were identified after removing the texts that still contained biomedical content, without open access,

or that fit as theses, dissertations, or technical documents. In the search "SCD *and* experience" on the same platform, 14 of the 22 articles found were part of our collection, applying the same inclusion criteria. The ARCA search under the same descriptors and criteria returned 17 articles, six of which were included in this proposed analysis.

Our final collection totaled 61 articles (Chart 1) after screening in light of the defined inclusion criteria and exclusion of duplicate articles. These works were submitted to full-text reading and content analysis. Then, we proceeded to extract the main considerations, discussions, or conclusions from the sources found.

In the second essay stage, we debated the extraction of the previous stage. To this end, as in Gomes[84], we applied the following question to thematic analysis[85], and the collection gathered and analyzed in its content: what are the analytical categories that emerge and thematize the discussion on the construct "sickle cell disease" that can make us assume the definition of sickle cell illness experience? Emerging themes are detached from the manifest content, based on a second-order interpretation. This interpretative process occurs through a dialogue between these themes and the theoretical-conceptual framework presented in the introduction because, based on Bardin[85], themes are units of meaning that we can identify in expressions, ideas, and sentences.

Thus, the themes' discussion is grounded on the dialogue between the content extraction from the sources and the theoretical-conceptual basis in the introduction of this study, which follows after the characterization of the consulted collection. We point out that the articles were included in the category with greater depth in the discussion, and some include and encompass other dimensions also found in our proposal.

Results

Thematic excerpts emerging from the analysis

The content analysis on the collection, which generated Chart 1, subsidizes our analytical category, which we underscore here as a sickle cell illness experience. This elaboration makes us organize the Thematic Tree below (Figure 1), whose constituent elements lead us to define the Sickle Cell Experience as something that transcends an understanding encapsulated in the individuals. As our synthesis of ideas shows, the collection provides eight dimensions: daily life and itineraries, care, reproductive decisions, stigma and its expressions, gender, participation, ethnicity, and religiosity.

The *first dimension*[22-33], daily life and itineraries, presents the academic literature focused on the SCD routine and recognizing the disease in family life and with children and adolescents. Living with this illness and its meanings are represented by the search for care based on therapeutic itineraries and their interference in everyday life. Based on Schutz[1,2], living is not just a private world of a single individual but an intersubjective world. In this sense, the sickle cell illness experience is built through the relationships established in living together. Thus, we highlight the extent of living with SCD, which, even when expressed in individual lines, has a collective representation of coping with it, from identifying the diagnosis to the daily care routine for the symptoms.

The *second theme*[34-57], care, guided several articles in the collection of this review from different perspectives. Self-care[34-39] focused on measures centered on people who live directly with the illness and their ways of coping with and controlling symptoms. Maternal care[40-42] emerges under the aegis of this figure as responsible for protecting people affected by the illness, either in an attempt to measure knowledge regarding SCD or in care or maternal dedication in the face of the severe complications of the disease.

Another axis pointed out about care refers to family care[43-49] and the importance of the family that, from the moment of diagnosis, even with feelings of fear for the severity of the illness, becomes a protective space guaranteeing the quality of life of those living with the SCD. The term coexisting, raised in an article[21] of this review, demarcates how the experience of this illness extends to the family members, given the great mobilization required in providing care.

Health professionals[50-55] are part of the collection under the role of care in formal health environments in hospitalization contexts. They identify the vulnerabilities and attributions of these professionals in dialogue with those living with SCD. The subcategory care and technology[56,57] emerges, showing how diagnostic and treatment strategies and technologies integrate the care experience in the daily lives of people living with sickle cell disease.

From the discussion in the articles included in this category, we question the naturalization

Chart 1. Characterization of the analyzed collection.

Category	References		Source
Daily life and therapeutic itineraries	Batista *et al.*, 2011[22]		BVS
	Cordeiro *et al.*, 2013[23]		BVS
	Forrester *et al.*,2015[24]		BVS
	Foster and Ellis, 2018[25]		BVS
	Freire *et al.*, 2015[26]		BVS
	Martins *et al.*, 2019[27]		BVS
	Ola *et al.*, 2016[28]		BVS
	Petri *et al.*, 2020[29]		BVS
	Roman *et al.*, 2019[30]		BVS
	Silva *et al.*, 2013[31]		BVS
	Souza *et al.*, 2011[32]		BVS
	Weis *et al.*, 2013[33]		BVS
Care	Self-care	Tavares *et al.*, 2017[34]	BVS
		Cordeiro *et al.*, 2014[35]	BVS
		Costa *et al.*, 2018[36]	BVS
		Lacerda *et al.*, 2019[37]	BVS
		Matthie *et al.*, 2019[38]	BVS
		Nascimento *et al.*, 2021[39]	BVS
	Maternal care	Ramos *et al.*, 2020[40]	BVS
		Rocha *et al.*, 2021[41]	BVS
		Silva *et al.*, 2021[42]	BVS
	Family care	Bernal and Patten, 2010[43]	BVS
		Figueiredo *et al.*, 2018[44]	BVS
		Gesteira *et al.*,2020[45]	BVS
		Graff *et al.*, 2010[46]	BVS
		Miranda *et al.*, 2020[47]	BVS
		Olwit *et al.*, 2018[48]	BVS
		Silva *et al.*, 2013[49]	BVS
	Health Professionals	Campelo *et al.*, 2018[50]	BVS
		Del Pino-Jones *et al.*, 2019[51]	BVS
		Ferreira *et al.*, 2013[52]	BVS
		Pimentel *et al.*, 2021[53]	BVS
		Rodrigues *et al.*, 2010[54]	BVS
		Soares *et al.*, 2014[55]	BVS
	Care and Technology	Calvo-Gonzalez, 2016[56]	ARCA
		Hawkins *et al.*, 2020[57]	BVS
Reproductive decisions	Guimarães and Coelho, 2010[58]		BVS
	Cox and Beauquier-Maccotta, 2014[59]		BVS
	Guedes, 2012[60]		BVS
	Pedrosa *et al.*, 2021[61]		BVS
	Silva *et al.*, 2021[62]		BVS
Stigma and its expressions	Brito *et al.*, 2021[63]		BVS
	Carvalho *et al.*, 2021[64]		BVS
	Santos *et al.*, 2022[65]		BVS
	Sinha *et al.*, 2019[66]		BVS
Gender	Berghs *et al.*, 2020[67]		BVS
	Cordeiro and Ferreira, 2011[68]		BVS
	Cordeiro *et al.*, 2015[69]		BVS
	Silva *et al.*, 2018[70]		BVS
	Sousa *et al.*, 2021[71]		BVS

it continues

Chart 1. Characterization of the analyzed collection.

Category	References	Source
Participation	Bakshi *et al.*, 2020[72]	BVS
	Chakravorty *et al.*, 2018[73]	BVS
	Cho *et al.*, 2020[74]	BVS
	Jabour *et al.*, 2019[75]	BVS
	Lopes and Gomes, 2020[21]	ARCA
	Young *et al.*, 2009[76]	BVS
Ethnicity	Figueiró and Ribeiro, 2017[77]	BVS
	Maio and Monteiro, 2005[78]	ARCA
	Ramos *et al.*, 2020[79]	ARCA
	Rizzo and Fonseca, 2019[80]	ARCA
	Silva *et al.*, 2020[81]	ARCA
Religiosity	Cotton *et al.*, 2012[82]	BVS
	Gomes *et al.*, 2019[83]	BVS

Source: Authors, 2023.

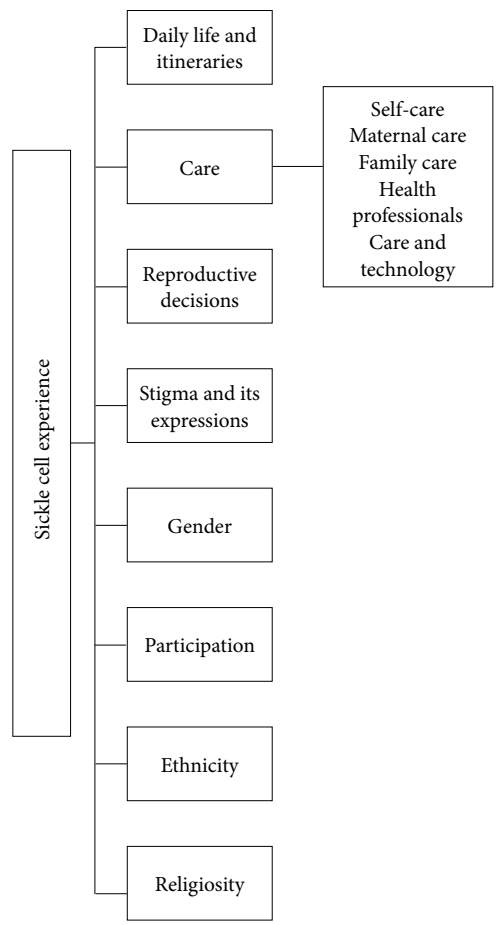

Figure 1. Thematic tree: Sickle cell experience.

Source: Authors, 2023.

of care as a women's vocation. In order to break this cycle, we refer to Tronto[86], interpreting within practices with relational materiality, immersed and traversed by class, race, and gender inequalities. Such a reference refers to the definitions of reproductive work by Federici[87] to interpret maternal overload in assuring care for children living with SCD. We also establish, under hooks[88], how dedication to others is uniquely reflected in Black women, historically delegated and imposing, perpetuating stereotypes inherited from the enslavement period.

The *third theme*[58-62] refers to the reproductive decisions of those living with SCD. Given its hereditary nature, the statements of "prevention" and "eradication" prowled the illness in Brazil and still permeate actions in several countries. Genetic counseling emerges as a health education practice directed to conscious decision-making and oriented to the reproductive decisions of people living with SCD.

The coercive discourse for women with SCD about the immediate denial of possible gestation was also found in the analysis. According to the articles, the risk discourse and the lack of knowledge around SCD escalate uncertainties for pregnancy under the lens of specialized care and remove the process from the decision of women's power.

We should emphasize how decisions and reproductive freedom are at the heart of feminist and Black women's movements. As bell hooks[88] points out, in discussing the right to abortion, the rationale that operates and guides reproduc-

tive rights is still grounded on white Eurocentric ideals, excluding Black or impoverished women from autonomy over their bodies.

Genetic counseling in this niche stumbles on possible eugenic practices[81]. We cannot fail to emphasize how eugenia trailed with racism, for the white ideal of Nazi purity and oppression of Black and Indigenous populations. Directing genetic counseling in the light of "prophylaxis" or "eradication" partake of the ideas of exclusion of individuals suffering from chronic diseases such as sickle cell disease[81].

On the *fourth dimension*[63-66], the social location based on stigma permeates how people build their sickle cell illness experience. As with Lopes and Gomes[21], the chronicity of the SCD diagnosis is traversed by stigma[63-65], the Afrocentrality linked to the disease, and the blatant ignorance about illness. We employed stigma here by resorting to Goffman[89] in understanding this attribute that operates as the basis for what can be read as discrimination, stereotype, and exclusion. SCD displays visible trauma that can put people in a non-place, escaping a specific body model free of marks and everything that can still join other demands generated by living with the disease, such as the pain that interrupts work routines and ordinary life.

Another theme imbricated to the context of stigma overarches the main SCD symptom, which is chronic pain, first, for the devaluation of the algic crisis, under the discourse of health professionals who do not recognize the severity and intensity of the pain experienced by those living with SCD, and because they disapprove the reactions against pain, such as screaming and crying. We highlight here how this agenda also communes with racism embedded in society, for the dehumanization of Black bodies, which are not allowed physical suffering manifestations.

Algic crises refer to stigma due to the necessary use of opioid-derived painkillers with dependence potential. The stigma of addiction to these medicines is evidenced in this review[66]. SCD pain integrates an invisible mark that produces and reproduces the expression of opiophobia.

The stigma regarding the functionality of those coexisting with the disease is highlighted by Carvalho *et al.*[64]. The authors point to the labels involved in fatigue-fracture interpreted as laziness and demotivation. Overlapping stereotypes and obstacles to remain in the formal labor market increase stigma and interfere with the construction of the sociality of those coexisting with the SCD. They also establish social relationships that reinforce the stigmatizing process, affecting the construction of a positive self-image.

The stigma described here, illuminated by literature, which is bound beyond visible marks, adds to the concept of corporeality described by Trindade[17], who affirms that Black bodies encapsulate trauma, memories, ways of living, and resilience before several experiences. As bell hooks[18] highlights, these marks, trauma, pain, and suffering, coupled with a racial marker, underpin a close experience and producer of knowledge and expertise.

The *fifth dimension*[67-71] refers to gender relationships within SCD. Feminist perspectives emerge by analyzing the perspective of mothers or reproductive decisions. In contrast, gender inequality undergoes strong obliteration. From the collection, we could observe how the articles highlight the imposed logic of masculinity, which distances men from self-care measures and health environments and highlights their functionality as providers and workers. Although closer to health environments, women fail to be housewives and exert a socially customized maternity.

In the Sierra Leone setting, Berhs *et al.*[67] mention maternal blame for SCD in the family. Beyond the logic of care, women are placed under genderized surveillance of violence in child upbringing, encouraging men to initiate sex life and encouraging girls to postpone maternity. Although the disease genetically affects both sexes, the way to experience illness and reactions are different, given the aspects such as care, posture towards symptoms, acceptance of illness, and even treatments. Gender asymmetries are also expressed by the erasure of male discourses as caregivers of people with SCD.

The *sixth dimension*[72-76] that emerges in the collection is the participation of those living with SCD in decision processes, either in participating in clinical research or communicating with health professionals to choose treatments. We highlight how participation is crucial in building self-esteem in the face of illness. It promotes the consent of treatment and can enhance the quality of life of those coexisting with the disease, as they integrate autonomously, listening to their bodies. We emphasize here, as would Lopes and Gomes[21], the great role of the associative movements of those living with the disease in promoting social participation in the health councils or disseminating information to secure rights and access to healthcare.

Regarding the *seventh dimension*[77-81], the racial discussion is inserted in countless controversies, for example, how to integrate sickle cells as a health agenda of the Black population and the Black people and Black women movements. Revised articles on the racial bond of illness were, and the field, diverse and contradictory, regarding the origin of the disease, the role of miscegenation in the current incidence of the illness, and high frequency in the Black population and social implications aggregated to the racial marker.

Another field of interpretations of the SCD in the collection – which theoretically supports this exercise of rehearsing and defending the analytical category of sickle cell experience – turns to the aspects and definitions of intersectionality. Although the term is not cited as such in some cases, the need to highlight the intersections between race, class, and gender was in place. By this concept, we understand, with Collins and Bilge[90], the non-hierarchization of social markers of difference.

The collection provided supporting elements to incorporate institutional racism as a relevant component of the analytical category we propose as a sickle cell experience. Regarding care in the Unified Health System (SUS), we underscore the Black population's low social and therapeutic indicators. Dialoguing with Mota *et al.*[91], we understood how the action of institutional racism also feeds on the lack of knowledge about SCD and the insipience of health professionals vis-à-vis the subject.

Starting from the analysis of the racial theme, as proposed under the light of Souza[16], Trindade[17], and Oyěwùmí[10], we shed light on the role of ancestry in building the setting of the sickle cell illness experience. Ancestry is addressed here beyond the genomic sense but in the sense of African cultural belonging, which can be represented by having (or not) sickle cell disease. The origin of illness and its historical burden that crosses oceans brings strong clashes over race centrality in the discourses around the disease.

The *eighth and last dimension*[82,83] of the collection points to religiosity, also raised as one of the values treated by Trindade[17]. Under the collection, religion emerges as an important practice for coping with SCD illness. Searching for miraculous healing, support for the constant fear of death, or facing the disease's clinical manifestations are the main motivations for integrating individual or group religious rituals. The receptiveness/encouragement promoted by religiosity to those coexisting with the disease should be observed as a well-being promoter and part of a sickle cell illness experience grounded on this article. Religiosity combined with health and well-being is still strongly distanced from the Eurocentric care logic. It needs to include dialogue with health professionals in their understanding and practice of living with SCD and configuring sickle cell experience.

Conclusions

We have achieved two goals from the thematic analysis and meanings in the collection: (1) Defining sickle cell experience as something proper to the intersections of people living with this health condition markedly related to race components and stereotypes that can relate treatment to devaluation, ignorance, dependence, and invisibility. Singularizing care is part of this analytical construct to assign value and political strength for effective transformation of care, decisions, and reproductive justice, recognition of differentiated needs in work and education, however, not reinforcing historical and socially constructed stigmas; (2) Given the questions asked to the collection, we underscored which inequalities and asymmetries are enlightened or deleted in the face of exposed positions. Importantly, absence in this setting is as relevant as presence.

In our interpretation, we considered looking at the social markers of the traditionally recognized difference – class, race/ethnicity, territory, gender – to understand how they are triggered and intersected (or not) to discuss specific expressions typical of the sickle cell illness experience, such as pain, and a compromised functionality that is often not recognized.

The sickle cell illness experience sheds light on the hierarchization and erasure suffered by chronicity intercepted by the race-discriminatory debate as a historical and political category. This statement emerges as one of the contributions to the field of studies on chronic illness experience, which removes it from an alleged generic perspective of this category. That said, it is urgent to assume needs not limited to the definitions of chronicity and reach the experience and its anchorages related to the meanings of body and race. The racial issue is present and linked to SCD, discussing the institutionalized racism ex-

perienced by those living with sickle cell disease and strongly integrating how the sickle cell experience is configured in a markedly racist society.

We highlight how the sickle cell experience we have built here can subsidize public policies aimed at quality of life and access of patients with the disease to health services. Although this category did not emerge from the statements, it was identified in theses and dissertations not included in our proposed analysis. As a result, we strongly recommend that other efforts be made in future works that cover the sickle cell experience construct and health policies for their patients.

Thus, we aim to delimit the analytical construct – sickle cell experience – to measure its distancing from the generic chronic illness. We understand the illness experience for its unique and intersubjective dimension of the encounters it entails. We recognize that a stock of memories, representations, and discriminations act in the intersubjective exercise of the encounters. We outline how sickle cell disease uniquely marks the experience of those living with it, underscoring its racial, social, and political aspects in specific dimensions that demand attention to the theme.

Collaborations

WSL Lopes and MCN Moreira were responsible for data collection and analysis, drafting, and reviewing the manuscript. R Gomes was responsible for drafting and reviewing the article and adding significant parts.

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References

1. Schutz A. *El problema de la realidade social*. Buenos Aires: Amorurtu; 2008.
2. Schutz A. *Sobre fenomenologia e relações sociais*. Petrópolis: Vozes; 2012.
3. Bondía JL. Notas sobre a experiência e o saber de experiência. *Rev Bras Educ* 2002; 19:20-28.
4. Kikuchi BA. Assistência de enfermagem na doença falciforme nos serviços de atenção básica. *Rev Bras Hematol Hemoter* 2007; 29(3):331-338.
5. Lira A. Doença falciforme: invisibilidade e racismo nas práticas de cuidado. In: Pinheiro R, Asensi FD, Hebert F, Barros MEB, organizadores. *Amor mundi, políticas da amizade e cuidado: a integralidade e a polifonia do cotidiano da saúde*. Rio de Janeiro: FGB/ Pembroke Collins; 2019. p. 143-149.
6. Almeida S. *O que é racismo estrutural?* Belo Horizonte: Letramento; 2018.
7. Munanga K. *Uma abordagem conceitual das noções de raça, racismo, identidade e etnia. Palestra proferida no 3º Seminário Nacional Relações Raciais e Educação*. Rio de Janeiro: PENESB-RJ; 2003.
8. Duarte LFD, Giumbelli EA. *As Concepções Cristã e Moderna da Pessoa: paradoxos de uma continuidade. Anuário Antropológico/93*. Rio de Janeiro: Tempo Brasileiro; 1995.
9. Duarte LFD. Classificação e Valor na Reflexão sobre Identidade Social. In: Cardoso R, organizador. *A Aventura Antropológica: teoria e pesquisa*. São Paulo: Paz e Terra; 1986. p. 69-92.
10. Oyèwùmí O. *A invenção das mulheres: construindo um sentido africano para os discursos ocidentais de gênero*. Rio de Janeiro: Bazar do Tempo; 2021.
11. Barsaglini R. *As representações sociais e a experiência com o diabetes: um enfoque socioantropológico*. Rio de Janeiro: Ed. Fiocruz; 2011.
12. Canesqui AM, organizador. *Adoecimentos e Sofrimentos de Longa Duração*. São Paulo: Hucitec; 2015.
13. Castellanos MEP, Trad LAB, Jorge MSB, Leitão IMTA. *Cronicidade: experiência de adoecimento e cuidado sob a ótica das ciências sociais*. Fortaleza: EdUECE; 2015.
14. Fleischer S. Como as doenças compridas podem nos ensinar sobre os serviços de saúde? *Equatorial* 2018; 4(7):24-44.
15. Moreira MCN. Trajetórias e experiências morais de adoecimento raro e crônico em biografias: um ensaio teórico. *Cien Saude Colet* 2019; 24(10):3651-3661.
16. Souza NS. *Tornar-se negro: as vicissitudes da identidade do negro brasileiro em ascensão social*. Embu das Artes: Edições Graal; 1983.
17. Trindade AL. *"Fragmentos de um discurso sobre afetividade"* [Internet]. [acessado 2021 jan 13]. Disponível em: http://www.acordacultura.org.br/sites/default/files/kit/Caderno1_ModosDeVer.pdf.
18. hooks b. *Ensinando a transgredir: a educação como prática da liberdade*. Rio de Janeiro: Editora WMF Martins Fontes; 2013.
19. Carneiro S. *Escritos de uma vida*. São Paulo: Editora Jandaíra; 2020.
20. Davis A. *Mulheres, raça e classe*. São Paulo: Boitempo; 2016.
21. Lopes WSL, Gomes R. A participação dos conviventes com a doença falciforme na atenção à saúde: um estudo bibliográfico. *Cien Saude Colet* 2020; 25(8):3239-3250.
22. Batista TF, Camargo CL, Morais AC. O cotidiano de adolescentes com(vivendo) com anemia falciforme. *BIS Bol Inst Saude* 2011; 13(2):114-124.
23. Cordeiro RC, Ferreira SL, Santos FC, Silva LS. Itinerários terapêuticos de pessoas com anemia falciforme face às crises dolorosas. *Rev Enferm UERJ* 2013; 21(2):179-184.
24. Forrester AB, Barton-Gooden A, Pitter C, Lindo JLM. The lived experiences of adolescents with sickle cell disease in Kingston, Jamaica. *Int J Qual Stud Health Well-being* 2015; 10(28104):1-9.
25. Foster N, Ellis M. Sickle cell anaemia and the experiences of young people living with the condition. *Nurs Child Young People* 2018; 30(3):36-43.
26. Freire MHS, Pereira RA, Ramos EJ, Matos VFA, Migoto MT. O impacto da anemia falciforme na vida de adolescente. *Cogit Enferm* 2015; 20(3):547-553.
27. Martins LA, Silva TCC, Santos HAS, Aguiar ACSA, Whitaker COM, Camargo CL. Itinerário terapêutico de crianças quilombolas com doença falciforme. *Cien Cuid Saude* 2019; 18(2):e45177.
28. Ola BA, Yates SJ, Dyson SM. Living with sickle cell disease and depression in Lagos, Nigeria: A mixed methods study. *Soc Sci Med* 2016; 161:27-36.
29. Petri TCN, Nascimento LCS, Depianti JRB, Brotto LDA, Almeida MVS. O itinerário terapêutico da criança com doença falciforme. *Cien Cuid Saude* 2020; 19:e50382.
30. Roman C, Campos MS, Bueno D. Itinerário terapêutico como busca do cuidado ao paciente com doença falciforme. *Rev Baiana Saude Publica* 2019; 43(3):523-538.
31. Silva AH, Bellato R, Araújo LFS. Cotidiano da família que experiência a condição crônica por anemia falciforme. *Rev Eletr Enferm* 2013; 15(2):437-446.
32. Souza AAM, Ribeiro CA, Borba RIH. Ter anemia falciforme: nora prévia sobre seu significado para a criança expresso através da brincadeira. *Rev Gaucha Enferm* 2011; 32(1):194-196.
33. Weis MC, Barbosa MRC, Bellato R, Araújo LFS, Silva AH. A experiência de uma família que vivencia a condição crônica por anemia falciforme em dois adolescentes. *Saude Debate* 2013; 37(99):597-609.
34. Tavares NBF, Nascimento NMA, Luna Neto RT, Gonçalves Júnior J, Christofolini DM. Self-Care Practice in People with Sickle Cell Anemia. *Rev Bras Promoc Saude* 2017; 30(4):1-7.
35. Cordeiro RC, Ferreira SL, Santos ACC. Experiências do adoecimento de pessoas com anemia falciforme e estratégias de autocuidado. *Acta Paul Enferm* 2014; 27(6):499-504.
36. Costa DO, Araújo FA, Xavier ASG, Araújo LS, Silva UB, Santos EA, Ferreira SL. Self-care of men with priapism and sickle cell disease. *Rev Bras Enferm* 2018; 71(5):2418-2424.
37. Lacerda FKL, Ferreira SL, Nascimento ER, Costa DO, Cordeiro RC. Self-care deficits in women with leg ulcers and sickle cell disease. *Rev Bras Enferm* 2019; 72(Supl. 3):72-78.
38. Matthie N, Ross D, Sinha C, Khemani K, Bakshi N, Krishnamurti L. A Qualitative Study of Chronic Pain and Self-Management in Adults with Sickle Cell Disease. *J Natl Med Assoc* 2019; 111(2):158-168.

39. Nascimento LCN, Souza TV, Oliveira ICS, Morais RCM, Andrade MAC. Internalização do cuidado: um estudo qualitativo com escolares que convivem com a doença falciforme. *Esc Anna Nery Rev Enferm* 2021; 25(1):e20190337.
40. Ramos CM, Pacheco ZML, Vargas IMA, Araújo PA. Existential analysis of mothers in the care of their children with Sickle Cell Disease. *Rev Bras Enferm* 2020; 73(Supl. 4):e20180521.
41. Rocha R, Souza TV, Morais RCM, Nascimento LCN, Couto LL, Farias IFA. (Lack of) knowledge of mothers about sickle cell trait and disease: a qualitative study. *Rev Bras Enferm* 2021; 75(1):e20201217.
42. Silva GS, Sousa BVN, Oliveira EF, Martins KD, Jesus VS, Nascimento OC. Busca pelo tratamento da crise álgica na doença falciforme: concepções das genitoras. *Rev Bras Promoc Saúude* 2021; 34:1-11.
43. Bernal ILL, Patten AS. La investigación familiar y el valor de la metodología cualitativa para el estudio del afrontamiento a la enfermedad sicklemica. *Rev Cuba Salud Publica* 2010; 36(1):38-53.
44. Figueiredo SV, Lima LA, Silva DPB, Oliveira EMC, Santos MP, Gomes ILV. Importance of health guidance for family members of children with sickle cell disease. *Rev Bras Enferm* 2018; 71(6):2974-2982.
45. Gesteira ECR, Szylit R, Santos MR, Ichikawa CRF, Oliveira PP, Silveira EAA. Family management of children who experience sickle cell disease: a qualitative study. *Rev Bras Enferm* 2020; 73(Supl. 4):e20190521.
46. Graff JC, Hankins JS, Hardy BT, Hall HR, Roberts RJ, Neely-Barnes SL. Exploring parent-sibling communication in families of children with sickle cell disease. *Issues Compr Pediatr Nurs* 2010; 33(2):101-123.
47. Miranda FR, Ivo ML, Teston EF, Lina IGT, Mandetta MA, Marcheti MA. Experiência da família no manejo da criança com anemia falciforme: implicações para o cuidado. *Rev Enferm UERJ* 2020; 28:e51594.
48. Olwit C, Mugaba M, Osingada CP, Nabirye RC. Existence, triggers, and coping with chronic sorrow: a qualitative study of caretakers of children with sickle cell disease in a National Referral Hospital in Kampala, Uganda. *BMC Psychol* 2018; 6(50):1-11.
49. Silva HD, Paixão GPN, Silva CS, Bittencourt IS, Evangelista TJ, Silva RS. Anemia Falciforme E Seus Aspectos Psicossociais: O Olhar Do Doente e Do Cuidador Familiar. *Rev Cuid* 2013; 4(1):475-483.
50. Campelo LMN, Oliveira NF, Magalhães JM, Julião MAS, Amorim FCM, Coelho MCVS. The pain of children with sickle cell disease: the nursing approach. *Rev Bras Enferm* 2018; 71(Supl. 3):1381-1387.
51. Del Pino-Jones A, Bowden K, Misky G, Jones CD. Improving Care for Patients with Sickle Cell Disease: a Qualitative Study of Hospitalized Sickle Cell Patients. *J Gen Intern Med* 2019; 34(12):2693-2694.
52. Ferreira SL, Cordeiro RC, Cajuhy F, Silva LS. Vulnerabilidade de pessoas adultas com doença falciforme: subsídios para o cuidado de enfermagem. *Cien Cuid Saude* 2013; 12(4):711-718.
53. Pimentel EDV, Pimentel CRBD, Leal ELG, Carvalho GCN, Vieira ACS, Barroso LMFM. Anemia falciforme: percepção dos profissionais de saúde e gestores acerca da estruturação da rede de atenção. *R Pesq Cuid Fundam Online* 2021; 13:510-516.
54. Rodrigues CCM, Araújo IEM, Melo LL. A família da criança com doença falciforme e a equipe enfermagem: revisão crítica. *Rev Bras Hematol Hemoter* 2010; 32(3):257-264.
55. Soares EPB, Silva DS, Xavier ASG, Carvalho ESS, Cordeiro RC, Araújo EM. Cuidar de pessoas com doença falciforme na unidade de emergência: discurso de uma equipe multiprofissional. *Cien Cuid Saude* 2014; 13(2):278-285.
56. Calvo-Gonzalez E. Biotecnologias de baixa complexidade e aspectos cotidianos do "cuidado": a triagem neonatal e a detecção da doença falciforme no Brasil. *Hist Cien Saude Manguinhos* 2016; 23(1):79-94.
57. Hawkins LH, Sinha CB, Ross D, Yee MEM, Quarmyne MO, Krishnamurti L, Bakshi N. Patient and family experience with chronic transfusion therapy for sickle cell disease: A qualitative study. *BMC Pediatr* 2020; 20(1):172.
58. Guimarães CT, Coelho GO. A importância do aconselhamento genético na anemia falciforme. Cien Saude Colet 2010; 15(Supl. 1):1733-1740.
59. Cox FEM, Beauquier-Maccotta B. Representações maternas durante uma gravidez patológica: o caso da anemia falciforme. *Estilos Clin* 2014; 19(2):309-324.
60. Guedes C. Decisões reprodutivas e triagem neonatal: a perspectiva de mulheres cuidadoras de crianças com doença falciforme. *Cien Saude Colet* 2012; 17(9):2367-2376.
61. Pedrosa EN, Corrêa MS, Ferreira ALCG, Sousa CHS, Silva RA, Souza AI. Contracepção e planejamento reprodutivo na percepção de mulheres com doença falciforme. *Rev Gaucha Enferm* 2021; 42:e20200109.
62. Silva UB, Ferreira SL, Cordeiro RC, Almeida LCG, Santos EA. Experiências de mulheres com doença falciforme que vivenciaram perdas gestacionais. *Acta Paul Enferm* 2021; 34:eAPE02394.
63. Brito LS, Carvalho ESS, Cerqueira SSB, Santos LM. Da superproteção ao estigma: relações familiares de pessoas com úlcera de perna e doença falciforme. *Rev Baiana Enferm* 2021; 35:e37793.
64. Carvalho ESS, Carneiro JM, Gomes AS, Freitas KS, Jenerette CM. Por que sua dor nunca melhora? Estigma e enfrentamento de pessoas com doença falciforme. *Rev Bras Enferm* 2021; 74(3):e20200831.
65. Santos LM, Peixinho Neta TS, Brito LS, Passos SSS, Jenertte CM, Carvalho ESS. Ser adolescente apesar das restrições e da discriminação imposta pela doença falciforme. *Acta Paul Enferm* 2022; 35:eAPE0243345.
66. Sinha CB, Bakshi N, Ross D, Krishnamurti. Management of Chronic Pain in Adults Living with Sickle Cell Disease in the Era of the Opioid Epidemic: A Qualitative Study. *JAMA Netw Open* 2019; 2(5):e194410.
67. Berghs M, Dyson SM, Gabba A, Nyandemo SE, Roberts G, Deen G. "You have to find a caring man, like your father!"; gendering sickle cell and refashioning women's moral boundaries in Sierra Leone. *Soc Sci Med* 2020; 259:113148.
68. Cordeiro RC, Ferreira SL. Narrativas de Mulheres com Anemia Falciforme. *Rev Baiana Enferm* 2011; 24(1,2,3):33-42.
69. Cordeiro RC, Ferreira SL, Santos ACC. O adoecimento de mulheres e homens com anemia falciforme: um estudo de Grounded Theory. *Rev LatAm Enferm* 2015; 23(6):1113-1120.

70. Silva JGT, Carvalho ESS, Xavier ASG, Ramos MSX, Maia HAAS, Araújo TM. Repercussões da dor social, gênero e pessoas com doença falciforme: um estudo exploratório. *Online Braz J Nurs* 2018; 1:98682.
71. Sousa AR, Jesus AC, Andrade RCS, Lopes TFA, Jenerette CM, Carvalho ESS, Pereira Á. Ser homem com doença falciforme: discursos sobre adoecer e cuidar de si. *Acta Paul Enferm* 2021; 34:eAPE03384.
72. Bakshi N, Katoch D, Sinha CB, Ross D, Quarmyne MO, Loewenstein G, Krishnamurti L. Assessment of Patient and Caregiver Attitudes and Approaches to Decision-Making Regarding Bone Marrow Transplant for Sickle Cell Disease: A Qualitative Study. *JAMA Netw Open* 2020; 3(5):e206742.
73. Chakravorty S, Tallett A, Witwicki C, Hay H, Mkandawire C, Ogundipe A, Ojeer P, Whitaker A, Thompson J, Sizmur S, Sathyamoorthy G, Warner JO. Patient-reported experience measure in sickle cell disease. *Arch Dis Child* 2018; 103(12):1104-1109.
74. Cho HL, Kim SYH, Fitzhugh C, Hsieh M, Tisdale J, Grady C. Motivations and Decision-Making of Adult Sickle Cell Patients in High-Risk Clinical Research. *Biol Blood Marrow Transplant* 2020; 26(6):1225-1232.
75. Jabour SM, Beachy S, Coburn S, Lanzkron S, Eakin MN. The Role of Patient-Physician Communication on the Use of Hydroxyurea in Adult Patients with Sickle Cell Disease. *J Racial Ethn Health Disparities* 2019; 6(6):1233-1243.
76. Young AJ, Richardson F, Fitzgerald D, Heavrin BS, Tweddell B, Gettings L, Cooper A, Grant CC. Let Their Voices Be Seen. *Ann Emerg Med* 2009; 76(3S):S-73-S77.
77. Figueiró AVM, Ribeiro RLR. Vivência do preconceito racial e de classe na doença falciforme. *Saude Soc* 2017; 26(1): 88-99.
78. Maio MC, Monteiro S. Tempos de racialização: o caso da 'saúde da população negra' no Brasil. *Hist Cien Saude Manguinhos* 2005; 12(2):419-446.
79. Ramos EMB, Ramos PRB, Carvalho MHP, Silva DM, Dutra Júnior PHF. Portadores da doença falciforme: reflexos da história da população negra no acesso à saúde. *Rev Eletron Comun Inf Inov Saude* 2020; 14(3):681-691.
80. Rizzo TP, Fonseca ABC. Concepções e práticas de educação e saúde da população negra: uma revisão integrativa da literatura brasileira. *Rev Eletron Comun Inf Inov Saúude* 2019; 13(4):896-910.
81. Silva GS, Mota CS, Trad LAB. Racismo, eugenia e doença falciforme: o caso de um programa de triagem populacional. *Rev Eletron Comum Inf Saude* 2020; 14(2):355-371.
82. Cotton S, Grossoehme D, McGrady ME. Religious coping and the use of prayer in children with sickle cell disease. *Pediatr Blood Cancer* 2012; 58(2):244-249.
83. Gomes MV, Xavier ASG, Carvalho ESS, Cordeiro RC, Ferreira SL, Morbeck AD. Waiting for a miracle: Spirituality/Religiosity in coping with sickle cell disease. *Rev Bras Enferm* 2019; 72(6):1554-1561.
84. Gomes R. Participação dos movimentos sociais na saúde de gays e lésbicas. *Cien Saude Colet* 2021; 26(6):2291-2300.
85. Bardin L. *Análise de conteúdo*. Lisboa: Edições 70; 1979.
86. Tronto J. Mulheres e cuidados: o que as feministas podem aprender sobre a moralidade a partir disso? In: Jaggar AM, Bordo SR, organizadores. *Gênero, corpo, conhecimento*. Rio de Janeiro: Record, Rosa dos Tempos; 1997.
87. Federici S. *O ponto zero da revolução: trabalho doméstico, reprodução e luta feminista*. São Paulo: Elefante; 2019.
88. hooks b. *O feminismo é para todo mundo: políticas arrebatadoras*. Rio de Janeiro: Rosa dos Tempos; 2020.
89. Goffman E. *Estigma: Notas sobre a manipulação da identidade deteriorada*. Rio de Janeiro: LTC; 1988.
90. Collins PH, Bilge S. *Interseccionalidade*. São Paulo: Boitempo; 2021.
91. Mota C, Trad LAB, Queiroz MCA, Dias AL. Os desafios do cuidado integral à doença falciforme sob os diversos olhares: o olhar da gestão, o olhar das famílias e usuários e o olhar do serviço e seus profissionais. In: Castellanos MEP, Trad LAB, Jorge MSB, Leitão ISMTA, organizadores. *Cronicidade: experiência de adoecimento e cuidado sob a ótica das ciências sociais*. Fortaleza: EdUECE; 2015. p. 392-425.

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