**Title**

**Social disparities producing health inequities and shaping sickle cell disorder in Brazil**

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**Abstract**

Sickle cell disorder (SCD) is a severe recessive genetic condition manifesting in several complex forms. It is a cause of high mortality rates across the world, affecting predominantly non-white populations. This article aims to discuss how persistent social disparities and health inequalities in the Brazilian context can produce negative effects in lifelong conditions such as Sickle Cell Disorder. Appearing usually in the patient’s first year of life, when not treated, SCD may lead to several life threatening complications and impact on a person’s quality of life. In order to understand the link between health and social circumstances, it is important to consider the socio-economic transformation of Brazilian society over time, as well as cultural and historical aspects of the country. The concept of inequity will ground this analysis, facilitating an understanding of the process of producing an extra burden for people with SCD as a result of social disparities, including the existence of racism.

**Keywords**

Sickle cell disorder; health inequalities; social disparities; Brazil

**Introduction**

The single Portuguese speaking country in Latin America, Brazil has 200,000,000 inhabitants and an immense landmass, divided into five regions, with great socio-cultural diversity and persistent social inequalities. Disproportionate distribution of wealth is an historically recognised problem in Brazil. Despite the huge variation of skin tones and other physical features of the Brazilian population, income inequality can be associated to lack of opportunities based on skin colour (Mitchell, 2010). This ‘ethnoracial hierarchy’ is not exclusively present in Brazil, but assumes different shades in Brazilian society, which can be related to a Latin American type of social stratification (Telles, Flores, & Urrea-Giraldo, 2015). Marked by ‘race’ mixture (mestizaje) and ethnic diversity, Latin American countries share a history of slavery and ‘long-denied race-based inequalities’ (Telles et al., 2015, p. 40).

For twenty years, Brazil experienced a military dictatorship, a period of intense political repression and violence by the state that lasted until 1985. The period of democratisation fostered an extensive debate and political mobilisation that resulted in the current Constitution, published in 1988, which legally guarantees the rights of Brazilians and the social protection of the state, and can be considered an advanced constitution with regard to citizenship and the state’s commitment to health. The constitutional design sought to articulate universality and equity. In other words, it assured universal access to healthcare without distinctions regarding colour, class, faith, social or any other barriers. At the same time, it foresaw the need to implement targeted policies for social inclusion of vulnerable groups (Duarte, 2000; Fleury, 2011).

Currently, Brazil is facing a major political crisis resulting in a negative impact on the economy and living conditions. One of the first impacts of this crisis is the reduction of investment in social policies, the threat to democratic values and the extinction of equitable policies. In these circumstances health policies focused on minority populations are often the first to be abandoned due to neoliberal political strategies.

Equity is one of the main principles of the Brazilian National Health System (SUS), meaning that assuring full access to health care is crucial for a democratic society (Paim, 2006). In this sense, equity presupposes universality, since it is not possible to overcome inequities without ensuring that there is unrestricted access to services and decent health (Travassos, 1997). It also means that, in unequal contexts, universalist macrosocial public policies are not able to repair the inequities arising from the historical process of exclusion (Munanga, 2014). In other words, it is not a choice between one or the other principle, or to establish which is the most important, but indeed, to discuss the challenges of effecting equity. While the Brazilian Constitution legally provides the guarantee of access, equity seeks to provide social justice. It requires thinking about different health necessities of individuals and groups and the importance of policies of redistribution.

Inequities are unjust differences between groups and often emerge from unfair distribution of power, money and resources (Bhopal, 2014). Especially in multicultural societies, health policies must take into account cultural, social and economic factors that might influence health needs. Meeting the needs of different ethnic groups is challenging, but necessary to obtain improvements in health care. From the belief of inferiority of some groups, feelings of superiority may emerge, along with racist results. Racism is rarely explored in the understanding of health outcomes, although it can lead to socio-economic inequalities. Direct racism occurs by insults, harassment and mistreatment justified by feelings of superiority in relation to other groups, and is prohibited by law in most countries. Indirect racism is more subtle and results from decisions that favour some groups, which can be conceived as institutional racism when applied to organisations (Bhopal, 2014).

In this article we aim to discuss social disparities and health inequities in Brazil producing disadvantages for people with Sickle Cell Disorder, a condition more frequent among the non-white population. In order to understand how poorer life conditions and social inequalities produce negative health determinants it is crucial to examine social, cultural and historical variables. The historical background relating sickle cell disease to the ‘black’ population and slavery is very important when considering the social economic conditions of the people living with sickle cell disease today, mainly with a low socio-economic status and poor living conditions.

Racism is a result of historical social relations marked by slavery and reinforced by material deprivation and cultural-ideational structures such as negative stereotypes (Carter, 2000). In Brazil, the intersections between social class and racism have proved to be a determining factor in the accumulation of disadvantages among non-white groups. Santos (2009) emphasises the need to consider an analytical distinction between inequality of access and unequal treatment, to understand the racial inequality in Brazil.

There is no intention in discussing concepts of race neither considering race in the biological sense. Rather, to examine racism as unequal social relationships and the result of social forces, such as which reaffirm and develop hierarchies and inequalities (Ianni, 2004, p. 143). It is considered, furthermore, essential to recognise the peculiarities of social formation in the historical course of a given society (Omi & Howard, 1994), to analyse the social inequalities in their areas, as well as their effects. This process is especially required when trying to understand the complex dynamics of Brazilian society.

**SCD: from a global scenario to the local context of Brazil**

The S gene is carried by 7% of the population in the world and over 70% of all affected births occur in Africa (Ebrahim et al., 2010). Despite this, SCD is still considered the most neglected tropical disease worldwide (Ebrahim et al., 2010). It is estimated that there is a total amount of 300,000 births of children with SCD each year (Aygun & Odame, 2012; Dormandy et al., 2010) and projections for the future reveal that the frequency of SCD is expected to increase in sub-Saharan Africa and decrease in Eurasia, Americas and Arab-India by the year 2050 (Piel, Hay, Gupta, Weatherall, & Williams, 2013). Migration also contributes to the presence of this condition worldwide (Modell & Darlison, 2008), pointing towards the need of international effort to improve quality of life and assuring public health care for those facing this chronic disease.

Some studies show that the quality of life of SCD patients and their families is worse when compared to the general population and that the life expectancy of these people varies depending on the development of the country in which they reside (Dyson & Atkin, 2011). While some authors highlight a ‘global burden of haemoglobin disorders’ (Piel et al., 2013), mortality rates are disproportionately distributed over the world. In high-income countries the chance of surviving with a chronic disorder is much higher than in low-income countries, where children are at greater risk of dying before the age of 5 years (Modell & Darlison, 2008).

Historically, SCD was considered a ‘childhood disease’ that produced premature mortality, mostly due to infection, which can be directly related to social and environmental disadvantages (Platt et al., 1994). This pattern of mortality changed with early diagnosis, prophylactic penicillin and general improvements of socio-ecomomic conditions, which raised the life expectancy (Dennis-Antwi, Culley, Hiles, & Dyson, 2011). But still, in some parts of Africa, haemoglobin disorders contribute to 6.4% of mortality in children aged under 5 years, compared with 3.4% worldwide (Modell & Darlison, 2008).

The high mortality rates result not only from precarious living conditions, but also due to the difficulty accessing treatment, as well as the lack of research (Ebrahim et al., 2010). Full access to comprehensive health care can be lifesaving, since regular monitoring can prevent or minimise the complications of the disease. Nevertheless, Piel and collaborators (2013) will address the high costs of comprehensive health care, that usually involves a multi-professional team of health professionals.

All this leads us to reflect on the inequities in health and how they are differently expressed around the world. Considering SCD is present in many countries and has a global history, it is clear that there is a broader context that needs to be analysed.

However, the Brazilian context is marked with the ambiguous character of its development model, which combines social achievements with remnants of poverty and inequalities.

Brazil is a developing country that has undergone major changes in recent years especially due to policies focused on redistribution of resources and poverty eradication. Between 1991 and 2008, the gross domestic product doubled and the Gini index fell from 0.637 to 0.547 and the poverty rate fell from 68% in 1970 to 31% in 2008. The living conditions also changed (Paim, Travassos, Almeida, Bahia, & Macinko, 2011). In 1970 only 33% of households had piped water and less than half had electricity. In 2007, the number of homes with piped water increased to 93% and almost all the houses have electricity. These changes affected the country’s epidemiological profile raising the so-called ‘diseases of modernity’. Cardiovascular diseases are the leading cause of death, followed by cancer and external causes, especially those resulting from traffic accidents and urban violence. Despite advances in living and health conditions, Brazil still suffers from inequalities (Paim et al., 2011), which mostly affects non-white populations (Heringer, 2002; Soares, 2008).

According to the census of 2010, from the Brazilian Institute of Geography and Statistics (IBGE), the so called ‘black population’ corresponds to more than half of the population (50.7%), a total of 190,732,694 people. It is worth noting that the term ‘black population’ is a social concept that corresponds to the total sum of all black and ‘mixed-race’ which are categories used by the national census. Therefore, a ‘black person’ in Brazil is anyone who claims to be black or of mixed race by self declaration in census surveys. The unification of these two categories was a political decision that occurred in 1996, to bring evidence towards statistical data regarding the social disadvantages of the non-white population in Brazil.

According to data from the Ministry of Health (SEPPIR) the ‘black population’ represents 67% of SUS (National Health System) users. In the last fifteen years, the country has reached some important goals to overcome extreme poverty and improve the living conditions of the most impoverished groups. Affirmative action policies such as quotas in education system, in addition to redistributive programs such as Bolsa Familia has been trying to overcome social inequalities. Especially income inequality between whites and non-whites has decreased from 2003 to 2010, even though it remains, as white workers still earn 1.8 times more than non-whites (Paixão & Rossetto, 2011).

Considering indicators of public health, studies on infant mortality indicated a reduction in their rates in the 70’s and 90’s, which, however, occurred unevenly between white and non-white children, with a 43% reduction rate for white children and 25% for non-white children. In 2006, the northeastern region had an infant mortality rate 24.2 times higher than that of the southern region, although this disparity has decreased (Paim et al., 2011).

Another equally suggestive indicator is the number of deaths of children under 5 years of age according to the cause of death, in which non-white children accounted for 55.6% of those who died due to acute diarrhoea (compared with 27.2% of white children), 49.0% who died from acute respiratory infection (37.5% of white children), 51.7% who died from malnutrition (28.9% of white children) and 54.4% of those who died of unknown causes from lack of medical care (24.7% of white children) (Paixão & Carvano, 2010).

In Brazil, the Ministry of Health estimated that there is one case of SCD per 1000 live births yearly (Cançado & Jesus, 2007). Screening is universally conducted, with 92% of newborns being screend, regardless of ‘race’/colour (Amorim et al., 2010). In general, SCD is present in states and municipalities where there is a higher concentration of ‘black population’. In Brazil the highest incidence is concentrated in Bahia, 1 per 650 live births (Cançado & Jesus, 2007). A higher incidence (1: 500) is registered in the state capital, the city of Salvador. A survey released by the Ministry of Health estimated a prevalence of 5.3% of Hb AS (sickle cell anaemia) in Bahia (Diniz Guedes, Barbosa, Tauil, & Magalhães 2009). Despite the high prevalence rates of sickle cell disease in Brazil, there are still very few studies focusing on the characterisation of the socio-demographic profile of SCD patients.

Recent studies show a reduction of up to 40% in SCD mortality with the use of Hydroxyurea in Brazil (Cançado, Lobo, & Ângulo, 2009). In November 2002, based on Decree 872, the Health Ministry approved the free use and distribution of HU for SCD patients. In the last fifteen years, the access to medication has shown a significant increase in quality of life for people suffering from the disorder, especially among the adult population (Silva & Shimauti, 2006). However, this same adult population born before the inclusion of the SCD in neonatal screening, which in general had a late diagnosis, presents a greater commitment to their health and quality of life.

In addition, one of the big challenges facing Brazil is the lack of reliable health data about this disease. This may itself be the result of a process that reveals a relative lack of political and academic interest in the subject and that certainly contributes towards the epidemiological and social invisibility of the disease and especially of the needs of those who face it. The enormous amount of research in biology and genetics, apart from the investment in clinical and pharmacological studies, has not been accompanied to the same extent by either epidemiological or sociological studies. Above all, there is a clear gap of systematic records of the number, spatial distribution, socio-demographic, morbidity and mortality profile of the people affected.

Due to the severity of the clinical manifestations of the disease, Brazil still faces high mortality rates. Such an outcome can happen to all types of SCD, however, patients with Sickle Cell Anaemia (Hb SS) commonly have the most severe clinical manifestations, and consequently, an increased risk of death (Fernandes, Januário, Cangussu, Macedo, & Viana, 2010). It was observed that 76% of deaths due to SCD occurred up to 29 years of age, with a concentration of 37% in children under nine, showing the severity of the disease (Loureiro & Rozenfeld, 2005). Considering that SCD is more frequent among the most impoverished, it is estimated that up to 25% of children do not reach 5 years of life. Perinatal mortality is also still very high in Brazil, ranging from 20% to 50% (Simoes, 2010).

In Brazil, it is observed, for example, that 85% of adults with SCD have a low level of education and those who manage to enter the labour market have jobs that require great physical effort, often incompatible with the course of the disease (Guimarães, Miranda, & Tavares, 2009). It is, therefore, a population with high social vulnerability, but the relationship between this issue and the course of the disease remains underexplored.

The daily routine of people with SCD involves a continuous process of care, both in the family context, as well as in the healthcare services, demanding rearrangements from the family in their routine, definition of responsibilities around the required care and availability of several types of resources. The routine of care, especially for children with SCD, interferes throughout the family system and often hinders the performance of other external functions, such as work, especially for mothers (Dias, 2013; Guimarães, 2009). Therefore, the disease can have dramatically different effects on employment opportunities, creating a cycle of impoverishment and commitment of family income, with a strong impact on the quality of life.

Absence from school may also be seen as a source of disadvantage that can limit social mobility. Frequent hospitalisation can lead to school absence and makes educational success even more challenging (Dias, Trad, & Castellanos, 2015). Mothers and young people with SCD usually have to negotiate and deal with some restrictive aspects of school routine and environment (Dyson, Atkin, Culley, Dyson, & Evans, 2011). It should also be considered that experiences of discrimination in school are a source of limitation, which can be associated with racism, although usually very subtly. Therefore, ‘racism cannot be assumed to be absent on the basis of the lack of explicit references to the phenomenon, and consider the subtle ways that racism structures school experiences’ (Dyson, Atkin, Culley, & Dyson, 2014, p. 2379).With historical roots, racism continues to inform relationships producing negative experiences both at the individual and collective level.

Furthermore, qualitative studies on experiences of people with SCD in Brazil show how they report recurrent feelings of being mistreated, neglected and discriminated against, inside the health services. These studies, based on the lived experiences of people with SCD, have consistently shown late diagnoses of the disease, lack of knowledge by the health professionals on how to manage the condition and symptoms and the search for care in different services. The suffering presented by these works are not only related to the condition per se, but as a result of the lack of knowledge, misconceptions and negative perceptions related to sickle cell disease, in some cases are present in the families, communities and also health services (Cordeiro, Ferreira, Santos, & Silva, 2013; Dias, 2013b; Xavier, 2011).

**Can racism be taken as a form of social inequity affecting SCD?**

Persistent health inequalities can also be interpreted as a result of social discrimination and political exclusion justified by negative conceptions around ‘race’, ethnicity, gender, sexual orientation, religion, and language. Patterns of advantage and disadvantage in society are not only socially constructed, but also (re-) produce inequalities in access, power, and status, thus marginalising some individuals. In this sense, the politics of equity represent the struggle for the human right to health (Hayden, 2012).

Reflections on how racism is present in our society makes it possible to understand the processes of production and reproduction of the disadvantages that certain individuals and population groups face and their negative impacts on health (Spencer, 2014). Although it is very complex to measure and demonstrate the effects of racism, it is important to consider in order to develop antiracist policies (Bhopal, 2014). In this section, we examine other variables besides material deprivation that may contribute to the understanding of social disadvantages faced by individuals with SCD. Thus, it is crucial to present historical aspects of Brazil, exploring social disparities as historically constructed social hierarchies, prejudices and discrimination.

Brazil was the Latin American country that imposed slavery on the largest number of individuals and the last Latin American country to end slavery. From 1538 to 1888, three hundred years of slavery marked Brazilian society and produced negative effects in its constitution as a nation. In post abolition years there was no effort towards social inclusion of this population, which means that racism needs to be considered as part of the cultural system available to powerful social agents who failed to initiate any strategies aimed at improving the material circumstances of the black population. Former slaves had no educational training and job places were most commonly occupied by skilled workers. At the end of the nineteenth century, there was a Brazilian government campaign to attract European immigrants to replace former slaves in the job market. Projections about the future of Brazil guided this policy, with the intention of ‘improving’ Brazilian ‘racial stock’, gradually ‘whitening’ future generations (Santos & Maio, 2004).

The failure to confront the racial issue in Brazil, historically covered up by the myth of racial democracy, ends up perpetuating inequalities. More than a myth, racial democracy should be seen as a historical political commitment by the Brazilian Government towards the establishment of a society with no inclusion of ‘blacks’ and other minorities (Guimarães, 2006). As a result, ‘social inequalities in Brazil are tied to invisible mechanisms of racial discrimination that favour their expanded reproduction’ (op cit, p. 280). Moreover, there was a political and ideological project of denying racism and concealing its consequences (op cit). Often, hidden dynamics of racism in society can produce shared experiences of misrecognition and non-recognition, rendering second-class citizenship.

The Brazilian system of racial classification is very complex. Characterised by a set of fluid categories, it combines skin colour with many other variables (Telles, 2002). Not only are physical traits, such as hair, lips and nose considered to be variables, but also social position (Guimarães, 2012). It is also crucial to consider how these categories change over time and a historical sight must be taken in order to fully understand these issues. More recently, a race-based identity is becoming stronger, associated with the involvement with ‘black’ activists’ movements, with the emergence of a ‘black’ middle class and with political mobilisation (Kay, Mitchell, & White, 2015; Maio & Monteiro, 2005).

Considering racism as an obstacle to social mobility, it is possible to examine how it operates in a Brazilian context. First, as a cultural system, in which non-whites are perceived in a depreciatory way, commonly related to criminal violence, poverty, ignorance etc. These perceptions negatively affect the labour market and family income as a consequence.

Second, there are indicators of social vulnerability that affects mostly non-white families, such as poor housing conditions, neighbourhoods with lower quality of public services as well as high rates of violence, including police violence and homicides. These families usually cannot afford private schools, which makes it harder to enter universities, negatively affecting social mobility.

Therefore, admitting that there is a structural dimension that goes beyond interpersonal relations, and that racial inequalities in Brazil are not just a matter of material deprivation, means recognising the complexity of this phenomenon. Sickle cell disorder is not immune to this process, since ‘experiences of racial harassment and discrimination, and perceptions of living in a discriminatory society, contribute to ethnic inequalities in health’ (Nazroo, Williams, Marmot, & Wilkinson, 2006, p. 260).

According to Bediako and Moffitt (2011), studies that explore the social meanings and attitudes around SCD may have important implications in clinical care. In the UK, SCD became associated with the politics of ‘race’ rather than the disadvantage associated with having a long term condition, which might create disabling consequences (Berghs, Atkin, Graham, Hatton, & Thomas, 2016). The policy neglect of SCD, could be attributed to institutionalised racism, in which the needs of ethnic minority groups were ignored or misrepresented (Kalckman, Santos, Batista, & Cruz, 2007; Lopez, 2012; Silvério, 2002). While relevant, such an analysis tends to ignore the broader social disparities associated with having a long term condition.

Race ideas and stereotypes may emerge from negative perceptions carried out in society that potentially influence how people see SCD (Bediako & Moffitt, 2011; Tapper, 1999; Wailoo, 1997, 2001). For example, the association with drug use, has led health professionals to deny pain medication, labelling people with SCD as being addicted to painkillers (Atkin & Anionwu, 2010; Rouse, 2004). Other studies also claim that SCD association with race has led to poor health services, where racism is one of the explanatory factors for the low priority that haemoglobinopathies have in public health care (Cordeiro and Ferreira, 2009; Dyson & Atkin, 2011).

In the Brazilian context, where people with sickle cell disorder are predominately blacks, it is worth analysing how social disadvantages can add an extra burden to the disease experience. It is essential to discuss the convergence between social disparities and racism, when making sense of SCD. It is possible that poverty will interact with depreciative representations produced by racism to create negative consequences for health outcomes. Nevertheless, this association is not simple to prove, since the relationship among health inequalities and racism is a complex and dynamic one (Carter, 2000). Further studies are required, in order to examine more carefully the interaction between racism and material deprivation as determinants of health inequalities (Chor & Lima, 2005; Kabad, Bastos, & Santos, 2012; Chor, 2013).

In order to measure these inequalities, it is not only a question of observing the discrepancy in mortality patterns, but also considering aspects related to quality of life. Apart from the clinical vulnerability caused by the very symptoms of the disease, social vulnerability interacting with racism can set up a process of disadvantage overlays. Such disadvantages, when not causing premature death, are responsible for consequences that could be prevented with health provision and good living conditions.

There are few studies in Brazil that analyse the impact of racism in the care offered to people with SCD. Considering the potential interactions of income, gender and skin colour in understanding how appropriate care is accessed, one’s relationship to health service provision represent social relationships and therefore reproduce social hierarchies and existing forms of discrimination. Especially if we consider that, in general, the health policies are devised and planned by hegemonic sectors of society, which often disregard the needs of minorities (Bhopal, 2007).

Moreover, the disabling consequences of chronic, life long conditions such as SCD are also produced by various structural disadvantage that people might face. Nonetheless, to make sense of these structures, we need to treat them as analytically distinct and in particular explore material circumstances independently from the ideas that generate discriminatory practices such as racism. It is equally important to distinguish between the structures of discrimination and the human actions, which can reinforce them. Focusing on human actions, rather than the inevitably of structural determinism, creates the possibility of transformative action, which may (or may not) transform those structures. To be successful, such transformative action, requires reflexive engagement in which analytical distinctions are understood, as the basis of knowing insight, in which specific consequences can be attributed to specific interventions (Carter, 2000).

**Final considerations**

In the 25 years since the World Health Organization identifıed SCD as a relevant problem of public health signifıcance, ‘the majority of children in resource-poor countries have not benefıted from the many advances in treatment and care’ (Ebrahim et al., 2010). Although it is a serious disease with complex and varied manifestations, the course of SCD could be improved by better access to full, continuous and humanised care.

Frequently, in periods of economic crisis like the one Brazil faces today, minorities are most penalised not only because of intensification of poverty, but also as a consequence of the extinction of social policies focused on (re-) distribution of wealth and power. Those are the times in which the struggle for equity as social justice needs to be intensified, while individuals and groups need to raise their attention to the risk of losing constitutional rights.

Equity is especially relevant to SCD policies because, despite advances in treatment, in many countries people still don’t have full access to it. It is possible that in some contexts, SCD received less public and professional support compared with other less prevalent diseases, including research funding.

To reduce inequalities and promote equity, health policies should address the needs of groups (Bhopal, 2014). In the Brazilian Universal Health System, social participation is another principle that establishes mechanisms of dialogue and control of society. In the history of health policies for SCD in Brazil, the role of health activism was, and still is, very important. Most achievements are results of pressure from organised social movements, specifically formed by people suffering from the condition and their families. The social movement of people and families with SCD is an example of mobilisation and struggle for rights to health. This is a good example of how ethnic minorities have conquered significant political achievements and developed resilience despite adversity (Anionwu & Atkin, 2001; Dias, 2013).

The discussion about racism presented here is grounded in the fact that the ‘race’/ colour should not be taken in the biological sense. Nevertheless, it must be considered that ‘racial bias adversely affects the availability of resources not only for research and the delivery of care, but also for the improvement of that care’ (Smith, Oyeku, Homer, & Zuckerman, 2006, p. 1767). It is crucial to examine the results of social disparities in the production of health inequities, and the necessity of redistributive policies aimed at the promotion of equity as social justice. Although explained by historical roots, the continuation of these inequalities concerns and encourages us to think of the challenges for the achievement of a just society.

By bringing the issue of social inequalities linked to a chronic disease such as SCD, an attempt was made to consider the unique aspects of the Brazilian social context. Providing elements to understand to what extent the socio-economic disparities and shared experiences of racial harrassment can be a source of vulnerability. Other researchers have already discussed this correlation, but Bediako, Lavender, and Yasin (2007) points to the need for more studies to explore the different socio-cultural factors that interfere with the course of the disease. Not only macro-economic variables, such as income and social status, but also aspects related to the dynamics of the family, social support, and personal experience should be investigated. Regarding the absence of such studies, he warns: ‘until sociocultural influences such as racial identity are explicitly investigated and well understood, treatment strategies for sickle cell pain will continue to have a one-dimensional pathophysiological focus’ (op cit, 2007, p. 434).

Although the correlation between life and health conditions is relevant to any form of disease, there are specific aspects relevant to SCD, given its chronic condition. That is, one cannot deny that impoverishment affects any chronic disease, but in the case of a condition whose symptoms appear already in the first year of life, inequities can greatly affect the entire course of the patient’s life. All too often, adults at a productive working age find themselves unable to work due to the degree of sequelae. There is then the broader impact to the adults’ quality of life. It is, therefore, urgent to take into account in future research the weight that racism brings to the experience with illness, as it often exceeds even the weight of the disease itself (Atkin & Ahmad, 2001).

It is also crucial to invest in training professionals at primary healthcare centres to identify risks and signs of complications. Neonatal screening, prophylactic penicillin, immunisation and self care strategies are simple, but necessary, interventions (Fernandes et al., 2010). In addition, the articulation of the primary care network with hospital services and haematologist clinics remains a goal to be achieved.

It can be concluded that a greater effort to understand Latin American countries and their cultural singularities can bring new insights to health determinants and patterns of disease. Considering the similarities between these emerging economies, new partnerships can render joint efforts towards different ways of thinking, coping and living with Sickle Cell Disorder.

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