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Contribution To The Care Of Children With Sickle Cell Disease

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Abstract – This study analyses the factors that explain the irregular attendance of sickle cell patients in health care services. The study used a mixed quantitative and qualitative approach. This enabled us to arrive at the results that the announcement of sickle cell disease is a period of crisis and disrupts the life of the patient. The family builds resilience in the face of their child's new identity status. This new recomposition of identity subsequently conditions the patient's eating habits and rebuilds social relationships.

Keywords – Care, Children, Sickle Cell Disease.

INTRODUCTION

The fight against sickle-cell anaemia involves several sectors, and the public health impact is significant, with consequences that can be assessed in terms of infant mortality, particularly under-5 mortality. Systematic screening for the disease at birth is not common practice, and diagnosis is generally made late. (Evariste Luboya, Jean-Christophe Bukasa et al, 2014).

In Africa, precisely in Côte d'Ivoire, this pandemic is on the increase. The theme of the 2020 event was screening. According to specialists, there are 4 million sickle cell sufferers in Côte d'Ivoire. According to Professor Ibrahima Sanogo, two spouses of AS type will have sickle cell children. The President of ADTCI (the sickle cell and thalassaemia association of Côte d'Ivoire), wants people to be taken care of quickly by instituting a pre-marital check-up, to enable prospective spouses to find out their status, and a neonatal check-up to correct any abnormalities in their children. In 2014, the haematology departments of the three university hospital centres in Côte d'Ivoire registered 1,1972 patients suffering from sickle cell disease, including 8,572 in Yopougon, 3,000 in Cocody and 400 in Treichville, with an average of 600 new cases each year. (Saliou Amah, published on Saturday 20 June 2020 APA).

In view of the above, the haematology department receives children with sickle cell anaemia in order to check their blood levels if they require a blood transfusion. Patients also have access to a medical file for follow-up. In addition, there is a clinical protocol for the care of children with sickle cell disease and the effective presence of care specialists to administer care to sick children. Despite all the strategies and standards for the care of children with sickle cell disease, patient attendance at the CHU de Cocody is irregular. What factors explain the irregular attendance of sickle cell patients in the sickle cell department at the CHU de Cocody?

A number of scientific studies have focused on children with sickle cell disease. The existing scientific literature illustrates the double stigma of the disease and race. Sickle cell anaemia is said to be "a black disease"; this is one of the most common stereotypes about the condition. To understand the origin of this idea, we need to look at the history of the discovery of sickle cell

anaemia. In 1910, HERRICK (1910) made a laboratory discovery in the United States of the presence of sickle cell red blood cells in the blood of a West Indian patient suffering from chronic anaemia. This discovery came at a time when biological characteristics were beginning to take over from anatomical characteristics in human typology, before the notion of race was called into question. Nevertheless, the first screenings for sickle cell trait in Africa were published in the 1940s (40), almost half a century after the first discovery in the United States. All this took place in a context of colonial medicine, where research focused on "exotic pathology", of little interest to doctors in metropolitan France (Lehmann, H. 1952). Subsequent studies showing the presence of the "S" gene in the Middle East in an Arab-Jewish population and its absence in South Africa in "authentic negroes" posed political problems for the whites imposing apartheid, as no racial explanation could be found. It was not until 1964 that Livingstone, an American geneticist, formulated the hypothesis that heterozygotes had a selective advantage in a malarial environment, which made it possible to relativise the question of the origins of the disease, which until then had been limited to the black race (Livingstone, 1964). For Bonnet, D., (2001), "the treatment of sickle cell anaemia is recent and reveals stigmatisation, a culture of secrecy and dysfunctional health systems". However, BONNET (ibid.) explains the socio-cultural foundations of this culture. "The stigmatisation of women deemed responsible for transmitting the disease to their children, the fear in Africa of being a financial burden for the husband (frequent purchases of medicines, repeated hospitalisation) and of being abandoned for this reason, the fear of ostracism of young sickle cell anaemia sufferers by their school and even family environment, etc., are all factors which fosters the idea that disclosure of this state of health may lead to a situation detrimental to their interests". It has to be said here that the identity categorisations or "labelling" processes (Goffman, 1973) of which sickle-cell sufferers are victims, raise the question of the origins of races, cultures, interbreeding, etc. And all these have a considerable influence on the management of sickle-cell anaemia. According to Amselle J.L (1985:170): "the technicisation of immigrant populations is therefore the product of a racist conception of assimilation, which must result either from the absorption of a minority group by a majority group, or miscegenation through marriage (mixed, consanguineous)". In this way, the concept of culture is assimilated to that of ethnicisation, and applies to a wide variety of realities; this is why Izard, M. (1991:191) states that culture is "a result of analysis, not a given". The ethnic approach is therefore entirely relative and depends on the representation of identity markers by each user of the term. The different African interpretations of the disease mentioned, i.e. witch-child, revenant-child, cursed-woman, are all part of health contexts, but also social contexts, because in most cases they are considered to be Thus, the construction of the pathological entity depends on many factors which highlight the link between imaginary figures and social processes. These models also help us to identify "the social origin of categories, of 'representations'" (Balandier, G., 1999:16). the dimension of inter-individual behaviour is discovered progressively throughout life in society, and the common point of all this is to mark a difference and assign a place: a difference between those who call themselves 'normal' and men who are not quite so, or more exactly, the 'abnormal' who are not quite men (Goffman, E., 1963).

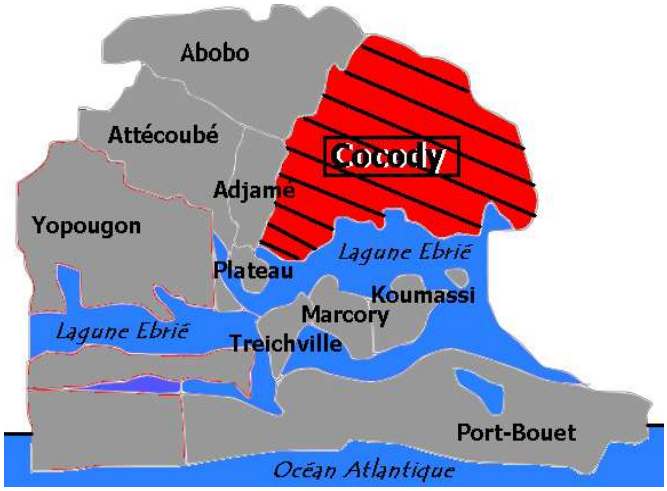
In short, all the studies used in this literature review suggest the existence of a relational framework between sickle cell disease and many factors. Sickle cell anaemia is the result of chronic and often emotional anaemia: ignorance, poverty and family financial difficulties prevent parents from providing their children with adequate and necessary care. This is why we have come to the following conclusion: successful management of sickle cell anaemia requires recognition of the disease itself and the resolution of medical and social problems. However, this review has enabled us to understand how sickle-cell anaemia is perceived and what means need to be used to deal with it.

I. METHODOLOGY

1-1-Site of the study

In order to gain a better understanding of the social reality under study, the setting for this study was the CHU. Located in the commune of Cocody. The University Hospital of Cocody is a third-level public referral hospital inaugurated in June 1970, located in Abidjan in Côte d'Ivoire. It became a public industrial and commercial establishment on 6 June 1984. It is located not far from the Félix Houphouët Boigny University (FHB) Cocody centre. The choice of this geographical area is explained by the fact that the CHU de Cocody has a haematology department, as children with sickle cell disease are treated by haematologists.

- Map of the Cocody commune



1-2-Target population

Our aim is to identify people who are relevant to the social situation we are studying. Having said that, the question we are asking ourselves here is who we are interviewing in order to gather information. It refers to all those who are in direct or indirect contact with the field of this study. Thus, the study will concern (2) categories of stakeholders who make up our target population:

- Parents of children with sickle cell disease. Because they could inform us about the relationships structuring the care of their relatives suffering from sickle cell disease;
- Doctors, who provided information on the determining factors in the clinical management of sickle cell disease patients at the CHU de Cocody.

1-3-Data production and analysis methods

The study used a dual qualitative and quantitative approach with appropriate tools. These included a literature review and semi-structured interviews. The data collected from the above-mentioned stakeholders was analysed using Karl Popper's (1956) dialectical method and methodological individualism. The combination of the dialectical method and Popper's theory

The combination of the dialectical method and Popper's theory made it possible to understand the issues at stake in the different positions taken by the players in the process of caring for sickle-cell anaemic children, linked to the way in which their recovery was constructed, but above all in the search for solutions to reintegrate them into the social sphere. The dialectical method highlighted the contradictions and strategies of the players in the care process.

II. RESULTS

2-1-the social profile of respondents

Analysis of the social characteristics of respondents is important because these results can be used to explain non-observance of barrier measures. The present study concerns age, sex, level of education, marital status and religion.

SUMMARY TABLE OF THE SOCIAL CHARACTERISTICS OF THE SURVEYS				
Age	(20 ans – 25 ans)	(26 ans – 30 ans)	(31 ans – 35 ans)	(36 ans – 40 ans)
	3	5	12	7
Gender	Men		Woman	
	9		18	
Education level	Primary	Secondary school	University	Out of school
	4	12	9	2
Marital status	Married		Single	
	6		21	
Religion	Christian		Muslim	
	15		12	

Source: (our field, 2021)

We note that 19 out of 27, or 70.4% of our respondents are aged between 31 and 40. In fact, we can see that from this age onwards, parents are mature enough to look after and monitor their children well, especially when they are ill. This is unequivocally why J.E., the treating physician, said: "The older the parents, the easier it is to understand the illness, and the easier it is to follow them" (Testimony of J.E., treating physician). However, out of a sample of 27 respondents, 9 were men. This shows that women are more involved in children's health and well-being.

K. S said: "We women understand children better, but Dad's never at home, he's always away. If we're not there, the children are really there...". (Testimony of K. S., treating)

It should be noted, however, that in addition to women, men are also willing to look after children. Legal marital status refers to a person's marital status under the law: single, married, widowed, divorced. In the case of our study, our target population is heterogeneous because it is made up of men and mainly women. It is made up of two statuses: married and single. This analysis shows, unsurprisingly, that single people account for 66.6%. This is due to the fact that this was the category that had used the centre the most at the time of the field visit. This analysis is reflected in the following comments:

"Ya papa pour nous aider on va faire comment ils sont nos enfants. We have to support them because they are going through a very difficult time in their lives" (Testimony of K. A., parent).

"A long time ago, my dad left me because of that illness, he says it's witchcraft, he says or I took the child away from him to go and take it over there" (Testimony of A. I., parent).

As far as marital status is concerned, we found that 25 of the respondents in our study population had at least a primary education and as many had a university degree. This situation favours knowledge of the disease and its implications. However, one member of our sample did not attend school. This is a handicap for proper monitoring and treatment of sick children both at home and at the centre.

By way of example, one doctor said: "the lack of education is a situation which causes us inconvenience in the care of patients, especially when it comes to returning to collect the results of screening through haemoglobin electrophoresis. Mothers either don't come back or take a long time before they do. So these women don't understand" (Testimonial from a patient P. A).

Religious beliefs also play a considerable role in the daily lives of patients and their ability to attend sickle cell centres. Out of 28 people surveyed, there were 15 Christians (55.5%) and 12 Muslims. As the difference is not great, it is understandable that each of these religions influences the choice of patients to attend its health centres.

Y. A, a Christian, is quick to point out: "I'm a Jehovah's Witness, I believe in God. Our religion doesn't allow us to have blood transfusions. If it wasn't for my husband talking about it, I wouldn't be here. I miss so many appointments" (Testimony of Y. A., Parent)

As for K. M., a Muslim, she said

"Inchallah Allah will cure my child. I don't like the way they look after my child at the hospital here when I get there" (Interview with K. M., parent).

III. PERCEPTIONS OF SICKLE-CELL ANAEMIA AMONG THE PLAYERS

3-1-From the announcement of the clinical signs of sickle cell anaemia to the bifurcation of identity

The study carried out by Agnès Lainé (2007) showed that: "The attitude of some parents in the consultation does not depend solely on the quality of the relationship established by the doctor - who systematically invites parents to ask all the questions and takes the time to answer them - but the lack of knowledge places patients in an attitude of inferiority such that some do not dare ask any questions. The diagnosis suddenly confronts parents who have lived in sub-Saharan Africa for a large part of their lives with a predictive health culture to which they are not accustomed".

As the following comment illustrates: "It wasn't easy for me when I was told I had the disease. It was a real shock for me" (Testimony of D. H, patient).

It is clear from this observation that the situation of screening at this stage of the announcement places the parents of patients in a tormented wait for the diagnosis, resulting in some cases in a state of shock that only calms down with the advice of the treating physician. The moment when the patient is told about the disease is crucial to strengthening their resilience.

Man always searches for the causality of the illness from which he suffers. Knowledge of the etiology of the disease allows in certain cases a more appropriate therapeutic approach, while uncertainty about the causes of an illness hampers all therapies, even if this does not prevent us from resorting to empirical techniques. which sometimes prove effective. On this subject, it would be appropriate to show the etiological aspect of sickle cell diseases according to those involved in the care of sickle cell patients. This statement illustrates: "… Aaah Sickle cell anemia is a hemoglobin disease, let's put it simply, it's a blood disease which consists of a bit of a sickling of the hemoglobin, I say that in a simple way. It is not a scientific term, is in simple terms, which is also, above all hereditary which is transmitted from parents to children and which manifests itself by bone pain and anemia depending on the types of sickle cell anemia, that is in a somewhat simple way…" (Testimony of the treatment Y.P)

It is with this in mind that this interviewee testifies in these terms: "…. Sickle cell anemia is a blood disease if you have to explain it in a vulgar way or if you have to talk about it scientifically, there are several definitions, there is the genetic definition, it is precisely a blood disease hemoglobin which has a replacement because hemoglobin is formed the animated acid so there are several acids therefore it will have a replacement on the genetic level a replacement of the animated acid which is glutamine which will be replaced by valine and this replacement which will cause a modification of the hemoglobin and after that it will cause a modification of the red blood cell, because hemoglobin is a constituent of red globin as soon as there is a modification inside it will cause a direct modification of the red globin, it is this modification therefore on the BA chain in position 6 at the level of combination 11 that is on the genetic level so the deformation of the red blood cell will lead to an obstruction of small vessels, as is is deformed it is like in the shape of a sickle and finally it will also be responsible for hemolysis because the poorly formed red blood cells cannot reach their lifespan and which is 120 days but before 120 days they will die and when they die before 120 days, it is responsible for anemia in sickle cell patients. So that's a simple way to silence sickle cell anemia…" (Testimony of the treater K.I)

3-3-Social representations of sickle cell anemia and construction of links between treaters and patients

Sickle cell disease and the social representations attached to it, as well as the relationships that unite the patient with their loved ones affected by the disease, are changing and complex. The treating person is confronted with the chronic illness of the patient suffering from sickle cell anemia, allows him to decipher what is at stake in the relationship that links the patient to each of his loved ones, while maintaining the patient in his central place in the medical relationship.

3-3-1-Social representations of the sickle cell patient: a perception seen from the perspective of the treating person

The actors' speech reflects the idea that respect for the dignity and privacy of the person is at the center of the ethical charter of the medical profession. Thus, all health personnel must give the greatest consideration and attention to all people regardless of their physical or mental condition, their culture, their social origin, their political opinions and their age. Indeed, the diagnosis of sickle cell anemia is seen as one of the treatments for the disease which allows patients to survive this pathology perceived as fatal.

In fact, the patient is attached to a medical treatment protocol. To do this, as evidenced by an attending physician:

“The patient must comply with the prescriptions of the treating person. Sickle cell disease is a hernia disease. The treatment is lifelong. The patient's healing is more psychological before being physical. Yes, the patient is willing to follow the treating person's instructions, for example. Better yet, he is doing well (Comment by A.P, attending physician).

In view of this, treating people are unanimous that sickle cell disease is a fatal disease. However, thanks to medical advances, the lifespan of patients can be extended. It is still necessary that these actors manage to comply with the injunctions of regular treatment following the treatment protocol prescribed by the treaters. Furthermore, even if patient care is intended to be close to the principle of ethics, it nonetheless remains true that it is devoid of a fundamental principle as expressed through the charter: that of respect for human dignity. This statement illustrates:

“Here the treating doctors are insufficient in number, but the few who are assigned to our center are not regular and our care leaves something to be desired; This disturbs us a lot” (Comment by T.M, attending physician).

3-2-Social representation of the sickle cell patient: a perception seen from the perspective of the patient himself

The survey shows that for individuals with sickle cell disease, debilitation, fatigue, disability and body changes are associated with treatments. It is for this reason that the treatments are perceived in a negative way: “When I was informed of the illness from which I was suffering, I was very dejected. At that moment, I thought I had lost everything.” (Testimony of J.V. with sickle cell disease).

It is in this vein that testifies:

“The news of my daughter’s illness affected me a lot. Sickle cell disease is linked to several constraints in life in society. The suffering person is almost marginalized.” ". (testimony of

Y.M. Parent of sickle cell patient).

In view of this, the announcement of the illness in the patient is perceived as serious, chronic or as a handicap and remains engraved as terrible news, which can mark the end of a life where experiencing the illness was absent or even unthinkable. Indeed, the announcement of the illness a priori affects the patient as well as their loved ones and causes a psychological trauma whose extent and characteristics depend on the personality of each individual, their history, the period of life they are in. crosses and above all family ties and balances.

Furthermore, at the end of treatment, patients have difficulty adapting to treatments, in particular because they are associated with significant side effects, which do not necessarily lead to cure but which impose temporal restrictions. due to their pace, as well as dietary restrictions. This statement illustrates:

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3-3-Perceptions of caregivers about loved ones and their patients

The speech of all the treating people who constitute one of the first circles of entourage of the relatives has a favorable opinion of the relatives of their patients. Indeed, for treatment providers, the role of those around them in the care of people with sickle cell disease is expected to develop and consider that those around them are more visible and interactive with them. The potentially beneficial role of those around them in caring for the sick person is clearly stated and can prove to be a real partner in care. As such, they recognize it as having a beneficial role in terms of health economics. As one patient says: “The contribution of those around us could help reduce health costs. ". That said, if the presence of the entourage is considered generally beneficial for the patient, it is far from without difficulties. Among those that treaters say they most often witness include: the exhaustion of those around them and their intrusive nature towards the patient.

This statement illustrates in these terms:

“Living with a loved one with sickle cell disease is not at all easy, especially the dietary restrictions with the difficulties of lack of money to be able to feed themselves. It happens that parents or loved ones are financially exhausted” (Testimony of A.M. parent of sickle cell patient).

IV. Relations between patients and parents

Parents are involved in the history of the illness. This upsets the family balance and the balance of power. Thus, the illness inflicts a deep wound on the patient, but it also represents a psychological trauma for those close to them, depending on the bond that unites them to the patient (spouse, children, brothers, cousins, etc.), their personalities, their story and the moment of life they are going through. This statement illustrates:

“I feel guilty seeing my child suffer from sickle cell anemia. It is a hereditary disease. Yes, I was in good health. My child would know this too. Unfortunately, he contracted an illness of which he was not the author” (Testimony of A.T. Parent of sickle cell patient).

4-1-Biographical rupture of the sickle cell patient: reinterpretation of social roles

Michael Bury's concept of biographical rupture (1982) develops: “the idea that a person affected by a chronic illness goes through a process of rupture allowing them to then rebuild themselves. First, there is a break in taken-for-granted behavior. Then, there is a breakdown in the system of self-explanation, which will require the person to undertake a review of their biography and the definition they have of themselves.”

Sickle cell disease is seen as an unexpected event that disrupts patients' perceptions, as well as all areas of their existence. M.G. sickle cell patient, tries to adapt and accept the escapades of this illness which has been eating away at him since his birth:

“I was born against my will with sickle cell anemia. At the beginning when I was diagnosed with the illness, I can tell you that I thought my life was ending when I was diagnosed with the disease. After I met a health specialist to benefit from his advice, I subsequently understood that I had to give another life trajectory to my daily life. That is to say, follow the prescriptions of the treating person. Today, my activities are planned also taking into account the fatigue that the illness inflicts on me at times. » (Testimony of sickle cell A.O.).

It emerges from this statement that the experience of illness is analyzed as a process which is composed. Indeed, the actors reinterpret their relationship to themselves differently between survival and death. They are no longer the same, nothing is the same as before. From now on, actors will have to adapt to their new way of life, adopting new habits at all levels of life.

4-2-Reconstruction of the links that unite parents and patients between psychological trauma and the feelings of loved ones around sickle cell anemia.

The sickle cell disease is accepted a priori among the patient's parents, as serious information conveying an omnipresent fear of death and capable of introducing discomfort within the family. Parents are faced with a double trauma: the trauma of the death of a loved one and that of the death of a child which goes against the usual order of things (the parents die before the child). The death of the child constitutes in itself a paradox which upsets our very conception of death, which must logically only occur at an advanced age (Brognon, 1998). As soon as the diagnosis is announced, parents are confronted with questions and concerns related to their desires and projections about the child: “Life is unfair these days the child is innocent. The illness he is currently suffering from is linked to blood behavior passed on to my child. He suffers from an illness for which he is not responsible. This situation shocks me morally and I feel guilty for my child’s illness” (comment by Y.K. patient’s parents) These words touch on the difficulty of continuing to invest in a being who will perhaps not respond to their desire for perpetuation and who risks abandoning them, thus confronting them with their powerlessness. However, family solidarity strengthens the family bond in order to give hope of life to the patient. This statement illustrates:

“We should not abandon a loved one who is suffering. The affection of the family towards a sick loved one could constitute a source of comfort and even healing for the patient who has lost all hope of recovering” (comment by T.N. parents of the patient)

It emerges from this statement that the family plays an important role in social recomposition with the sick. The period of returning home after the announcement of a chronic illness such as sickle cell anemia radically disrupts the daily life of the sick individual but, above all, family relationships with new distribution of roles. The family is then forced to make important decisions, sometimes in haste and most often without any prior preparation. Insidiously, the long-term evolution of the sickle cell patient will place increasing demands on the family to the point of resulting in a restrictive and often repetitive workload.

Added to this is the role of the loved one in assisting the patient suffering from sickle cell anemia as a prerequisite for the patient's social rebirth. The figures closest to the patient regarding the parents take into account alongside the classic cell (father mother brother sister etc.) those from separated or reconstituted families (sometimes with differences in perception), even can be unrelated people: a friend, a neighbor, a doctor or even a family helper who also became a confidante Indeed, the importance of loved ones is essentially measured for three main reasons: first, because loved ones have knowledge of the situation and lived experience which make them allies of the caregiver; then because they generally remain in contact with the patient. Relatives are expected to facilitate the patient's social reintegration. Because they themselves suffer from the situation of their patient and they may therefore be in need of care:

“We cannot reject our blood because of illness. This is why we live with him. So, we take care of him because of his diet. We have hope by the grace of God that he will recover. But we don't know when? ". (Comments by Y.N. patient parents)

In view of the above, emotional support predominates relationships, gives hope and helps consolidate ties around the patient suffering from sickle cell anemia. The results of the study show that there are differences in the care needs of patients, and therefore also in the degree of involvement of families. It is always a 'tailor-made' collaboration and the intensity can vary depending on the family. Indeed, the family context seems complex and relationships with the patient are sometimes tense and degraded. Sickle cell disease affects individuals' ability to carry out daily activities and has the potential to significantly influence the demand for health services. Indeed, illness increases dependence on others and reduces quality of life, particularly through access to opportunities for social and economic participation and a feeling of exclusion.

In such cases, the sickle cell patient is associated with an increased risk of depression and institutionalization and the patient may succumb to premature mortality.

In terms of diet, an appropriate diet is recommended for sickle cell patients, which they should follow to avoid the occurrence of complications. Thus, with the help of medical support and therapeutic education, each patient can adopt the diet that suits their state of health. However, difficulties are encountered in situations where family financial conditions cannot always meet their needs.

For both men and women with sickle cell disease, the mode of transmission of the disease leads to a loss of sexual desire. Information from the present study shows that men have more difficulty expressing their sexual desires while women suffer from vaginal dryness and have more difficulty experiencing pleasure during sexual intercourse. This statement testifies:

“These sexual disorders are generally the consequence of a combination of several factors. Namely, fatigue due to anemia and sex hormone deficiency are treatable causes, both in men and women. In men, from a medical point of view, erectile dysfunction can be the consequence of damage to the nervous system or an alteration of blood circulation in the penis. All these factors noted have a devastating sociological effect that can constitute an additional source of tension in an already tense intimate relationship, potentially weakening socio-family ties” (Testimony of A.D. health specialist).

It is with this in mind that:

“I have lost all sexual pleasure with this illness from which I suffer. Even when I have sexual intercourse, the risk of fathering a biologically ill child makes me lose all sexual desire” (Testimony of K.D. sick)

According to Agnès Lainé (op cit): “The prevention and care protocol for screened children includes daily constraints (medication, lifestyle) and occasional constraints, scheduled or not (regular consultations; recourse to emergencies) which require an adaptation of families, or even a reorganization of lifestyles. These constraints may conflict with other constraints. The hierarchy of priorities that the caring parent establishes between the constraints, eminently individual, leads to partial, complete, or even excessive compliance in certain cases of very anxious parents. This, of course, is not unique to sickle cell disease. In other rare cases, the parent's anxiety and the constraints of the illness generate a rejection of the healthcare system which is perceptible on certain occasions: consultations (the child is ill when he or she has to come to the hospital), medication (such mother reduced the doses of oracillin because according to her, it promotes attacks) or in the relationship with the doctor. Exasperated parents may insist heavily on obtaining a bone marrow transplant and blame the doctor for not complying with their wishes.” This statement illustrates:

“At the beginning, it wasn’t easy for me to work. I was able to overcome this difficulty of the disease by following the prescriptions of the doctor. Today I feel able to freely go about my activities. I plan my daily life. That is to say, I include in my program of my activities the occurrence of the effects of the illness. The sickle cell patient is tired all the time. So I include this behavior of fatigue which could slow down my activities in my schedule” (Testimony of sick K.J.)

It is in this same vein of idea that testifies:

“When you have sickle cell disease, you accept the effects of the disease. Because the disease is lifelong. However, we include in our daily lives the effects of the disease, namely repeated fatigue, a source of weakening of our social or daily activities. We go about our daily activities better” (Testimony of a sick D.O.)

It emerges from these findings that sickle cell patients build their resilience around the effects or manifestation of the disease.

V. PROCESS FOR MANAGING PATIENTS ADMITTED TO THE HEMATOLOGY DEPARTMENT OF COCODY UNIVERSITY HOSPITAL.

5-1-Reception and emergency treatment

In the emergency room, the mission of the staff who greet patients is therefore to sort according to pre-established clinical criteria and to prioritize. But apart from formalized elements, practices relating to reception and care are focused on children with sickle cell disease arriving in crisis at the consultation.

Comments in this same vein serve as an illustration:

“There are two levels of patient reception at the back-to-school level and at the doctor level. If I have to say what it is about the doctors because I'm not at the door there. We have our level, at the level of doctors the welcome goes pretty well, in fact these are patients that we already knew each other, most of the time we know what they are like, and then we are obliged to welcome them warmly, there is also the social side which weighs a little on the illness so we welcome them as it should” (Testimony of K.S., a treatment worker).

In this same sense we also note:

“The reception of patients, that is to say that the patient, most often when there is the presentation of symptoms, sometimes he finds himself in the emergency room and it is from there that we refer them to the emergency service. hematology. After having managed the emergency, we direct them if there is a blood problem they come here, they go through the reception and after the reception they now find the doctor available and we now welcome them given the tests that they have already had to do we will try to request tests to confirm sickle cell anemia in the meantime we put them on a certain number of treatments against anemia upon hearing the results, and when they come and it is confirmed we start taking it in charge…” (Testimony of a treatment K.J)

As soon as patients are admitted to the hematology department during their crises, quality follow-up must follow and this follow-up must be done in a way that follows the different stages given the dangerousness of sickle cell anemia, which is reflected in these about :

“Now in children there are joint pains due to the complications of sickle cell anemia that we could make the diagnosis so the pain there is the pain which concerns the joints sometimes it is abdominal pain and sometimes it is is anemia, sometimes because when it causes infections and other factors that can influence and cause sickle cell crises which manifest through pain, generally through bone pain, there are people who relate this to rheumatoid arthritis or This is sickle cell anemia. Urine can turn dark and so can eyes can also be yellow if really, however long and chronic and can lead to jaundice, yellow coloring of the eyes and we can also have the increase of the spleen and the increase of the liver all this is linked to hemolysis. Hemolysis is the destruction of these red blood cells and like, the spleen is like the red blood cell cemetery so it's ultimately, when it is hyper active because that's where it takes place. the destruction. Now this activity of this spleen which will ensure that there has been an increase in the spleen and also an increase in the liver, so these are the signs which can point towards sickle cell anemia, this is the manifestation as such. . So it is the destruction of these red blood cells which will sit in the spleen which will cause that... No you did not understand me when the person comes, He most often complains of pain, bone pain that he It's important to remember that when it's a sickle cell crisis, they come with bone pain, the pain can't just be bone pain, but it can also be abdominal pain. (Testimony H. K, a treatment)

5-2- Problems linked to the technical platform

Very often doctors are subject to problems linked to technical platforms which is sometimes painful and difficult in the care of patients. Doctors do what they can with what is present and available to them in order to manage sickle cell crises. These are the ideas that emerge from this statement:

“Aaah we are going to say that the technical platform is more or less acceptable but there is already that even something we cannot say that there is nothing, but it is even insufficient . Because as my colleague unfortunately said here in Ivory Coast there is no national care center for sickle cell anemia, a bit like in certain countries it is already a bit of a failure and in current practice, if we see here we have not, since the closure of the Yopougon University Hospital which was the only service for the management of sickle cell anemia, it has become very complicated for the regular monitoring of patients and for the management of patients in crisis it is that is often the most important thing, it has become very complicated. If we realize here we only have two consultation boxes, two beds or three for the care of patients coming in crises, and during a consultation day we can have ten crises so you agree with me that it is very complicated to take care of them” (Testimony of treating D.I).

To bid higher:

“… So that is to say that, we must recognize currently here, we do not have a service, so the service was in Yopougon, the State of Yopougon they are in the process of arranging, it is not not finished yet, so if we have to talk about our context now, the technical platform is not also like that if it was in our department there is space there are a lot of things, so it is a little that. Now on the other side it may be that there are times in the care there are parents who do not have enough means to come, really to take care of the children, that too causes difficulties » (Testimony of T.K treating)

VI. Discussions

Based on the functionalist theory (P. N'da, 2000), the irregular attendance of children with sickle cell disease in the sickle cell service is considered as a reality constructed and institutionalized through the perceptions of parents regarding of the disease. From this angle, the ideologies are based on the patient and parent relationship, the burification of identity, experience of illness, the construction of patient treatment relationships and the resilience factor. Furthermore, the subjective beliefs and knowledge of the actors regarding the treatment of sickle cell anemia constitute elements of recomposition of the reproduction of the actors. In

this context, the results of this study are consistent with the analysis of D.L.A. Desgrées (1998). Indeed, the author analyzes how the AIDS epidemic calls into question sexual and reproductive practices within the couple, where the risks of mother-child transmission are minimized or trivialized by the couple. Furthermore, the author questions the changes observed in the couple and which are mainly linked to the sharing of information on HIV testing within the couple. On this aspect, the results of the present study do not agree with the author's approach. Then, the process of caring for children with sickle cell disease, during this study, involves reception, emergency treatment and problems related to the plateau. It must be mentioned, in this regard, that the results of this study are the opposite of the results of the study by J.F. Delfraissy (2004). The author shows that psychological support is essential, as well as support for this journey from the doctor following HIV infection. Finally, the process of caring for the sexuality of people living with HIV/AIDS highlights the relationship of dependence between people living with HIV/AIDS and treating doctors. Indeed, treating doctors have objective knowledge and experience on the mode of transmission of HIV/AIDS but especially on the sexual management of reproduction of people living with HIV/AIDS. The theoretical results of Agobe Ablakpa Jacob, Adjoumani Kobenan & Koffi Koffi Gnamien Jean-Claude in DEZAN, NUMERO 017, December 2019 by C. Criton & P. Fener (2007) illustrate this case. Indeed, the authors place at the center the procreation of people living with HIV/AIDS, their care and the need to carry out regular assessments of their sexual health.

Indeed, discussions around the prevention of those are linked to sexuality and the risk of viral transmission within the couple. These techniques are defined by the laws of bioethics (1994 revised 2004). Clearly, let us note that the empirical results as a whole agree with the theoretical results with regard to the response to the problem of irregular attendance of sickle cell patients in the sickle cell service.

VII. Conclusion

At the end of our analysis we reached the following results: The irregularity of attendance of children with sickle cell disease in the sickle cell service is as stipulated by our hypothesis; linked to parents' perceptions of the disease. Indeed, as our hypothesis tends to show, the parents' ideologies on this disease reflect the irregular attitude of the children. The patient-parent relationship, the bifurcation of identity, religious beliefs, are obvious products of the construction of this disease by the parents. Therefore, we propose to provide recommendations in order to regularize attendance at the sickle cell service.

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