

Factors Influencing the Management of Musculoskeletal Pain among Children with Sickle Cell Disease in Western Kenya

Roselyne Asiko Abwalaba¹
Professor Fabian Esamai²
Professor John Okoth¹

¹rabwalaba@mmust.ac.ke
²fesamai2007@gmail.com
³jokoth@mmust.ac.ke

¹<https://orcid.org/0000-0001-6165-9579>

²<https://orcid.org/0000-0003-2412-9450>

³<https://orcid.org/0000-0002-0302-1750>

¹School of Nursing, Midwifery and Paramedical Sciences, Masinde Muliro University of Science and Technology

²Professor of Child Health and Paediatrics, Moi University

³Professor of Nursing, Masinde Muliro University of Science and Technology

ABSTRACT

Keywords: Caregivers, Children, Factors, Musculoskeletal Pain, Sickle Cell Disease

I. INTRODUCTION

Musculoskeletal pain is a common symptom experienced by children suffering from sickle cell disease (SCD) due to the occlusion of blood vessels. It is important to support the children during this painful period (Walker, 2020). However, there is limited literature on the factors influencing the management of musculoskeletal pain in children with SCD. These factors determine the quality of life that the child will have. For example, healthcare provider factors, individual factors, and socio-demographic factors

The role played by health care providers is critical in the management of MSK pain in children with SCD. Brown et al. (2020) suggested that healthcare provider knowledge and experience significantly impact the outcomes of pain interventions. The sample size was small, and self-reported data in this study may lead to the unreliability of the findings. A study by Kamper et al. (2016) found that healthcare providers' had limited knowledge on the factors that influenced the management of musculoskeletal pain in chronic conditions. There is insufficient clinical evidence to support interventions for different factors. This calls for adherence to guidelines in pain management, as indicated by Busari et al. (2021).

Individual factors such as age, pain beliefs, and pain coping strategies have been identified as significant factors influencing the management of musculoskeletal pain in children with SCD. Older children and adolescents have a higher chance of musculoskeletal pain than younger children, which supports age as a contributing factor (Walker et al., 2019). In another study, Amusa et al. (2021) found that higher levels of pain were associated with poor pain management outcomes. Children who believed that their pain was related to sickle cell anemia experienced more musculoskeletal pain, frequent pain episodes, and a lower quality of life (Adigwe et al., 2023). Joseph et al. (2021) found that coping strategies for some factors, like praying, had better pain management outcomes.

A socioeconomic factor has been proven to influence musculoskeletal pain, possibly due to limited access to healthcare and resources for pain management (Samar et al., 2019). A study conducted by Anie et al. (2022) stated the effects of cultural and ethnic differences on the expression and management of musculoskeletal pain. This calls for culturally sensitive approaches to pain management. Furthermore, Amusa et al. (2021) found that children with SCD from low-income households experienced reduced access to healthcare and a higher likelihood of musculoskeletal

pain. There is still a need for further research on the long-term factors that influence musculoskeletal pain in children with SCD and their impact on the overall quality of life of the children.

II. METHODOLOGY

The study employed a cross-sectional research design and focused on 176 caregivers, who were responsible for 176 children experiencing musculoskeletal pain due to sickle cell disease (SCD). Among these caregivers, there were 98 caring for female children and 78 caring for male children. The data collection process involved conducting semi-structured one-on-one interviews with each caregiver, with each interview having a duration of approximately 25 minutes. During these interviews, skilled interviewers posed open-ended questions to caregivers, with a specific focus on understanding the factors influencing the management of musculoskeletal pain in children afflicted with SCD. Notably, the interviewers diligently documented detailed field notes throughout each interview session, capturing contextual information and observations.

Subsequently, each interview was painstakingly transcribed verbatim to create a comprehensive written record of the caregivers' responses. These transcripts served as the primary data source for the subsequent analysis. To analyze the data, two authors independently coded the interview transcripts, utilizing a thematic approach. Initially, a codebook was crafted based on insights garnered from the literature review. However, this codebook underwent expansion as recurring themes emerged from the interview transcripts. The data was systematically categorized into various themes and sub-themes, aided by a comprehensive coding system.

Thematic analysis played a pivotal role in scrutinizing the interview transcripts and uncovering influential factors. The coded segments from these transcripts were methodically matched with pertinent themes and sub-themes, which encompassed psychological factors, economic factors, sociocultural factors, individual factors, nutritional factors, environmental factors, and hospital-related factors. This process of data summarization continued until no novel themes surfaced.

The research team took great care to ensure the reliability and validity of the analysis. This was achieved through an inter-coder agreement process where two authors independently coded the interview transcripts and resolved any disparities through discussion. Additionally, member checking was employed, affording a select group of caregivers the opportunity to review and validate the interview transcripts and coding results, thus confirming the accuracy of their responses.

Throughout the study, ethical considerations were given utmost priority. Ethical approval was sought and obtained from the relevant institutional review board. Informed consent was diligently acquired from all participating caregivers, who were duly reassured regarding the confidentiality and anonymity of their responses. Caregivers were also explicitly informed of their right to withdraw from the study at any juncture.

Ultimately, the study's findings were presented with the aid of descriptive statistics, including frequencies. Additionally, illustrative quotations from caregivers were incorporated to vividly portray and exemplify the factors that were identified as exerting influence on the management of musculoskeletal pain in children with SCD.

III. RESULTS

3.1 Psychological factors

Caring for a child with a chronic condition like sickle cell disease with frequent musculoskeletal pain is stressful. When discussing the factors, the majority of caregivers caring for their children reported feeling overwhelmed with the ongoing care. Caregivers reported that the unpredictable nature of the disease and its complications made them feel hopeless during a painful crisis. Painful experiences by children increased the stress levels among most of the caregivers. Most of the time, the caregiver's mental status was altered because of what the children were going through. Some felt that they were the cause of the suffering of their children. That really affected the care of the children, as some caregivers felt withdrawn and overwhelmed.

One of the caregivers commented:

"I feel so sad because I know that my son is experiencing all this pain because of the two of us, and that he will live with it the rest of his life. I didn't know that I had the trait, and I didn't know that his father had the trait, so I sometimes feel responsible...like it was my fault that my son has this disease. Managing him when he has the painful attacks make me sick too, and caring for him becomes a big problem." (PR29).

3.2 Economic factors

Economic factors were among the most common factors mentioned by caregivers that affected the care of children with musculoskeletal pain. Common themes included financial strain, the cost of drugs, hospital bills, and missed days of work. Caregivers reported absenteeism from school occurred due to a lack of finances to manage the children in time, leading to poor performance. When a child is admitted in severe pain, the hospital requests that they buy everything, including gloves and branulars, which becomes a challenge due to limited resources. One of the caregivers stated:

"Lack of enough finances to manage children with sickle cell disease more so when they experience the painful attacks is a very big problem to many of us. My son had a very bad experience and I felt going to the hospital was a waste of time unless one had money. The painful events started abruptly and I was very low financially. I rushed to the nearby county hospital and the system could not allow him unless we paid registration fee of five hundred shillings and a deposit of two thousand shillings. My son kept suffering until we rushed to a private facility where they admitted him and offered the emergency care and the bill was paid later. We had to sell a cow to pay the bill but his condition was stabilized with no more pain. This made me believe that my son would have complicated just because of lack of money." (PR126).

3.3 Socio cultural Factors

It was reported by caregivers that some communities believe that the mothers are the cause of these illnesses, and this was associated with a 'curse' from ancestors, which really influenced the kind of care accorded to the child. The mothers carried the responsibility of taking care of the children. Some families had even broken up because the fathers avoided being associated with such children. Rejection by other family members was also a problem, and the children were isolated from other extended family members. Some female parents had to explain to their children the reasons for their separation, and these really affected the care of the child. These caused a lot of psychological trauma to the family, especially the mother and other siblings. The entire community did not accept these children and had an attitude towards parents. This contributed to a lot of stigma from both family and community.

One of the caregivers stated:

"I experienced tough moments when my husband abandoned me because of our sickling child. This happened when we really needed his support as a family. When I probed to find why he did that, he said he had to leave because there was no history of SCD in their family and he didn't want to be associated as it was regarded as a curse." (PR 71)

3.4 Individual Factors

Some of the children were exposed to many infections, which was a contributing factor to the musculoskeletal pain among these children with SCD. The most common infections included malaria, diarrhea, and upper respiratory tract infections. If infections are not treated well, then the child will have frequent musculoskeletal pain attacks. The general immune status of the child also influenced musculoskeletal pain, as reported by caregivers. If the immune status was low or compromised, the child would experience more attacks. If the immune system was strong, the



frequency of musculoskeletal pain would be reduced. The hemoglobin level of the child was vital when managing musculoskeletal pain. Low hemoglobin levels predisposed these children to musculoskeletal pain, which posed a problem compared to high levels. So, these factors affected the care of children with musculoskeletal pain, more so when the immune status was compromised.

3.5 Nutritional factors

It was reported through the interviews conducted that malnutrition was a factor that affected the management of musculoskeletal pain among children with SCD. This contributed to frequent musculoskeletal pain experiences due to less oxygen being supplied to tissues, cells, bones, and other organs. Many children were reported to lose appetite, most times more so when they experienced the pain. Children became irritable and cried due to pain, hence refusing to feed, which affected their nutritional health. Getting the required nutritious diet is also hard due to financial implications. This affected the general care that children received.

A key informant stated the following regarding nutrition:-

“These children with musculoskeletal pain in SCD need a nutritious diet. However, with the hard economic times, most parents are not able to afford and so it becomes difficult for them to provide a nutritious diet. They need a lot of fruits to boost their immune status and a balanced diet. This makes the child’s body system to be weakened and so managing the child becomes more complicated.”(KII4).

3.6 Environmental factors

The change in weather from hot to cold seasons had implications for the care of these children with musculoskeletal pain. Caregivers reported having experienced many difficulties during cold seasons, unlike dry seasons. This provoked frequent attacks of musculoskeletal pain among these children, with frequent absenteeism from school. Children frequently miss school, most times during rainy seasons.

One of the participant caregivers stated:

“I normally get worried when rainy season approach because my child is frequently admitted during this season due to musculoskeletal painful attacks. He becomes dull, always sick looking and complains of feeling pain all over the body most times. She remains at home most of the time and this has actually affects her academic performance. During dry season, her health becomes better and she looks healthy and active.”(PR22).

3.7 Hospital Factors

The caregivers reported that the care provided to the children during previous admissions to hospitals was a concern because of the bad experiences. This contributed greatly to parents buying over-the-counter medication for their children instead of seeking medical attention in health facilities. Health care system delivery was not friendly and patient-oriented, but money-oriented. Instead, they are mostly money-oriented. Caregivers reported facility-related factors (lack of resources), while health workers mentioned health worker-associated factors (attitude). Some of the children were also not comfortable because of the hospital environment, which was not pleasant. The admission made them miss school, and so it made them not happy at all. They preferred being managed at home to being in a hospital environment. These affected the care of these children with musculoskeletal pain and their outcome.

Table 1

Themes and Associated Caregivers Quotes on Factors that Influence Management of Musculoskeletal Pain among Children with Sickle Cell Disease

Codes/Themes	Quotes
Caregivers’ factors; Psychological factors	<i>“I feel so affected when my child is experiencing musculoskeletal pain, I try all means to ensure that my child copes, but I really feel for him. Sometimes I cry before him, it is really traumatizing and overwhelming.”</i>
Economic factors	<i>“Financial burden is a key factor when managing children with musculoskeletal pain. Drugs, good nutrition and other basic needs are required. All these requires money. Without money, it is true that your child will suffer. No one supports</i>



<p>Sociocultural factors: Community and family support</p>	<p>us.”</p> <p><i>“My husband’s community believe that this disease occurs as a result of generational curse from the side of the child’s mother. So, we have very little support from the family. He supports us although with a lot of pressure from the elders. Otherwise, he was advised to divorce me, if not the child will die”. Whenever the child experiences musculoskeletal pain, we are isolated and as a family, it really affects the care.”</i></p>
<p>Individual factors: Immune status of the child</p>	<p><i>“My daughter becomes sick most of the times due to other illnesses like malaria and pneumonia. She becomes sick almost every month. This is because of the low immunity she must be sick. We used to be stressed as a family, but nowadays. We have learnt how to cope by taking measures to prevent such infections.”</i></p>
<p>Hemoglobin level</p>	<p><i>“I try to ensure that my child’s hemoglobin levels do not go down below 6g/dl. This is because whenever her hemoglobin level goes low, she becomes sick and she commonly presents with musculoskeletal pain. I ensure that her diet is prioritized with a lot of vitamins and iron.”</i></p>
<p>Nutritional factors; Nutritional status of the child</p>	<p><i>“I provide the required diet for my son, but sometimes challenges occur whereby I have no finances to provide all that is required. Good nutrition is good for him because it boosts the body immunity. With poor nutrition, he becomes sickling because of the weakened immunity.”</i></p>
<p>Environmental factors; cold seasons/hot Seasons</p>	<p><i>“The cold weather is always unfavorable for my daughter. She is always in and out of the hospital because of pain. I just don’t like the seasons. I prefer the dry season. In the wards, we are normally many with the same problem. So, when it starts raining, I take a lot of precautions in ensuring he is always warm. But when he goes to school, it becomes a challenge. She gets frequent pain all over the body. I really spent a lot of time and money to manage her.”</i></p>

3.8 Discussion

The themes that emerged from the caregivers’ interviews in this study were consistent with factors identified in previous research. However, these interviews revealed economic factors as a major theme, which was attributed to the high cost of health care and drugs as significant factors affecting the management of children with musculoskeletal pain in sickle cell disease. Caregivers expressed their fears about the costs of managing these children. It is important for hospitals to be equipped with drugs and other resources; unfortunately, there are no drugs. Parents spend a lot of money buying drugs for their children. Other alternative options for the management of children with musculoskeletal pain would be appropriate. The themes that emerged also included sociocultural, individual, nutritional, environmental, and hospital factors, which aligned with the majority of previous research on the subject.

A systematic review and meta-analysis were carried out on health-related quality of life (HRQL) in children with sickle cell disease. The results showed that children with SCD had high chances of experiencing poor quality of life as compared to healthy children. This was related to the effects of several biological, psychological, and social factors. Future research was recommended to examine how sociocultural factors affect the population and their overall quality of life (Stokoe et al., 2022). The results concur with the findings of this study, whereby biological, economic, and social factors were found to influence the management of musculoskeletal pain among children with sickle cell

disease. This means that these factors determine the quality of life these children live. For example, in this study, many children reported missing school because of musculoskeletal pain because they could not cope. If they are not able to perform their normal activities, like going to school, when in pain, this already indicates that their quality of life is already compromised.

Amusa et al. (2021) investigated the socio-economic determinants of musculoskeletal pain in children with SCD in Nigeria and found that socio-economic factors such as poverty and a lack of family support played a significant role in the management of musculoskeletal pain in children with SCD. This conforms to the study's findings on the impact of a lack of finances and family support on the management of musculoskeletal pain among children with SCD. A study by Brown et al. (2020) showed that children with SCD had a higher prevalence of musculoskeletal pain, which was associated with poor physical function. However, they did not find a significant association between musculoskeletal pain and cold weather, which this study found to be significant factors.

IV. CONCLUSIONS & RECOMMENDATIONS

4.1 Conclusions

Musculoskeletal pain is associated with various factors, and the findings of this study are consistent with the majority of previous research, but there are also inconsistent results from some studies. This study found that psychological, economic, sociocultural, individual, nutritional, environmental, and hospital factors determine the care that children with MSK pain receive.

4.2 Recommendations

The government should provide affordable and sustainable mechanisms for addressing the identified factors for improved management of MSK pain among children with SCD. This may include training of health care workers, creating awareness in the communities, providing counseling services, and providing economic support. Further research is needed on the factors influencing musculoskeletal pain in children with SCD and to identify effective interventions for different factors. Studies need to be conducted in different populations in different settings, as well as to consider other factors that may influence the outcome of musculoskeletal pain among children with SCD, such as genetic and environmental factors.

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