

The Resilience Issues in a Sickle Cell Disease Context: The Experience of a Cameroonian Child

Njifon Nsangou H^{1,*}, Mefire Nsangou A², Dong T¹, Meda A³, Gesteira ECR⁴ and Oliveira PP⁴

¹Research Unit of Philosophy and Social Applied Sciences, University of Dschang, Cameroon

²Clinic, Psychoanalysis and Development Research Groupe, Paris Nanterre University, France

³Hopital Robert Debre in Paris, France

⁴Department of Nursing, Federal University of Sao Joao del Rei- UFSJ

*Corresponding author: Njifon Nsangou H, Research Unit of Philosophy and Social Applied Sciences, University of Dschang, Cameroon; E-mail: hassannji@75yahoo.fr

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Abstract

Objective: This research aims to understand the resilience issues in Fidele, a 17-year-old girl, sister of a child with sickle cell disease in Cameroon.

Material and Method: The data were collected through an interview and a family drawing in Fidele Family's home. These data were analysed through the thematic analysis and a drawing analysis approach.

Results: The family taboo regarding sickle cell disease makes Fidele feel strange about her sick sister. She remains powerless in the face of the crises of her sister with whom she is prettified by the parents concerning her surveillance and protection against crises and aggressive behaviour coming from people outside the family. This prettification is a potential factor of resilience insofar as it makes her active with the child and hence his illness.

Conclusion: This study highlights the relationships between resilience and culture and shows the need to support the sick child, his siblings, his parents and the professionals within healthcare institutions.

Keywords: Culture; Taboo; Resilience; Sickle cell disease; Siblings; Cameroon.

Introduction

Sickle cell disease (SCD) is a genetic disease that confronts the sick child and his family with his painful and chronic crises associated with his physical changes, his regular and expensive hospitalizations, his death thought to be imminent. It remains a taboo disease in Cameroonian families where it is difficult to meet families with less than 5 children [1]. Few studies have focused on the psychological impact of this taboo on siblings of children with SCD. However the elaboration by a subject of a traumatic event which he faces is important in the attenuation of the impact of the effects that it generates on the subject concerned and constitutes, via its narrative function, a factor of resilience in this subject [2-4]. This research which poses the problem of

resilience in siblings of children with SCD presents the psychological repercussions of the family taboo concerning this disease on Fidele, a sister of a child with SCD met in Cameroon. It includes the analysis of an interview and a drawing of the family made by this child in the context of a research whose framework and method will be briefly presented. It highlights the complexity of the experience of this young girl and her parents in the face of SCD and the taboo concerning this disease. Its objective is therefore to build on this knowledge to open up the design of care systems that take better account of the family and the siblings of children with sickle cell disease.

Theoretical Considerations

SCD is a genetic disease, supporting social and cultural representations.

Sickle cell disease's clinic

SCD is a genetic, chronic and fatal disease.

A serious and fatal genetic disease: SCD is the most common genetic disease in the world with approximately 500 million individuals carrying the sickle cell trait and 50 million individuals worldwide [5,6]. Initially distributed in areas endemic for malaria such as sub-Saharan Africa, the migratory movements of populations have gradually modified its distribution around the world [7]. Therefore, this disease is present in practically all countries with populations originating from Africa and regions around the Mediterranean. This disease is a public health problem in Africa which is the continent most affected by it with a prevalence rate of 2% in the general population and mortality estimated at more than 70% in children under 5 years old [8]. Cameroon is one of the countries most affected by this disease with a prevalence of 8.34% in the general population. In Africa, the management of SCD is expensive and the unavailability of bone marrow transplants and gene therapy, the only effective treatment against crises, means that the deaths of children under 5 years of age are numerous [9]. SCD is an autosomal recessive pathology transmitted to children by both parents and due to the presence in the blood of an abnormal hemoglobin which causes a deficiency in the oxygen supply of different organs of the body by red blood cells which have a reduced lifespan. The rapid destruction of red blood cells leads to anemia and chronic, unpredictable pain with which the patient identifies itself giving rise to multiple hospitalizations and costly care for their parents [10-12].

A figure of persecution: In a sub-Saharan African cultural context, the disease is thought of as an "evil" capable of attacking all members of the family event after the death of the patient [13]. The sick child is immersed in a society structured by prohibitions, rites and traditional attitudes of which women are the custodians [14-16]. A child's illness or disability is embedded in this cultural structure that gives it meaning and produces effects. SCD is thought of as a manifestation of the possession of the sick child and his family by a sorcerer or by an evil spirit [17,18]. It can also be experienced, depending on the case, as a request from the ancestors to repair a transgression of an ancestral norm, addressed to the patient's family [19,20]. The mother is usually blamed for this transgression; the overprotection of the affected child by her and by the members of the family constitutes a psychological defense allowing them to free themselves from guilt and to place the child in the history of the family.

A family taboo: Talking about SCD is a taboo among African families or those originating from Africa. As a result, children with this disease more often have difficulty talking about their disease and verbalizing their experience, emphasizes that parents

hide the name of the disease from children or some of them and that children hide their knowledge of the disease from their parents [21]. She points that this taboo constitutes for the children a means of protection of their parents and for the latter the desire not to aggravate the suffering of the children. This author also emphasizes that parents use this taboo as a means of protecting sick children against social and family stigmatization.

The resilient function of narrative capacity

Speech has a potentially calming effect and a communicative, affective and containing function for the subject and those close to him. According to, the free speech between parents and children frees the one that can be deployed between children, which promotes movements of identification and differentiation between them, founders of their fraternity. She formulates the hypothesis according to which this "good experience" with an adult allows the child to experience the benefit of "thinking together" in a co-construction of a story on the pathology and emphasizes it is in this "Thinking together" that the pathology succeeds best in inscribing itself in time, the time of the sick subject, the time of the other, the time of the groups to which it belongs. The recounting of the disease has a resilient function like the secondary elaboration for the dream, and the possibility of recounting a traumatic event is essential in the attenuation of the impact of the suffering on the sick child and for those close to him [22-25]. The resilient function of speech also opens up possibilities for creativity, the thought work it involves being both restorative and inventive. Therefore, talking to the child, with the child and his siblings about his illness can help each of them to contain it, to think about it and to transform it. The narrative capacity in a subject concerning a potentially traumatic object such as a chronic disease such as SCD is a factor of resilience for the patient and his relatives confronted directly or indirectly with this trauma.

Material and Method

The meeting with the participant took place at her parents' home.

Encounter clinic and ethical devices

This article is based on research conducted with families with a child with SCD in Cameroon where the floor is given; a subject who talks about himself, about others or about anything else, is supposed to have been authorized by his group, by his family to do so [26]. Fidele is the child who is the subject of this research. Fidele's mother was met during a meeting of the Association of Parents of Sickle Cell Children of the Chantal Biya Foundation in Yaoundé to which the object and methodology of the research as well as its inclusion criteria were presented some participants. Fidele's mother, like 8 other parents, registered as a volunteer to participate with her family in this research. The meeting with her family and with Fidele took place at her parents' home 3 days

after the association meeting. For ethical and confidentiality reasons, the data was anonymized and fictitious first names assigned to the participants. The mother, in the father's absence, signed the consent form regarding Fidele's participation in the research. Fidele was reminded of her freedom to participate or not to participate in the research. Fictitious first names were given to participants to ensure the anonymity and confidentiality of the research. The recorded tape was destroyed after the interview data was transcribed.

Fidele and her siblings

Fidele's siblings grew up in a polygamous family. The father, in his sixties, retired civil servant and converted into an entrepreneur in the field of public works, after several years spent with his first wife without having children, married Angela's mother, and housewife with whom he had 7 children, 5 girls and 2 boys (Figure 1).

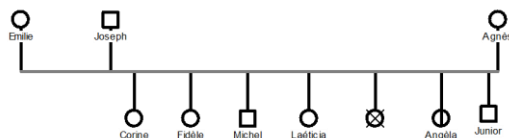


Figure 1: Family genogram of Fidele.

Aged 17 and a first year student, Fidele is the second child of her siblings. She is described by her mother as very calm and very motherly towards her younger siblings in general and Angela in particular. Angela is a 13-year-old girl with sickle cell disease, a middle school student, first year and penultimate of her siblings. The fifth born of this sibling died before the age of 2. The cause of her death is not known, everything suggests, according to the mother, that she died of sickle cell crises. Angela is the only child in the siblings with sickle cell disease. Her illness was diagnosed at the age of 7 during one of her regular hospital admissions for attacks of pain that were widespread all over her body. These attacks lead her, once or twice a month, to spend a short stay of about 2 to 3 days in the hospital.

Data collection and analysis

The data was collected through a semi-structured interview followed by a drawing of the family. At the end of the interview, Fidele was invited to draw her family on a sheet of paper with the coloured pencils made available to her. The drawing of the family was made by drawing inspiration from the protocol of with the instruction "I would like you to draw your family on this sheet". The interviews were the subject of a thematic analysis and the drawing, an analysis according to the grid of taking into account cultural specificities.

Results

The results highlight the psychic impact of the family taboo concerning SCD on Fidele.

Talking about SCD as a family: a psychological issue

Fidele maintains, as a family, a specific relationship with the sharing, with members of the restricted and / or extended family of her experience concerning her sick sister and her illness.

Silence her experience to protect parents and siblings: Fidele says of her parents' experience of her sister's illness "They are often worried. They are also afraid. I don't want to aggravate their discomfort. If I tell parents, it's like I'm just reinforcing their concerns". There is, here, mutual parent / child protection via the family taboo on the disease and on the experience of the disease. Fidele knows that her parents are suffering. She wants to help them and alleviate their suffering. To do this, she is ready to "lose" her place as a child to help her parents. She therefore maintains this taboo so as not to psychically infect her mother with her suffering. The taboo reflects the recognition, by Fidele, of her mother's suffering and her desire not to aggravate this suffering.

SCD spoken through injunctions of care and protection of the patient:

The disease is spoken in the family through parental and fraternal injunctions concerning the care and protection of the patient. Siblings and other family members do not talk to each other about their feeling and experience concerning Angela's disease. Siblings of the sick child are de facto parentalized by the parents. Their parents' involvement in Angela's protection and surveillance does not allow them to say and tell each other what they are experiencing regarding Angela's illness. Expressing or talking about their experiences to parents, adults and siblings seems to them not legitimate, not allowed. The only discussions between adults and children concerning Angela's disease focus primarily on what to do with siblings to avoid or limit her crises. Fidele and her siblings are in fact receptacles for these parental injunctions that pay little attention to what they experience about their brother's illness. This arouses in Fidele a feeling of abandonment by the family for the benefit of her sick sister who draws the family's full attention to herself. This feeling of abandonment is accompanied by a feeling of jealousy towards Angela who, too, is kept away from any talk about her illness with her siblings.

Feelings and their expression

Fidele expresses special feelings about her sick sister and her illness.

The feeling of strangeness concerning the sick sister: Fidele expresses her anger at Angela who cannot tell him how she feels during her fits. "When she's sick she screams, she just screams. It annoys people". The absence of words to express her experience of the illness and ultimately to express herself as a sick sister makes Angela a strange person to Fidele. The absence of this word causes Fidele not to be able to imagine her sick sister. There is, in fact, in this family, the absence of a group or family ready to

think about who can structure and contain the children's experience of Angela's disease, which remains strange. Fidele's suffering lies in her difficulty in telling her parents, siblings and sick sister what she feels and experiences regarding her illness. This suffering reflects her desire to have power over her sister's illness, to make sense of it through a precise representation of her crises. It also reflects in her, the alteration of the mechanism of identification / differentiation with the sick sister. Angela remains a strange person who arouses in Fidele suffering and a feeling of helplessness; helplessness in the face of crises that cannot be avoided or eliminated, and helplessness in the face of a sister whom it is difficult to imagine. Obviously, not understanding what the sick sister is going through concerning her illness, not understanding what is happening in her body and not representing her crises, leads Fidele to ask questions about herself and her own identity when we know that children's ego is built through the process of identification and differentiation from others [28].

The feeling of guilt about the disease: Angela's fits send Fidele to the image of her as a bad sister. She says she wants to educate her sister. But this desire comes up against the vulnerability of the sick sister. The education Fidele speaks of is in fact the protection of her sister against crises. Failing to know what her sister is going through, failing to speak with her about her experience, Fidele becomes aggressive towards her. This aggressiveness here has the function of creating a link between her and her sick sister. It translates not only the psychic work of search for meaning concerning the crises of this sister who does not speak about it but also her desire to enter in relation with this sister who is distant and who constitutes for her a broken mirror which sends her back a strange image of herself. Fidele is convinced that her sick sister sees her as a bad sister. She specifies "It hurts me too much. I know when she is in pain she needs us to help her. But we do everything, her illness does not end. That's all that hurts when I see her in pain like that. "Everything happens as if between the brothers and sisters, it was not a question of games and exchanges with the patient, but of a relationship aimed at the never-ending repair of the vulnerability of the latter. This marks the difficulty Fidele and her brothers and sisters have in living themselves as "brother" of Angela.

Contribution of the drawing

Between the interview and the drawing, a 5-minute break was scheduled to allow the child and the researcher to recharge their batteries and rest. This non-compulsory break was designed to make the meeting less exhausting for the child and for the researcher. Fidele wanted to take this break during which she remained in the living room, without going out. The interview would have been exhausting for Fidele. It is also possible that she took this break to better prepare the drawing or to better think about the family and the people to draw.

Parents' investment: The drawing was done very quickly. The various members of the nuclear family were simultaneously drawn, by order, without correction or improvement; the father (Joseph), the mother (Agnes), the first child of the siblings (Corine), the participant (Fidele), her younger brother (Michel), her younger sister (Laeticia), the younger sister suffering from SCD (Angela) and the youngest of the siblings (Junior). The table, placed in the center of the sheet, on which is placed a bouquet of flowers is the last element drawn. This order of appearance in the drawing provides information on the affective investment in relationships with parents. With this drawing, Fidele highlights her parents, the importance she gives to her subjective relationships with her father and mother. The mother-in-law (Emilie) is absent from the drawing. It is a monogamous family that she drew. This absence may reflect possible family conflicts that Fidele witnesses within this polygamous family. In fact, it is known that SCD often rekindles conflicts between co-wives who reject responsibility for the onset of the disease (Figure 2).

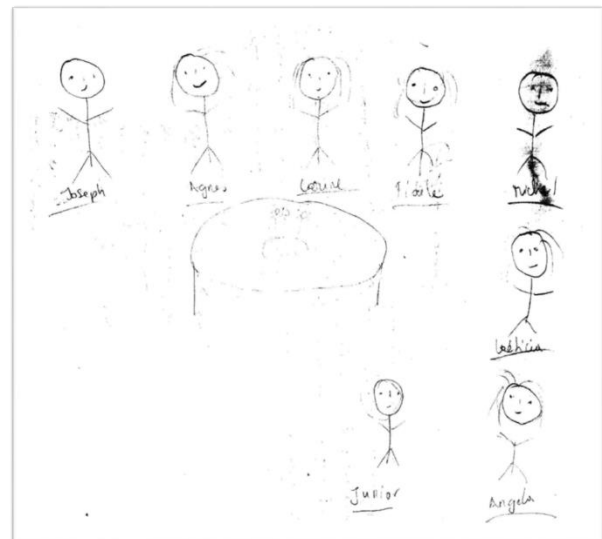


Figure 2: Fidele's drawing.

Expressing anger at the sick sister: Fidele says she drew her family members in the living room talking about the results of the school year. From his drawing, Fidele designates her father (Joseph) as the happiest person. He's actually happy because, she says, all the kids did well in school. Fidele's younger brother (Michel) is named by the latter as the least happy person in the drawing, "because he does not express his emotions". In a social context where it is forbidden to enter into conflict with one's parents, this complaint formulated against her brother can be understood as a displacement on this sister of the complaint against parents who do not express not their experience of the disease to the children and which do not allow them to express theirs to them. Fidele manifests by this anger her desire to see

- Her parents talk about SCD to children and with children;
- Her siblings talk about SCD among themselves;
- Her sick sister talk to her and talk to her other siblings about her illness experience.

The mother is considered the nicest person because she takes good care of everyone, unlike the child with SCD (Angela), who is considered the least nice person in the picture because. She expresses, in this way, her anger at her sick sister, whom she designates as responsible for the suffering of the family. Fidele therefore thinks of himself as a victim of her sister's illness.

Identification with the father

If Fidele had been asked to take the place of one person in the drawing, she would have taken that of her father (Joseph) because he is the decision-making center of the family. Fidele thus manifests her identification with the father and reflects her desire to possess, like her father, power within the family.

By identifying with her father, it is possible that Fidele wishes to have the power necessary to reconfigure the family bonds and to bring the parents, the mother, to no longer affectively isolate the non-sick children and by allowing the members of the family to speak about SCD and their experiences with this disease and the sick child.

The presence of Angela and Fidele in the drawing: The sick child is present in the picture despite the fact that it is seen as strange in the interview. This strange child should, in principle and in accordance with the pleasure principle, be excluded from the mental universe of Fidele because it constitutes for her a kind of broken mirror which gives her a bad image of herself. The presence of Angela in this drawing can reflect the Fidele desire to understand what is happening to this strange sister and the intensity of the psychic work in connection with this sister and with her illness. She is in fact a sister who, despite her strangeness, is very present in Fidele on a psychic level. The drawing highlights the effort she makes to make this sister less strange, efforts that come up against the taboo of the disease, the refusal of parents to allow family talking about this disease. The presence of Fidele in the drawing reflects her feeling of belonging to her family. All the characters are similar, with a more noticeable gender difference in the head; females have hair unlike males. All these people are drawn in sticks and do not touch each other. They are roughly similar people, apart from the difference in sex perceptible by the absence or presence of hair as mentioned above. This similarity of cartoon characters may reflect Fidele's recognition of the suffering of other family members who, like her, cannot tell others what they are going through regarding Angela's illness. It can also refer to Fidele to the alteration of the identification / differentiation mechanism with her siblings. It is possible that Fidele translates this into her difficulty in thinking of

her siblings as likely to live decently with Angela's disease. No person in the drawing is in physical contact with others. This can mean the feeling of emotional isolation that Fidele experiences within her family and her recognition from that experienced by other members of her family. This lack of contact can therefore provide information for Fidele on the lack of composure of her family group regarding her experience with the sick sister and her illness. However, we are in a cultural context where the expression of affection and support does not always translate into physical contact such as touching, kissing and hugging, among others. What makes this interpretation, like the fraternal and family relations very complex in the sub-Saharan African context? In addition, Fidele is on the same line as her parents. This can provide information on her identification with the parents and translate the parenting process at play for her concerning the care of her sick sister, located at the bottom of the drawing, with a gaze directed upwards, as if to request the presence and help too as much from her parents as from Fidele and her other siblings.

Discussion

One of the results that provokes discussion is the identification of Fidele with her father. The father is the guarantor of the family taboo concerning sickle cell disease. This identification highlights the psychic transmission of the taboo to this girl by her parents. This psychic transmission can be represented in a subject by projective identification with the parent; the subject therefore inherits narcissistic needs and has a mission of narcissistic continuity and reparation concerning the parents. This research shows how Fidele, forced by her parents to fall under the taboo of sickle cell disease, strives to break this transmission by asking for recognition of her experience as well as that of her siblings by her parents in connection with the disease of her sister. However, as the results show, Fidele, out of recognition of the suffering that her parents and siblings experience in the face of her sister's illness, refuses to express her own to them so as not to aggravate theirs. This recognition reinforces her feeling of belonging to the family, therefore, can be thought of as a factor of resilience in Fidele. Fidele's parentification regarding the care and protection of the sick sister, the aggressive behavior against this sick sister and the feeling of guilt that follows are potential factors of resilience as they make her active with her sister, sick and hence of her illness. Activity, unlike passivity, constitutes a factor of resilience in a subject when faced with a traumatic event. In addition, the treatment of Fidele and her sick sister by the traditional therapist can constitute in this girl a factor of resilience in the face of SCD and the sorcerers appointed responsible for this disease. This result highlights the relationships between resilience and culture which, through the study of traditional care

practices, constitute a new way of examining resilience in subjects [31]. Public health policy should therefore take account of anthropological and psychological specificities in the care of people with SCD and in their psychological support as well as that of their relatives. The integration of this data can help strengthen the resilience of health care systems, patients and their families in the face of this traumatic disease of sickle cell disease [32]. In addition, the chronicity of Angela's crises can be a factor of resilience in Fidele. This chronicity is in fact likely to generate in the latter a habituation to her crises which are generally manifested by pain and anaemia. This habituation would make these crises, less strange for Fidele and this, despite the absence of words, as well in the latter as in her sick sister and her parents to tell about these crises and to say about these crises in family and in outside the family. The consideration of anthropological and psychological specificities in prevention and in care in general remains the soft underbelly of public health policies in sub-Saharan Africa in general and in Cameroon in particular; an environment in which, however, populations show an addiction to their habits and customs and from which any attempt to digress would be punished by the curse. Thus, despite some progress marked in particular by the erection of health districts following the 1992 reform and guided by taking demographic, socio-cultural, economic and technical criteria into account, this concern persists [33]. "Taking into account the social determinants of health is almost non-existent" in Cameroon to the extent that health promotion remains focused exclusively on the prevention of diseases and to health education, more often than not, without socio-cultural roots [34,35].

Conclusion

This research presents results similar to those of other studies concerning the presence of the sickle cell taboo in African families. The absence of speech reinforces the young girl's sense of abandonment and her feeling of strangeness regarding her sick sister and her illness. This can pose a risk to her psychological health if it persists over time. Following other researches, this research shows the need for professionals to remain extremely sensitive to the way in which the experience of the disease is a part of the family psyche with a view to transforming it and making the family and siblings a resource for the child with SCD and his siblings. The establishment of a space of speech between the sick child, his siblings, his parents and the care professionals within the institutions can help to achieve this objective and to reduce the potentially harmful effect of the family taboo concerning SCD on the sick child, on his brothers and sisters and even on his parents because the negative pact can have a transient protective effect for the sick child, his parents and his brothers

and sisters if he does not prolonged too long. However, it is necessary that the various people concerned by this space of speech understand the merits of it for each potential participant and agree to integrate it as a participant.

Conflict of interest: None

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