ClinicoEconomics and Outcomes Research

Dovepress
Taylor & Francis Group

Open Access Full Text Article

ORIGINAL RESEARCH

Socio-Economic Impacts of Childhood Sickle Cell Disease on Households in Lubumbashi: An Exploratory Mixed-Methods Study

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Introduction: Sickle cell disease is a common genetic disorder in Africa, particularly In the Democratic Republic of Congo (DRC), sickle cell disease causes anemia, pain, and complications in young children. It places a heavy burden on families, both medically and economically, especially in the absence of support or health insurance. This study examines how this disease affects the daily lives of households in Lubumbashi.

Methods: This mixed-methods study combined quantitative and qualitative approaches to explore the impact of sickle cell disease on households with children in Lubumbashi. It included 70 children aged 0 to 15 years and their families, with data collected from hospital records and in-depth semi-structured interviews. The data were analyzed using descriptive statistics for the quantitative component and thematic analysis for the qualitative component, thus integrating statistics and personal accounts for a comprehensive understanding of family life.

Results: The study showed that children with sickle cell disease, mostly aged 0 to 5 years, experience frequent painful crises that disrupt their daily lives and those of their families. Treatment, often symptomatic and costly, leads to repeated hospitalizations, stress, and income loss for parents. The disease also affects children's schooling and social lives, with learning difficulties and frequent stigmatization. Limited access to hydroxyurea and regular follow-up care exacerbates the vulnerability of families. They express an urgent need for financial, psychological, and educational support, as well as improved access to treatments and healthcare facilities.

Conclusion: Sickle cell disease profoundly disrupts the lives of children and their families, causing painful crises, hospitalizations, and academic and financial difficulties. Early screening, access to hydroxyurea, prophylaxis, and specialized clinics, combined with educational and psychosocial support, could improve their daily lives. Solidarity-based financing mechanisms or targeted subsidies are essential to alleviate the economic burden on families.

Keywords: sickle cell disease, crisis, socioeconomic impact, households, Lubumbashi

Introduction

Sickle cell disease is a clinically recessive, biologically codominant, autosomal dominant hereditary disorder characterized by the presence of an abnormal hemoglobin called hemoglobin S in red blood cells.[1,2] It causes several problems, including anemia, painful episodes, and an increased risk of infections, and is associated with episodes of acute illness and progressive organ damage.[2,3] Nearly 500 million individuals carry the sickle cell trait,[1,2] and it is the most common genetic disease worldwide and the fourth leading cause of pandemics in Africa.[2,4] In Africa, its prevalence increases from west to east and north to south: the sickle cell trait prevalence rises from 15% in Senegal to over 40% in Central Africa.[2,4] Tanzania ranks fifth globally in terms of birth prevalence of sickle cell disease,[5,6] and in Uganda, 15,000 babies are born with sickle cell disease each year.[7]

https://doi.org/10.2147/CEOR.S571343
Received: 30 September 2025
Accepted: 4 February 2026
Published: 7 February 2026

The DRC is the second most affected country in Africa after Nigeria, with approximately 40,000 births of children with sickle cell disease recorded annually.[1,8] Studies conducted in the DRC in the city of Lubumbashi in 2020 and in Butembo in 2022 found a prevalence of 5.01% and 2.67% of newborns with sickle cell disease, respectively.[9,10] Sickle cell disease is a burden on families and the national economy due to the cost of laboratory tests, hospitalizations, travel, and school absenteeism. In our countries, health insurance mechanisms do not exist, and many affected families lack sufficient income to pay for treatment.[11–13] Parents live in poverty, lacking social security and knowledge of how to manage crises at home. These sickle cell crises lead to unexpected family expenses, the management of which requires significant resources throughout a lifetime;[5,6,14] thus, poverty constitutes a major obstacle to managing this disease.[6,14]

The objective of this study is to explore the socioeconomic repercussions of sickle cell disease on households with children living in Lubumbashi.

Methodology

We conducted a mixed study, combining quantitative and qualitative approaches, in order to better understand the impact of sickle cell disease on households with children living in Lubumbashi (DRC). The study took place over three months, from January 20 to April 20, 2025, in households in the city of Lubumbashi. The study population consisted of children aged 0 to 15 years with sickle cell disease, receiving care in health facilities in Lubumbashi. Their households were chosen for their daily experiences, which reflect socio-economic realities. All children within the specified age range whose households agreed to participate were included in this study, while children over 15 years old and those whose parents refused to participate were excluded. We chose this dual approach, whereby quantitative data allows us to measure the extent of the difficulties encountered, while the testimonies of families provide a human and social depth to these figures. We adopted a sequential explanatory design: the statistical results served as a basis, and the qualitative interviews illuminated them by providing meaning and context. Both components were therefore integrated from the participant selection stage and during the final interpretation of the results.

Quantitative Component

Inclusion Criteria

Children meeting all of the following criteria were included in the study:

- Being between 0 and 15 years old at the time of the survey; - Having a confirmed diagnosis of sickle cell disease, recorded in the consultation or hospitalization records of the pediatric services; - Having been seen for consultation or hospitalized in one of the three hospitals participating in the study during the period from January 20 to April 20, 2025; - Residering in Lubumbashi; - Having a parent or legal guardian who has given informed consent for the child and household's participation in the study.

Exclusion Criteria

Children over 15 years of age and those whose parents or guardians refused to participate in the study were not included. Data were collected from consultation records and hospitalization records of the pediatric departments of the three hospitals.

Qualitative Component

To better understand the families' experiences, we conducted semi-structured interviews with the parents or guardians of the included children. Each interview lasted on average 20 to 30 minutes and took place in a location chosen by the families to foster a climate of trust. The discussions focused on three themes:

1. The difficulties 1. Daily encounters, 2. The impact of the illness on the child's school and social life, and 3. The solutions that households are considering.

The interviews, conducted in French or Swahili, were recorded (using a Sony voice recorder and a Tecno Camon 18 smartphone), then transcribed and translated into French. A double-check ensured the accuracy of the translations. Data collection continued until saturation was reached. These interviews were recorded using two devices: a Sony 2022 voice recorder and a Tecno Camon 18 Android device. The interviews were conducted by the principal investigator, assisted by a note-

taker, with parallel analysis during data collection until data saturation was reached. Conducted in French and Swahili, they were transcribed and then translated, with consistency between versions verified through double translation and harmonization in case of discrepancies. A pre-tested interview guide and questionnaire were used and then adapted to local conditions.

Data Analysis

- Quantitative data underwent descriptive analysis using Microsoft Excel 2016 and then STATA 15.1.
- Qualitative data were analyzed using thematic analysis with ATLAS.ti 6. After careful review, the interviews were coded, emerging categories were refined, and the results were validated through triangulation between the principal investigator and the co-investigator. The study received approval from the Ethics Committee of the University of Lubumbashi (No. 028/CEM/UNILU/ESU/2025). The ethical regulations set out in the Helsinki Declaration were followed throughout the study. Participants were fully informed of the study's objective and that the oral informed consent process was acceptable and approved by the ethics committee. Oral consent, recorded before each interview, was obtained from the parents and included the publication of anonymized responses/direct quotes.

Results

Sociodemographic Characteristics of Households of Children with Sickle Cell Disease

During our study, we identified 70 children with sickle cell disease, aged 0 to 15 years. The characteristics of their households (Table 1) show that the majority of children were between 0 and 5 years old (51.4%), with a slight

Table 1 Sociodemographic Characteristics of Households with Children Affected by Sickle Cell Disease

Variables	**Number (n= 70)**		**Frequency (%)**	
Children's Age (years)	**Median Age= 4,9 years (IQR: 8.2 years)**			
0-5	36		51.4	
6 −10	18		25.7	
11-15	16		22.9	
Children's Sex				
Female	33		47.1	
Male	37		52.9	
Tribes				
Tribes Hemba	8		11.4	
Tribes Luba	24		34.3	
Tribes Rund	6		8.6	
Other Tribes	32		45.7	
Parents' Education Level	Father	Mother	Father	Mother
No Schooling	3	6	4.3	8.6
Primary	9	8	12.9	11.4
Secondary	28	35	40	50
University	30	21	42.9	30

(*Continued*)

Table 1 (Continued).

Variables	**Number (n= 70)**		**Frequency (%)**	
Parents' Occupation	Father	Mother	Father	Mother
Business Owner	20	11	28.6	15.7
Unemployed	6	44	8.6	62.9
Civil Servant	22	8	31.4	11.4
Other	22	7	31.4	10
Marital Status				
Single	8		11.4	
Divorced	9		12.9	
Married	48		68.6	
Widowed	5		7.1	
Number of Children	Non-Sickle Cell	Sickle Cell	Non-Sickle Cell	Sickle Cell
1	19	51	27.2	72.9
2	11	14	15.7	20
3	12	3	17.1	4.3
4 and over	28	2	40	2.9
Family history				
Yes	52		74.3	
Yes	12		25.7	
Membership in a facility				
No	57		81.4	
Yes	13		18.6	
Monthly income Median	**Median = 262 $ (IQR = 298 $)**			
<100 $	16		22.9	
100$-500 $	47		67.2	
> 500 $	7		10	

male predominance (52.9%). The majority of parents belonged to the Luba tribe (34.3%), and more than 70% of both fathers and mothers had a secondary or university education, with fathers more often holding a university degree (42.9%). In terms of employment, the majority of mothers were unemployed (62.9%), unlike fathers, who were more often merchants or civil servants. The majority of parents were married (68.6%). It was noted that most children with sickle cell disease came from families with only one child (72.9%). A family history of sickle cell disease was reported by 25.7% of families, and 81.4% of families were not enrolled in a follow-up program. The monthly income of the majority of households was between $100 and $500 (67.1%).

Clinical, Paraclinical, and Therapeutic Characteristics of Children with Sickle Cell Disease

Age at Diagnosis

The majority of cases are discovered between 0 and 5 years of age, highlighting the importance of early monitoring. Parents often express a period of uncertainty before diagnosis, which is often perceived as a worrying phase. One parent told us:

> When the child is unwell, it reminds me of the beginning. We went through months of uncertainty, not knowing what was wrong. When we finally received the diagnosis, it was a relief, but also a source of anxiety. At first, we thought it was a normal phase of growth, but when the seizures started, we understood that it was something more serious; this feeling of uncertainty is common among families. » P7 [DIIFF-TRAV-SOINS-ENF]

The Most Frequent Type of Crisis

Painful musculoskeletal crises are a daily reality for many, and can have significant consequences on families' daily lives.

> As soon as it gets cold, she becomes weak; she can't stand the cold. During the dry season, she suffers terribly. It reminds me of her first crisis; it was just another day. My child started crying in pain for no apparent reason; that's when we knew there was a serious problem. P25 [DIIFF-TRAV-SOINS-ENF]

Paraclinical Examinations Already Performed

Paraclinical examinations, such as blood tests and X-rays, were regularly performed. However, these examinations are often perceived as stressful by children and their parents. One parent emphasized:

> It's not easy to live with, but my child needs support for these exams. They are distressing, and it's difficult to reassure them every time they have to undergo an exam. I feel terrible anxiety. I know it has to be done, but it's hard to bear. P48 [DIIFF-TRAV-SOINS-ENF]

The Average Number of Seizures per Year

In most cases, families report two to three seizures per year. These are often unpredictable, but significant enough to disrupt family life and are a source of stress and strain. One parent explained:

> The stress, the fear of losing your child even if it's only twice a year—each seizure is an ordeal…you never know how it's going to go. » P54 [DIIFF-TRAV-SOINS-ENF]

Duration of Crises

The average length of hospital stay during crises was 9 days, which can severely disrupt family life. One parent noted:

> Because of my child's illness, it takes a lot of effort to care for him. The crises often occur at night, and this disrupts everyone at home. We never know when it's going to happen, and these crises sometimes last more than a week. Sometimes we have to take him to the hospital urgently. And it's very tiring. P57 [DIIFF-TRAV-SOINS-ENF]

Average Number of Hospitalizations per Year

The testimonies gathered indicate that the majority of children with sickle cell disease are hospitalized at least two to three times a year, in connection with crisis episodes. The parents interviewed described hospitalizations as a difficult experience, both emotionally and logistically:

> With the heartbreak I currently have because of my son, hospitalizations. We know they're coming, we just don't know when. It's always a difficult time. P42 [DIIFF-TRAV-SOINS-ENF]

Medical Follow-Up of Care

The interviews revealed that the majority of children do not receive regular medical follow-up. One parent explained:

> Regarding my child's illness, we only go to the hospital when things get really bad; otherwise, we stay home. P39 [DIIFF-TRAV-SOINS-ENF]

Usual Treatment

The analysis revealed that children with sickle cell disease receive treatment primarily focused on managing symptoms. Pain relievers, vitamins (especially folic acid), and antibiotics in case of infection are the most commonly used medications. Some parents report using hydroxyurea, but access to it remains limited. One parent reports:

> When you have a sick child, your whole life is turned upside down. Sometimes I can't afford to buy all the medications, so I give what I can, but it's not always enough. P38 [DIIFF-TRAV-SOINS-ENF]

The Economic Burden

The Direct Cost of Care During Hospitalizations

Interviews with parents indicate that hospitalization is the main financial burden. Direct costs include admission fees, room and board, additional tests, medication purchases, and related consultations. These expenses are paid directly by households, without any systematic coverage mechanism.

One parent testifies:

> It was mainly a question of saving money during my child's last crisis; I was completely lost. Hospital fees were piling up quickly; I spent over $100 on medications and tests. And yet, we hadn't even budgeted for it for the month, and it put us in financial difficulty. » P34 [DIIFF-TRAV-SOINS-ENF]

The Direct Cost of Outpatient Care

Outpatient care, essential for monitoring children with sickle cell disease, also generates recurring costs: medical consultations, prophylactic treatments, regular blood tests, and transportation to healthcare facilities. These expenses, although more spread out, accumulate and weigh heavily on household monthly income.

One parent shared with us:

> Well, the situation is difficult all the time. I have to buy his medication every month and repeat his tests even when he's not having an attack. Sometimes I have to choose between his follow-up care and putting food on the table P32 [DIIFF-TRAV-SOINS-ENF]

> Yes, in fact, with this illness, the costs aren't limited to medical visits. There's also the transportation to get to appointments. This can become exorbitant. Every trip is a source of stress. P25 [DIIFF-TRAV-SOINS-ENF]

Indirect Costs

Indirect costs mainly concern the loss of income due to parents' absences from work to accompany the child to medical appointments or during extended hospitalizations. Added to this are unexpected household expenses (childcare, family support). These costs are less visible but further destabilize the economic balance of households. Parents mentioned that:

> I want people to understand that the economic burden isn't just about money; it's also emotionally exhausting. It affects our family on every level. P9 [DIIFF-TRAV-SOINS-ENF]

> Crises don't give any warning. As a working mother, I have to be available for both the child and work. It's not easy, especially since my job is demanding. When the child has a seizure, I have to ask to leave, and it's a recurring problem. It's also difficult to find someone available to stay with the child in the hospital. P40 [DIIFF-TRAV-SOINS-ENF]

> My child has put me in serious difficulty. And at the end of the month, I'm almost completely broke. Fatigue is another dimension. I'm exhausted not only from caring for my child but also from the constant financial stress. This affects our entire family. » P6 [DIIFF-TRAV-SOINS-ENF]

Intangible Costs

Beyond the financial aspects, families experience intangible costs that are difficult to quantify: psychological stress, anxiety related to the child's survival, and the impact on social and academic life. These dimensions, although non-monetary, must be recognized as an integral part of the overall burden of sickle cell disease.

The Social Impact of the Disease and Proposed Solutions

The Difficulties Faced by Parents in Balancing Work and Caring for Children with Sickle Cell Disease

Parents of children with sickle cell disease face considerable challenges. Here are some illustrative accounts:

> Generally, the biggest difficulty is fatigue and stress.
>
> The stress of thinking that the child will have another crisis, that we'll have to go to the hospital, think about medical care. It's this constant stress that we live with. » P21 [DIIFF-TRAV-SOINS-ENF]
>
> The difficulties are numerous: financial, emotional, psychological. Even the family is starting to abandon us, as if this child were a burden. […] To be honest, I'm having a lot of trouble. Financially, it's very complicated. There's the stress, the pain related to my child's illness. Seeing him suffer tears me apart. Society's judgment is also a heavy burden. […] The care is extremely expensive. I can no longer take proper care of him, or his brothers and sisters. He takes up all my time. I don't even know where to turn anymore. P36 [DIIFF-TRAV-SOINS-ENF]
>
> The cost of care is high, and sometimes we have to think about work and illness; that's what costs us so much. P71 [DIIFF-TRAV-SOINS-ENF]
>
> In my opinion, the difficulty lies in the financial resources because when he has his seizures at night, given the security situation in the country, and the lack of transportation and the fact that health centers are not nearby, it's really difficult. P15 [DIIFF-TRAV-SOINS-ENF]

The Impact of Sickle Cell Disease on a Child's School and Social Life

The disease has significant repercussions on a child's school and social life. Here are some testimonies from parents:

> The discrimination starts first within the family, with her siblings, but also in society, with other children, neighbors, etc. P1 [REPERC-MAL -VI-ENF]
>
> She's a brave child, but she has academic difficulties. Every time she (the child) gets sick, she misses school. Sometimes, she has to repeat a grade simply because she was sick for too long and couldn't finish the year. So she's behind in her schooling. P4 [REPERC-MAL -VI-ENF]
>
> He's subjected to criticism and mockery from some people who say to him, 'You're always sick.' This has a psychological impact on him. » P11 [REPERC-MAL -VI-ENF]
>
> Yes, indeed. He's a bit marginalized. He's grown up, he goes to school. But as soon as he understood that the disease is fatal, it deeply affected him. He's often preoccupied, worried, and he cries often. Even if we try to comfort him, sometimes it's not enough. P42 [REPERC-MAL -VI-ENF]
>
> To be honest, it's complicated. We encourage him a lot, we talk to him so that he accepts himself and leads a normal life. But there's still a bit of discrimination. He doesn't feel like the others. He often gets sick, he misses school, he interrupts classes for treatment. So yes, there are academic delays and social difficulties. P63 [REPERC-MAL -VI-ENF]
>
> The other children are afraid to touch him and even to play with him, thinking that he'll infect them. » P56 [REPERC-MAL -VI-ENF]

Solutions Envisioned by Parents to Improve the Care of Their Children with Sickle Cell Disease

The daily challenges faced by parents of children with sickle cell disease are often overwhelming. However, many yearn for concrete solutions to improve their situation and that of their child. Here is an overview of the solutions these parents desire, illustrated by their testimonies:

A support group for parents of children with sickle cell disease would be a good thing; it would allow us to exchange ideas, share experiences, and see how others manage their children's health. P4 [SOL-AMEL-SUIV-ENF]

We need NGOs to provide free care for our children and, where possible, to locate centers nearby for appropriate care, as we currently have to travel to the city center. » P15 [SOL-AMEL-SUIV-ENF]

First and foremost, we need financial assistance. Caring for him requires enormous resources. Psychological support for the whole family would also be very helpful. […] Better access to treatments, which are very expensive, as well as support groups with other families facing the same situation, would help us share experiences. P36 [SOL-AMEL-SUIV-ENF]

I hope there will be solutions to reduce the cost of vaccines and medications and to simplify the procedures related to care. P34 [SOL-AMEL-SUIV-ENF]

Anyone who comes to talk to us about this illness is welcome. We need support. P38 [SOL-AMEL-SUIV-ENF]

Discussion

Sociodemographic Characteristics of Households with Children Affected by Sickle Cell Disease

In our study, the majority of children with sickle cell disease were between 0 and 5 years old. This age group corresponds to a period of great vulnerability, during which complications are frequent and sometimes serious. Katamea T. et al had already shown in Lubumbashi that early childhood represents a critical stage of the disease, which confirms the importance of close monitoring from the first months of life.[5] We also observed a slight male predominance, consistent with other Congolese studies.[12] The parents' level of education, particularly that of mothers, remained generally limited to secondary school. This has direct consequences on their understanding of the disease and on their ability to follow recommendations.

In other words, it is not only a medical issue but also an educational one. Economically, the majority of mothers did not have formal employment, while the fathers most often worked in the public sector, with modest incomes. This profile reflects a well-known reality in the DRC: families struggling with limited resources to meet significant and recurring medical needs.[9] The social impact is palpable: some marriages do not withstand the psychological and financial pressure, as illustrated by the divorce rate, which is higher than the national average.

Finally, many parents reported not knowing of any family history of sickle cell disease. This finding, typically African, is explained by the lack of systematic neonatal screening, unlike in Europe where this type of program makes it easier to identify healthy carriers and inform families.[2,13]

Clinical, Paraclinical, and Therapeutic Parameters

The diagnosis of the disease was most often made after a painful attack or a severe infection, ie, late in the course of treatment. This illustrates a delay in care, already highlighted in other Congolese studies.[5] Families often recount a difficult journey, marked by multiple consultations before the diagnosis was confirmed.

Attacks were frequent, averaging two to three per year, and each episode meant days of hospitalization, unexpected expenses, and great suffering for both the child and their parents. These observations are consistent with those made by Banza et al.[12] In contrast, European data show that regular monitoring and preventive treatments drastically reduce the frequency of these attacks.[13] In the DRC, treatment remains essentially symptomatic: analgesics, antibiotics, and transfusions. Hydroxyurea, although validated by several large African trials such as REACH,[3,4] remains underutilized due to a lack of accessibility and information. This molecule has proven its efficacy and safety in our context. It therefore represents a priority avenue for improving children's daily lives.

Economic Burden

Behind every hospitalization lies a painful equation for families: how to pay? Direct expenses (medications, hospitalization) often absorb more than an average monthly income. Indirect costs—lost workdays, transportation, disrupted family

life—weigh even more heavily.[15,16] In Tanzania, for example, it has been shown that indirect costs can exceed medical expenses themselves.[15] Our results, like those of other African teams, confirm this reality: sickle cell disease is not limited to physical suffering; it impoverishes households. However, experiences with health insurance in East Africa show that solutions exist, such as prepayment mechanisms and targeted coverage, that can reduce catastrophic expenses related to sickle cell disease,[15,16] and that they could be adapted in the DRC.

Social Impact

Sickle cell disease not only affects the body, but also disrupts lives. Many parents in our study described a heavy burden, marked by the high cost of care and the lack of psychological or financial support.[6,17]

In children, repeated absences from school, chronic fatigue, and peer stigmatization often lead to educational delays and a feeling of isolation. Here again, the findings align with those of the Lancet Haematology Commission.[2] In European countries, families benefit from social programs and support networks.[13,18] In the DRC, this dimension remains largely absent, leaving parents to face their difficulties alone.

Policy Perspectives and Implications

Globally, the WHO reports that 7.74 million people are currently living with sickle cell disease and that approximately 515,000 children are born with the disease each year, the vast majority in sub-Saharan Africa.[1] These figures place our findings in a broader context and highlight the scale of the challenge.

In the DRC, recent data from neonatal screening in Lubumbashi[5] demonstrate the potential for earlier identification of affected children and the implementation of appropriate care. This supports the nationwide rollout of systematic screening.

Major international guidelines, whether the recommendations of the Lancet Commission[2] or the new WHO guidelines for sickle cell pregnancy,[1] all emphasize an integrated approach: neonatal screening, infection prevention, expanded access to hydroxyurea, and strengthened healthcare networks.

Finally, it would be impossible not to mention recent therapeutic advances. In 2023, the FDA approved two gene therapies, exa-cel (Casgevy) and lovo-cel (Lyfgenia), which offer unprecedented possibilities.[19–22] However, their exorbitant cost and the necessary infrastructure currently place them beyond the reach of our healthcare systems. Above all, they serve as a reminder that equitable access to care must remain a priority. This is why, for the DRC as for many African countries, the urgent need is to strengthen basic healthcare now, in order to save lives here and now.

It is important, however, to acknowledge certain limitations of this study. The relatively small sample size, the focus on a single city, and the reliance on self-reported data expose the study to potential biases, including inaccuracies related to parents' recollection of expenses. These factors may limit the generalizability of the results to the entire country.

Despite these limitations, our study provides relevant and contextualized data on the multidimensional burden of sickle cell disease in the DRC. It highlights the urgent need to strengthen basic healthcare and social protection policies in order to sustainably improve the quality of life of children with sickle cell disease and their families.

Conclusion

In conclusion, the results of this study highlight the need to strengthen public health policies for sickle cell disease, particularly in resource-limited settings. The integration of sickle cell disease into national health priorities, the strengthening of decentralized care through approaches such as PEN-Plus is strongly encouraged for the management of sickle cell disease and other severe chronic illnesses, in order to improve local access to essential care and reduce indirect costs borne by families,[20] and the development of protective financing mechanisms could improve equity of access to care and reduce the economic burden on households.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically

reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Funding

This research was funded by the authors' own resources, without external or institutional financial contributions. No commercial funding was solicited.

Disclosure

The authors report no conflicts of interest in this work.

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