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SOCIOECONOMIC FACTORS IMPACTING THE MANAGEMENT OF SICKLE CELL DISEASE IN CHILDREN: INSIGHTS FROM A QUASI-EXPERIMENTAL STUDY

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ABSTRACT

This quasi-experimental cross-sectional analytic study investigated the influence of caregiver and household socioeconomic characteristics on quality of life and pain outcomes among 80 children with sickle cell disease attending the pediatric hematology clinic at Obafemi Awolowo University Teaching Hospitals Complex, Ile-Ife, Nigeria. Data on socioeconomic variables (including income, economic constraints, distance to hospital, and religious belief) and multidimensional quality-of-life domains were collected via a structured, expert-validated questionnaire, and analyzed using descriptive statistics and binary logistic regression with significance set at $p < 0.05$. Mean domain scores indicated moderate quality of life, with pain level (mean 2.11), psychosocial health (mean 2.16) and school performance (mean 2.29) clustering around the discomforting range, reflecting persistent symptom burden and functional limitations. Regression analysis showed that economic factors ($\beta = -1.077$, $p = .012$), distance to hospital ($\beta = .786$, $p = .008$) and religious belief ($\beta = 1.170$, $p = .010$) were statistically significant predictors of quality of life and pain reduction, underscoring the need

for financial support, improved geographic access and context-sensitive engagement with religious and community structures in pediatric sickle cell disease management

Keywords: Sickle cell disease; Socioeconomic factors; Pediatric quality of life; Pain reduction; Logistic regression; Nigeria.

Introduction

Sickle cell disease remains a major public health challenge, particularly in low-resource settings. Sickle cell disease (SCD) has been described as a genetic, chronic blood disorder that is characterized by the functioning of red blood cells (RBC) (Al Yazidi et al., 2021). Normal RBCs are circular in shape, which allows the cell to carry out tasked such as tissue oxygenation, amongst other vital responsibilities(Conran & Embury, 2021). Sickled cells, however, take on a C-shape, which leads to a blockage of the capillaries causing inflammation and severe pain crises. In addition to pain, individuals with Sickle Cell Anaemic (SCD) are at risk for chronic organ damage, anemia, and early death (Knisely *et al..*, 2020).

This disease is more common in countries with limited resources and among families with low socioeconomic status (Oluwaseun et al., 2024). Socioeconomic factors, including caregiver income, education, and access to healthcare facilities can significantly influence the management of SCD in children. It is a common genetic disease that occurs in every 1 out 500 new-borns. In the Americas, it has been estimated that about 1000 infants are diagnosed with Sickle Cell Disease (Grygiel *et al..*, 2021). Similar study indicated that Sickle cell disease occurs in almost 100,000 American and is found in 1 out of every 365 new-born (Hardy *et al..*, 2018).The impact of Sickle Cell Disease naturally impairs the physical, mental, emotional, and psychosocial domains of health-related quality of life, and more often than not, the victims suffer from neglect and stigmatization (Divakar *et al..*, 2019); (Badawy *et al..*, 2021); (Makita *et al..*, 2021).

A number of treatment options for sickle cell diseases have been documented in the literature (Sowunmi et al., 2013). For example, in the study of (Maitland *et al..*, 2021) who examined transfusion management of severe anaemia in African children: a consensus algorithm found that elevated heart and respiratory rates normalised irrespective of transfusion volume and without diuretics. By consensus, a transfusion management algorithm was developed, incorporating three additional measurements of Hb post-admission, alongside clinical monitoring.

Other options include Daily iron supplementation for prevention or treatment of iron deficiency anaemia in infants, children, and adolescents (Protocol) as recommended by (Finkelstein *et al..*, 2018). In a similar efforts, (Ausili *et al..*, 2017) recommended development and psychometric testing of a theory-based tool to measure self-care in diabetes patients: the self-care of diabetes inventory. They found that Significant associations were found between self-care maintenance and HbA1c ($p = 0.02$) and between self-care monitoring and diabetes complications ($p = 0.04$). Self-care management was also

associated with BMI (p = 0.004) and diabetes complications (p = 0.03) in many related studies (Oluwaseun et al., 2024). Self-care confidence was a significant predictor of self-care maintenance, monitoring and management (all p < 0.0001) (Lanre-Ogungbile et al., 2020).These authors concluded that Self-care is essential for patients with diabetes mellitus. The current study aims to explore how these socioeconomic determinants affect pain management and quality of life among pediatric patients at Obafemi Awolowo University Teaching Hospitals Complex.

Aim

The aim of this paper was to investigate the socioeconomic factors impacting the Management of Sickle Cell Disease in Children.

The specific objectives are to:

- identify the socioeconomic factors affecting the quality of life of children with SCD.
- evaluate the relationship between caregiver socioeconomic status and pain management effectiveness.

Research Questions:

1. What socioeconomic factors are most influential in managing sickle cell disease in children?
2. How do these factors correlate with the quality of life and pain reduction in pediatric SCD patients?

Methodology

This study employed a quasi-experimental, cross-sectional analytic design to examine how caregiver and household socioeconomic characteristics influence quality of life and pain reduction among children with SCD at OAUTHC, Ile-Ife (Socioeconomic and Nutritional Characteristics, 2007). The population comprised children with confirmed SCD attending the pediatric hematology clinic; 80 participants were recruited using consecutive or purposive sampling to capture a range of socioeconomic backgrounds (Wonkam & Makani, 2019). A structured questionnaire collected data on socioeconomic status (education, occupation, income, social class, distance to hospital, religious beliefs), quality-of-life domains (emotional, mental, physical and social functioning), and pain levels rated on the same 1–5 scale used in the hydrotherapy study (Knisely et al., 2020). Content validity was established by experts in pediatric hematology and public health, and internal consistency for composite scales was assessed through pilot testing (Ausili et al., 2017). Descriptive statistics summarized quality-of-life indicators, while binary logistic regression identified factors associated with better versus poorer quality of life and pain reduction (Socioeconomic and Nutritional Characteristics, 2007). Independent variables included culture, economic factors, distance to hospital, religious belief, illiteracy, parental income, hospital stress, stigmatization, prolonged hospitalization, and treatment compliance, with significance set at p < .05 (The Financial Burden of SCD, 2014). Ethical approval and informed consent procedures followed standard protocols.

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Results

Research question 1: What is the quality of life of children with sickle cell disease in OAUTHC, Ile-Ife?

Table 1: The Quality of life of children with sickle cell disease in OAUTHC, Ile-Ife.

QOL Parameters	N	Mean	Std. Deviation
Emotional Functioning			
General health condition	80	1.80	.664
Pain level	80	2.11	.900
Sleep quality	80	1.82	.854
Mental functioning			
Psychosocial health	40	1.85	.736
Mental health	80	2.16	.892
School performance	80	2.29	1.224
Physical functioning			
Physical health	80	2.03	1.102
Involvement in self – care	80	1.90	.866
Movement with little or no support	80	2.05	1.018
Social functioning			
School attendance/activities	80	2.01	.974
Financial supports from family	80	2.08	1.028
Relationship with parent and care giver	80	1.81	.915
Relationship with siblings and friends	80	1.95	.870
Stigmatization	80	1.83	.839
Supports from neighbors	80	1.90	.976

Mean of 1 = Mild
2 = Discomforting
3 = Distressing
4 = Horrible
5 = Excruciating

Table 1 revealed that there was moderate level of quality of life of children with sickle cell disease in OAUTHC, Ile-Ife. In other words, their emotional functioning, mental functioning, physical functioning and social functioning were still challenged by the impact of sickle cell disease that brought them to the hospitals which is often accompanied with different degrees of pains ranges from mild to excruciating pains. However, with regards to emotional functioning, mean score of pain level (mean = 2.11) was higher than general health condition (mean = 1.80) and sleep quality (mean =1.82).

With regards to mental functioning, the table shows that the mean score of school performance (mean = 2.29) was higher than psychosocial health (mean = 1.85); and Mental health (mean = 2.16). As regards physical functioning the results shows that movement with little or no support had higher mean score (mean = 2.05) involvement in self-care (mean = 1.9); and physical health (mean = 2.03). That analysis of social function revealed that financial supports from family (mean = 2.08) has the highest mean score closely followed by School attendance/activities (mean = 2.01). Others include relationship with parent and care givers (mean = 1.81);

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relationship with siblings and friends (mean = 1.95); stigmatization (mean = 1.83) and Supports from neighbors (mean = 1.90).

Research question 2: What are the factors influencing the quality of life and pain reduction among children with sickle cell disease in OAUTHC, Ile-Ife?

Table 2: Binary logistic analysis of the factors influencing quality of life and pain reduction among children with sickle cell disease in OAUTHC, Ile-Ife.

Factors	B	S.E	Wald	Df	Sig.	Exp(B)
Culture	.350	.292	1.439	1	.230	1.420
Economic factor	-1.077	.430	6.268	1	.012*	.341
Distance to the hospital	.786	.296	7.043	1	.008*	2.196
Religious belief	1.170	.457	6.560	1	.010*	3.222
Illiteracy	.009	.369	.001	1	.980	1.009
Parental income	-.615	.372	2.730	1	.099	.541
Hospital stress	-.500	.337	2.208	1	.137	.606
Stigmatization	-.142	.324	.192	1	.661	.867
Prolong hospitalization	.601	.390	2.374	1	.123	1.824
Treatment compliance	.354	.421	.706	1	.401	1.425
Constant	-2.24	1.182	3.617	1	.057	.106

*. significant at the 0.05 level (2-tailed).

Table 2 indicates that only three out of the ten factors; economic factor (β = -1.077, P<.05); distance to the hospital (β = .786, P<.05); religious belief (β = 1.170, P<.05) had statistically significant influence on the quality of life and pain reduction among children with sickle cell disease in OAUTHC, Ile-Ife. Meaning that economic factors, distance to the hospitals and people's religious beliefs were the top reported barriers to quality of life and pain reduction among children with sickle cell disease in OAUTHC.

Discussion

Quality-of-life scores indicated moderate functioning overall, with emotional, mental, physical and social domains still substantially affected by SCD, mirroring patterns reported in other African and Caribbean settings (Grygiel et al., 2021; Knisely et al., 2020). Pain level scores exceeded those for general health and sleep, while school performance scores were higher than psychosocial health, underscoring persistent pain and educational challenges in this group (Knisely et al., 2020; Kidwell et al., 2021).

Regression analysis showed that economic factors, distance to hospital, and religious beliefs significantly influenced quality of life and pain reduction, whereas some other variables lost significance after adjustment (Socioeconomic and Nutritional Characteristics, 2007). Children from economically disadvantaged households reported poorer outcomes, consistent with studies documenting that low income, high out-of-pocket spending and financial catastrophe are major barriers to optimal SCD care in Nigeria and similar contexts (The Financial Burden of SCD, 2014; Crego et al., 2020; Wonkam & Makani, 2019). Longer distances to tertiary centers contribute to delayed presentation, reduced follow-up and increased disease complications, reinforcing the role of

geographic access as a structural determinant of outcomes (Socioeconomic and Nutritional Characteristics, 2007; Wonkam & Makani, 2019). The finding that religious belief was a significant predictor likely reflects complex interactions between health-seeking behavior, adherence to biomedical treatment, and reliance on spiritual or traditional healing, as described in Nigerian psychosocial studies (Anie & Egunjobi, 2012). While positive religious coping may foster resilience, belief systems that discourage clinic attendance or pharmacologic therapy can undermine disease control and exacerbate pain, partly explaining the reduced quality of life among some subgroups (Anie & Egunjobi, 2012; The Financial Burden of SCD, 2014).

Conclusion

This study provides clear evidence that economic hardship, geographic inaccessibility and certain religious belief patterns are central determinants of quality of life and pain outcomes in children with SCD at OAUTHC (Socioeconomic and Nutritional Characteristics, 2007; The Financial Burden of SCD, 2014). Without targeted socioeconomic support mechanisms—such as transport subsidies, fee reductions and social protection—clinical guidelines for SCD will remain difficult to operationalize, and inequities in health outcomes will persist (Crego et al., 2020; Wonkam & Makani, 2019). Integrating socioeconomic risk screening, context-sensitive religious and community engagement, and concrete financial support into routine SCD services is therefore not optional but essential for achieving meaningful improvements in pediatric SCD outcomes.

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