International Journal of Science and Research (IJSR)
ISSN: 2319-7064
Impact Factor 2025: 7.089

# Social Management of the Sickle Cell Child in Lubumbashi

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**Abstract:** ***This study analyzes the social management of children with sickle cell disease in Lubumbashi, a Congolese metropolis shaped by complex economic shifts and competitive therapeutic pluralism. To capture the non-medical dimensions of this chronic genetic disease, the research combines House's social support theory with Bronfenbrenner's ecological model of human development. Adopting a qualitative clinical approach with a phenomenological focus, the study utilizes survey questionnaires, document analysis, and semi-structured interviews with parents. The investigation focuses on the socioeconomic determinants of healthcare pathways, domestic dynamics governed by gender relations, and reliance on alternative therapeutic systems. Ultimately, this research contributes to the movement toward humanizing medicine by examining how the community, family, and spiritual environment organize to support or isolate the sick child.***

**Keywords:** Social management, Sickle cell child

## 1. Introduction

Sickle cell disease in Lubumbashi transcends clinical boundaries to become a total social phenomenon: the incurability of the condition and the prohibitive cost of specialized care represent an explicit medical impasse that forces families to navigate a complex therapeutic pluralism-combining emergency biomedicine, traditional medicine, and spiritual care in churches. To understand this support network, the study integrates House's social support theory and Bronfenbrenner's ecological approach to examine the interactions between the child and their living environments. Using a qualitative clinical approach with a phenomenological focus, this research relies on semi-structured interviews and surveys to capture the lived experiences of parents in Lubumbashi facing these crises. The collected data explore the socio-economic determinants of healthcare pathways, the gender divide shaping domestic involvement, and the impact of alternative treatments, whether traditional or religious. Ultimately, this work demonstrates how managing this chronic condition daily serves as a indicator of marital tensions, urban poverty, and survival strategies in contemporary Congolese society.

## 2. Theoretical Foundations

This section presents the theoretical foundations of the study regarding the social management of children with sickle cell disease. It clarifies key concepts, anchors the research within its scientific framework, outlines relevant theories, and highlights related studies.

### 2.1. Definition of Concepts

This section presents the primary concepts related to the study, specifically Social Management and Sickle Cell Child, clarifying their meaning within the context of this research.

#### 2.1.1. Social Management

According to Durkheim (1893), social management refers to the social mechanisms that enable an individual's integration into society through norms, values, and social institutions. Durkheim posits that society exerts a significant influence on individual behavior to ensure social stability and adaptation.

According to Maisonneuve (1973), social management consists of a set of support, guidance, and orientation actions provided by the family, school, and social institutions to foster the individual's integration and harmonious development within their social environment.

For Bronfenbrenner (1979), social management is expressed through the relationships between the individual and the various social environments in which they grow. The author emphasizes that the family, school, healthcare facilities, and the community directly influence the physical, psychological, and social development of the child.

#### 2.1.2. Sickle Cell Child

The World Health Organization (2023) defines a sickle cell child as a child affected by sickle cell disease, a hereditary blood disorder characterized by an abnormality in hemoglobin that causes red blood cells to deform. This disease causes frequent pain, chronic anemia, and several complications affecting the child's health and development.

Graham R. Serjeant (2001) asserts that a child with sickle cell disease suffers from a chronic genetic condition responsible for recurrent vaso-occlusive crises, frequent infections, and physical and social complications. The author stresses the importance of tailored medical and psychosocial care to improve the child's quality of life.

Robert J. Hay (2010) considers the sickle cell child as one exposed to multiple health and social difficulties linked to the progression of the disease. According to Hay, physical limitations, repeated hospitalizations, and school absences hinder the child's social integration and harmonious development.

UNICEF (2019) explains that a child with sickle cell disease requires permanent health, psychological, and social protection due to the impact of the illness on their well-being and development. The organization emphasizes the vital role

of family, school, and community support in managing these children.

### 2.2. Theories of the Study

This section outlines the primary theories used in the study, notably James S. House's Social Support Theory and Urie Bronfenbrenner's Ecological Systems Theory, which provide the conceptual framework for understanding the social management of children with sickle cell disease.

#### 2.2.1. James S. House's Social Support Theory

The social support theory developed by James S. House highlights the importance of social guidance in the lives of individuals living with chronic illnesses. According to this theory, an individual needs emotional, material, informational, and moral support to cope with life's challenges. Social support stems primarily from family, friends, school, healthcare facilities, and the broader community. For a child with sickle cell disease, this backing promotes psychological and social balance while helping them better endure disease-related crises. Thus, this theory illustrates the importance of social management in improving the child's living conditions.

In our study on the social management of children with sickle cell disease in Lubumbashi, this theory helps clarify the role played by the child's immediate environment. Parents, teachers, healthcare workers, and social organizations all contribute to the child's social and academic adaptation. When the child receives adequate support, they build self-confidence and achieve strong social integration. Conversely, a lack of support leaves the child vulnerable to isolation, stigmatization, and psychological distress. This theory underscores the necessity of collaboration among various social actors and provides an essential foundation for analyzing social management mechanisms for children with sickle cell disease.

#### 2.2.2. Urie Bronfenbrenner's Ecological Systems Theory of Human Development

The ecological systems theory of human development developed by Urie Bronfenbrenner posits that child development depends on multiple interacting social environments. According to this theory, a child grows within different systems such as the family, school, neighborhood, healthcare services, and society at large. Each environment influences the child's behavior, physical development, and psychological balance. The author demonstrates that the relationships established between these different spheres determine the child's living conditions; thus, a favorable environment contributes to healthy child development. Consequently, this theory emphasizes the vital importance of the social context in a child's growth.

In this research, the ecological theory helps analyze the social conditions under which children with sickle cell disease live in Lubumbashi. Social management relies on the relationships between the family, school, medical facilities, and the community. When these spheres collaborate effectively, the child benefits from support tailored to their health and social needs. This comprehensive care improves their social integration and promotes emotional stability. Conversely, economic hardship, lack of information, and discrimination negatively affect their development. This theory thus provides a better understanding of how the social environment influences the life of a child with sickle cell disease.

### 2.3. Literature Review / State of the Art

Malemba N'sakila (2017), in his work devoted to "Family Dynamics Tested by Chronic Child Illness in Urban Congo," notes that care management is often restricted to the purely logistical and domestic aspects of health. The author explains that it can be understood as the mother's perception of her own loneliness in the face of the disease and its consequences on her daily marital life which prevents her from living peacefully and depends on the patriarchal structure and socio-economic status of the household. He emphasizes that the mother of the sick child acts as a domestic sacrifice, with the onset and resolution of sickle cell crises reactivating the same dynamics of isolation. He found in his research that while the burden of mental strain is experienced differently by each woman, the financial and emotional involvement of the father is universally poor. His results suggest that paternal disengagement negatively impacts their quality of life.

Buc-Caron (2019) addresses the issue in her research titled "Therapeutic Pathways and Spiritual Recourse Facing Biological Incurability: The Case of Sickle Cell Disease in Kinshasa." According to her, the quest for healing is often restricted to key aspects of faith and can be understood as parents' perception of their own medical helplessness and its consequences on adherence to clinical treatments which prevents them from living peacefully and depends on prophetic beliefs and the financial accessibility of official healthcare. She emphasizes that turning to church temples acts as a last-hope shelter, and that modern diagnosis and the excesses of revivalist churches are conflicting stages of the same ordeal. She observed in her research that while the spiritual journey differs for each parent, treatment adherence within specialized facilities is universally poor. Her findings suggest that religious wandering negatively impacts their quality of life.

A different perspective is provided by Le Breton (2016) in his reference book "Anthropology of the Suffering Body and Lay Perception of Genetic Pathologies in Central Africa." This anthropologist demonstrates that clinical care is often restricted to the technical aspects of biology. It can be understood as the patient's perception of their own hospital-induced reification and its consequences on their identity as a human being which prevents them from living peacefully and depends on the style of listening and the humanization of healthcare facilities. He highlights that a sickle cell child treated as a mere guinea pig becomes a fragmented body, where the coldness of laboratories and the silence of caregivers represent identical forms of violence. He noted in his research that while the feeling of abandonment varies among patients, the overall hospitalization experience is universally poor. His results suggest that the dehumanization of care negatively affects their quality of life.

The investigation conducted by Pliya (2020), titled "Evaluation of Self-Medication Practices and Recourse to

Traditional Pharmacopeia Among Sickle Cell Children," reveals that biological survival is often restricted to informal makeshift strategies. The study shows that this can be understood as the family's perception of their own economic exclusion and its consequences on managing acute anemia crises which prevents them from living peacefully and depends on the level of urban poverty and the transmission of maternal knowledge. He emphasizes that using composite herbal remedies acts as a makeshift medicine, where street pharmacies and family ethnomedicine represent identical survival responses. He noted in his research that while the arsenal of home remedies varies for each mother, the clinical safety of these mixtures is universally poor. His findings suggest that relying on informal selfmedication negatively affects their quality of life.

## 3. Lubumbashi: A City of Therapeutic Pluralism

As the second-largest urban center in the Democratic Republic of the Congo and the provincial capital of Haut-Katanga, the city of Lubumbashi historically presents itself as a cosmopolitan metropolis shaped by mining activities. Founded in 1910 during the colonial era, this city developed around copper extraction, attracting diverse migratory flows from various regions of the country, neighboring nations, and other continents. This distinct demographic configuration gave rise to a fragmented urban space, characterized by high population density in working-class townships such as Kamalondo, Katuba, Kenya, and Rwashi. It is within this contrasting urban fabric that family structures deploy themselves to manage chronic pathologies at the intersection of regional traditions and urban modernity.

On an economic level, Lubumbashi is undergoing complex structural changes marked by the coexistence of a predominant industrial mining sector and an informal subsistence economy. Declining purchasing power, structural unemployment, and household financial insecurity directly impact the capacity to handle major public health issues. Access to specialized healthcare institutions remains a financial privilege for the affluent classes, forcing the majority of impoverished families to make daily trade-offs between basic survival expenses and the cost of biomedical treatments. This material precarity constitutes the primary determinant of disruptions in clinical care pathways and structurally drives populations toward less expensive therapeutic alternatives.

Healthcare delivery in Lubumbashi reflects a pronounced therapeutic pluralism, where official biomedical institutions such as the Polyvalent Center for Sickle Cell Anemia (CPCD) coexist competitively with other care systems. Faced with the financial and geographical limitations of modern medicine, the city has seen a proliferation of private clinics, informal pharmacies, and especially urban traditional practitioners and herbalists. Concurrently, the medico-social landscape in Lubumbashi is characterized by a strong presence of Revivalist Churches and Pentecostal movements that position themselves as alternative healing entities. This pluralistic landscape transforms the city into a complex healthcare marketplace where patients constantly navigate between the hospital, the home, the neighborhood dispensary, and the religious temple.

From a socio-cultural perspective, Lubumbashi's urban environment is governed by a syncretism in which lay representations of illness interact with local legislative and ethnic realities. Although theoretically governed by the Congolese Family Code and modern principles of gender equality, family structures in Lubumbashi remain deeply rooted in patriarchal divisions of labor. The chronicity and incurability of sickle cell disease act as a revealer of cultural tensions within households, where accusations of witchcraft coexist with genetic rationality. Lubumbashi thus becomes an ideal analytical laboratory for observing how gender roles and community solidarity networks are redefined to either support or isolate a sick child.

## 4. Methodological Framework

To reach the sensitive core of the social management of children with sickle cell disease in Lubumbashi, this study selected a qualitative clinical approach firmly rooted in phenomenology. The goal was not to reduce the suffering of families to cold mathematical equations, but to access the deep subjectivity of care actors where despair and resilience intertw. This approach made it possible to capture the meaning mothers give to their convoluted journeys and to decode the unspoken dynamics that govern domestic life behind closed doors. By prioritizing immersion in the intimate lived experiences of parents in Lubumbashi, the qualitative method proved to be the only tool capable of restoring the human depth and complexity of gender dynamics when facing illness.

The operational foundation of this research relies on survey methods, which were essential for structuring the exploration of therapeutic pathways across the city. Far from an unorganized collection of data, this method guided our deployment in the field, making it possible to systematically map out the healthcare choices of our sample of parents. It offered the rigorous framework necessary to systematically observe disruptions in care pathways, domestic retreats, and shifts toward spiritual recourse. Thanks to this methodological compass, the apparent chaos of family decisions amidst urgent sickle cell crises could be translated into a coherent sociological picture, highlighting true economic and cultural fault lines.

Foremost among the data collection tools, the semi-structured interview technique functioned as a powerful medium for bringing forth the confined voices of mothers. By breaking away from the cold distance of standardized questionnaires, these in-depth dialogues provided "watchful caregivers" with a safe space to share their truth regarding the loneliness of caregiving. Each interview became a narrative arena where the pain of childhood crises, the weight of mental strain, and the moral wound of paternal disengagement came to light. This technique allowed for the gathering of exceptionally rich verbal data, capturing the nuances of anxiety and the creativity of mothers facing the limitations of modern medicine.

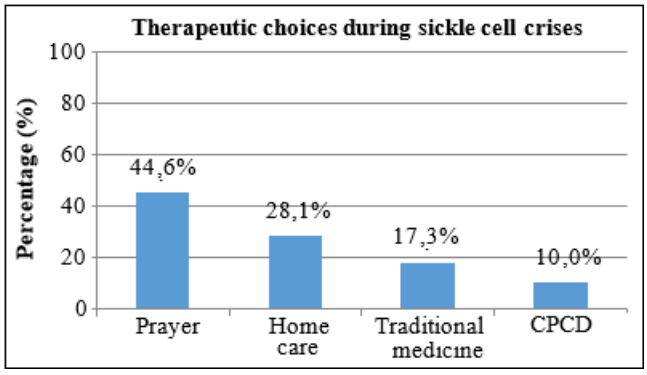
To complement these accounts, document analysis was utilized as an essential historical and theoretical anchor, allowing subject testimonials to be cross-referenced with scientific literature. Clinical archives, public health reports, and foundational literature on the sociology of the Congolese family were thoroughly examined using our analytical framework. This painstaking work contextualized field data and situated the distress of Lubumbashi households within the broader structures of urban patriarchy and economic precarity. Document analysis thus provided the critical distance required to transform field accounts into solid scientific conclusions, validating our hypotheses through academic discourse.

## 5. Study Results

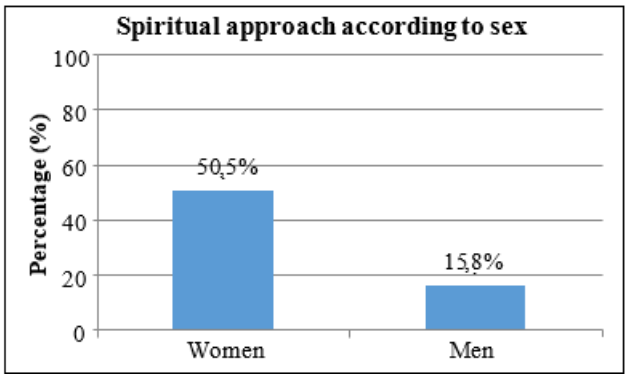
The results of this survey conducted in Lubumbashi explore the non-biomedical management of children with sickle cell disease, aligning with the movement toward humanizing medicine theorized by Le Breton (2015). Through a multidimensional approach, the collected quantitative and qualitative data highlight the complexity of the therapeutic pathways chosen by families when facing crises. The analysis is structured around three major scientific axes: first, the epidemiological evaluation of healthseeking behaviors and their sociodemographic determinants; second, the analysis of domestic dynamics and the gender divide in parental involvement; and finally, the evaluation of alternative therapeutic approaches, whether traditional or religious. These data reveal how a chronic genetic pathology deeply redefines social roles, family solidarity, and survival strategies in an urban environment.

### 5.1. Epidemiological Analysis of Therapeutic Pathways and Socioeconomic Determinants

Drawing on Le Breton's (2015) framework, this study underscores the shift from purely biomedical care focused on organ reification to a more human model grounded in active listening. This theoretical perspective fully justifies researching the non-medical management of children with sickle cell disease in the city of Lubumbashi. The analysis examines parental care through a gender lens while evaluating the competing interventions of traditional healers and religious practitioners in managing the disease.



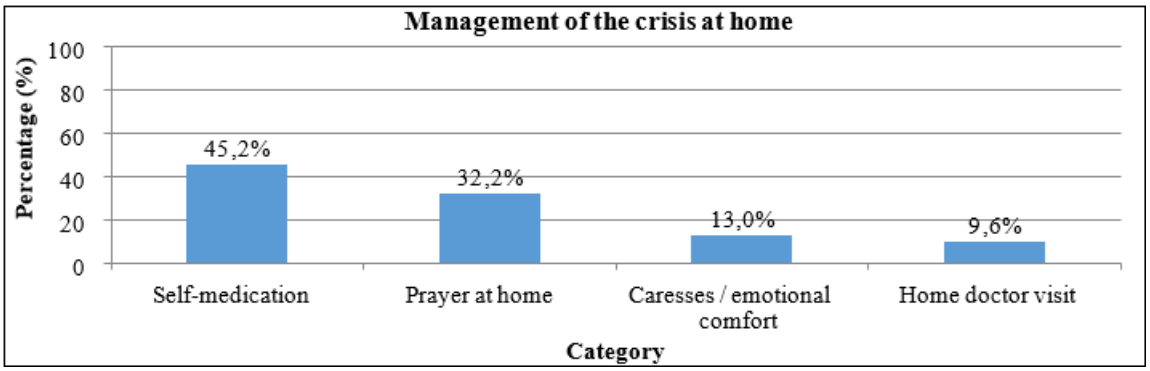

When facing childhood crises, parents in Lubumbashi deploy diverse, fluid, and often combined strategies during a single painful episode. Quantitative data reveal that turning to prayer largely dominates, representing the primary choice for 44.6% of survey respondents. Keeping the child at home accounts for 28.1% of families, while traditional medicine attracts 17.3% of them. Finally, consulting a specialized medical center such as the Polyvalent Center for Sickle Cell Anemia (CPCD) accounts for only 10.0% of choices among interviewed parents.



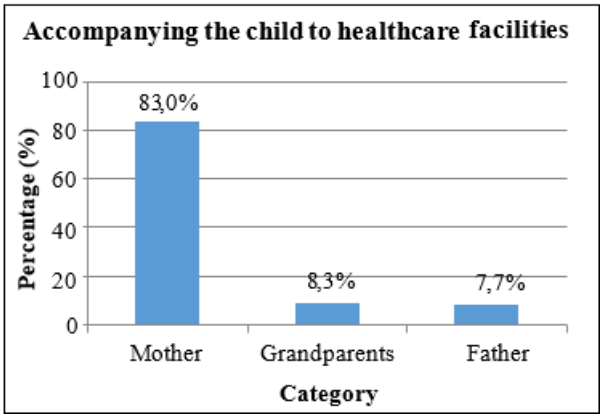

Raw count analyses show a massive female presence across all care-seeking categories, directly reflecting their traditional role as primary caregivers. However, percentage interpretations nuance this trend: men are proportionally more inclined to choose home-based treatment, traditional healers, or the CPCD. Conversely, women are overrepresented in seeking spiritual solutions, showing a rate of 50.5% compared to only 15.8% among fathers. Educational attainment was generally higher among men within the sample.

Determinants of care pathways strongly depend on the family's financial capacity and crisis severity (Graff et al., 2010). Economically vulnerable households historically navigate a low-cost therapeutic triangle consisting of home care, prayer, and local healers. Affluent classes preferentially turn toward official biomedical institutions like the CPCD, whose costs remain prohibitive for the majority. Economic rationality thus frequently supersedes pure belief in the efficacy of Western medicine.

### 5.2. Domestic Care Dynamics, Self-Medication, and Gender Sociology




For the 28.1% of parents who keep their child at home, crisis management revolves around specific domestic routines. Self-medication emerges as the initial reflex for 45.2% of this subgroup, closely followed by home prayers (32.2%). Moral comfort through physical affection represents 13.0% of practices, while calling a doctor for a home visit remains marginal (9.6%). These choices vary depending on the time of crisis onset and perceived financial costs.

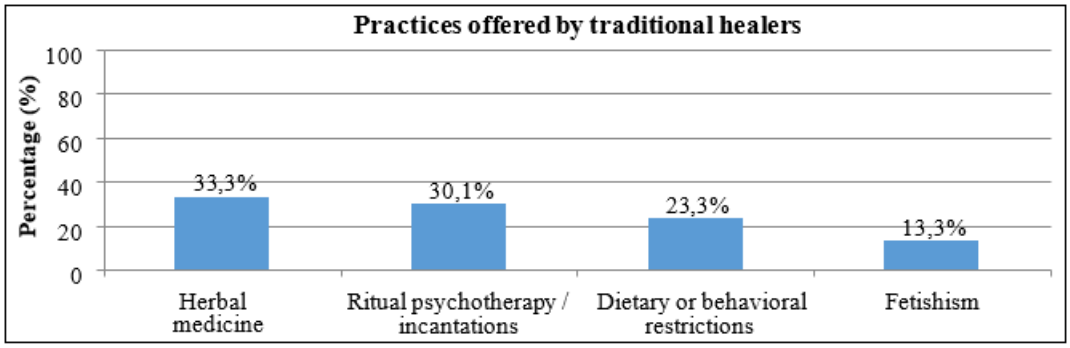



Domestic self-medication in Lubumbashi extends beyond pharmaceutical products; it incorporates traditional concoctions and composite mixtures intended to "boost the blood." Mothers' accounts reveal the combined use of popular ingredients such as egg yolk, lemon, and condensed milk. This domestic pharmacopeia relies on internalizing former medical prescriptions alongside ancestral knowledge transmitted through maternal lineages. Parents ultimately resort to clinical emergency services only when these alternatives fail.

The study confirms a stark divide regarding parental involvement, exposing the nearsystematic disengagement of fathers in favor of maternal omnipresence. Escort figures to care locations are telling: mothers assume this burden in 83.0% of cases, far ahead of grandparents (8.3%) and fathers (7.7%). As noted by Malemba N'sakila (2003), being a mother entails exclusive responsibility for early childhood and general child care.

This marital imbalance stems from socioprofessional factors, financial constraints, and guilt- inducing cultural representations. Some fathers flee the emotional distress of crises or formally accuse their wives of causing the genetic anomaly. Society reinterprets the Family Code and traditional roles, turning the mother into a "watchful caregiver" (responsable veillante) and the father into a "financial controller." This dynamic generates an urban anomie challenged by modern discourse on gender equality.

### 5.3 Evaluation of Alternative Therapeutic Systems: Ethnopharmacology and Religious Ethnomedicine




For the 17.3% using traditional medicine, practitioners in Lubumbashi offer diverse therapies that remain closely guarded secrets. Herbal phytotherapy dominates treatment options (33.3%), closely followed by ritual psychotherapy and incantations (30.1%). Prescriptions involving behavioral or dietary taboos account for 23.3% of cases, whereas pure fetishism remains at 13.3%. Although Chan (2013) highlights its financial and cultural accessibility, and Pliya (1991) notes its success where modernity fails, objective efficacy remains debated.

A strong ethnic contrast emerges in Lubumbashi regarding access to traditional healers, as this act carries a political dimension. In local Katangan traditions- particularly among the Baluba and Aruund—taking a child to a diviner is traditionally the father's exclusive responsibility. This step

can lead to divination and the naming of a guilty party accused of witchcraft within the extended family.

Yet, survey findings reveal that fathers shirk this obligation as well.

Recourse to religious therapies, chosen by 44.6% of families, involves deliverance, fasting, and anointing with holy oil or water. While pastoral support offers psychological comfort in accepting the ordeal (Buc-Caron et al., 2018), it also exposes families to destructive prophetic excesses in revivalist churches. Rituals using photos of the child or demands for name changes generate severe marital conflicts. These practices transform sickle cell disease into a site of power struggles and social disruption.

Sickle cell disease in Lubumbashi extends beyond clinical laboratories and traditional biomedical settings. It sits at the core of family dynamics, exposing marital vulnerabilities, economic pressures, and cultural tensions between modernity and tradition. The sick child becomes the locus of pluralistic, often chaotic therapeutic strategies driven by mothers' desperation. This study demonstrates the urgent need for comprehensive care that incorporates the psychosocial dimensions of this chronic condition.

## 6. Contribution of the Study

This research enriches the anthropology of health in an urban African context by modeling the fluidity of therapeutic pathways when facing a chronic genetic pathology. It moves beyond the traditional dichotomy between biomedicine and alternative systems to demonstrate how families construct a "rationality of urgency" dictated by economic precarity and the perceived incurability of the disease. By integrating Le Breton's concepts of reification and humanization, the study offers an innovative analytical framework documenting the transition from an organ-centered model toward holistic care- where spiritual and cultural dimensions become indispensable resilience strategies.

At the sociological level, the study makes a major contribution to the analysis of gender relations during domestic health crises in Lubumbashi. It deconstructs the illusion of shared parental management to reveal a stark divide characterized by a physical and mental burden borne almost exclusively by the mother, reframed here as the "watchful caregiver" (responsable veillante). By highlighting mechanisms of paternal disengagement legitimized by lay reinterpretations of the disease and traditional-legal structures, this research documents an urban anomie where the child with sickle cell disease becomes an unwitting revealer of marital tensions and deep shifts within the Lubumbashi family unit.

On a clinical level, the findings provide crucial empirical data to rethink public health policies and psychosocial support within specialized facilities. Identifying prophetic excesses in religious settings and the secrecy surrounding ethnomedicine underscores the urgent need to establish transparent communication channels between healthcare personnel, families, and community actors. This contribution thus advocates for the development of an integrated intervention model- combining therapeutic education, psychological support for couples, and financial decentralization of care- as the only approach capable of effectively easing the daily lives of mothers and ensuring a better quality of life for sick children.

## 7. Discussion

The predominance of reliance on prayer (44.6%) and mixed therapeutic pathways highlighted in our study corroborates the findings of Buc-Caron et al. (2018). These authors emphasize that when confronted with the shock of hereditary transmission and the incurability of sickle cell disease, religion and alternative rituals cease to be simple options and instead become vital psychological anchors enabling families to accept the unacceptable. In Lubumbashi, this quest for meaning drives mothers to saturate the therapeutic space with spiritual devotions, validating the premise that the chronicity of an illness disrupts the rational structures of Western biomedicine to reactivate magico-religious survival strategies.

The gender divide and almost exclusive maternal burden (83%) observed in caring for the sick child in Lubumbashi directly extend the work of Malemba N'sakila (2003) on childhood in urban Congolese settings. The author demonstrates that within the local socio-anthropological context, the patriarchal structure exclusively delegates early childhood responsibility and daily care to the mother figure. Our results accentuate this finding by showing that chronic illness does not strengthen marital bonds; rather, it rigidifies this division of labor: the father limits himself to a distant role as a passive financial provider, while the mother assumes the mental and physical toll of crises alone.

The significant reliance on composite self-medication and traditional remedies (17.3%) to compensate for the helplessness of modern medicine echoes Pliya's (1991) analyses on sickle cell management in Africa. Pliya documented that traditional medicine and ethnopractitioners achieve their greatest popular success where allopathic medicine fails or proves financially inaccessible. In Lubumbashi, this reality is exacerbated by urban poverty; homemade recipes passed down through maternal lineages (egg yolk, lemon, milk) and medicinal plants become first-line substitutes, with official medical facilities consulted only as a last clinical resort.

Finally, the marked tendency toward patient reification within medical facilities- which drives families toward these parallel networks- validates Le Breton's (2015) fundamental thesis on the evolution of medical sciences. Le Breton argues that the hyper-technological development of biomedicine has resulted in the fragmentation of the human body, turning it into a collection of organs to be treated at the expense of the patient's identity. The convoluted journeys of Lubumbashi parents between the CPCD, home, and revivalist churches bear witness to this flaw: by fleeing purely quantitative clinical care, mothers seek from religious healers and traditional practitioners the spaces for listening, expression, and humanization that standardized hospital institutions no longer provide.

## 8. Conclusion

This study demonstrates that sickle cell disease in Lubumbashi transcends medical boundaries to serve as a revealer of local socio-economic realities. Constrained by urban precarity and the prohibitive cost of official healthcare facilities, family therapeutic pathways highlight an escape from hospital dehumanization. The results reveal a overwhelming reliance on spiritual and domestic resources with prayer dominating at 44.6% and home-based care at 28.1%, while traditional medicine attracts 17.3% of choices compared to only 10% for specialized centers.

On a relational level, managing this chronic condition exacerbates a major gender divide within the Lubumbashi household. The research exposes the systematic disengagement of fathers during crises, leaving the mental and physical burden to mothers as the sole "watchful caregivers." Mothers account for 83% of direct child care alone and deploy artisanal self-medication rooted in maternal knowledge. Consequently, alternative remedies alternate between the secrets of phytotherapy and the destructive prophetic excesses of revivalist churches.

In light of this urban anomie, the primary contribution of this work lies in the necessity of rethinking health anthropology within African contexts. Uncovering parallel care circuits and magicoreligious logic demonstrates the urgency of building transparent communication bridges among healthcare providers, families, and community stakeholders. Designing integrated public policies that unite therapeutic education, couples' psychological support, and financial decentralization of care is imperative to sustainably improve the quality of life for children living with sickle cell disease.

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