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Sickle Cell Anemia, Representations and Care: Experience of a Brother of a Sick Child in Cameroon

Hassan Njifon Nsangou and Régine Scelles

Abstract

In Africa, families often with more than one child consult with both modern and traditional African medicine to treat their child with sickle cell anemia. This research aimed to understand how a child experiences both the medical and traditional care of his sister. We collected data from an interview and family drawing of a young boy growing up with an affected sister in Cameroon. Results showed this child persisted to feel as though his sister had fallen victim to a sorcerer and that he was at risk of the same fate even after the two of them received traditional treatment. He also felt neglected about his suffering because of his sister's disease by hospital professionals that were caring for her. It is therefore necessary to establish a support system for affected children and their family by providing a safe space in hospitals where they can express and contain their experiences with the disease.

Keywords: sickle cell anemia, care, tradition, modernity, siblings, Cameroon

1. Introduction

Sickle cell anemia is a genetic disease that confronts families with iterative, intense and unpredictable crises associated with the physical manifestation on the sick child [1] to his death thought to be imminent and inevitable. It is a taboo in most sub-Saharan African families [2] where it is difficult to meet unique children. Few psychological studies have focused on what happens to children who grow up with a sibling with sickle cell disease which is characterized by severe pain, frequent hospitalization and early death not to mention the high cost of treatment (traditional and medical) for families. However, it is unclear how families live the traditional and medical care of the disease.

This article includes an interview and drawing analysis done with a brother of a sick child in the context of research whose framework and method will be briefly presented. It highlights the way in which a child perceives the healthcare of his sister, both by Western medicine professionals and traditional healers—two types of care specialists with virtually different processes and goals. It is therefore a question of understanding the psychological impact of the concurrent consultation of medical and traditional care of a sick child on his brother. The article illuminates and questions the simultaneous existence of two sickle cell care systems within a

Cameroonian family and tries to understand its effects on a brother of a sick child. It shows the complexity of the experiences of children growing up with a sick sibling and its close interweaving with the family experiences as they care for the child. The objective is to build on this knowledge to open up the design of care devices that better take into account the specificity of the experiences of siblings of children with sickle cell anemia.

2. Theoretical consideration

2.1 The sickle cell anemia, a serious and deadly genetic disease

Sickle cell anemia is the most prevalent genetic disease in the world, with approximately 500 million individuals with sickle cell traits and 50 million individuals with the disorder itself worldwide [3]. Originally spread across malaria-endemic areas such as sub-Saharan African countries, historical migrations linked to the slave trade and the recent acceleration of migration flows have gradually changed its distribution worldwide [4]. It is found in almost all countries with large populations from Africa and regions around the Mediterranean. In France, for example, it is a rare disease, but nonetheless the most common genetic disease with a prevalence of one child per 1900 births [5].

With a prevalence rate of at least 2% in the general population and an estimated mortality rate of more than 70% among children under the age of 5 [6], the African continent is most affected by sickle cell anemia. Cameroon is one of the most affected countries, with a prevalence of 8.34% in the general population [7]. In sub-Saharan Africa, the unavailability of bone marrow transplantation—the only effective treatment for seizures—increases the risk of death in children under 5 years old [8].

The disease is an autosomal recessive pathology transmitted to the child by both parents. The presence of abnormal hemoglobin in the blood causes a deficiency in the supply of oxygen to various organs in the body by the red blood cells that have reduced life cycles. This leads to anemia and chronic, unpredictable pain [4, 9] that the patient identifies [1], resulting in multiple expensive hospitalizations and care organized by their parents [10] both in the hospital and among traditional healers.

2.2 The sickle cell anemia, a persecution figure of the family group

In the sub-Saharan African cultural context, sickle cell anemia is thought of as an “evil” that can attack any member of the family, even after the death of the patient [11]. The sick child is immersed in a society structured by traditional taboos, rituals and attitudes of which women are custodians [12]. The illness or handicap of the child is inscribed in this cultural structure, which gives it meaning and produces effects.

Sickle cell anemia is thought to be a manifestation of the possession of the sick child and his family by an evil spirit or bewitchment by a wizard [13]. It can also be perceived as a request of the ancestors to repair a transgression of an ancestral norm, addressed to the patient’s family [14]. Generally, the mother is designated as responsible for this transgression and the overprotection of the sick child, by her and by the family members, constitutes a defense allowing them to feel guilt-free and to put the child in the family’s history [14] alongside his brothers and sisters.

2.3 The specificities of the medical care of sickle cell anemia in Cameroon

The hospital is a place regularly frequented by sick children and their families. Described as the disease of hospitals in several African countries [15], sickle cell

anemia makes hospital services a second home for the patient and their families around them. The frequency of hospitalizations in Cameroon is estimated to be between three and four hospitalizations per month in children under five, between five and seven hospitalizations per month in adolescents and two hospitalizations per month in adults [16]. The reasons for these hospitalizations are sometimes varied in one subject and identical in others. In general, sick children are regularly hospitalized for pain attacks, severe anemia and/or chronic complications (stroke and heart attacks). Stroke is also a cause of hospitalization for sickle cell patients. For the latter, the probabilities of having a stroke before the ages of 20, 30 and 45 are, respectively, 11, 15 and 24% [17]. In Cameroon, the prevalence of stroke is 6–7% in patients aged 7 months–35 years [18].

The medical management of patients has undergone an important evolution within the past 20 years due to the intensification of available treatments for children at risk of severe complications [19]. These treatments consist mainly of yoglycurea, transfusion programs and family transplants. Indeed, yoglycan significantly reduces the frequency of onset of occlusive seizures, acute thoracic syndrome and the degree of hemolysis. The establishment of transfusion programs for children detected as at risk of stroke by transcranial Doppler has significantly reduced this risk from 11 to 2% [19].

Allogeneic transplantation is currently the only treatment that can cure approximately 95% of children with sickle cell anemia [8, 20]. This treatment involves grafting from a brother or sister of the patient, based on their genetic compatibility with hematopoietic stem cells located in the bone marrow of the patient.

Sickle cell anemia is essentially a disease of the south whose treatment is in the north. This caricature seems more appropriate to address the lethal nature of this pathology in sub-Saharan African countries, including Cameroon, where it remains a chronic and orphan disease [21] because of the absence of hematopoietic stem cell allograft and the gene editing systems, the only treatments available against this disease [8, 9, 22]. Therefore, the therapeutic approach of the disease remains curative and focuses on the nature of the crises. The patient is supported in relation to the type of crisis he manifests. The primary purpose of medicine, in this case, is to alleviate the suffering of the patient by managing the symptoms. Crisis treatment incorporates several therapeutic products and postures. Severe attacks (mild pain, modeled fever) are often treated at home in collaboration with a doctor or by self-medication. The patient is advised to rest, drink abundantly and is given an analgesic treatment including acetylsalicylic acid, paracetamol or Di-Antalvic. In case of severe attacks involving localized or generalized pain, rest and rehydration are recommended. If these measures do not calm the crisis, a transfusion is performed.

The management of anemia, meanwhile, requires a transfusion of phenotyped erythrocyte concentrates, leukocyte depleted and filtered. The intervention in cases of severe pain attacks is based on the transfusion and/or hydroxyurea of the patient. Hydroxycarbamide is the only current attenuator therapy used in the management of vaso-occlusive seizures and severe anemias. The price of these products, combined with that of many hospitalizations, is relatively high for most Cameroonian families who generally do not have social security [16].

2.4 Balancing between traditional care and medical care

Parents of sick children, supported by the members of their extended families, are frequently searching for ways to relieve their suffering. With the advent of globalization, they resort to several therapies. The therapeutic route is, in this sense, a sort of mosaic between traditional therapies and imported Western and messianic therapies. In this way, the traditional therapist, the doctor and the Imam, pastor or

priest are consulted at the same time. This system of “round care” [23] is one that perfectly summarizes the therapeutic path of most African families in sub-Saharan Africa. At each source, they seek the healing of a specific aspect of the child’s suffering. The quests for meaning of the child’s illness, ancestral protection and reconciliation with the ancestors lead parents to traditional healers. With the priest, the pastor or the Imam, families seek the divine therapy to ensure protection from God. They usually do this because they yearn for the healing of the child under the mercy of God. With the medical doctor, they seek the somatic healing of the child. These families are part of a permanent search for identity reconstruction [24, 25]. The identities of Africans remain very complex as they continually attempt to find their identities, following the effects of globalization [14, 26].

The traditional treatment of sickle cell anemia is based on cultural representations of this disease that people have. It does not aim to repair physiological disorders. It focuses on restoring social order by reconciling the patient and their groups with their social and supernatural environments [14]. This therapy considers the sick child as a messenger, a person who talks about the transgressions of ancestral norms by a member of his family or the persecution of his family by a wizard. This is the reason why parents, uncles, aunts, brothers, sisters and cousins of the patient are all also patients of the traditional therapists.

2.5 Cameroonian families oscillating between modernity and tradition

African families have retained certain intrinsic cultural values such as polygamy and the maintenance of family life through the births of several children. They have also opened up to modernity by gradually applying family planning practices.

In Cameroonian families, the cultural tradition is neither past nor “outdated” [14]. The behaviors of the subjects are always marked by identifiable traditional elements. These families have neither resisted nor surrendered to modernity. These are simultaneously modern and traditional families, not necessarily modern or traditional. In Cameroon, there are several types of families; nuclear families, extended families, polygamous families, monogamous families, etc. [27]. These categories reflect the diversity and complexity of family dynamics in Cameroon, and potentially the lives of children confronted by a sick sibling.

2.6 The experiences of the brothers and sisters of sick children

A child’s illness has repercussions on their siblings who experience ambivalent feelings towards them. These relate specifically to shame, guilt, love, hatred, complicity, rivalry, anguish and the desire for the death of the sick child [28]. In order not to aggravate the suffering of their parents and that of the patient, brothers and sisters often attempt to prevent them from suffering [29].

Studies on sickle cell anemia patients indicate the psychological suffering of sick children and their parents [9, 14, 30]. The experiences of their siblings are often studied from the parents’ stories. Overprotection of the child causes parents to progressively neglect caring for their other children [31]. The latter experience emotional breakdowns resulting in feelings of rejection, marginalization and exclusion on the part of parents and the extended family [32, 33]. They express jealousy towards the patient that they designate as the main person responsible for crises that destabilize the family financially and emotionally [34]. They feel guilty for having negative thoughts such as jealousy towards the patient; they consider themselves “bad siblings” [35]. They experience, at the same time, the desire for the death of the patient and the fear of this death [36]. Their experiences are usually influenced by parental intrusions in their relationships with the sick child because they are

often parented by parents [36]. In the absence of the parents, they are the ones who supervise the sick child. Supervision ranges from daily monitoring of treatment and observation of medical instructions by the patient [2] to the bodily care of the patient and their assistance during hospitalization [37]. This has great implications on the sisters of sick children, particularly on girls' education. In many sub-Saharan African societies, the main objective is to bring up girls to be good mothers, thus making them the person most likely to take care of children [21].

3. Material and method

3.1 Specificities of the method

The methodology of this research is similar to that presented in a previous research [36]. In sub-Saharan African cultures, children who talk to professionals about themselves or anything else are supposed to have been given permission by their families to do so [38]. It is usually parents who talk to professionals about their children, who on their part are obliged to listen and to talk only when adults allow it [39]. Talking with children about sickle cell anemia is not easy and it requires the researcher to make an alliance with the family. This research, which took place in Cameroon worked to get parents to allow their children to talk with the researcher about the way they experience the care of their sick brother or sister. In fact, many children are not allowed to speak to strangers and to speak only to adults who are intimate with the family [40].

The parents signed consent forms concerning the participation of the family and children in the research and designated which of their children would participate. These children were allowed by their parents to speak with the researcher about their family, their sick brother or sister and his/her illness. Indeed they had a mission to talk to the researcher who informed them about their freedom to participate in this research. The method includes an individual interview with each child and a drawing, preceded and followed by a group time. Before the interview, the mother, in front of the whole family, talks about the relations between her sick child and his siblings; the children listen and keep quiet. After the interview and the drawing, the adults question the researcher and the participating child about the content of their meeting. It is therefore an individual meeting, but it takes place in a group setting allowing children to speak as freely as possible.

We report in this article the case of Jules. With Jules, we talked about the illness, his relationship with the sick child and the family. In Jules' interview, there is an important place for treatment and its effects on the sick child, on his siblings, on his mother and father and on extended family members. This interview was done in the absence of the other members of the family whom we asked to leave the family room to allow for confidentiality. The interview was followed by the drawing session after which the analysis of the drawing was done. The family drawing test followed the approach of [41], taking into account the cultural referent as advocated by [42]. We asked Jules to draw his family on a sheet. The drawing, complementary to the interview allows the child to project on the sheet what he thinks and experiences about his family, his sick brother and his place in the family.

3.2 Jules and his family

In accordance with the ethical requirements, we gave fictitious first names to the persons to guarantee the anonymity and the confidentiality of the meeting.

Aged eleven and a student in fifth grade, Jules is the third child out of five siblings and the older brother of Paulette, his sister with sickle cell anemia. After the death of his father, a nurse who had previously worked in his home village, Jules, accompanied by his sick sister and his mother emigrated from the village to settle in Yaoundé at his elder sister's home. This sister was a public school teacher. One of the reasons for this rural exordium is the medical follow-up of Paulette, eight, with sickle cell anemia. She is the second-to-last of the five siblings, three boys and two girls. The youngest of two siblings and three boys would probably have died, according to Jules's older sister, following sickle cell anemia crises. In Cameroon, sickle cell anemia is not well enough known by all public health professionals and some people still do not recognize nor know its symptoms.

Paulette's illness was diagnosed at the age of seven, when she was first hospitalized following an anemic crisis in a hospital in Yaoundé. The unavailability of prenatal diagnosis and the non-systematization of neonatal diagnosis of sickle cell anemia in Cameroon leads to children being diagnosed relatively late during one of their hospitalizations.

Paulette is usually hospitalized between one and two times a month following anemia attacks, the main symptom of her illness. Her mother, estimates the average duration of each of her hospitalizations to be between 2 and 3 days. During these hospitalizations, her older sister and her mother often assist her.

Jules lives with the eldest daughter in the family, his mother, his sick sister and his one-year-old niece. The eldest daughter of the siblings is separated from the father of her daughter and she is the only child who is a parent herself. Paulette is the only sick child and the mother of the family is unemployed. The eldest daughter and the second child of the siblings contribute to the financing of Paulette's care. Siblings are therefore a family resource in the financing of care. These first two siblings are employed and the last two are students.

4. Results

Paulette's fits give rise to many hospitalizations.

4.1 The financing of medical care

Jules does not know the cost of Paulette's medical care. He knows, however, that it is his older sister and his paternal uncle who finance this care. He exclaims *"Ah! I do not know the price. Mom and my older sister do not tell me the price. My older sister pays the hospital. There is also my uncle and my brother who also gives the money for the hospital."*

He behaves as though he was forbidden and/or forbade himself from knowing or asking adults questions about the cost of his sister's medical care. However, he is grateful for the uncle's financial support to his mother and older sister. He does not mention the involvement of his brother who is a taxi driver in financing the care.

Her older sister and mother usually accompany Paulette to the hospital. This elder sister plays both the role of father and sister to Jules and Paulette. She finances the care and assists her mother at Paulette's bedside during hospitalizations. In the end, she plays the role of substitute for the deceased father and the mother for the sick sister. Her status as the eldest daughter of her siblings demands that she cares for her younger siblings, in keeping with the cultural norm that [40] makes the eldest son especially, and the eldest sister also, a parental figure for her brothers and sisters in African families. Jules specifies, *"My sister brings Paulette to the doctors of the foundation when the blood reduces."* Therefore, he refers to this sister as a mother for both Paulette and himself.

Jules refers to the fact that the medical professionals at the hospital do not care about his family and his siblings. Their interest is in Paulette and the relief of her crises. Medical treatment is only given to the patient. Jules feels abandoned, forgotten and neglected by these professionals. He says, *“they do the remedies only to Paulette”* which signifies the sentiment of disregard of his own suffering at the hands of the professionals in the hospital.

4.2 The attendance at the hospital during crises

Jules refers to the fact that Paulette is usually brought to the hospital during her seizures. *“When her hands turn white or the eyes start to turn red, it’s because the blood is already reducing. When the blood reduces, she becomes very tired and heats a lot. We bring her to the hospital.”*

The hospital is invested as having a curative function, given in urgency. All of this suggests that the family seeks hospital care only after failures of self-medication and preventive measures that it would have implemented to avoid or to relieve the crises. Obviously, this behavior of the family is an adaptation to the expensive nature of healthcare in a context where it is not reimbursed and where health insurance is non-existent [16]. This poses the problem of crisis prevention via the check-up of children with sickle cell anemia in sub-Saharan Africa, in general, and in Cameroon, in particular.

4.3 Recognition of non-effectiveness of crisis treatment in hospitals

Paulette’s seizures are treated in the hospital via transfusions, which relieves seizures for a time without eliminating them. Jules evokes the infernal cycle of crises, hospitalizations and returns home. He says, *“in the hospital, she is given a lot of blood. When she takes the blood from the hospital, she comes home. It’s always like that for Paulette.”* He recognizes the effectiveness of transfusion in relieving crises, but temporarily. What arouses him is an anguish of death concerning his sick sister *“When I see it like that, my body trembles.”*

Paulette’s illness is thought of as *“a disease of the blood.”* Jules knows, therefore, that the *“affected”* blood must be removed from Paulette’s body. *“In order for it to end, you have to empty all the blood from your body. Like that it will come out with the disease.”* In his view, this is not what hospital care professionals do because they put new blood in the sick child’s body and do nothing about the *“bad”* blood.

Hospital care professionals are referred to as *“responsible”* for the chronicity of crises. Jules disqualifies them and thinks that they cannot permanently relieve these crises. *“The people in the hospital just put the blood into the bad blood. That is why the disease always comes back. When they put the good blood in their body, the bad blood eats up all the good blood, and the disease begins again.”* This recognition of the inefficiency of hospital care arouses his anger against these professionals whom he designates as ineffective against the worsening of his sister’s state of health. It is possible that Jules, by this anger, projects on these professionals, his feeling of helplessness concerning the crises his sister goes through and the feeling of concomitant guilt. Medical professionals can also understand it as a cry for recognition and take into account his experience.

The hospital is designated as responsible for the death of the last daughter of the mother, who died from a sickle cell anemia crisis during her hospitalization. *“They put false blood in her body and she died. It was not necessary to put this blood in her body. When they put that blood, she died two days later. We were only called to be told that the child is dead, that we should take her body to the morgue.”* As a result, Jules shows distrust of the hospital, hospital professionals and the handling of crises by these professionals whom he designates as responsible for the death of his sister.

4.4 The traditional healer treats the patient and his family

The traditional healer cares for the sick child, her siblings, her parents and her extended family because the illness is considered an ailment of the patient and his family.

4.4.1 *The care of the sick child*

The traditional healer cares for the sick child's body. The body is thought to be possessed by an "evil spirit," an illness that manifests itself in the patient by chronic anemia and the seizures of pains in the back and feet. These symptoms inform the traditional healer about the extent of possession and persecution of the sick child's body by wizards. In response to this possession/persecution, the traditional healer provides bodily care to the patient.

Jules says that he was wounded on the body. The painful parts of the sick child's body are scarified to allow the therapist to act directly on the evil and to limit the destruction of the body by the wizards. He does this by administering a powder with magical powers, effective against sorcerers. Therefore, the care of the patient has a curative aim of "*freeing*" the patient from this possession and persecution by wizards. Thus, not only is the blood treated here, but also the body too.

4.4.2 *Care of the brothers, sisters and the mother*

Jules' mother and his paternal uncle accompanied Paulette to the traditional healer. The brothers and sisters, who were absent from the consultation, received through the uncle the treatment given by the traditional therapist. Jules refers to the fact that his paternal uncle administered on him and his other siblings scarifications and he applied the powder from the traditional healer. Because the father is deceased, the paternal uncle went accompanied his mother and the sick sister to the traditional practitioner. This shows the involvement of the extended family in traditional care and support for the mother in this process apart from acting as an intermediary between the traditional healer and the family. He is also responsible for monitoring the application of the traditional medication.

At the request of the traditional healer, his paternal uncle scarified Jules just as he did to his sister. The treatment was administered orally and via scarification of the back. "*Even my mother and my older sister ate the same medicine. After eating it, the remaining was put in the blood.*" Thus, Paulette's siblings and her mother who were considered at risk of becoming, and of being persecuted by witches were also subjected to the traditional treatment against sickle cell anemia. The goal of this treatment is to protect them against the ailment.

The traditional practitioner, through these treatments, sought to domesticate the harm represented by the disease. He did not seek to exclude this evil from the family, but to transform it into an entity likely to cohabit in harmony with family members. The "bad" blood of the sick child is thus transformed into "good" blood, into a blood that is no longer a threat to him or to the family members. This therapy does not aim at excluding the "evil" from the family, but to make the ailment an entity of the family and to bring the family members to accept it as such [43].

4.5 The experience of traditional treatment

With Jules, there is a before and an after of traditional treatment. An "unsecured" pre-treatment period where the threat of contamination by the disease

looms, and a more “secure” post-treatment period when the threat is contained by receiving traditional treatment.

4.5.1 Treatment reduces feelings of insecurity

Jules thinks of the traditional treatment as a protection against its contamination by the disease. Taking this treatment is associated with a reduction of fear regarding the disease and possible contamination. He says, *“I’m not too scared. Before I was very scared. Now, with the remedy in my body, I’m not as afraid as I was before.”* It is interesting to note that although the fear of his sister’s death has diminished, it still lingers in his mind. He experiences his body as less vulnerable and more protected against the disease. This indicates that at this point, Jules feels safer with the disease and with the wizards.

The receiving of traditional treatment against sickle cell anemia thus helps Jules contain the fear and anguish that arises in him because of his sister’s illness. It helps him to contain his feelings of persecution by the wizards and the fear of infection with the disease even if it does not totally eliminate this fear.

4.5.2 Treatment makes blood bad for wizards

For Jules, the blood of the patient is a dead blood, a blood possessed by the wizards. In this sense, “a bad blood” attacks the “good blood” transfused into the patient during hospitalizations. According to him, this gives meaning to the chronic anemia and the iterative crises of pain that his sick sister experiences.

The traditional treatment is thought by Jules to be effective against wizards. It makes the blood of the sick and the non-sick unassailable by wizards. His treatment reduces the feeling of persecution by wizards, even in the event that his sister dies. *“They will not look for me anymore,”* he says. The traditional treatment is thus invested as a protection against the attacks of wizards, against the disease and, of course, against Paulette’s and his own death.

Jules does not associate the death of a patient with the end of the disease as in the case of his mother’s youngest daughter, which preceded that of their father. According to him, the disease survives and invests another child or family member. This leads Jules to think of himself as the next potential victim of the disease in the event of Paulette’s death. *“If Paulette dies after her little sister, that means we’re going to get another person to kill. If she dies, another person will die. That’s what scares me.”* Jules has a fear of death concerning his sister. He suffers more from this fear of death that he feels threatened by the disease, this “death”. He thinks of his sister’s imminent death and, therefore, his infection with the disease and his own death.

The administration of the traditional treatment leads Jules to say this about the wizards, *“it’s over for them, everyone ate the cure, everyone is armored,”* and specifically, *“when wizards enter the family they do not leave.”* In connection with receiving traditional treatment, he says one thing and then contradicts it. He expresses ambivalent feelings of protection against and vulnerability to wizards. This suggests that the sense of security against witchcraft remains feeble, as the feelings of insecurity were never really eliminated.

4.6 The contribution of the drawing

The drawing was made, after the interview, on the dining table in the living room, lit by sunlight.

4.6.1 The complexity of the instructions

Following the instruction “*I would like you to draw your family*” Jules says he does not know how to draw human beings. Regarding his family, he thinks he is too tall to be represented on a sheet of paper and he asked for a second drawing sheet. He was told that for this drawing, it is recommended that he use a single sheet.

Jules persisted in his request by asking whether he could draw the other people on the back of the paper. To this question, the answer was negative. Following these requests for clarification of the instructions, he resigned himself to drawing according to the rules. This behavior is informative about the limits of family design in this context where the family is not limited to the father, the mother and the children. It is an extended family leading to the need to (re)think the handover, analysis and interpretation of this drawing in a sub-Saharan African context following [42].

4.6.2 The drawing of the extended family

The eldest daughter in the family (“*grande soeur*,” on the drawing) is the first character drawn by Jules, followed by his father (“*papa*” on the drawing) the second character. This can signify in Jules that this sister is the most important person in the family because she provides a home near the hospital and money for medical bills. She took the role of the father. That can be why the father is then drawn second. Mother (“*maman*” on drawing), older brother (“*grand frère Willie*” on drawing), cousin (“*grand frère Hugo*” on drawing), maternal uncle and aunt, mother’s aunt, paternal aunt, other maternal uncle, cousin mother (“*grande soeur Manuella*” on drawing), her maternal cousin (“*petit frère*” on the drawing) and her maternal grandmother were, respectively, drawn by Jules. All the characters in the drawing are real. There are no fictional characters. The drawing is invested as a projective support on which Jules illustrates what he lives and thinks about his family in connection with the illness of his sister.

That Jules’s drawing includes his extended family reflects his sense of belonging to it and the support it brings to his immediate family in the face of his sister’s illness and the successive deaths of his father and youngest sister. It is thus a drawing on which is projected the family solidarity surrounding his sister’s illness (**Figure 1**).

The characters are not very invested by Jules, who drew them in a very minimalist way. It is possible that he wanted to draw all the members of the extended family, which would have led him to drawing his characters in a minimalist way on the sheet. It may also reflect an inhibition of affects in Jules concerning his family ties.

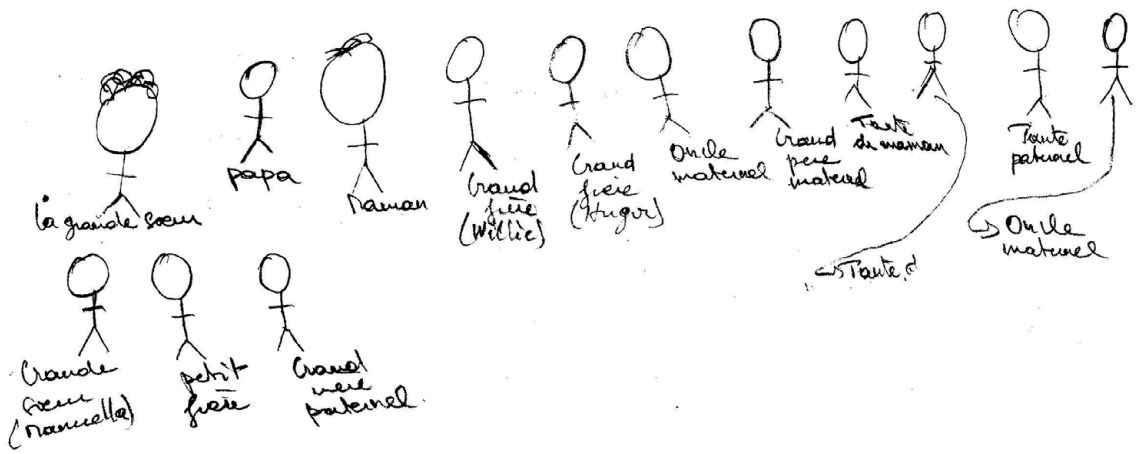


Figure 1.
Jules Family drawing.

Moreover, this is the first time that he drew human characters without drawing on a predefined model as he often does at school. However, a large part of the sheet is empty. The drawing is in the “upper central part” high center of the sheet, in a portrait orientation. The drawing location in the upper part of the document can signify the escape of the present, the escape towards the unreal and the distance from oneself according to [41]. It is therefore possible that this drawing signifies Jules’ avoidance concerning his family, which is “inhabited” by death and disease. This may justify his lack of drawing.

No character is in contact with others as they do not touch each other. This can be interpreted as lack of family support and the isolation of family members according to [41]. This interpretation is questionable, however, in a cultural context where affection and support do not necessarily manifest themselves through physical contact [26] through touch, caress or hug, for example, thus reflecting the complexity of this child’s life.

4.6.3 *The elder sister, a father figure*

Jules says he drew “*these people*” in his father’s house, at his father’s funeral in his village. Of all these characters, the elder sister (“*la grande soeur*” on the drawing) is designated as the happiest person. This is because, according to Jules, she bought the coffin for the burial of his father. The mother is referred to as the least happy person in the drawing because “*she was crying because she had lost her husband.*” The elder sister is invested psychologically and symbolically as the father of the family. She is the one who provided financial support for the funeral. She is designated as the nicest person in the drawing because she looks after her siblings. The fact that Jules first drew his older sister might reflect her emotional over-investment. She is invested as a mother emotionally and symbolically. The least kind person is the paternal aunt (paternal aunt, on the drawing). Jules justifies himself by declaring, “*It is they who caused the village to be fired. They are mean. They said that mom killed her husband.*”

When asked what role he would like to take within the family dynamic in the drawing, if he had the opportunity, Jules points to his mother saying, “*She is kind. As I go to school, she always buys me lunch.*” This reveals the mother’s nurturing role in the family and invests her as an identification figure.

4.6.4 *The absence of Jules on the drawing of a mourning scene*

Jules said he had drawn his family members in his father’s house during his father’s funeral in his village. This tells us that he is still suffering grieving the death of his father. It is possible that Jules represents himself and associates his family with death, due to the past deaths of his father and his youngest sister, along with the imminent and distressing risk of the death of his sick sister. The family is therefore thought to be inhabited by death.

Jules’s absence from the drawing may reflect his avoidance of the family, which he associates with disease and death. With this, he avoids living psychologically in this family dynamic, where he feels insecure about the circumstances. The sick child is also absent from the drawing. This can translate, for Jules, the anguish regarding the potential death of his sister. The sick sister is thus excluded from the family dynamic, thought of as not making/leaving her because of an illness that makes her a “dead” person. It could also be a way of distancing himself from this sister who reminds him of the suffering of the family. This absence contrasts with the presence of his later father.

The presence of the father in the drawing can explain in Jules the incomplete mourning process of this father who is still invested as alive. He remains present

beyond his death; unlike the other daughter who died before him. While the dead father remains present (illustrated on the drawing), the sick sister's absence from the drawing may signify Jules' avoidance of this sister and therefore, avoidance of the threat of death that accompanies her illness. On a psychological level, Jules' drawing may signify that, the living sister is dead, while the dead father remains alive. This complexity of Jules's experiences is illustrated within his drawing.

4.6.5 *Friends and other supporters of Jules*

Jules perceives the children in the neighborhood as helpers and supporters concerning his sister's illness. They are friends who support him by protecting his sister during games and other interactions with her. *"The children do not bother Paulette. They go to school and come back together. They do not cause any problems. Even when we play together, there are no provocations."* Of course, these friends know that Jules is protective of his sick sister. They support him in this way by also protecting her and he is grateful for this.

Jules' friends are curiously absent from the drawing. He differentiates them from the members of the family. He does not make them part of his family; and hence their absence. In a cultural context where people with whom the subject has special relationships are considered to be members of their family [14], the absence of friends of the drawing is significant. This can tell you that Jules differentiates his friends from family members. Therefore, the support provided by the friends does not compensate for his feeling of abandonment by family members. They are considered outsiders and they may have no obligation over his situation. It could also exhibit his need for more support from within as the outside support could be a privilege.

4.6.6 *The absence of care professionals*

Healthcare professionals (hospital and traditional healers) are completely absent from the drawing. This absence can translate into their investment by Jules as outsiders to the family.

It is also possible that Jules did not draw them because their presence acts as that of the disease and, obviously, the risk of contamination and death. This absence can indicate a psychological effort to avoid anything that reminds him of the disease. In Jules, this absence can refer to the feeling that the traditional therapist does not protect him against the idea of possible contamination by the disease. It is possible that he did not draw the hospital professionals in order to protect himself against the feeling of abandonment by them.

4.6.7 *The request for recognition of his experience*

At the end of the drawing, Jules handed his drawing to me while smiling and he asked me to protect it well because it is very fragile. By a projection mechanism, he could be asking me to pay attention to his psychological suffering.

At the end of the meeting, with the agreement of Jules and following the requests of his elder sister, we presented the drawing to her and the mother. It is possible that Jules found by this means a way to make them understand his experience with Paulette's disease in a family context where talking about the disease remains taboo. Particularly moved by finding themselves in the drawing, the elder sister and the mother criticized the "non-human" nature of the characters he drew and the absence of the use of many colors on the drawing. The elder sister put this in relation to the pedagogical approaches used at school, which do not enable children to draw freely.

5. Discussion

With the exception of the sick child who is named by Jules during the interview, parents and siblings are referred to as parents or siblings. The eldest daughter is referred to as *“my big sister,”* the brother who is a taxi driver as *“my older brother,”* the sick sister as *“the last daughter of mother,”* this is very important as she also died of sickle cell anemia. He does not refer to her as ‘sister’ maybe because he wants to distance himself from the condition which eventually led to her death, the things he fears most, and that have become a part of his family. This shows the specificity of his links to his sick sister. Jules refers to her niece as *“the daughter of my older sister,”* thereby differentiating his brothers and sisters from his niece. He referred the father and mother as *“father”* and *“mother.”*

Four people appear in Jules’s drawing. Referred to in the interview as *“my older sister,”* the eldest daughter is designated on the drawing as *“the big sister.”* The brother who is a taxi driver is, however, named *“big brother Willie”* on the drawing while he is referred to as *“my big brother”* in the interview. The father and the mother are designated in the drawing by *“daddy”* and *“mother.”* However, the father is absent from the interview. The absence of the father within Jules’ speech is not synonymous with his absence in the psychological universe of the interviewee, as he is present on the drawing. This makes the drawing a mediator to speech and a complementary tool in the interview.

Not all the people mentioned in the interviews appear in the drawing, and those in the interviews are named differently in the interviews. This account for Jules’ psychological dynamics concerning his links to family members and the complexity of these links.

The valorization of the traditional treatment (as financially expensive for the families as the medical treatment) contrasts with Jules persistence of the feeling of insecurity regarding wizards. It suggests that the treatment is not necessarily valued for its therapeutic efficacy. In a context where the traditional practitioner is considered as the intermediary between the ancestors and the living [44], it is forbidden to devalue their treatment. To do so would amount to devaluing the ancestors and running the risk of punishment, which could lead to death. The ancestor is incomparable [45] and therefore not criticizable. It can be dangerous to criticize the traditional treatment, as Jules emphasizes that it *“alleviates”* the fear and concerns the whole family.

Jules did not mention any consultation with a pastor, a priest or an imam. This is a problem in a context where families normally invest religious institutions (churches and mosques) to express their suffering and overwhelming misfortune [46]. It is possible that Jules, whose family is Christian, avoided talking about the care of his sister by the priest or by the pastor to a researcher whose family is of Muslim descent. He would have considered it disrespectful to talk about his religion to a researcher belonging to another religious denomination. It is also possible that, in not telling the researcher about his sister’s consultation with priests or pastors, this young boy avoided hitting the researcher’s religious sensitivity. He may not have talked to the researcher about this so as not to make him feel uncomfortable during the meeting.

In addition, this study showed that the traditional healer assigns, the uncle rather than the mother in the administration and follow-up of the care of the children and the family. This can be understood by the fact that the woman is often considered by traditional healers, as a being who can reduce the effectiveness of the treatment if she were to touch the patient [47]. Consequently, men are more often empowered to monitor and to enforce the prescriptions of traditional healers. It is also possible that the exclusion of women in this follow-up is motivated by the fact that they are considered to be responsible for the transmission of the disease

to the child [14] and hence as a “stain” in family [4] and a hindrance to traditional treatment. In this case, it would be interesting to understand how mothers and fathers experience the care of their children with sickle cell anemia by hospital and traditional healers.

Jules’s family agreed to participate in the research despite the fact that sickle cell anemia remains a taboo subject in African families [2]. It is possible that this family invested the research as a means of understanding the experience of the brothers and sisters of the sick child. The researcher can be considered a mediator who allows the family to talk indirectly about sickle cell anemia with the sick child and his siblings. The parents do not themselves talk with the children about this disease, but they prefer that someone else did it. Although this can be a coping mechanism due to the guilt they experience regarding the situation, they consider themselves as parents who have transgressed a cultural norm whose consequence is the child’s illness. This behavior of the parents remains complex. Anyway, the participation of the family in this research shows the interest they had in understanding the experience of all the children in relation to the disease.

This research also allowed Jules to tell the researcher, his family and care professionals his experience with his sister’s illness despite it being a taboo subject. It has therefore disrupted the norm or violated the family taboo on sickle cell anemia. It would be interesting to understand the impact of Jules and his family’s participation in this research on the mother, the sick child and Jules himself.

6. Conclusion

This article presents results similar to those of other works concerning the co-existence of traditional and modern representations of sickle cell anemia among sub-Saharan African families [9, 36] and their involvement in traditional and modern care systems [46]. Finally, Jules knows that in the event of seizures, only the hospital (where she is taken only for emergencies) can mitigate them and that there is a possibility that the treatment can fail and lead to her death, the brothers and sisters are then absent from this care. The traditional healers, meanwhile, intervene before crises in order to prevent them before they occur. This intervention protects the sick child and their family against the wizards, who are designated as responsible for the attacks and thereby the danger of a possible transmission of the disease to the patient’s brothers and sisters.

This research indicates the need for spaces of speech within healthcare institutions that can enable families, parents and children to express their experiences with illness and care. It also indicates the need for professionals to take these experiences into account. It would therefore be interesting to question the experience of the sick child with the side by side existence of two care systems within the family.

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Conflict of interest

None.

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