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What Sociological Perspective of Drepanocytosis in Parents living in Kisangani, D.R. Congo?

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ABSTRACT:

The lack of basic structures for the screening and management of the sociocultural sickle cell disease remains a major problem in the cure of this pathology in DR Congo. Hence the need to carry out our investigation of the experiences and emotions of these parents. Our study is a qualitative research conducted with parents in Kisangani in December 2017. Inclusion criteria (parents living with their child sickle cell under 18 years of age living or dead) and, that of non-inclusion (living parent away from his sickle cell child). The qualitative approach is used to establish the community diagnosis in order to identify the problems, needs and resources related to a good management of this pathology as the parents feel. Our results were drawn based on a thematic analysis articulated on the circumstances of discoveries of the disease, the repercussions of the disease and the perception of management. This analysis showed significant psychosocial repercussions for the parents of sickle cell children and the stigmatization in the social and school life of children with sickle cell disease. The care of children with sickle cell disease is very expensive and remains only medical. However, the family of sickle cell does not benefit any psychological support. The Congolese State must put in place a care management policy based on a total approach to the disease.

Keyword: *Sickle cell disease, sociological perspectives, parents, Kisangani, Democratic Republic of the Congo.*

INTRODUCTION:

In the world, sickle cell disease is the most common genetic disease. The various migrations have favored its expansion in the world [1]. In its 2006 report, WHO estimates that 500 million people carry the sickle cell trait and that about 50 million people live with the disease [2]. Every year, 300,000 children are born with the disease, 2/3 of them in sub-Saharan Africa [1].

In Africa, the frequency of carriers of the sickle cell gene is variable and can reach prevalence of 40% in some populations [3,4]. In the Democratic Republic of Congo (DRC), recent epidemiological data have shown that in the neonatal period, 2% of newborns are homozygous for the disease and about 40,000 births of sickle cell children are estimated each year, while in the population adult the carry of the line is 25% and the homozygous form affects about 2% of individuals [5,6]. Although this figure is epidemiologically significant, the disease remains poorly known, with a high mortality rate in a developing country [7-9].

In the world, the Democratic Republic of Congo occupies the third place and the second in Africa. While India is the first country in the world most affected by sickle cell disease, followed by Nigeria is in second place [10]. More than 20 million people, one third of the estimated 65 million people, are heterozygous sickle cell patients, considered as "healthy carriers AS". Two out of every hundred babies are born SS.

However, in Kisangani, the prevalence of people carrying the S gene, (either AS or SS), is proportional to 27% of its population of which 3 to 5% has the symptoms of sickle cell disease. However, nearly 27% of anemic children die before the age of five [11].

Sickle cell disease is characterized by painful seizures and hematologic seizures that expose to significant transfusion risk and susceptibility to infection. This accounts for the high morbidity and mortality recorded in sickle cell patients and that 50 to 80% of children born on the African continent will not reach the age of five [8,9]. In addition to these acute manifestations, sickle cell disease is associated with chronic degenerative complications in the organs [12,13] and delayed weight and pubertal retardation [14,15]. It leads to frequent stays in the hospital. In Congo-Brazzaville, painful crises represent the first cause of hospitalization [16].

The fight against sickle cell disease involves several sectors and the impact on public health is significant, the consequences of which can be assessed in relation to infant mortality, particularly for children under five [8,9]. In most countries where sickle cell disease is a major public health concern, the basic means for its management have remained inadequate, routine screening for the disease at birth is not common practice and diagnosis is generally postponed [8, 9,17].

In contrast to northern countries, sickle cell patients in the DRC do not benefit from rigorous and regular medical monitoring in search of the organic complications to which the disease is exposed [8, 9, 17-19]. In addition, human, financial, material and specialized centers for the management of sickle cell disease and its complications are rare. The care is almost solely medical. The health system is dominated by vertical programs geared to particular pathologies (malaria, tuberculosis and HIV / AIDS), disrupting the integrated health care system. In addition, sickle cell patients, like the rest of the population, live in a system without social security.

In parallel with medical care, studies have shown that the success of the management of the disease resides in a global approach centered on the patient and his family [20]. Sickle cell disease is a chronic debilitating disease that is subject to many taboos and stigma in our African societies, ranging from isolation and abuse of the patient to parental divorce [21-26].

This alarming picture of the experience of this disease in the African socio-cultural context shows the importance of conducting a study of information collection on the lived experience and emotions shared by parents of sickle cell families. However, the aim of this study is to identify, on the

one hand, the psychosocial repercussions of sickle cell disease experienced by the parents of sick children: the announcement of the diagnosis, management and after death; on the other hand, the needs or problems related to the specific management of sickle cell disease in their community. The community diagnosis was used to identify different representations of sickle cell disease among parents, considering that health and quality of life are intimately linked.

FIELDS OF STUDY AND METHODS

Fields of study

Given the sensitivity of the information we were seeking, a qualitative approach was used to highlight the psychosocial implications, issues and needs related to the management of sickle cell disease in our study setting. In this context, this approach facilitated the use of community diagnosis processes in order to identify problems, needs and resources for good care. And this survey was organized in December 2017, in the commune of Tshopo and Lubunga of the city of Kisangani, Democratic Republic of Congo.

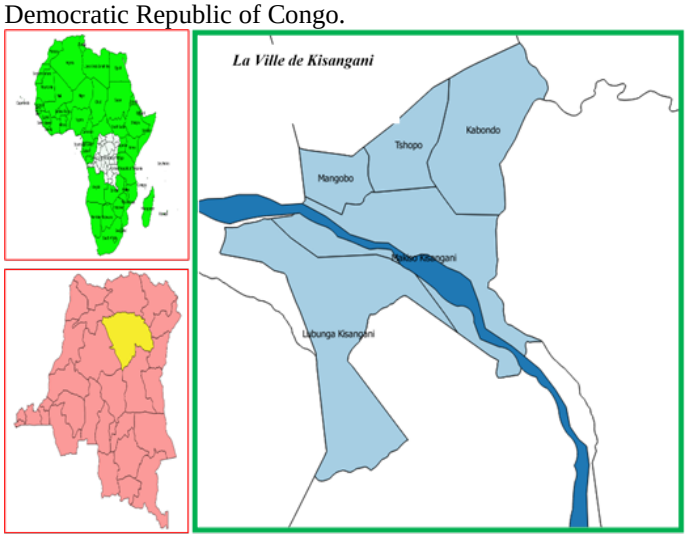

Figure 1: Location of Kisangani's city in DR Congo.

Size of the sampling

The interviewees were recruited from the NGO: FORUM OF MANAGEMENT AND DEVELOPMENT OF THE PERSON DREPANOCYTEIRE in acronym FEDPD headquartered in Kisangani. The inclusion criterion was defined by any parent with sickle cell children under 18 years of age living or dead and the non-inclusion criterion: by any parent with sickle cell children over 18 years of age. However, the city of Kisangani has no reliable structure for the full management of sickle cell disease. And over the contacts, the method called "snowball" allowed us to recruit a sample 24 parents. The interview took place in the language spoken by each of the participants: 2 interviews in French, 7 interviews in Lingala and 15 in Swahili (language mainly spoken in Kisangani).

Type of study

Our study is a qualitative research.

Study parameters

This study exploited in particular:

- The circumstances of discovery of the disease.
- The impact of the disease.
- The perception of care.
- The needs and issues of case management.

Analysis

According to the data collected in our interview guide, this method of collecting qualitative data is commonly used and it allowed us to understand the divergence of data collected or observed between parents who live in the same social reality and understand differently the situation.

RESULTS

Characteristics of interviewees

The study population consisted of 24 parents or guardians of children with sickle cell disease. They had met the selection criteria of our survey and provided reliable information about the disease under study. This small sample is explained by the fact that many parents did not want to speak about sickle cell disease. They felt they were talking about their sickle cell child and remembered the bad memories they had. Among the people we met: mothers were in first place (10/24), fathers (5/24), grandmothers (2/24), sisters (4/24) and brothers (3/24) of sickle cell disease. Eight parents had already lost their child under 18 years old. Among sickle-cell patients living with their parents, the oldest was 16 years of age and the youngest, three years, nine months.

Context of discovery of the disease

According to the interviews of parents or guardians of children with sickle cell disease who received medical care, in the majority of cases, the disease was discovered during hospitalization and, the main causes of consultation were fever, paleness and hand-foot syndrome. For some parents surveyed, the consultation was requested by people with knowledge on the care of patients.

From our interviews, we will present three cases of sickle cell disease, in medical load

When we were in the village of Isangi when my daughter was four months old; she suffered from repeated high fevers and cried a lot until about six months of age. At nine months of age, I had thought she had chronic malaria, so I administered her and I started quinine but the child was growing more and more. In the end, my grandmother had taken the child for care. But the child grew more and more pale. So we called a nurse who referred us to Kisangani at Dr. Alworong Health Center. From there, we did the electrophoresis that revealed the disease. (Mrs. S)

At two years old, my boy had both feet and both swollen. His dad and I were asking ourselves a lot of questions about this situation. One day we decided to go to the hospital: a lot of exams were requested and the child and was declared SS 100%. And in our turn, we had been examined; but what a surprise too; I am in Group B and his father is O, donor. But we do not know why our child is sickle cell. (Mrs. K)

In general, analysis of respondents' histories reveals that not all parents of sickle cell children had the requisite knowledge to detect precursors of sickle cell disease. They would confuse the symptoms presented by their children with those of the usual diseases of early childhood (malaria, isolated fevers, etc.). The circumstances of the discovery of the disease seem fortuitous.

The sociological prospective of sickle cell disease

At the announcement of the disease

Sense of panic: The image of sickle cell disease in sub-Saharan societies is that of a shameful disease, linked to the curse, to a punishment of nature for a fault committed in the past whose unique evolution is the death of the child. The majority of the interviewees had known that sickle cell disease, in their environment, sickle cell patients display a feeling of panic. This feeling is due to information conveyed in society: for example, children with sickle cell disease have a life expectancy that is too short. However, this disease, described as chronic, modifies the family atmosphere. Generally parents are afraid to see that the discovery of this disease will end their marriage; women suffer a lot.

Anxiety and worry: analyzing the comments of our respondents, it should be noted that no one had thought of sickle cell disease, although the prevalence of the disease is important among the Congolese population. The announcement of the disease plunges parents into permanent anxiety and

worry; anxiety because the disease is chronic and often lethal in poor countries like the DRC. The feeling of worry comes from imagining the suffering that the child will endure throughout his life. Faced with this situation and under the pressure of the in-laws, especially that of the man, the divorce is perceived as the solution to put an end to the curse. And the woman is perceived as a vector of the disease.

Child's growth

To childhood

For the majority of parents, children do not have major problems outside of crises. They often lead their lives like all other normal children. However, those who have severe or recurring seizures, are late or drop out of school. These sickle cell children with severe symptomatology are not accepted in the community. This attitude leads to stigmatization and marginalization between them. In the community, children are called wizards as a result of various seizures and complications related to poorly understood disease.

This community behavior often leads adolescent sickle cell patients to deny the disease and give up care in order to maintain their dignity in this community. The words of these parents illustrate this observation: "We often insult my child in the neighborhood, even at school. While the child is walking on the road, his friends sometimes insult him "in the name of the SS children". That's why his angry grandfather went to blame his children at school. But, unfortunately, by the time this information was given to the students, they were making more and more fun of him. During one of his hospitalizations, he confided in me telling me: not to tell the Doctor that I am sickle cell. I'm melted with crying. (Mrs. Olk)

In the family setting

The presence of sickle cell child in the family has important consequences. Parents interviewed about their daily experience say that the disease changes the family atmosphere. Although the general trend is to divorce to avoid giving birth to other children with sickle cell disease, most of the parents interviewed did not give in to pressure from members of the community in general and their families in particular. Thus, sickle cell disease remains hidden from the family circle; parents manage the situation alone during or outside crises so that the information is not disseminated within the community.

In some cases, parents tend to overprotect their sick child and show more attention than other family members. The siblings of the patient tend to condemn the patient because of his multiple crises which unbalance the family budget by entailing a significant cost of health care. "It's painful, as I have welcomed my nieces to my house, every time he gets sick, they make fun of him. They say: why only you who suffer at all times, you make the money of our mother spend "(Madame Ski)

In the life of the parents couple

Questions and concerns about the future of the child create family tensions, and therefore alter the quality of life of the couple. Some parents initially denied the disease, which means that, despite the announcement, they persisted in not going to care facilities that made the occurrence of certain complications and death more likely. From an economic point of view, the parents or guardians interviewed had modest incomes and most did not have paid jobs.

The most worrying situation we had was that of a mother with her daughter in hospital for non-payment of the US $ 50 bill. A day later, her child relapsed causing the extension of the stay in the hospital and as a result the increase in the amount of the bill. In addition to these repercussions, we have also learned that parental anxiety remains permanent, exacerbated by frequent, unpredictable and often sudden vaso-occlusive seizures, especially in the patient. Crises are often brutal and unpredictable. These crises require frequent hospitalization leading to increased expenses and the restriction of the parents' professional activities and thus a financial loss of income for the family.

Following the death of the sickle cell child

These interviews concerned only parents who had already lost a child with sickle cell disease and who came to the health center for care for the second child with sickle cell disease; in total 3 parents are in this situation. These parents feel physical and mental exhaustion. They seek to understand the reasons for this dramatic situation in their lives. This first experience reinforces their feelings of guilt and increases their isolation, such as the mother who has broken relations with her family who would like to end her marriage after the death of her son. Here is what she says: "I no longer have contact with my family because my brothers wanted me to divorce my husband after the death of our son. As I refused, everyone gave me up. This moment of mourning is a moment when psychological support is essential to continue caring for other children, especially if there are other sickle cell patients.

Perception of full care

All of our respondents had stated that care was not comprehensive. It is essentially focused on the medical aspects of the disease. The socio-cultural and psychological aspects that the disease engenders are not taken into account many structures. Apart from doctors and nurses, no other institution or profession is involved in the care.

Since care is expensive and there is no funding, parents are inclined to self-medicate and bring children to the center only when the situation becomes critical: "When the child is in crisis, I buy myself some drugs that I know, I give it and it goes. Otherwise, if there is no change, especially if his abdomen remains distended, I am obliged to bring it here. There we make the examinations and prescribe the drugs "(Mrs. Ros).

Problems and solutions related to the full management of sickle cell disease

Community involvement in the management of sickle cell cases begins with the identification of the primary signs of this disease. At the community level, all medical facilities operate without subsidies, they are not equipped and, this explains the dilapidation of the center. The majority of parents say that the problem of the quality of care and the cost of managing the disease prevents many children with sickle cell to regularly monitor their care.

To improve the overall case management, the parents propose the involvement of the government of the republic in financing the health care of their children in the same way as malaria, tuberculosis and HIV / AIDS. For example, here is the excerpt of some parents on this subject: "The care of my family is possible only if we had means. There are times when we do not have one. If the care was almost free as they are given to the tuberculosis patients, it will be a lot of relief for the parents ".

DISCUSSION

This work, to our knowledge, is among the first qualitative studies on sickle cell disease in Central Africa. However, some studies were conducted on the subject in Nigeria in West Africa [27, 28], Kenya in East Africa [29] and DR Congo in Central Africa [30]. This qualitative study was conducted in the city of Kisangani, with an NGO of sickle cell families. It is a non-governmental organization grouping sickle cell patients and their families living in the city of Kisangani; this center aims to provide psychosocial support to families who are victims of this disease.

The choice of this center was motivated for practical reasons: the ease of finding the parents of sickle cell children living in

Kisangani. The parents regularly visit this NGO and will therefore constitute an essential population for this study.

In our research, in families where the child was sick, the father was often absent; It is the mother who often keeps the sickle cell child at home or in the hospital. Dad is away from home, he's gone either to work, or looking for financial means that can pay for the care of the child. The presence of the sick child in the family has a negative influence on interpersonal relationships. Living with a child with a chronic illness is an experience that requires a lot of patience and resources from parents. The parents' panic reaction to the announcement of the disease is more related to the misunderstanding of sickle cell disease. The denial of the disease and the silence that the parents keep, testify the devaluing character of sickle cell disease in African society [27-29]. These experiences have been reported in other African studies [21-24, 29].

In the light of what our respondents said, sickle cell disease poses a heavy financial burden for families in Kisangani. They have become accustomed to bringing children to the hospital only when the situation becomes serious and / or after raising financial means to enable them to take first aid. These parents live in an environment of poverty, lack of social security and ignorance of the management of home sickle cell crises.

Sickle cell crises often result in unexpected family expenses. To alleviate this situation of exaggerated expenditure of care, Hamza et al. in Tunisia had proposed in their study the granting to patients of a handicap card to relieve some families financially [31]. Free or subsidized care for this category of patients and the development of a microfinance project to enable these families, in the medium term, to meet certain expenses but also to ensure regular monitoring of their patients. The creation of sickle cell management structures in the different levels of the Congolese health system and their integration into integrated care could also facilitate patients' access to care by avoiding long distances in a system where outpatient emergencies do not occur. Are not insured. To date, there is no supply chain for essential drugs for sickle cell disease. The patients are thus obliged to pay off their own pocket these drugs generally prescribed ad vitam [32].

According to what we heard from our respondents, some of them preferred to go to church or traditional medicine instead of bringing the child to the hospital. The repetition of crises, ignorance of the disease, poverty and the feeling of helplessness of Western medicine may indeed push parents to resort to alternative medicine as previous studies have shown in our environment [33, 34].

Management of the disease is possible as soon as the national community puts in place the necessary actions to reduce its incidence at birth but also the morbidity and mortality related to the various crises, notably through information, education and training campaigns. Awareness. Community participation helps to guide activities towards health promotion by involving an effort of each of its members [35-37].

CONCLUSION

This study focused on the sociological perspective analysis of sickle cell disease in parents or guardians of sickle-cell children living in Kisangani. As identified above, sickle cell disease remains a taboo disease with many problems related to its management, insufficient resources of parents and local beliefs of the disease.

Being identified by our respondents, it turns out that the resources of families of sickle cell children are often poor and the city of Kisangani has no specialized structure for the overall care and quality of this disease. The involvement of the Congolese State and the humanitarian organizations is desired to relieve the parents who are poor and unable to handle the case effectively. Thus the participation of the entire population in thefight against sickle cell disease will stop the spread of the said disease.

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