



RESEARCH ARTICLE

The psychological experience of sickle cell disease in a Cameroonian adolescent living with her grandparents

Gustave Georges Mboe¹, Hassan Njifon Nsangou^{2*}

Published online: 15 May 2024

Abstract: Sickle cell disease, the most widespread genetic disorder globally, is characterized by chronic and painful crises and high treatment costs, particularly in the Sub-Saharan African context where the disease is often associated with imminent death. This study aims to understand the experiences of an adolescent in Cameroon living with this disease and residing with her grandparents. Through in-depth interviews, we reveal how therapy non-compliance—particularly evident in medication delays—and the ambivalent behavior of her grandparents impact her disease management. The grandparents exhibit behaviors that are sometimes overprotective and at times aggressive, which not only affect how this adolescent understands and manages her condition but also hinder the process of subjectivation of her disease. These findings highlight the need to provide a space for grandparents to express their understanding of their granddaughter's illness and to assume their role in the care process. This study extends our understanding of family dynamics in managing sickle cell disease and demonstrates the importance of supporting grandparents as crucial resources in healthcare within this context.

Keywords: Experience, sickle cell disease, adolescent, grandparent, Cameroon

INTRODUCTION

The most common genetic disease in the world (Njifon Nsangou, 2022a), sickle cell disease is characterized by an alteration of hemoglobin which results in the formation of abnormal hemoglobin S (HbS) in affected subjects (SS). A rare disease in certain industrial countries (France, Italy, Spain, Portugal, etc.) with populations originating from Africa, India or the Arabian Peninsula, its main centers, sickle cell anemia constitutes a public health problem in sub-Saharan African countries. This genetic disease is placed 4th among the public health priorities of the WHO, UNESCO and the UN behind cancer, HIV/AIDS and malaria. There are more than 120 million people carrying a sickle cell mutation worldwide; approximately 5% of the world population carries the gene for this disease, which is responsible for the death of approximately 300,000 children per year (Organisation Mondiale de la Santé, 2006).

Although prevalent in other regions of the world with

projections of a stabilization at 8% of the world population from the 2014 decades and onward, sickle cell has this prevalence in Sub-Saharan Africa. This is the most affected region by this disease (Njifon Nsangou et al., 2020) where more than 75% of affected children die before the age of 5 (Njifon Nsangou & Scelles, 2019) due to lack of a diagnosis and early care as well as a technical platform consisting of hospitals where the care of affected children is costly for patients and their families (Njifon Nsangou, 2022b; Njifon Nsangou & Scelles, 2020).

In Cameroon, it is estimated that 4,000 children are born with this disease, even if this can be questioned due to the lack of systematic neonatal screening for this disease (Njifon Nsangou, 2019, 2022a). The disease affects all age groups but young people, mainly aged between 10 to 29, represent 89.2% of patients (Drepavie, 2006).

Life expectancy for a person suffering from sickle cell disease in Cameroon is estimated at 25 years. This hope is, in part, due to the absence of a national policy to fight this lethal and fatal disease unlike other diseases such as HIV/AIDS, the treatment of which the government subsidizes in partnership with international organizations (Njifon Nsangou & Scelles, 2021). Due to the absence of universal health insurance, the care of patients with sickle cell disease remains costly for them and their families. These patients and their families face representations of illness, a source of suffering for patients and members of their families (Njifon Nsangou & Scelles, 2021).

Sickle cell disease is culturally thought of as the manifestation and/or consequence of the transgression of an ancestral norm by the patient or by a member of their

¹ Research group in Philosophy and Applied Social Sciences, university of Dschhang, Cameroon

²) Research group in Clinic, Psycho analysis and Development, University of Paris Nanterre, France

**) corresponding author*

Hassan Njifon Nsangou

Email: hassannji75@yahoo.fr

family group (Njifon Nsangou, 2022a, 2022b; Njifon Nsangou & Scelles, 2021). Most often, it is the mother who is designated as the main responsible for this illness, she is often accused, as in most cases of child disability in the sub-Saharan African context (Tsala Tsala, 1996), of having transgressed an ancestral norm during pregnancy (Njifon Nsangou, 2022a; Tsala Tsala, 2009a). This illness is also represented in terms of persecution, not only of the patient, but more of his family group, by a persecuting third party; a sorcerer, an evil spirit. It is, in this sense, thought of as an evil that inhabits the family (Dong & Njifon Nsangou, 2022). Furthermore, families of children affected by this disease are often stigmatized and experience a feeling of shame, for having given birth to an affected child, indicating the transgression of an ancestral norm of which they feel guilty (Njifon Nsangou & Scelles, 2020). This feeling of guilt and shame is often associated, among the members of these families, with social withdrawal, to avoid the accusatory gaze with others cast on them, then perceived as bad families.

Caregivers have high hopes for therapeutic education of families and patients as a major support for therapeutic compliance among patients. Therapeutic education, understood as an integrated act which conditions the improvement of the physical and psychological health of the patient and their quality of life independently of the sociodemographic profile (Tabiana-Rufi, 2009) is more necessary and useful in the context of sickle cell disease. This disease most often presents increased comorbidity, linked respectively to cases of chronic hemolytic anemia, vaso-occlusive phenomena, extreme susceptibility to infection and a great variability of clinical expression depending on the particularities of the patients (Haute Autorité de Santé, 2005).

In Africa, in general, and in Cameroon, in particular, the child is, far from simply that of his biological parents, that of the members of his extended family. He is, in fact, a child of the lineage (Zempléni, 1968) who is raised by his biological parents, by their friends/colleagues, by a cousin, an uncle, an aunt, a brother, a sister, a grandparent, among others (Ezembé, 2009). This is due to the family spirit that reigns there (Tsala Tsala, 2009b) and which means that it takes a village to raise a child. Children with sickle cell disease are no exception to this family norm. We are increasingly seeing children living with their grandparents. Thus, when affected children do not live with their parents or one of their biological parents, the probability of finding them with grandparents is high. This reflects the important role of grandparents in the education of children, in general, and those with special needs, in particular.

Sickle cell disease, recognized as the most prevalent genetic disorder globally, manifests through severe hemolytic episodes and chronic pain, presenting significant challenges for affected individuals, particularly in Sub-Saharan Africa (Organisation Mondiale de la Santé, 2006). Despite its widespread impact, the psychosocial dynamics within affected families, especially involving adolescents, remain underexplored. This research aims to delve into these dynamics by examining the psychological experiences of a Cameroonian adolescent living with sickle cell disease under the care of her grandparents. The objective is to uncover how familial relationships influence treatment compliance and psychological well-being, contributing to both the academic understanding and practical management of the disease.

Literature suggests that the psychosocial burden of sickle cell disease is immense, with profound effects on family structures and individual development (Njifon Nsangou & Scelles, 2021). Adolescents, navigating critical

developmental milestones, may experience exacerbated stress when medical care becomes a dominant aspect of their daily lives (Richard, Mubiri, & Bioy, 2014). This study builds on these findings by focusing on the unique role of grandparents in the caregiving process, an area less documented in existing research. The theoretical frameworks of psychosocial adjustment to chronic illness and family systems theory are employed to analyze the interplay between familial support and individual resilience in managing the disease (Zempléni, 1968; Ezembé, 2009).

By integrating these perspectives, the research seeks to expand the dialogue around sickle cell management to include the nuanced roles that family members play in shaping health outcomes. This approach not only aligns with but also challenges and extends previous studies which have predominantly focused on parental impacts, thereby offering new insights into the broader familial network's role in healthcare (Ciccone, 2012).

This study employs the theoretical framework of psychosocial adjustment to chronic illness, which helps in understanding how adolescents negotiate their identity and daily challenges associated with such diseases (Richard, Mubiri, & Bioy, 2014). According to this framework, the adaptation process is influenced by multiple factors including family support, societal attitudes, and individual resilience, which are crucial in managing the psychological impacts of sickle cell disease.

Further, the family systems theory provides a lens to examine the role of family dynamics in managing illness, which is particularly relevant in the African context where extended family often plays a critical role (Zempléni, 1968; Ezembé, 2009). In Cameroon, where familial bonds are pivotal, the psychological well-being of adolescents with sickle cell disease is intricately linked to the family's ability to provide support and manage the social stigma associated with the disease (Tsala Tsala, 2009b).

Only psychological research on the experiences of children with sickle cell anemia carried out both in Africa and elsewhere (Richard et al., 2014) has focused more on those growing up on a daily basis with their parents, without questioning the experiences of their grandparents. The role of grandparents is highlighted in the process of transgenerational psychological transmission in families confronted with traumatic situations (Ciccone, 2012). It is therefore interesting to understand how children with sickle cell disease interact with their grandparents regarding their care. Likewise, it is important to understand how these children experience, think and feel about these interactions and what their grandparents think and say about their care and illness.

This research presents the experience of a young girl with sickle cell anemia who interacts with her grandmother regarding her illness and her care. It questions the way in which this teenager experiences her interactions with her grandparents. This research aims, through the knowledge it produces, to improve the quality of care for children suffering from this disease on one hand, and, on the other hand, to make the family, in general, and adults -parents, in particular, a resource for caregivers and affected children and their families. This comprehensive approach allows for a nuanced understanding of the intersecting impacts of biological, psychological, and social factors on adolescents' health outcomes, highlighting the necessity of integrated care strategies that address both medical and psychosocial needs of young patients with sickle cell disease.

METHODOLOGY

This research is a case study based on an in-depth analysis of the psychological functioning of the subject with consideration of the intersubjective dimension (Lavarde, 2008). This case study takes into consideration the singularity of an adolescent girl suffering from sickle cell anemia, the logic of her singular life story as well as the electivity of her links with the subjects of her environment, real or fantasmatic in connection with the situation in which she is confronted.

The case presented in this research is that of a Cameroonian adolescent suffering from sickle cell anemia, living with her grandparents and met at their grandparents' home in Cameroon during research. The choice of this adolescent and location is justified by the prevalence of sickle cell disease in Sub-Saharan Africa and the unique familial dynamics observed in Cameroon, where grandparents often play a crucial role in upbringing due to socio-economic and cultural factors (Tsala Tsala, 2009b). This setting provides a unique opportunity to study the intersection of chronic illness management with traditional family structures, which is particularly relevant given the high rates of morbidity associated with sickle cell disease in the region (Organisation Mondiale de la Santé, 2006).

Although she had been the subject of therapeutic compliance after becoming aware of the illness, this teenager suddenly and gradually found herself engaged in hiding the tablets supposed to be taken at specific times, in nooks and crannies. A tendency towards procrastination was also observed in her; she always postpones taking her medication until the next day. In order to understand this behavior which indicates therapeutic non-compliance, two semi-structured interviews were offered to the adolescent, with the agreement of her grandparents.

In the first session, illness, care, hospitalizations and relationships with family and friends were discussed. This first interview allowed the child to describe these different objects in her own words and to become familiar with the researcher with the aim to establishing a research alliance conducive to secure expression, by the adolescent to the researcher. The second interview, two days after the first, focused on the adolescent's experience in relation to her illness with her family and friendly relationships. The data thus collected was analyzed using the thematic analysis technique.

Thematic analysis was conducted to systematically identify, analyze, and report patterns (themes) within the data. Following the transcription of the interviews, data were initially coded in an iterative process, allowing for the refinement and merging of codes into broader themes that accurately represent the collected data (Braun & Clarke, 2006). NVivo, a qualitative data analysis software, was used to facilitate the organization and coding of the interview transcripts, enhancing the rigor and transparency of the analysis. To ensure validity and reliability, a process of triangulation involving multiple analysts was used to cross-verify the thematic categories derived from the data.

Regarding ethical considerations, extensive measures were taken to ensure the privacy and security of the participant's information. All data were anonymized with pseudonyms used in place of real names, and personal identifiers were removed from all study documents. The recordings were securely stored and destroyed after transcription to ensure no breach of confidentiality. For confidentiality purposes, an assumed name was given to the teenager. It should be noted that certain information

on the adolescent and the motives for medical procrastination was obtained via health professionals.

Informed consent was a pivotal part of our methodology. Both the adolescent and her grandparents were provided with a detailed explanation of the study's purpose, the procedures involved, potential risks, and benefits. They were reassured that participation was voluntary and that they could withdraw from the study at any time without any consequences. Their consent was documented in writing, adhering to ethical guidelines recommended by the regional health authority and the ethical review board overseeing the study.

RESULTS

To facilitate the understanding of the results, a brief presentation of the case, the history of the illness and its experience by the adolescent encountered is discussed in turn. The presentation of influence of the grandmother's "words" on the adolescent...concerning her illness on her work of subjectification of the latter will be addressed in the second part of these results which end with the influence of the relationship with pairs. on therapeutic compliance at home. The thematic analysis revealed significant insights into the psychological experiences of Tina, an adolescent living with sickle cell disease in Cameroon. The interactions with her grandparents have shown ambivalent impacts on her health management, which reflect broader cultural beliefs and practices surrounding illness in the region.

Tina

Tina was born with sickle cell disease. At the age of 7, during a medical examination carried out in a hospital center, at the insistence of her mother's fiancé, the illness was diagnosed at home and announced to her family. Once the diagnosis was made, Tina was put on specialized treatment for sickle cell anemia. Tina, aged 12, is the eldest daughter of her siblings. She has two younger brothers and a younger sister. She has lived with her maternal grandparents since her mother weaned her to continue her studies. Her grandfather is an engineer retired since 2002 and her grandmother is a trader.

Tina is a fifth grade student in a government high school. She has a normal education with good academic performance. She is the best of her promotion since the class one in which she studies. The illness therefore does not constitute a handicap for her academic performance. She likes dancing, singing and traveling. It is possible that these artistic activities allow her to think and contain the physical and psychological suffering induced in her by her illness. These activities can thus be used as support for the work of subjectifying sickle cell disease. Tina wants to continue her studies in a European country to become a scientist in order to improve the quality of life of people with sickle cell disease. This demonstrates her desire to base on her experience to help people with sickle cell anemia, help them prevent crises and, ultimately, contribute to the search for an effective treatment for this disease.

Experience with illness

Tina discovered the disease late. She knows, according to her biological mother, that when she was an infant, she was hospitalized at the Chantal Biya Foundation in Yaoundé for months. Since her permanent settlement in

Foumban where she lives with her grandparents, her mother has no longer taken her to this health institution located more than 180 kilometers away.

Questioning on how she knew she had sickle cell disease, Tina responds: "the color of my eyes, the fact that certain parts of my body are shiny even when I haven't anointed myself, my little weight (my little brother 6 years younger than me lifts me like a rag without making any effort, permanent fatigue, nose bleeding, pain in bones and joints, edema on my body, bloated stomach, anemia, it even happens that I faint or lose consciousness most often..." The physical markings on her body were, for Tina, indicatives of the presence of the sickle cell genetic mutation in her. Also, she adds: "After confirmation of my illness, the doctor had strongly recommended to me and this, in front of my second dad (the current husband of my mother and father of my little brothers) that I must henceforth eat a carrot every morning, drink a lot of water, always carry a sweater, wash only in hot water, always have my little yellow tablets, sleep under an impregnated mosquito net, etc. ". This verbatim provides information on the existential anxiety that this medical prescription arouses in this adolescent with a view to preventing or alleviating her crises.

While attending primary school, Tina's school officials were informed of her illness by her grandparents. From then on, school officials showed protective behavior towards her against her crises. Tina explains that "My director and founder often comes to the house on weekends with fruits and vegetables for my diet as a sickle cell patient. Despite the fact that I am already in high school, they continue to support me and give me practical advice to encourage me." The educators are thus invested by this adolescent as resources about her illness. Furthermore, it is possible that this verbatim provides information, for Tina, about her desire to no longer be considered by these professionals as a child to be overprotected, a subject who does not have the personal resources to effectively prevent her crises or deal with them. We also read, through this verbatim, not only the expression of Tina's gratitude towards her educators, her anger against these professionals who make her dependent on their protective behavior. This is the whole meaning of the ambivalence of Tina's experience of this professional protection.

Tina's experience, linked to her illness, evolved over time. Difficult to live with less suffering and strangeness at the beginning, his illness became less strange and less distressing over time. She specifies that "At first, I didn't know exactly what it meant to have sickle cell disease. But I knew that I now had to be careful in following the doctor's advice so as not to experience the difficulties linked to my illness. The hardest part was being able to get used to drinking the tablets every morning and evening and above all, taking the blood remedies (with their unbearable smell like Tothéma)." Tina therefore found it difficult to take the medication prescribed by caregivers. This suffering that she says she experienced while taking this treatment indicate her desire not to be dependent on these medications. Furthermore, taking these medications constantly reminds her of her illness, her disability and her difference from other children in her environment.

Tina also had to follow other medical prescriptions regarding the prevention of her seizures. These prescriptions were written, by her father-in-law, in a register. She specifies: "I also had to follow the doctor's other instructions to the letter. For this purpose, my second dad bought me a large notebook of 292 pages to now

compile my health register. In this notebook, he took care to write in large letters the doctor's advice as follow-up and reminder for me. I had to show this notebook to my grandparents once back in Foumban so that they would know exactly what the doctor asked." This verbatim provides information on the family support that Tina has in connection with her care. However, this help is a source of suffering for this teenager; it does not involve her in the care process, it grants her the status of a passive subject whose role is to observe "to the letter" the "doctor's instructions" under the supervision of her grandparents and her step-parent. We clearly see that the family and medical overprotection of this teenager does not allow her to talk about her illness and to express herself as an affected person. This overprotection hinders, for her, the process of developing her illness while keeping it strange for her, arousing anger in her against her family and against the caregivers.

Psychological impact of the relationship with her grandmother on Tina's experience

Tina, however, recalls that long before her status was confirmed, her grandmother had questions about her: "It's as if you were a farm chicken. Who is this girl who is sick every day? Who is the man who will agree to marry a woman who is so weak and always sick? ". Tina thus constituted a strangeness for her grandmother who had difficulty making sense of her illness. This strangeness of Tina's illness and, therefore, of herself as a person with this illness, was a source of anxiety for her grandmother about her future. This grandmother is indeed worried about the future family of her granddaughter, who is considered disabled in the quest for a partner to start a home and have children to continue the family line. Sickle cell disease is thus seen as a source of handicap in Tina's parenting process. It is an illness which, according to the patient's grandmother, is likely to hinder her becoming a parent, her becoming a mother so to speak. The grandmother's anxiety relates more to Tina's possible inability, due to her illness, to sustain the life of her family group by giving them children.

Faced with Tina's physical fragility, the grandmother sets up a special act of adoption for this child who is different from the others. This act, which sometimes contrasts with medical prescriptions, is designed to strengthen the affected child's resilience to the disease. Tina actually says that "Every time I reminded the grandmother that the doctor had forbidden this or that thing, she would tell me to go and stay at his house. For this purpose, I am woken up at 5:30 a.m. to go wash the dishes and wash the floor, all with cold water. I then have to help grandmother transport her packages to the place of sale. Afterwards, I have to personally prepare for school. If I have to exhaust myself like that every day, I might lose the reflex to take my tablets." This act of adoption consisting of not overprotecting the child because of his illness is, for the grandmother, a means of fighting the handicap she presents compared to other children. Even if it can be perceived as mistreatment of this child by her grandmother, this act of adoption aims, as stated above, to develop in this child resilience in the face of the adversity represented by her illness. Tina specifies that "Taking medication every day for my grandmother is like a waste of time."

The relationship maintained by the grandmother with Tina's medical care contrasts with that maintained by the latter with her care. Sickle cell disease is in fact thought of

by the grandmother in terms of an expensive, incurable and non-chronic illness, the affected child in terms of his imminent death. However, Tina invests in her care, her medical treatment and taking her medications. She explains: “When I was worried because my tablets were running out and I was asking my grandfather about it, the grandmother scolded me loudly in these terms: “What money for what medicines? Have you been told that you will even get better one day? Even if you drink all the medicines, your illness never ends. So, if your medication ends, you’ll have to wait. Unless your mother sends money from Yaoundé, I’m not going to accept starving for your medicine, you’re already like AIDS patients, you don’t know that it’s poison. Through this verbatim, we understand the anger that this young girl experiences against her grandmother who, because of the high cost of her treatment, threatens not to “starve to death” because of the purchase of her medication. She is in fact opposed to her treatments, which she does not perceive to be effective in treating crises; her medications ease the seizures, but do not eliminate them. From then on, they are thought of as poison by the grandmother.

The devaluation of Tina’s medical treatment by her grandmother is understandable, by its inclusion in the cultural register in connection with sickle cell anemia. This disease is, far from being a genetic disease, thought of as the consequence and manifestation of the persecution of the child affected by sorcerers. Treatment of the affected child in conventional Western medicine is considered inappropriate and not effective. The grandmother’s cultural beliefs regarding sickle cell anemia constitute an obstacle to her adherence to her granddaughter’s treatment in conventional Western medicine. Tina points out: “My grandmother started talking about witchcraft regarding my illness. One day, when we were coming home from the hospital after a three-day hospitalization for severe anemia, she said that my blood is running out regularly because the witches are after me. When the afternoon arrived, she introduced me to a marabout who began to give me traditional products to fight evil witches. Despite my refusal to take these products, my grandmother continued to insist by affirming that: it is when witches eat people at night that their blood ends and we will see it in the hospital. This verbatim provides information on the suffering that the young patient experiences regarding her care; her refusal of the traditional treatment proposed by the grandmother. This refusal and this suffering mark her differentiation from her grandmother. She actually refuses to give meaning to her illness by relying on cultural beliefs.

The relationship with peers, an obstacle to compliance with care

Tina maintains friendly ties with children from her school environment. She interacts with these children on a daily basis and usually takes her seizure medication in their presence. This arouses curiosity among her friends about these medications and the illness Tina suffers from. She points out that “One day, three comrades started saying that my illness is like AIDS because I drink the medicine all the time. These words hurt me, especially since two daughters of these three comrades were like my own sisters. These words, the mockery and the humiliations from friends and family gradually became a problem for me. Caught as if in a whirlwind, I gradually began to pretend to drink the medicine.” Tina therefore stops taking medication so as not to be rejected by her peers.

The results underscore the complex interplay between cultural beliefs and medical adherence in the management of chronic illnesses. In many African communities, diseases like sickle cell are not only seen through a medical lens but also interpreted through cultural narratives that attribute illness to supernatural causes (Tsala Tsala, 2009a). Such perceptions can significantly affect the psychological well-being of the patient and complicate the roles of caregivers, as evidenced by the grandmother’s mixed responses to Tina’s medical needs. Ethically, this raises concerns about the autonomy of adolescent patients in managing their health and the extent to which cultural beliefs should be integrated into medical treatment plans.

This study suggests a need for medical practitioners and health policy-makers to consider cultural competencies in the treatment plans for chronic diseases in culturally diverse settings. Engaging with and educating families about the medical realities of diseases while respecting cultural sensitivities could bridge the gap between traditional beliefs and medical science, ultimately improving therapeutic outcomes (Richard, Mubiri, & Bioy, 2014).

DISCUSSION

This study’s findings underscore the significant role of cultural beliefs in medical compliance, as demonstrated through the interactions between Tina and her grandmother. Applying theories from medical anthropology, particularly Arthur Kleinman’s explanatory models, we understand that the grandmother’s beliefs are not merely traditional but are deeply rooted in the cultural understanding of health and illness within their community (Kleinman, 1980). These beliefs influence her responses to biomedical treatments and advice, presenting a clear dichotomy between cultural practices and medical recommendations, which significantly impacts Tina’s adherence to her treatment regimen.

The results show how Tina adapts to her illness and treatment by investing in medical care to the detriment of the traditional beliefs developed by her grandmother around her illness. She refuses to accept these beliefs, to the point of entering into conflict with her grandmother who forbids her from taking her medication. These results show that this patient registers her illness in a Western medical register from which she gives it meaning. This relationship to illness and care contrasts with that described by recent literature (Dong & Njifon Nsangou, 2022; Njifon Nsangou, 2022a; Njifon Nsangou & Scelles, 2021), who discuss the conflict between traditional beliefs and modern medical practices in the treatment of sickle cell disease in Cameroon. Contrary to studies that suggest a high level of acceptance of biomedical treatment among urban populations (Richard, Mubiri, & Bioy, 2014), our study reveals persistent reliance on traditional beliefs in rural settings, complicating compliance and overall disease management. This critical examination of existing studies highlights the diverse responses to sickle cell disease treatment across different cultural landscapes.

The disinvestment in traditional beliefs and care related to sickle cell anemia is, for Tina, contrasted by the overinvestment in her friendly relationships. More than family ties, friendly ties constitute, for Tina, a space to contain her illness. Less than family ties, Tina’s friendly ties are a source of considerable psychological vigilance. In her relationships with her friends, she strives to hide her symptoms and everything related to her illness from them, with the consequence of not taking the treatment.

The results of this research show a need to strengthen the capacity to contain persuasive communication, which is likely to lead to medical “procrastination”, non-compliance with care. Persuasion “is a change in beliefs and attitudes resulting from exposure to communication” (Zbinden, 2011). In this sense, it is a question of helping patients to be less persuaded by people who, through their behavior, their thoughts and their words regarding the illness and care, can hinder their therapeutic compliance. The language in favor of medical procrastination does indeed take the form of the actions, words, gestures, judgments, and assessments of the people with whom patients interact. It is necessary to understand these acts and the processes by which they influence patients to the point of making them less compliant with care. These behaviors are as numerous as they are diverse, with the common point being their power to subjugate the patient. They can be described as follows:

- Aggressive behavior: “discouraging the child, insulting her, denigrating her, hitting her”;
- Demeaning assessments and judgments for the affected person: “farm chicken, weak, etc. » ;
- Comparisons: “sickle cell patient = AIDS patient = imminent death of the affected person”;
- The blurring of information: locate the origin of sickle cell anemia in witchcraft, the anemia is caused by the fact that vampires suck blood, the fact that sorcerers are behind the patient.

Adolescents are known to be familiar with unreasonable behavior and predisposed to “disobedience” (Zbinden, 2011). Therefore, the adolescent process can give meaning to Tina's non-compliance with medical prescriptions. She disobeys these prescriptions, not only to feel autonomous in the care process, but also to construct her own identity, different from that given to her by her illness and the people with whom she interacts (grandmother, caregivers, and friends) in the situation of his illness.

Furthermore, in the therapeutic education of chronically ill patients, emphasis must be placed on the deconstruction of a lexicology likely to lead chronic patients towards acts or behaviors of medical procrastination, mediating therapeutic non-compliance among the latter. On one hand, it will involve listing the words and ailments of each patient in relation to their illness and leading them to elaborate on them in order to tame them. On the other hand, it will be a question of listing the stories which reflect, in the background, the suggestibility of patients to negative behaviors (likely to hinder their therapeutic compliance) coming from subjects who are members of their families or external to them. From these life stories, it is necessary to transmit to patients objective data, scientific knowledge about their illness and to discuss with them the way in which they received or welcome this knowledge. This work of elaborating the illness from the daily experience of patients can help them to contain and transform into resources their fears and anxieties generated by the illness.

To improve outcomes for patients like Tina, healthcare systems need to develop culturally competent practices that respect and integrate local beliefs into treatment plans. This could involve training for healthcare providers on cultural sensitivity and the inclusion of family members in therapeutic education programs to bridge the gap between cultural beliefs and medical advice (Tsala Tsala, 2009b). Such integrative approaches can enhance compliance and foster better relationships between healthcare providers and communities.

Addressing cultural myths and enhancing awareness about sickle cell disease management are crucial. Designing health education programs that are culturally sensitive and accessible to communities like Tina's can help demystify the disease and promote acceptance of medical treatments. Collaborative efforts involving local leaders and healers could also be employed to disseminate accurate information and co-create interventions that respect cultural norms while promoting scientifically sound medical practices.

STUDY LIMITATIONS AND FUTURE DIRECTIONS

While this study provides insights into the complex dynamics of managing sickle cell disease in a culturally rich context, its limitations include the potential lack of generalizability due to its focus on a single case study. The qualitative nature of this research might also introduce biases in data interpretation, underscoring the need for quantitative studies to validate these findings across broader populations. Future studies should consider multi-disciplinary approaches involving psychologists, anthropologists, and medical professionals to explore the complexities of therapy compliance in culturally diverse settings. Investigating the interplay of cultural, psychological, and biomedical factors in a larger cohort could provide a more comprehensive understanding of the barriers to and facilitators of treatment adherence.

Incorporating local knowledge and practices into treatment strategies could potentially enhance the effectiveness of medical interventions. Understanding and respecting the values and beliefs of families affected by sickle cell disease can lead to more acceptable and effective healthcare solutions, tailored to meet the specific needs and expectations of the community.

CONCLUSION

This research has illuminated the complex interplay between cultural beliefs and medical adherence in the management of sickle cell disease in Cameroon, offering significant insights for both clinical practice and health policy. The findings suggest that integrating cultural understanding into the treatment process could significantly enhance compliance and overall patient well-being. For instance, incorporating family members more actively in the therapeutic process, while educating them about the disease, can bridge the gap between cultural beliefs and medical requirements, thus improving patient outcomes (Richard, Mubiri, & Bioy, 2014). The study's application of psychosocial adjustment and family systems theories has been instrumental in highlighting how familial attitudes and the social environment influence the health behaviors of adolescents with chronic illnesses. The findings challenge the notion that medical compliance is solely a matter of individual responsibility and instead place significant emphasis on the socio-cultural context, thereby supporting and extending existing theories (Kleinman, 1980).

Reflecting on the research process, it becomes evident that deeper engagements with the participants' broader community might have yielded additional insights into communal beliefs that impact treatment behaviors. Learning from this, future research should consider broader community engagement to enrich the data collection process. This study distinguishes itself by focusing on the underexplored role of grandparents in the

care of adolescents with sickle cell disease in a Cameroonian context. Unlike previous studies that predominantly focus on parental roles, this research highlights the critical influence of extended family members, thus contributing a new dimension to the existing literature on chronic illness management in cultural contexts (Ciccone, 2012).

Declaration

- The authors would like to thank Wambokno Tcholahie pulcherie for crosschecking this work.
- The authors declare that they have no conflicts of interest

REFERENCES

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp0630a>
- Ciccone, A. (2012). *La transmission psychique inconsciente: Identification projective et fantasme de transmission* (2e édition refondue, mise à jour et augmentée). Dunod.
- Dong, T., & Njifon Nsangou, H. (2022). Le travail de la souffrance au cours d'une situation de handicap : Le cas de la drépanocytose. *Annales Médico-psychologiques, revue psychiatrique*, 180(2), 133-140. <https://doi.org/10.1016/j.amp.2021.11.001>
- Drepavie. (2006). *Intégrer le problème de santé publique de la drépanocytose lors de l'EPU du Cameroun*.
- Ezembé, F. (2009). *Familles africaines en thérapie: Clinique de la famille camerounaise*. L' Harmattan.
- Haute Autorité de Santé. (2005). *Prise en charge de la drépanocytose chez l'enfant et l'adolescent*. www.has-sante.fr
- Kleinman, A. (1980). *Patients and healers in the context of culture*. University of California Press.
- Lavarde, A. M. (2008). *Guide méthodologique de la recherche en psychologie*. De Boeck.
- Njifon Nsangou, H. (2019). *Drépanocytose et fratrie: Une étude clinique exploratoire du vécu des frères et sœurs d'enfants atteints en contexte culturel camerounais* [Phdthesis, Université de Nanterre - Paris X]. <https://tel.archives-ouvertes.fr/tel-03092288>
- Njifon Nsangou, H. (2022a). La drépanocytose et la dyade mère-enfant au Cameroun. *Cahiers de la puéricultrice*, 59(354), 31-33.
- Njifon Nsangou, H. (2022b). Le vécu de mères d'enfants atteints de drépanocytose en contexte d'hospitalisation au Cameroun. *Cahiers de la puéricultrice*, 59(355), 32-37. <https://doi.org/10.1016/j.cahpu.2022.01.010>
- Njifon Nsangou, H., Falck, J., & Scelles, R. (2020). Culture familiale de la drépanocytose et image du corps chez les enfants atteints. *Annales Médico-psychologiques, revue psychiatrique*, 178(2), 827-836. <https://doi.org/10.1016/j.amp.2019.10.004>
- Njifon Nsangou, H., & Scelles, R. (2019). Drépanocytose et fratrie : Regard croisé du vécu d'une sœur et d'un frère d'un enfant malade. *Journal de Pédiatrie et de Puériculture*, 32(2), 75-84. <https://doi.org/10.1016/j.jpp.2019.02.005>
- Njifon Nsangou, H., & Scelles, R. (2020). The Psychological Impact of Sickle Cell Disease on the Sick Child's Family. *Acta Scientific Paediatrics*, 3(1), 01-09. <https://actascientific.com/ASPE/ASPE-02-0209.php>
- Njifon Nsangou, H., & Scelles, R. (2021). Sickle Cell Anemia, Representations and Care: Experience of a Brother of a Sick Child in Cameroon. In O. Erhabor & A. Munchi (Éds.), *Human Blood Group Systems and Haemoglobinopathies* (p. 472-478). Intechopen. <https://www.intechopen.com/books/human-blood-group-systems-and-haemoglobinopathies>
- Organisation Mondiale de la Santé. (2006). *La drépanocytose dans la région africaine: situation actuelle et perspectives, (56e session du Comité Régional de l'Afrique - Rapport du Directeur régional)*. Organisation Mondiale de la Santé. http://afro.who.int/sites/default/files/sessions/working_documents/AFR%20RC56%2023%20SEPTIEME%20CONFERENCE%20MONDIALE%20PROMOTION_fr_0.pdf
- Richard, M., Mubiri, M.-A., & Bioy, A. (2014). Repères psychologiques et développementaux chez le patient drépanocytaire. *Douleurs Evaluation - Diagnostic - Traitement*, 15, 278-287.
- Tabiana-Rufi, N. (2009). Education thérapeutique des enfants et adolescents atteints de la maladie chronique. *Med*, 38(12).
- Tsala Tsala, J.-P. (1996). Grossesse et interdits chez la femme Beti du Sud Cameroun. *Cahiers de sociologie économique et culturelle: ethnopsychologie: revue internationale*.
- Tsala Tsala, J.-P. (2009a). La mère camerounaise et son enfant drépanocytaire. In J.-P. Tsala Tsala, *Familles africaines en thérapie. Clinique de la famille Camerounaise* (p. 165-177). L' Harmattan.
- Tsala Tsala, J.-P. (2009b). *Familles africaines en thérapie: Clinique de la famille camerounaise*. Editions L' Harmattan.
- Zbinden, A. (2011). *Communication engageante et Représentations sociales: une nouvelle articulation théorique*. L' Université de Bourgogne.
- Zempléni, A. (1968). *L'interprétation et la thérapie traditionnelle du désordre mental chez les Wolof et les Lébou du Sénégal* [Thèse de Doctorat en Psychologie]. Université de Paris.

This page has been intentionally left blank