

# CHILDREN WITH SICKLE-CELL ANEMIA DISEASE AS A CHALLENGE FOR EDUCATIONAL POLICIES IN BRAZIL<sup>1</sup>

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## Introduction

Different countries around the world have, each other, very different demographic profiles. So, while Brazil, which has around 180 million inhabitants, has around 30% of the population in the age group of zero to 19 years, Finland, which has 5 million inhabitants, has only 18% being children and adolescents.

Different countries, regardless the size of its young population, hospitalizes more or less children and adolescents because of different diseases that affect those populations and because of different rates of incidence a same disease.

European youngsters fall ill and have to go to hospital, in general, because of cancer, diabetes, asthma and because of some chronic diseases, like cystic fibrosis. Despite these diseases are, indeed, very present in a scenario such as Brazil, they fight for space with several other diseases typical of the health problems of poor countries. Diseases such as infectious ones and also threats to health like complications of pregnancy, abortion or birth of many pregnant adolescents, as well as consequences of urban violence, which victimizes a large number of Latin-American young males.

In addition to these economic and structural differences, some countries still record, with great frequency, very specific diseases, generally typical of certain genetic inheritance of the population.

This is the case of Brazil, when taking into account its high incidence of sickle cell anemia. It is also the case for many countries in Africa. However, I found that highlight Brazil in this aspect is particularly important because we are a country outside the African continent, which mean that the prevalence of sickle cell anemia might not be seen so obviously.

Once we are gathering here different countries and different contexts, I found that it should be worth while, to show something that distinguishes Brazil and its sick children in a very significant way. There are so many other diseases - typical of poverty and an unfair distribution of wealth - that could frame Brazil in an especially problematic way. But for this Congress, I chose to talk about sickle cell anemia.

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### **Describing the meaning of sickle cell anemia in the life of a scholar-aged child.**

Sickle cell anemia, one of the most frequent genetic diseases with high prevalence in African-descendant population (19, 7), is characterized by changes in the hemoglobin, the red globules pigment which transports oxygen to the body tissues. Genes in people with sickle-cell anemia undergo mutations and fail to produce normal hemoglobin. Red globules have a crescent-type or are sickle shaped and do not have the common malleability of healthy ones. Since they have no flexibility in passing through small capillaries, red globules accumulate and obstruct the blood circulation which results in difficulty in oxygen demand to the tissues and organs of the body systems (8). Obstruction of such vessels and the failure of blood flow cause pain and frequently irreversible lesions owing to that lack of oxygen. Since blood vessels exist throughout the entire body tissues, risks may follow in any part of the body such as the central nervous system, lungs, liver, kidneys and spleen (22, 5).

Sickle cell anemia is not curable and treatment consists in palliative measures to deal with the frequent and sometime extreme pain crises in the belly, thorax, hand and feet joints and with the swelling and ulcers in the latter (15). Preventive measures are provided to reduce infection risks such as pneumonia and meningitis to which people with sickle-cell anemia are highly sensitive (16). Serious infections are one of the main causes for hospitalization and death in children with sickle-cell anemia (3,17).

Sickle-cell anemia is a challenge for inclusive educational policies within the governmental administrative area since the affected child fails to go to school as normal children do because of frequent painful events, routine medical treatments and recurring hospitalization (18).

Further, even when the child frequents school regularly s/he frequently has performance problems due to the characteristic crises of extreme weariness and memory difficulties caused by low blood flow to the brain which is easily affected by capillary obstructions common to the disease (13). Although schooling performance of sickle-cell anemia children and teenagers may be affected more due to the absence in lessons, are due to side-effects of the drugs, pain and fatigue crises, or family conflicts which result from the daily home coping with a chronic disease (21), it is not uncommon that small and silent strokes may be the main causes of low intellectual performance of sickle-cell anemia children and teenagers (2).

It is highly important to take into account that late sexual maturity, a typical consequence of the disease, highly jeopardizes the development of the sickle-cell anemia adolescent's self-esteem. The individual may already have unfortunately experienced the introjection of stigmatization effects hailing from people's lack of understanding of his/her condition (10).

Some 3.5 thousand sickle-cell anemia children are born yearly in Brazil. Besides Africa, Brazil is the country that has the highest number of cases in the world (9). Rates are higher than those of diseases such as AIDS, highly recurrent in Brazil. Highest

incidence occurs in Brazilian states with a great presence of descendants of former slaves during the colonial period, such as Rio de Janeiro and mainly Bahia. At Salvador, the capital city of the latter state, 3% of a population of 2,556,429 has the sickle-cell anemia disease. In fact, one in every 655 children has sickle-cell anemia disease. Rate is considered high when compared to the Brazilian average of 1 in 1,000 (1).

If one takes into account that ethnicity overlays class and since it is known that in Brazil African-descendant populations layers accumulate the worst indexes in earning and education, the variables poverty and disease converse in a perverse and dramatic manner to form a health framework in which many Brazilians with sickle-cell anemia disease, ranging between 20% and 35%, die before reaching ten years old (22). Sickle-cell anemia disease is thus a problem of public health especially in the state of Bahia, its capital city and its municipalities. Besides, Bahia shows the worst positions in illustrative social indicators such as the illiteracy rate of 20%, child mortality of 35/1000 newly born and Human Development Index of 0,6.

High prevalence of sickle-cell anemia disease has been tackled and problematized by Brazilian government initiatives which try to reduce social inequalities such as the Work Health Group of the Black People Population of Salvador city.

The above mentioned work group has analyzed the historical fragility of life conditions of black people, the pernicious and excluding effects of discrimination and racial bias and the genetic specificities of the African-descendant group. The groups has also described in detail and critically the epidemiological profile of the black population in Salvador, with special reference to the distribution of sickle-cell anemia disease in the city within the context of other diseases and threats to health (19).

Nevertheless, in spite of the acknowledgment that this disease is a public health problem (20), the meaning of sickle cell anemia in the context of children's school life with such condition has not provoked initiatives by the local government. Policies would diminish the hardships of these children to access school, maintain themselves in class and achieve learning progress.

This work aims at presenting and discussing some of the probable political and social reasons for the educational system managers not to give priority in their agendas for the educational demands of Brazilian children and adolescents with sickle-cell anemia.

### **1) The clinical and therapeutic approaches of the disease do not help revealing its social visibility.**

Although there is an increasing possibility of executing exams for the early detection of sickle-cell anemia, including neonatal screening, many families delay in reporting their children's disease (12). This is due to insufficient health system and diagnostic services. Brazil is a highly populous country with great territorial extension, with concentrations of hospitals and laboratories only in the great urban centers. However, a great percentage of the population with chances of having a sickle-cell anemia child lives outside the great urban centers. Even those who live in the cities have great difficulties

to access laboratories, blood centers and research institutions. So, even when there is an early discovery of sickle-cell anemia in children, the family has great problems in continuing the treatment, or rather, medicine, specialized diagnosis and hospital beds are lacking. Since poverty and African-descendant inheritance people are strictly related in Brazil, the families lack food and healthy sanitary conditions that would favor the diseased child. Mortality in sickle-cell anemia children, albeit high in Brazil, is even higher in Bahia. Children who are discovered late with the disease will not live for a long period of time to represent a specific demand to the educational system context.

## **2) Priority of sickle-cell anemia is not properly inserted within the country's health issues.**

Sickle-cell anemia in Brazil lies within a context of complex and largely numerous health issues. Public health administrators have to deal with various demands, some of which, such as infectious and parasite diseases, remain historically unsolved, the aftermath of urban violence and diseases caused by a lack of pre-natal and birth assistance. The scanty resources devoted to health in Brazil do not attend to such emerging demands as sickle-cell anemia. Sickle-cell anemia is an emergent demand since only recently epidemiological surveys have occurred in Brazil which evaluated the disease's numerical significance when compared to other public health issues. This fact may be proved once only recently the Brazilian government enacted a law that attributed accountability and duties to the public authorities with regard to the treatment and the prevention of sickle-cell anemia (4). Thus, if the health sector fails to evidence the priority of sickle-cell anemia, there are indeed very few chances for the educational sector to do so.

## **3) The insufficient political representation of the population with sickle-cell anemia does not enable them to demand the rights due.**

Sickle-cell anemia is a disease linked to African-descendant inheritance and is thus a black and crossbreed people disease. This portion of the population in Brazil, albeit numerically very high, lacks political power. This may be proved by the fact that only few black persons have posts in different government departments and that black voters, albeit numerous, are poorly schooled and unprepared to choose their representatives and demand actions that would attend their interests. We should also take into account that in a democracy one should expect that through a participating attitude a portion of the population directly implied in an issue is capable of demanding from the public authorities a series of decisions that would favor them (11). However, if this portion of the population lacks schooling and lives in a historical cycle of oppression, unqualified for work, rolling in poverty, there are in fact few conditions for them to demand and successfully claim government investment for the solution of their problems. Thus, parents of sickle-cell anemia children poorly affect the issue for an improvement of their children's life quality, especially with regard to schooling. We can say that it lacks civic empowerment. It should be emphasized that the low indicators and the schooling levels stated for Brazil as a whole, is especially true and more significant for the region of Bahia, which shows one of the higher incidences of the disease in world context.

#### **4) Disabilities and chronic diseases priorities are not properly evaluated by the country's educational policies.**

In Brazil schooling of hospitalized children or of those chronically sick is contained within a complex context of educational demands. There is a national average of 13% illiteracy which reaches 20% of the Bahia population. Only 12% of Brazilian within the 18 – 24-year age bracket goes to university. Last PISA results, measuring science learning, showed, through the performance of 15-year-old children, the improvement that should be done even when compared with data from other Latin American countries such as Chili. So, the context of generalized insufficiency in educational services hides the seriousness of the low school performance of sickle-cell anemia children and the urgency of attending them differentially. This fact may not be restricted to sickle-cell anemia children but also and equally to other chronic-diseases bearers and to other installed disabilities. Families of blind children or those with spinal cord injuries or, yet, with cerebral palsy, for example, have to face enormous challenges to put and maintain their children in a regular school. Besides, even special schools, albeit not always recommended, are not available with quality services to attend these families.

#### **5) Mentors of educational policies in general fail to conceive sick children's learning or even schooling them in hospitals.**

In the context of the dynamics of Brazilian social relationships, there is a cultural datum according to which “the sick person's place is his home”. The scanty offer of services in schooling attendance for hospitalized children and adolescents is evident. Even if in absolute numbers the 120 hospital schools in Brazil is an important number itself, when compared to those in Latin American countries, we conclude that a greater number of hospital schools should be conceived when Brazilian population and territorial extension is taken into account. Besides, there is also the complete ignorance with regard to the simple existence of such modality of educational attendance. Specialized Brazilian teachers find it difficult to acknowledge the role of a hospital school or just admit its existence. The difficulty in acknowledging the schooling needs of hospitalized children has to face the difficulty in acknowledging the learning potential of a sick child. If the relationship sickness/learning is not an equation that functions in people's mind and in teachers of special education, it is surely absent in the policies mentors. If this is true regard to children's cancer - which is a enormously announced and discussed disease - it is truer for a disease which few are aware of its severity and consequences. Thus, although the learning capacities of sickle-cell anemia children are not denied at once, the importance of differential following up of schooling is not stated with so much emphasis and conviction by those who promote education.

## Conclusion

The importance of investments in the schooling of hospitalized or sick children has been a leitmotif in discourses which favor the rights of children. We may repeat the following statement through different arguments. When compared to that in European countries, the role of the Brazilian hospital school is specially characterized by the great and sole opportunity of real learning for some children and adolescents. Many of them, regardless of the disease they carry, are excluded from school or they are in schools that would not help them to learn to read or calculate. The classrooms are full, without any pedagogical equipment, without libraries, lacking well-earning capacitated teachers. PISA's rate for Brazil during the last few years is an indicator of a bigger framework of structural deficiencies.

The hospital school and its working methodology which attends people individually favors heights of learning that might have been never reached before by Brazilian children, who are, in a great number, afro descendants. This way, the hospital schools for hospitalized children, in general, and for sickle-cell anemia children, in special, can be a real and unique opportunity in helping the rupture of the historical cycle of poverty, ignorance and exclusion.

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