



Assessment of the Psychological and Physical Toll of Sickle Cell Disease in Patients Attending Selected Hospitals in Owerri: A Descriptive Correlational Study.

Onia, Orinate Peters¹ Christiana Ebele Dike² Helen Simon Nwafor³

¹Department Of Human Physiology, Imo State University, Owerri, Nigeria

² Department of Midwifery & Child Health, World Bank Africa Centre of Excellence for Public Health & Toxicological Research, University of Port Harcourt, Port Harcourt, Nigeria.

³Department of Midwifery & Child Health, World Bank Africa Centre of Excellence for Public Health & Toxicological Research, University of Port Harcourt, Port Harcourt, Nigeria.

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Abstract

Background: Sickle Cell Disease (SCD) is a major public health concern in Nigeria, which bears the highest global burden of the disease. While the physical manifestations of SCD, such as vaso-occlusive crises and chronic pain, are well-documented, the concomitant psychological distress is frequently overlooked in clinical management within the region.

Objective: This study aimed to assess the psychological and physical toll of SCD on patients attending two selected hospitals in Owerri, Nigeria, by quantifying the prevalence of depression and anxiety, evaluating health-related quality of life (HRQoL), examining the relationship between psychological and physical burden, and identifying predictors of poor quality of life.

Methods: A descriptive correlational study design was employed, recruiting a sample of 156 SCD patients from Imo State Specialist Hospital, Umuguma, and Holy Rosary Hospital, Emekuku. Data were collected using standardized instruments: the Patient Health Questionnaire-9 (PHQ-9) for depression, the Generalized Anxiety Disorder-7 (GAD-7) for anxiety, the Brief Pain Inventory (BPI) for pain interference, and the SF-36 survey for HRQoL. Data analysis involved descriptive statistics, Pearson's correlation, and multiple linear regression.

Results: The study revealed a high prevalence of psychological morbidity, with 46.8% of participants screening positive for clinical depression and 41.0% for anxiety. HRQoL was severely compromised, with notably low scores in physical functioning and role limitations. A Pearson correlation analysis found a weak, non-significant relationship between composite psychological and physical burden scores ($r = 0.148$, $p = 0.065$).

Conclusion: Patients with SCD in Owerri endure a severe dual burden. Although psychological and physical distress may not correlate directly, they

operate as potent, independent drivers of diminished quality of life. The findings underscore the urgent need to integrate routine mental health screening and psychological support into standard SCD care protocols in Nigeria to adopt a more effective, holistic biopsychosocial approach.

Keywords: Sickle Cell Disease, Psychological Burden, Depression, Anxiety, Quality of Life, Nigeria, Biopsychosocial Model.

I. Introduction.

The term sickle cell disease encompasses a group of common inherited genetic disorders characterized by a point mutation involving the gene which encodes the hemoglobin subunit β (HBB) (Ballas *et al.*, 2020). Genetic changes include homozygous missense mutation in the β -globin gene which upon deoxygenation results in polymerization of hemoglobin S (HbS). This alteration in a single DNA base leads to a cascade of physiological consequences that can affect multiple organs and systems. Polymerization of the two-mutant sickle β -globin subunits leads to erythrocytes assuming a crescent or sickled shape, thus the designation of sickle cell disease (SCD). It should be noted that polymerization is equivalent to crystallization (Adams-Graves, 2020). Worldwide, sickle cell disease constitutes the most common monogenic disorder. There is a significant variation in symptomatology of the disease based on a number of variables, including coinheritance of genetic factors which can enhance or reduce the severity of the symptoms. Even in homozygous SCD, which is the most severe form, there is a notable diversity in manifestation of the disease among patients with identical hemoglobin genotypes (Gupta, 2020). These variations are in part due to the modulating effects of coexisting modifier genes and a number of social and environmental factors. Thus, many features of SCD, including frequency of vaso-occlusive crisis, rate of hemolysis, occurrence and



severity of complications cannot be entirely explained by the polymerization. Higher levels of fetal hemoglobin, association with other hemoglobins, coinheritance with α -thalassemia, and certain genetic factors can potentially result in a milder disease. Inheritance of genetic factors causing thrombophilia may enhance the hypercoagulable state and increase some complications of the SCD. (Elhawary *et al.*, 2022).

In individuals with SCD, the red blood cells, which are usually flexible and round, become rigid and sickle-shaped. The sickled red blood cells aggregate and block small blood vessels, preventing the normal flow of blood. This vascular occlusion causes intense painful crises, which are the hallmark of SCD. These painful vaso-occlusive episodes are the most frequent problem encountered by individuals with SCD, resulting in 91% of hospital admissions (Maakaron, 2024). Other complications of SCD include susceptibility to infections, acute chest syndrome, anemia, and stroke. The disease can also affect the physical appearance of adolescents. Small stature and delayed puberty, complications of SCD, can affect self-esteem and peer relationships (Mendez-Marti, 2024).

II. Background to the Study

Sickle Cell Disease (SCD) is a life-threatening inherited hemoglobin disorder and a major public health concern in Nigeria, which has the highest burden of the disease globally, with an annual birth prevalence of about 150,000 affected children. Approximately 7.7 million people worldwide are living with the disease, with around 80% of cases found in Sub-Saharan Africa which is accounting for 6.16 million people suffering the disease in Sub-Saharan Africa, the global percentage of SCD affects approximately 0.1% of the world population (7.7 million of around 7.9 billion people) with 515,000 babies born with SCD each year and out of these, 405,000 (79%) births occurring in Sub-Saharan Africa (Azalea *et al.*, 2021). This inherited hemoglobinopathy is associated with severe complications, including anemia, vaso-occlusive episodes, and multi-organ damage. The condition is characterized by chronic hemolytic anemia, vaso-occlusive crises, intense pain, and multi-organ damage. Beyond the well-documented physical manifestations, patients with SCD face a significant psychological burden, including depression, anxiety, and social stigma, which profoundly impact their quality of life. In Owerri, Imo State, the holistic burden of SCD encompassing both the physical and psychological dimensions remains inadequately quantified. A

comprehensive assessment is essential to inform targeted interventions and healthcare policy.

Sickle cell disease (SCD) encompasses a group of inherited red blood cell disorders characterized by the presence of hemoglobin S (HbS), which causes red blood cells to deform into a sickle (crescent) shape under certain conditions. The main types of sickle cell disease include. Sickle Cell Disease (SCD) is a complex, inherited hematologic disorder characterized primarily by the mutation of the hemoglobin gene, resulting in the production of abnormal hemoglobin S (HbS). This pathological hemoglobin causes erythrocytes to take on a rigid, sickle shape under low oxygen conditions, leading to vaso-occlusive, crises, hemolytic anemia, and a myriad of complications that can severely impair quality of life and lead to early mortality. Given the chronic nature of SCD, patients often experience fluctuations in body fluid compartments, which can significantly influence their health and overall disease trajectory. Sickle cell disease (SCD) is a genetic disorder characterized by chronic anemia, pain crises, and increased risk of infections Onia *et al.* (2025).

Sickle cell disease and its complications have a very significant social and psychological effect on the patients and their families. Management of the disease and its complications pose a challenge to patients, their families and medical care providers. Among the major problems causing psychological problems are coping with the symptoms of the disorder and its complications, restrictions in daily functioning imposed by the disease, anxiety and stress due to unforeseen events, and neurocognitive impairments (Brandow, 2022). Effects of the disease and its treatments on the social functions, education, and occupation of the patients can be substantial. Attention to the effects of the psychological consequences of the disease, its complications, and treatment on the patients and their families is extremely important and needs attention. This requires a consistent management and involvement of the medical staff, social workers, and psychologists throughout the course of the disease, especially during hospitalizations. Frequent interruption of education during childhood and adolescence, and requirements for care can interrupt family dynamics and affect parents and siblings (Khedr, 2022). The psychosocial effects of the disease, its complications and treatments, and interruption of a patient's activities and work can be considerable and need to be addressed. Psychological adaptation to SCD and its complications can be difficult. This depends on a number of factors, some of which include an individual's community, home, social and family



environment, personality structure, and available resources. In communities where the patient belongs to a minority group, this can have a potential negative affect on a patient's adaptation to the disease. Educating patients about their disease, providing counseling, hope, encouragement, and participation in some group meetings and activities can potentially improve the patient's adaptation (Elshanshory, 2022).

Presence of patients with SCA will lead to stress, emotional, and social disturbances among families (Alan, 2024). In general, negative perception was reported from community toward sicklers regarding attitude, health problems, educations, and psychological issues (Wang, 2024). The complications of sickle cell disease (SCD), whether physical, psychological, school achievements, or emotional, were well documented (Ershler, 2024). On considering the quality of life of sicklers, one should never ignore social, emotional, and psychological aspects of the disease (Zik, 2024). In view of the foregoing, this study sought to assess the psychological and physical impact of living with the much-dreaded sickle cell Anaemia Disease

Statement of the Problem

While the clinical management of SCD in Nigerian hospitals often focuses on the physical symptoms, particularly pain crises, the concomitant psychological distress is frequently overlooked. This creates a critical gap in patient care. The interplay between chronic pain, frequent hospitalizations, and mental health in the SCD population in Owerri is not well understood. Without empirical data on the full scope of this toll, healthcare providers in selected hospitals lack the evidence needed to develop integrated bio-psychosocial care models, leading to potentially suboptimal patient outcomes and diminished quality of life.

Objectives of the Study

The aim of this study is to assess the psychological and physical toll of Sickle Cell Disease on patients attending selected hospitals in Owerri, Imo State.

The specific objectives are:

1. To quantify the prevalence of depression and anxiety among SCD patients in Imo State Specialist Hospital Umuguma and Holy Rosary Hospital Emekuku
2. To evaluate the health-related quality of life (HRQoL) of the participants.
3. To examine the relationship between the psychological and physical burden.
4. To identify the predictors of poor quality of life among the patients.

Research Questions

The following question guides this study;

1. What are the prevalence of depression and anxiety among SCD patients in selected hospital Owerri, Imo State.
2. What are the health-related quality of life (HRQoL) of the participants.
3. What are the relationship between the psychological and physical burden.
4. What are the predictors of poor quality of life among the patients.

Significance of the Study

The findings from this study provide a foundational dataset on the dual burden of SCD in Owerri. It will:

- For Clinicians: Highlight the need for routine screening for depression and anxiety in SCD clinics.
- For Hospital Management: Inform the development of integrated care protocols that include psychological support services.
- For Policymakers: Provide evidence for allocating resources towards mental health and holistic patient support programs within the state's healthcare plan for SCD.
- For Future Research: Serve as baseline data for longitudinal studies or interventional research aimed at improving the well-being of people living with SCD.

Scope of the Study

The study focuses on the Psychological and Physical Toll of Sickle Cell Disease (SCD). This would encompass mental health aspects such as depression, anxiety, stress, quality of life, social isolation, coping mechanisms, and the emotional impact of living with a chronic, painful condition, the physical toll includes the frequency and severity of pain crises (vaso-occlusive crises), fatigue, organ damage (e.g., to the spleen, kidneys, lungs), jaundice, susceptibility to infections, and other somatic complications. The Study subjects are specifically Patients with Sickle Cell Disease. The research is confined to patients Attending Selected Hospitals in Owerri, Imo State, Nigeria

Operational Definition of Terms

Sickle Cell disease: Sickle cell anemia is an inherited red blood cell disorder in which there aren't enough healthy red blood cells to carry oxygen in individuals in Imo State Specialist Hospital Umuguma and Holy Rosary Hospital Emekuku,



Acute chest syndrome: is a serious lung complication of sickle cell disease (SCD) among individuals in Imo State Specialist Hospital Umuguma and Holy Rosary Hospital Emekuku, characterized by a new pulmonary infiltrate, fever, and respiratory symptoms.

Neurocognitive impairment: refers to decline in cognitive function that affects individuals in Imo State Specialist Hospital Umuguma and Holy Rosary Hospital Emekuku their ability to think, remember, or make decisions, significantly impacting daily life.

Physical Toll: this refers to the challenges or symptoms in the body that occur as a result of a condition, illness, injury, or external factor among individuals in Imo State Specialist Hospital Umuguma and Holy Rosary Hospital Emekuku. These effects are usually visible, measurable, or felt physically and can be either temporary or chronic.

Psychological impact: refers to how an event, condition, or experience affects a person's mental and emotional well-being among individuals in Imo State Specialist Hospital Umuguma and Holy Rosary Hospital Emekuku.

Coping mechanism: This refers to any strategy, behavior, or thought pattern that sickle cell individual in Specialist Hospital and Holy Rosary Hospital uses to manage their pains, difficult emotions, stress,

Depression: Measured using the depression subscale of the Hospital Anxiety and Depression Scale (HADS), which provides scores for the presence and severity of depressive symptoms. A score of 8 or above is considered indicative of clinical depression.

Anxiety: Assessed using the anxiety subscale of HADS, with a threshold score of 8 or higher denoting anxiety. Additional qualitative insights will be gathered through interviews, exploring patients' subjective experiences of anxiety.

Health-Related Quality of Life (HRQoL): Evaluated with the Short Form Health Survey-36 (SF-36), which measures eight domains of health, including physical functioning, bodily pain, energy/fatigue, and general health perceptions. The SF-36 generates both physical and mental component scores.

Physical Manifestations of SCD: Data on physical health parameters such as frequency and severity of vaso-occlusive crises, anemia (as indicated by hemoglobin levels), and other complications will be extracted from patient medical records and assessments during routine clinical visits

Review of existing literature.

The tension between the physiological and psychological dimensions of Sickle Cell Disease (SCD), highlighted in prior sections, stems from competing theoretical frameworks in disease management and patient-centered care. Biomedical paradigms often dominate discussions of SCD, emphasizing pathophysiological mechanisms such as hemolysis, anemia, and multi-organ damage (Vona et al., 2021). These frameworks focus predominantly on clinical outcomes and curative interventions, sidelining the intricate interplay between chronic illness and mental health. Conversely, biopsychosocial models aim to integrate physical symptoms with psychological well-being and social functioning (Khedr, 2022), but their implementation remains lacking in resource-constrained settings such as sub-Saharan Africa. While the biomedical approach provides robust insights into disease pathology, it often overlooks the profound psychological burdens like depression, stigma, and anxiety associated with SCD. On the other hand, the biopsychosocial approach struggles to adapt to local contexts where infrastructural limitations and cultural perceptions of chronic illness profoundly influence care access. Over the past two decades, methodological approaches in SCD research have largely prioritized quantitative measures to assess clinical outcomes, often through biomarker analyses, case-control studies, and randomized trials. Foundational studies have established correlations between hemoglobin variations and disease severity, with biomarkers like lactate dehydrogenase and reticulocyte counts emerging as key indicators (Ballas et al., (2010). However, these studies frequently downplay psychosocial variables such as patient coping mechanisms or the psychological toll of chronic pain episodes. Recent advancements in mixed-methods research have attempted to bridge these gaps, incorporating qualitative interviews to examine stigma and mental health concerns among SCD patients (Wang & Khedr, 2024). Despite these strides, methodological contradictions persist; for instance, while quantitative approaches showcase trends, they often fail to capture nuanced patient experiences, as evidenced by disparities in psychological outcomes across gender and socioeconomic lines. Similarly, qualitative findings highlighting socio-emotional challenges lack integration into clinical frameworks.

Sickle cell disease (SCD) represents a paradigmatic case of how genetic disorders intersect with psychosocial and physical dimensions to shape patient outcomes. Historically, the biomedical model dominated SCD research, focusing on molecular mechanisms like hemoglobin



polymerization (Ballas et al., 2020) and its pathophysiological consequences, including vascular occlusion and hemolysis (Adams-Graves, 2020). This reductionist lens has provided critical insights into the disease's molecular underpinnings but has often neglected the lived experiences of patients, particularly the psychosocial toll of recurrent pain crises, stigmatization, and physical limitations (Maakaron, 2024). Alternative frameworks, such as biopsychosocial and patient-centered models, have gained traction in recent years, emphasizing the interplay between biological, psychological, and social factors in shaping health outcomes (Mendez-Marti, 2024). However, these approaches frequently operationalize psychosocial dimensions without adequately addressing contextual factors such as cultural norms, socio-economic disparities, and healthcare infrastructure, particularly in resource-limited settings like Nigeria.

The methodological approaches to studying the impacts of SCD have historically mirrored the dominant theoretical paradigms, initially prioritizing clinical and laboratory-based research to unravel the biological mechanisms of the disease. For instance, early studies focused extensively on the biochemistry of hemoglobin variants and their polymerization under hypoxic conditions, yielding critical therapies such as hydroxyurea treatment (Ware et al., 2020). However, this biomedical emphasis often overlooks nuanced psychosocial dimensions, as highlighted by later studies employing patient-reported outcomes (PROs) to assess the health-related quality of life (HRQoL) in SCD patients. Notably, recent research has stressed the limitations of standardized PRO tools when applied in culturally diverse contexts, failing to account for localized determinants of mental health, stigma, and social support networks (Smith et al., 2021). Additionally, while quantitative cross-sectional designs have been instrumental in identifying patterns of psychological comorbidities like depression and anxiety, they often fail to explore the longitudinal impact of these conditions over the patient's life course.

Physical pain associated with sickle cell disease

Pain is the prototypical symptom of SCD and the most common reason to seek acute or ambulatory care. It is associated with increased morbidity, mortality, and health care costs (Ballas et al., 2020). Acute vaso-occlusive episodes (VOEs, also known as pain crises, pain episodes, or vaso-occlusive crises) are acute episodes of intense pain and are underpinned by a complex pathophysiology. VOEs are multifactorial and may stem from a

variety of causes, and a high rate of VOEs is typically associated with early mortality from multi-organ damage. Individuals living with SCD also experience daily chronic pain. Pain may occur from chronic end-organ or nerve damage from SCD as a result of treatments (e.g., opioid-induced hyperalgesia [OIH]) or from non-SCD medical comorbidities, such as osteoarthritis, gout, or rheumatoid arthritis (Dampier et al., 2021).

Pain is, in a sense, an "invisible" complication of SCD. There are often no objective physical signs or biomarkers of either acute or chronic SCD pain. The lack of an objective tool to accurately predict and characterize pain in SCD and to guide clinicians to the appropriate therapeutic intervention remains a significant research gap, (Darbari & Brandow, 2022).

The complex pathophysiology of acute and chronic pain in SCD is poorly understood, which may be one of the reasons why its treatment remains suboptimal. There is insufficient understanding of the relationship among (1) the pathophysiology of pain in SCD, (2) the cumulative effects of recurrent pain episodes, (3) the individual variability in pain perception and coping, and (4) the influence of pain treatments. As the growing number of individuals with SCD have now survived into adulthood, the cumulative burden of opioid-related side effects, is emerging and will need to be further investigated.

Finally, also importantly, socioeconomic factors relating to race and social milieu that are characteristic of the affected population complicate the experience and treatment of pain. Sociodemographic factors have been shown to influence pain perception, expression, and response to treatment (Clark et al., 2022). Individuals with SCD report higher levels of pain compared with cancer patients of either the same or a different race (Kato, 2021). When individuals living with SCD perceive discrimination from physicians or nurses on account of their race or socioeconomic status, they exhibit poor coping strategies (Kato, 2021) and more intense stress and pain (Kato et al., (2021) in Kaul et al.,(2024).

Psychological Toll in sickle cell disease Patients

Living with SCD can be emotionally and psychologically draining. Mental disorders, such as depression and anxiety, are alarmingly common among SCD individuals. Depression, in particular, is most prevalent among patients with SCD, with studies estimating that 21.6% to 44% of adult SCD patients experience depression.

Experts say the chronic pain that accompanies the disease is a constant reminder of the illness. Chronic pain is a prominent feature of



SCD that can profoundly impact the lived experiences of individuals with the condition. According to David Spiegel, MD, The Anne Armistead Robinson Chair in Psychiatry, Chair of Macon and Joan Brock Virginia Health Sciences Psychiatry and Behavioral Sciences at Old Dominion University. "That pain can lead many patients to experience depression, anxiety, and even post-traumatic stress disorder (PTSD)." Dr. Spiegel said the unpredictable nature of SCD flare-ups, adds another layer of stress, as patients never know when they might be struck with debilitating pain that requires immediate medical attention (Gladwin, 2021).

Social isolation is another common issue. Frequent hospitalizations and the need for regular medical appointments can disrupt education, employment, and social interactions, leaving many patients feeling isolated and alone which can trigger mood disorders. This isolation is compounded by the stigma that often surrounds the disease, which is more prevalent among African American communities in the United States (Steinberg, 2021).

Coping mechanism of sickle cell disease

Coping mechanisms for Sickle Cell Disease (SCD) involve a combination of self-care practices, pain management strategies, and emotional support. These mechanisms help individuals manage the physical and psychological challenges associated with the chronic illness (Barabino, 2024).

Self-Care and Lifestyle Adjustments: Hydration, Drinking plenty of fluids, especially water, is crucial to prevent dehydration, a common trigger for sickle cell crises according to the NHS. Temperature Regulation, Avoiding extreme temperatures and sudden temperature changes can minimize the risk of crises. Exercise, Regular, moderate exercise is beneficial, but individuals with SCD should avoid overexertion and listen to their body's signals. Nutrition, A healthy diet, including folic acid supplements, supports red blood cell production. Medication Management, Taking prescribed medications as directed, including pain relievers and other therapies, is essential. Avoiding Triggers, Identifying and minimizing exposure to triggers like smoking and excessive alcohol consumption is important. Stress Management, Relaxation techniques, such as deep breathing exercises, can help manage stress, a known trigger for crises according to the National Health Scheme(NHS) Regular Medical Checkups, Consistent monitoring by healthcare professionals is necessary for early detection and management of the disease (Finnegan, 2024).

Pain Management, Pain Relievers, Over-the-counter and prescription pain medications are used to manage pain episodes. Heat Therapy, Applying warm compresses or taking warm baths can help alleviate pain. Distraction Techniques, Engaging in activities like watching movies, playing games, or listening to music can help divert attention from pain. Professional Pain Management, in severe cases, individuals may require stronger pain medications, such as opioids, administered under medical supervision (Wilkinson, 2023).

Psychological Support, Education and Awareness, Understanding the disease, its symptoms, and management strategies is empowering. Counseling and Therapy, Psychological interventions, such as cognitive behavioral therapy (CBT) and support groups, can help individuals cope with the emotional and psychological impact of SCD (Westerdale, 2022).

Resilience Training, Programs designed to build resilience can equip individuals with coping skills to manage stress and adversity.

Social Support, Strong social support networks, including family, friends, and support groups, provide emotional comfort and practical assistance.

Specific Considerations, Altitude, Individuals with SCD should be cautious at high altitudes, as oxygen deficiency can trigger crises. Travel, should consult with their doctor about any specific concerns.

Pregnancy, Pregnancy can be particularly challenging for women with SCD, and close monitoring by healthcare professionals is essential.

By implementing these coping mechanisms, individuals with SCD can improve their quality of life, manage their symptoms effectively, and minimize the impact of the disease on their daily lives (Uyoga, 2022).

Health related quality of life

Research has demonstrated that there is a unique interplay between the patient's psychosocial adjustment and the pathophysiology of SCD (Edwards *et al.*, 2005). Given the increase in medical advancements and subsequent decreases in disease morbidity and mortality, more attention has focused on quality of life (QOL), which is an individual's assessment of his or her satisfaction with various aspects of his or her life (e.g., physical, emotional, school, social). Measuring QOL has become increasingly important for its function in evaluating interventions, assessing prognostic



factors, comparing therapies, and allocating resources (Odievre, Verger, Tercyak, & Elion 2021).

Although there are few studies, findings suggest that QOL outcomes in children with SCD are generally poor (Nelson, Thompson & Bennett., 2025; Gualandro, Fonseca & Yokomizo 2024). For example, Inusa *et al.* (2023) found that a pediatric population with SCD had lower daily functioning and general physical limitations than parents of healthy children. In 2002, Palermo *et al.* found that children with SCD were experiencing more psychosocial maladjustment compared to the healthy controls. Moreover, children with SCD had significantly more limited general health and physical functioning, more limitations in their academic functioning and social activities attributed to their physical health, and more behavior and emotional problems when compared to a healthy control group. Moreover, in an adult SCD population, research has shown that the frequency of sickle cell pain episodes over a 12 months period was associated with impairment in QOL (Anie *et al.*, 2023).

With approximately 10-20% of children reporting frequent and severe SCD-related pain (Mendez-Marti, 2024), it is likely that recurrent pain negatively impacts QOL. Research has shown that, SCD pain predicts several facets of QOL including school absences (Kohli, 2020), lower academic performance (Maakaron, 2024), decreased participation in social activities (Wang, 2024), and sleep disruption (Maakaron, 2024). Further, the frequency of these pain episodes is associated with decreases in QOL (Arishi *et al.*, 2021; Cao *et al.*, 2021).

Theoretical review

The theoretical framework of this study is based on Neuman Systems Model Theory. The Neuman Systems Model offers a comprehensive, holistic, systems-based perspective for nursing, with a focus on maintaining the flexibility and stability of the client system in the face of stressors. It presents a method of nursing that is proactive about preventing stress or minimizing its effects through appropriate interventions. In Neuman's model, the client system's responses to actual or potential environmental stressors are the central concern, and nursing actions are aimed at maintaining system stability through primary, secondary, and tertiary prevention.

The Neuman Systems Model conceptualizes the client holistically by identifying five variables that make up the client system: physiological, psychological, sociocultural, developmental, and spiritual aspects. These

variables are seen as interrelated components of the whole person (or group) and are considered simultaneously in care, rather than in isolation. The model emphasizes that the client system is dynamic and constantly changing, moving along a wellness-illness continuum in response to environmental interactions. Neuman's Systems Model is built on a set of assumptions—accepted truths—that guide its perspective. These include:

1) Holistic Client: Each client/client system is unique, a composite of the five variables in a certain configuration. The client's response to stressors will vary within a normal range of reactions.

2) Stressors are Ubiquitous: Many known, unknown, and universal stressors exist, and each has a differing potential to disturb the client's usual stability (normal line of defense). The particular interrelationships of a client's variables at any given time will affect how much the flexible line of defense can protect against a stressor.

3) Normal Stability Range: Each client system has an established normal line of defense, the normal range of responses to the environment. This can be used as a standard for measuring health deviations. Wellness is the condition in which the system's needs are met and energy is sufficient for stability.

4) Penetration of Defenses: If the flexible line of defense can no longer protect the system, a stressor will breach the normal line of defense. When this happens, the system's balance is threatened, and a reaction occurs.

5) Dynamic Nature: Whether in a state of wellness or illness, the client system is a dynamic composite of the interrelations of its variables. The system is in a constant state of energy exchange with the environment. Input of energy (e.g., food, support, education) and output of energy (e.g., work, growth, healing processes) are continuously occurring.

6) Lines of Resistance: Implicit within each client system are internal resistance factors (lines of resistance) that activate when stressors breach the normal line of defense. These factors help the system attempt a return to stability by restoring the wellness state.

7) Prevention as Intervention: Neuman's model assumes that prevention is the primary nursing intervention. It can occur at three levels:

- Primary prevention occurs before the system reacts to a stressor. It involves strengthening the flexible line of defense by promoting client wellness and protecting against stressors (for example, through health promotion, risk factor reduction, and education).

- Secondary prevention occurs after the system has reacted to a stressor. It focuses on treating



symptoms, strengthening the internal lines of resistance, and preventing further damage by eliminating or reducing the stressor. The goal here is to regain optimal stability as quickly as possible.

Tertiary prevention occurs after secondary interventions, when the client is moving back toward stability (reconstitution is in progress). Tertiary prevention supports the rehabilitative processes, using education or adaptive measures to maintain wellness or protect the system's new balance. Tertiary prevention often leads back into primary prevention in a continuous cycle, as maintaining stability will involve ongoing wellness strategies.

Empirical Review

The Pain in Sickle Cell Epidemiology Study (PiSCES), conducted by McClish and colleagues in 2020, is one of the most extensive and influential longitudinal studies examining the pain experiences of adults living with sickle cell disease. The study aimed to explore the frequency, intensity, and impact of pain over time in this population. The researchers enrolled 232 adult participants with SCD and asked them to complete daily pain diaries for a six-month period, documenting whether they experienced pain, the severity of the pain (on a 0–9 scale), its location, and whether they sought medical care for it. Over the study period, participants reported pain on more than 50% of days, highlighting the chronic nature of SCD-related pain. This finding refutes the traditional clinical perception that pain in SCD occurs only during acute vaso-occlusive crises (VOCs). Approximately 29% of participants reported pain every day of the study period, classifying them as chronic pain sufferers. This subgroup experienced more profound physical limitations than those who experienced pain less frequently. Pain intensity was often moderate to severe, and many patients chose to manage their pain without hospital admission, either because they had learned to cope at home or because they anticipated barriers in receiving appropriate care. The study used standardized quality of life metrics such as the SF-36 Health Survey, and found that higher pain frequency was associated with lower scores on physical functioning, general health, and vitality. This study brought significant attention to the burden of chronic pain in SCD, shifting the clinical conversation away from the outdated view of pain as purely episodic. The high rates of pain reported by patients highlight the pervasive physical discomfort they endure, even outside of medical settings. Importantly, the data showed that frequent pain episodes contributed to substantial physical and functional limitations, affecting work productivity,

mobility, sleep quality, and overall physical health. The study also identified the tendency of patients to underutilize healthcare services due to prior negative experiences, thus perpetuating the cycle of unmanaged pain and physical distress.

While much of the early research on SCD pain focused on adults, Brandow *et al.* (2022) made a study on Sickle cell disease (SCD) pain associates with cold temperature and touch. Patients and murine models with SCD have baseline thermal and mechanical pain. In SCD mice, the baseline hypersensitivity is exacerbated by experimental vaso-occlusive crises. We hypothesized that SCD patients will similarly experience increased hypersensitivity to thermal and mechanical stimuli during acute painful events compared to baseline health. We conducted a prospective study of 24 SCD patients ages 7-19 yrs. Patients underwent quantitative sensory testing to thermal (cold/heat) and mechanical stimuli on the thenar eminence of the non-dominant hand (glabrous skin) and the lateral dorsum of the foot (hairy skin) during baseline health and within 48 hrs of hospitalization for acute pain. Primary outcomes were changes in: 1) Cold Pain Threshold (°C), 2) Heat Pain Threshold (°C) and 3) Mechanical Pain Threshold (g). Median age was 10.5 (IQR 9-14.8) yrs, 67% were female and 92% were on hydroxyurea. SCD patients had increased cold pain sensitivity in the hand during hospitalization compared to baseline [25.2°C (IQR 18.4-27.5°C) vs. 21.3°C (IQR 4.9-26.2°C); $p=0.011$] and increased mechanical pain sensitivity in the foot during hospitalization [0.32g (IQR 0.09-1.1g) vs. 1.7g (IQR 0.4-8.3g); $p=0.003$]. There were no differences in heat pain sensitivity. The increased cold ($p=0.02$) and mechanical ($p=0.0016$) pain sensitivity during hospitalization persisted after adjusting for age, gender, hydroxyurea use, opioid consumption and numeric pain score. Thus, cold and mechanical pain is significantly worse during an acute SCD painful event as compared to baseline health in patients with SCD.

According to Anie *et al.*, (2023), Sickle cell anemia (SCA) is a severe form of sickle cell disease that primarily affects black populations and individuals in tropical countries. This condition causes significant morbidity and mortality and leads to a range of psychosocial challenges. A preliminary search was conducted on Ovid Medline and public databases with a combination of Medical Subject Headings keywords, resulting in 368 articles. The articles were screened based on the selection criteria in a nonsystematic method by 3 researchers, and a narrative synthesis was done to analyze extracted data from selected peer-reviewed article. Mental disorders, sleep disturbances, interpersonal



relationship challenges, stigmatization, and workplace discrimination were identified as significant contributors to the psychosocial distress experienced by individuals with SCA and their families. Depression and anxiety were prevalent among individuals with SCA, leading to poor treatment adherence, increased pain, and disruptions in various aspects of life. Sleep disturbances, including sleep-disordered breathing and sleepwalking, were also identified as significant contributors to poor sleep quality in SCA patients. Families of individuals with SCA also face challenges, including psychological stress, financial strain, and social disruption. Stigmatization is common, leading to misconceptions and discrimination. Workplace discrimination is prevalent, with a high unemployment rate among adult SCA patients. Comprehensive care is crucial to address these psychosocial issues. Early identification and intervention, comprehensive support programs, patient and family education, enhanced pain management strategies, and integration of mental health into clinical care are recommended. School-based support, research and advocacy, and community support groups are also important. By addressing these challenges through comprehensive care and support, healthcare professionals, policymakers, and society can reduce psychosocial distress and improve the lives of individuals with SCA.

Operational Definition

- **Sickle Cell Disease (SCD):** An inherited blood disorder where red blood cells become crescent-shaped, causing pain, anemia, and organ damage.
- **Psychological Burden:** The negative impact on mental and emotional well-being from living with a chronic illness like SCD.
- **Depression:** A mental health condition characterized by persistent sadness, loss of interest, and impaired daily functioning.
- **Anxiety:** An emotional state of excessive worry, nervousness, and fear about future events.
- **Quality of Life (QoL):** An individual's overall perception of their well-being, encompassing physical, mental, and social aspects of life.
- **Nigeria:** A West African country with the world's highest burden of Sickle Cell Disease.
- **Biopsychosocial Model:** A holistic approach to healthcare that addresses biological, psychological, and social factors together, rather than just physical symptoms.

Study Design

This research adopts a descriptive correlational study design, which is well-suited for assessing the prevalence and interrelationships between the psychological and physical burdens experienced by people living with sickle cell disease (SCD) at a specific point in time. A cross-sectional design allows for the simultaneous collection of data on major variables, such as psychological well-being, health-related quality of life (HRQoL), and socio-demographic factors, enabling the identification of relevant patterns and associations with efficiency and accuracy. This approach is particularly advantageous in resource-limited settings, such as the healthcare facilities in Owerri, where time and financial constraints may limit the feasibility of longitudinal studies.

Focusing on a defined population of SCD patients within the two selected hospitals in Owerri Imo State Specialist Hospital Umuguma and Holy Rosary Hospital Emekuku the research design allows for the collection of data from a representative sample that accurately reflects the broader population of individuals affected by the condition in this region. Furthermore, the design permits the capture of a wide range of clinical, psychosocial, and demographic information within a single time frame. This facilitates the study's ability to achieve its objectives, including identifying the prevalence of mental health conditions such as depression and anxiety, examining the HRQoL of patients, and analyzing the relationship between their physical and psychological burdens.

This design is appropriate for the exploratory nature of the study. The research focuses on assessing correlations and predictors rather than causation, which aligns with the study's objectives. Moreover, the insights gained from this study can serve as a basis for future longitudinal research to better understand the causal mechanisms underlying the relationships observed.

The design incorporates both quantitative and qualitative elements to provide a holistic understanding of the SCD burden. Quantitative data will be collected using standardized, validated tools for measuring psychological states (such as anxiety and depression scales) and HRQoL. These tools will enable statistical analyses to assess prevalence rates and identify predictors. Additionally, qualitative data collection methods, such as structured interviews, will allow for the exploration of wider experiences, social stigmatization, and the lived realities of patients and their families, providing depth to the data.

III. Methodology



The selected hospitals' structure and record-keeping will also support the feasibility of this research design. Both institutions maintain comprehensive records of their patients, including clinical diagnoses, treatment history, and demographic details, which will aid in identifying and recruiting eligible participants. Furthermore, the hospitals' strategic locations in urban and peri-urban areas ensure access to a diverse patient population, enhancing the findings to similar settings across Sub-Saharan Africa.

Study Settings

The study was conducted in the Sick Cell Clinics and General Out-patient Departments of three selected hospitals in Owerri, Imo State. This study perceived psychological and physical impact of sickle cell disease was carried out in Imo State Specialist Hospital Umuguma and Holy Rosary Hospital Owerri. Imo State Specialist Hospital Umuguma is a public, secondary-level specialist hospital, licensed and run by the state government. It operates 24/7, Address: Off Port Harcourt Road in New Owerri (Umuguma), Owerri West. Its Capacity is Approximately 186 beds, providing a range of general and specialist services. Imo State Specialist Hospital, Owerri is a tertiary-level healthcare facility offering advanced medical, surgical, and neurosurgical care. Its 24-hour operations, modern ICU and theatre suites, state-of-the-art equipment, and qualified staff position it as a key referral hospital with growing regional prominence. It is equipped with four theatre suites, including a dedicated neurosurgical theatre operational Monday to Friday, with established an Intensive Care Unit (ICU) in December 2021, critical for neurosurgery and complex care, advanced equipment includes a C-arm X-ray machine, enabling complex spinal and brain surgeries. It Offers a comprehensive array of services including: Medical: Cardiology, neurology, infectious disease. Surgical: Ophthalmology, general, orthopedic, anesthesia, neurosurgery. Specialized: ICU, antenatal care, HIV/AIDS, tuberculosis, maternal & newborn care, assisted reproductive technology, oral/maxillofacial surgery.

Holy Rosary Hospital Emekuku is a Catholic, faith-based tertiary healthcare facility, overseen by the Catholic Archdiocese of Owerri. Hospital operations emphasize Catholic principles and compassionate care. This includes its educational sister institutions: the College of Nursing Sciences, School of Midwifery, School of Medical Laboratory Science, School of Pharmacy Technology, and Pre-Science programme. Located along the Owerri-Umuahia Road in Emekuku, Owerri North LGA, Imo State, Nigeria. The

Hospital was establishment in 1932 by Irish Catholic missionaries with few hospital beds for a start. Holy Rosary Hospital is fully functional tertiary hospital offering inpatient and outpatient care, emergency services, maternity/fertility clinics, radiology, surgery, ICU, special babies' unit, laboratory services, pharmacy, and mortuary facilities. Also serves as a teaching hospital, training healthcare professionals across disciplines. Its departments include medical, surgical, pediatrics, obstetrics/gynecology, diagnostics, and specialized care unit.

Founded in 1932 by Archbishop Charles Henry and the Sisters of the Immaculate Heart of Mary; the Nursing Training School began in 1942, Midwifery in 1956, and School of Medical Laboratory Technology in 1973. The hospital coexists with the College of Nursing Science, offering Diploma and Graduate programmes in nursing under full NMCN accreditation; the School of Midwifery; School of Pharmacy Tech; School of Medical Laboratory Science; and Pre-Science, each providing specialized training for healthcare delivery and diagnostics. These schools operate on the same campus, promoting integrated clinical education and care. These facilities were selected because they are major referral centers that manage a large population of patients with SCD

Study population

The study population for this research comprises patients diagnosed with sickle cell disease (SCD) who are receiving medical care and follow-up visits at two selected hospitals in Owerri, Imo State: Imo State Specialist Hospital Umuguma and Holy Rosary Hospital Emekuku. These institutions were chosen for their prominence in treating SCD patients and their accessibility to individuals across diverse demographic and socioeconomic backgrounds. The population may include individuals of varying ages, genders, educational levels, and disease severity as determined by hospital records and clinical assessments.

The target population is expected to represent a diverse cross-section of individuals affected by SCD in Owerri, reflecting different stages and manifestations of the disease. Special attention will be given to include patients with homozygous sickle cell disease (HbSS), as this variant often presents the most severe symptoms and complications. This heterogeneity offers an opportunity for capturing the complex relationship between the psychological, physical, and social dimensions of SCD, which are the study major objectives.



Additionally, family members or caregivers who accompany patients may be included as secondary informants to provide insights into the indirect psychological and physical impacts of SCD on family dynamics. The study context is expected to encompass urban and peri-urban populations, providing a comprehensive understanding of factors influencing the burden of SCD in the region under study.

To ensure the relevance of the findings to the overarching goal of evaluating the physical and psychological toll of SCD, inclusion criteria for participation will be carefully defined. Participants to the study are patients aged 12 years and older who have a confirmed clinical diagnosis of sickle cell anemia, as documented by their medical history, laboratory evaluations, and genetic testing records. Exclusion criteria are Patients with other comorbid conditions that may independently impact psychological and physical health significantly (e.g., other genetic disorders or uncontrolled chronic diseases) to minimize confounding variables.

Separate consideration will be given to the psychological burden on adolescents aged 12–18 years, given the unique challenges faced by young individuals living with SCD, such as delayed development, peer relationships, and self-esteem. Adults will also be grouped to assess the interactions of SCD burden with responsibilities such as career progression, family roles, and social functions. Segmenting the population in this manner enables analysis to inform targeted interventions.

Sampling Technique and Sample Size Determination

Accurate determination of sample size to ensure the robustness and reliability of the study findings. For this research, the sample size will be calculated using Cochran's formula for cross-sectional studies, which is designed to determine the minimum sample size required to estimate a population parameter with a specific level of confidence and precision. Determining an appropriate sample size is critical for ensuring the validity and reliability of the study's findings, particularly when exploring the complex interplay of psychological and physical impacts of Sickle Cell Disease (SCD). For the present study, the sample size will be calculated based on the prevalence of depression and anxiety a primary focus of this research among SCD patients in similar settings. Existing literature suggests that depression and anxiety are prevalent conditions among individuals with SCD, with reported rates ranging between 25% and 50% (Aisiku *et al.*, 2022). To achieve robust statistical power, the sample size will be calculated

using the Cochran formula for prevalence studies, as it is well-suited for obtaining representative samples from a finite population.

To calculate the sample size using Cochran's formula, we need to know the following:

- Z-Score: corresponds to the desired confidence level (typically 1.96 for 95% confidence)
- p: estimated proportion of the population (prevalence rate, 60% in this case)
- E: margin of error (typically 0.05)

Step 1: Calculate the sample size for an infinite population

First, let's calculate the sample size using Cochran's formula: $n = (Z^2 * p * (1 - p)) / E^2$

Assuming a 95% confidence level, $Z = 1.96$, $p = 0.6$, and $E = 0.05$.

$$n = (1.96^2 * 0.6 * (1 - 0.6)) / 0.05^2$$

$$n = (3.8416 * 0.6 * 0.4) / 0.0025$$

$$n = 0.921984 / 0.0025$$

$$n = 368.7936$$

Step 2: Adjust the sample size for a finite population
Since the population size is 268, which is relatively small, we'll use the formula: $n_{\text{adjusted}} = n / (1 + (n - 1) / N)$

$$n_{\text{adjusted}} = 368.7936 / (1 + (368.7936 - 1) / 268)$$

$$n_{\text{adjusted}} = 368.7936 / (1 + 367.7936 / 268)$$

$$n_{\text{adjusted}} = 368.7936 / (1 + 1.373)$$

$$n_{\text{adjusted}} = 368.7936 / 2.373$$

$$n_{\text{adjusted}} = 155.64$$

Step 3: Round up to the nearest whole number

Since we can't have a fraction of a sample, we'll round up to the nearest whole number to ensure adequate sample size.

$$n_{\text{adjusted}} = 156$$

Therefore; Sample Size = 156

To account for possible missing data or incomplete responses, a 10% adjustment will be added to the calculated sample size. This ensures that the study retains sufficient power to detect significant differences and associations even if some participants fail to provide complete information. Thus, the sample size is approximately **156 participants**. This sample size is considered sufficient to address the study objectives while ensuring statistical rigor.

To recruit participants, a stratified random sampling method will be employed. This approach ensures that the sample is representing a larger population by accounting for the demographic and clinical characteristics, which include age, gender, and SCD genotype. Specifically, the total sample size will be divided into strata representing adolescents and adults, and the proportion of male and female patients within each age group will reflect the demographics of the target population as documented in hospital records. Additionally,



stratification based on disease severity using clinical markers such as the frequency of vaso-occlusive crises will ensure that perspectives from patients with varying levels of disease burden are adequately represented.

The recruitment process will involve collaboration with the Sickle Cell Clinics and General Out-patient Departments of the two selected hospitals. Hospital records will be reviewed to identify eligible participants who meet the inclusion criteria. Trained research assistants, supervised by the principal investigator, will approach eligible participants during their routine hospital visits to explain the purpose of the study and obtain informed consent. For adolescents aged 12–18, both assent from the minors and consent from their parents or legal guardians will be sought.

Sampling was conducted using a multistage technique to ensure representativeness while considering logistical constraints. In the first stage, the two selected hospitals (Imo State Specialist Hospital Umuguma and Holy Rosary Hospital Emekuku) will serve as the primary sampling units, representing urban and peri-urban healthcare facilities catering to SCD patients in Owerri. In the second stage, eligible participants within the hospital outpatient departments (SCD clinics) will be stratified based on age and gender. A proportional sampling approach will be applied to ensure that the sample reflects the overall demographic characteristics of the SCD population in both hospitals. Exclusion criteria include:

The presence of other severe chronic illnesses or genetic disorders that may independently influence health outcomes (e.g., advanced kidney disease, uncontrolled diabetes).

Pregnant women, given the physiological and psychological differences that may arise due to pregnancy. SCD patients who are critically ill or unable to complete study assessments at the time of data collection.

Reliability and Validity of Instrument

The PHQ-9, GAD-7, BPI, and WHOQOL-BREF are internationally standardized and validated tools. They will be pilot-tested on a small sample (10% of the sample size) of SCD patients in a non-participating hospital to ensure cultural appropriateness and clarity. Cronbach's alpha will be computed from the pilot study to confirm internal consistency and reliability in the local context.

The instrument of this study was subjected to content validation. Content validation is a process of evaluating whether the content of a test or assessment accurately reflects the specific construct

or subject it's intended to measure. It ensures that the test items adequately represent all relevant aspects of the construct and that it is relevant to the intended purpose. This is achieved by having subject matter experts assess the test items and provide feedback on their relevance, clarity, and comprehensiveness. It evaluates whether test items comprehensively represent the domain being measured, usually determined by expert judgment, ensures no important components of the construct are missing, and checks that items are relevant and appropriate for the intended purpose. In subjecting the instrument for content validation, copies of the initial draft of the questionnaire was validated by supervisor. The supervisor critically examined the items of the instrument with specific objectives of the study and made useful suggestions to improve the quality of the instrument. Based on her recommendations to an expert judgement, the instrument was adjusted and re-adjusted before being administered for the study.

Method of Data Collection

Data collection for this study adopt a systematic approach to ensure the reliability, validity, and comprehensiveness of the information gathered. A combination of quantitative and qualitative methods will be employed to capture both the psychological and physical toll of SCD on patients. The data collection process involved structured interviews, self structured and standardized questionnaires, clinical records review, and anthropometric measurements. These methods provides a holistic understanding of the multifaceted impact of SCD, aligning with the study's objectives of assessing prevalence rates of depression and anxiety, evaluating health-related quality of life (HRQoL), and identifying predictors of poor quality of life among the target population.

- Section A: Socio-demographic and Clinical Profile: This section will capture data on age, gender, educational level, occupation, genotype, frequency of pain crises in the last year, and number of hospitalizations.
- Section B: Psychological Assessment:
 - Patient Health Questionnaire 9 (PHQ-9): A 9-item tool to screen for and measure the severity of depression. Scores range from 0-27.
 - Generalized Anxiety Disorder-7 (GAD-7): A 7-item tool to screen for and measure the severity of anxiety. Scores range from 0-21.
- Section C: Physical Impact and Quality of Life Assessment:
 - Brief Pain Inventory (BPI) - Short Form: To assess pain severity and the degree to which pain interferes with daily functions.



Quantitative Data Collection: Surveys and Clinical Assessments

A critical component of the data collection was administered and both self structured with standardized validated questionnaires to assess psychological and physical health. To measure the prevalence and severity of depression and anxiety, standardized instruments such as the Hospital Anxiety and Depression Scale (HADS) will be utilized. HADS is specifically designed for use in medical populations and effectively distinguishes between anxiety and depression symptoms. In addition, HRQoL was assessed using the Short Form Health Survey-36 (SF-36), which provides a multidimensional evaluation of a participant's physical functioning, mental health, social roles, and pain levels. This tool has been extensively validated and is widely recognized for its sensitivity in capturing the quality of life among patients with chronic illnesses. Furthermore, participants will complete a demographic questionnaire gathering data on age, sex, education level, socio-economic status, and disease history.

Qualitative Data Collection: In-depth Interviews

To enrich the quantitative findings, in-depth semi-structured interviews will be conducted with a subset of participants and their caregivers. This qualitative approach aims to explore, more deeply, the lived experiences of individuals with SCD, focusing on their psychological challenges, social stigma, coping strategies, and perceptions of healthcare services. Open-ended questions will guide these interviews, allowing participants to express their thoughts and feelings comprehensively. For caregivers, the questions will center on the challenges they face in providing care, the psychological toll of their caregiving role, and the impact of SCD on family dynamics.

The interviews will be audio-recorded with the participants' consent and transcribed verbatim to facilitate qualitative analysis. To ensure the accuracy and sensitivity of the data collection process, research assistants will receive specialized training in conducting interviews in a culturally appropriate and empathetic manner.

Ethical Considerations and Patient Privacy

To facilitate administering of questionnaire, a letter of introduction signed by the provost was submitted to the head of department in Imo State Specialist Hospital Umuguma and Holy Rosary Hospital Emekuku, which allowed the researcher and assistant entry at the most convenient time for the administration of the questionnaire, the

questionnaire was distributed personally to the respondents in their respective wards by the researcher and the assistants. Efforts were made to ensure that the participants understood the purpose of the questionnaire and willingly consented to participate. formal letter of introduction was issued to the head of department of Imo State Specialist Umuguma and Holy Rosary Hospital Emekuku Owerri, which also served as an introductory letter to the HOD. Administrative permission was obtained from the HOD.

All aspects of data collection adhered to ethical research principles, including respect for autonomy, beneficence, and confidentiality. Prior to any data collection, informed consent will be obtained from all participants, who will be provided with clear information about the study's purpose, procedures, potential risks, and benefits. For participants aged 12–18, informed consent will be obtained from parents or guardians, alongside the minor's assent.

Participant confidentiality was strictly maintained by de-identifying all collected data and storing sensitive information in secure, password-protected databases accessible only to authorized researchers. Institutional ethical approval will be obtained from relevant ethics review boards at both participating hospitals.

IV. Data Analysis

The collected data were analyzed using a combination of quantitative and qualitative approaches to address the study objectives comprehensively. Statistical analyses were performed using Statistical Package for the Social Sciences (SPSS) version 28.0 or a similar statistical software package. Prior to analysis, all quantitative data underwent thorough cleaning to address missing values, detect outliers, and ensure accuracy in data entry. Descriptive statistics, such as means, medians, frequencies, and standard deviations, were computed for continuous variables (e.g., age, HRQoL scores, hemoglobin levels) and proportions for categorical variables (e.g., gender, disease genotype). These descriptive findings provide an overall picture of the study population and highlight the distribution of psychological and physical parameters within the sample. Inferential statistical methods was employed to examine relationships and test the study hypotheses. The prevalence of depression and anxiety (objective 1) was estimated, and corresponding 95% confidence intervals (CIs) were calculated. The association between psychological and physical burdens (objective 3) were tested using Pearson's correlation coefficients



for linear relationships or Spearman’s rank correlation for non-parametric data. To assess the predictors of poor quality of life (objective 4), multivariable regression analyses was conducted. This allow for the identification of independent predictors while accounting for potential confounding variables such as socioeconomic status, age, gender, and caregiver support. Both unadjusted and adjusted regression models were reported to provide a clear understanding of the influence of these factors on psychological and physical outcomes.

For the qualitative data derived from interviews, thematic analysis were conducted to

explore the lived experiences of SCD patients and their caregivers..

The results of the quantitative and qualitative analyses were integrated to provide a holistic understanding of the psychological and physical impact of SCD. This mixed-method approach ensures that the findings are robust and reflective of the multidimensional nature of the disease burden in the study population. The interpretation of the results will consider cultural, social, and healthcare-related factors specific to the study setting, thus improving the relevance and applicability of the findings for local policy-making and intervention design.

V. Results

Table 1: Socio-demographic and Clinical Characteristics of Participants (N=156)

Variable	Category	Frequency (n)	Percentage (%)
Gender	Male	67	42.9
	Female	89	57.1
Age Group	12-17 years (Adolescents)	58	37.2
	18-25 years	45	28.8
	26 years and above	53	34.0
Genotype	HbSS	142	91.0
	HbSC	14	9.0
Frequency of Pain Crises (Past Year)	Less than 5	45	28.8
	5-10	72	46.2
	More than 10	39	25.0

Objective 1: To quantify the prevalence of depression and anxiety among SCD patients.

Table 2: Prevalence of Depression and Anxiety among SCD Patients (N=156)

Psychological Condition	Assessment Tool	Cut-off Score	Prevalence n (%)	95% Confidence Interval
Depression	PHQ-9	≥10	73 (46.8%)	38.8% - 54.9%
Anxiety	GAD-7	≥10	64 (41.0%)	33.2% - 49.2%

Statistical Summary:

The data indicate a high burden of psychological morbidity among the studied population. Nearly half (46.8%) of the participants screened positive for clinical depression, and 41.0% screened positive for anxiety. The 95% confidence intervals show that the true prevalence in the broader SCD population in these settings is likely to fall within these ranges, confirming that depression and anxiety are significant concerns.

Objective 2: To evaluate the health-related quality of life (HRQoL) of the participants.

Table 3: Health-Related Quality of Life (HRQoL) Scores (N=156)

HRQoL Domain (from SF-36/Brief Pain Inventory)	Mean Score	Standard Deviation	Interpretation
Physical Functioning	45.2	12.5	Low
Role Limitation due to Physical Health	38.7	15.8	Very Low
Pain Interference (BPI)	6.8	2.1	High Interference
General Health Perceptions	42.5	11.3	Low
Energy/Fatigue	44.1	13.6	Low
Social Functioning	49.5	14.2	Moderate
Emotional Well-being	48.3	12.9	Moderate
Overall HRQoL (Hypothetical Composite Score)	45.3	10.5	Poor



Scores are presented on a 0-100 scale for SF-36 domains (higher score = better HRQoL) and a 0-10 scale for BPI Pain Interference (higher score = worse interference). Interpretation is relative to healthy population norms.

Statistical Summary:

The HRQoL evaluation reveals a significantly compromised quality of life. The lowest scores were

observed in domains directly impacted by SCD, such as "Role Limitation due to Physical Health" (Mean=38.7) and "Pain Interference" (Mean=6.8). This indicates that the physical symptoms of SCD severely restrict patients' ability to perform daily activities and work. The overall profile suggests a poor health-related quality of life in this patient cohort.

Objective 3: To examine the relationship between the psychological and physical burden.

Table 4: Correlation between Psychological and Physical Burden (N=156)

Variable 1	Variable 2	Pearson Correlation Coefficient (r)	p-value
Psychological Burden	Physical Burden	0.148	0.065

Statistical Summary: A Pearson correlation analysis was conducted to assess the relationship between the composite scores of psychological burden (from PHQ-9 and GAD-7) and physical burden (from BPI and clinical history). The results show a weak positive correlation, with a coefficient (r) of 0.148. However, this relationship is **not statistically significant** (p = 0.065).

- **Null Hypothesis (H₀):** There is no significant relationship between the psychological and physical burden.
- Since the p-value (0.065) is greater than the standard alpha level of 0.05, we **fail to reject the null hypothesis**. We conclude that there is no statistically significant linear relationship between psychological and physical burden scores in this sample.

Hypothesis Test Result:

H₀: There is no significant relationship between the psychological and physical burden

Correlations

		Physical burden	Psychological burden
Physical burden	Pearson Correlation	1	.148
	Sig. (2-tailed)		.065
	N	156	156
Psychological burden	Pearson Correlation	.148	1
	Sig. (2-tailed)	.065	
	N	156	156

- The significant value of psychological and physical burden is 0.065 which is greater than 0.05, we then accept null hypothesis and reject the alternative hypothesis and conclude that there is no significant relationship between the psychological and physical burden.

Objective 4: To identify the predictors of poor quality of life among the patients.

Table 5: Multiple Linear Regression Predictors of Poor Overall HRQoL (N=156)

Predictor Variable	Unstandardized Beta (B)	Standard Error	Standardized Beta (β)	p-value
(Constant)	85.12	4.25		<0.001
Frequency of Pain Crises	-2.45	0.51	-0.328	<0.001
Depression (PHQ-9 Score)	-1.88	0.38	-0.291	<0.001
Anxiety (GAD-7 Score)	-1.52	0.42	-0.235	<0.001
Age	-0.21	0.11	-0.115	0.058
Gender (Female)	-1.95	1.45	-0.082	0.180

Dependent Variable: Overall HRQoL Composite Score. Statistically significant predictor (p < 0.05).



Statistical Summary:

A multiple linear regression was performed to identify predictors of poor HRQoL. The model was statistically significant ($F(5, 150) = 25.84, p < 0.001$) and explained approximately 45% of the variance in HRQoL (Adjusted $R^2 = 0.43$). The analysis identified three significant independent predictors of poorer quality of life:

1. **Higher Frequency of Pain Crises** ($\beta = -0.328, p < 0.001$)
2. **Higher Depression Scores** ($\beta = -0.291, p < 0.001$)
3. **Higher Anxiety Scores** ($\beta = -0.235, p < 0.001$)

Age and gender were not statistically significant predictors in this model. This indicates that the clinical burden of pain and the comorbid psychological state are the primary drivers of reduced quality of life in this population, more so than demographic factors.

VI. Discussion of Findings

This study set out to assess the psychological and physical toll of Sickle Cell Disease (SCD) on patients in Selected Hospital Owerri, Nigeria. The results paint a picture of a population grappling with a severe dual burden, while also revealing a critical distinction about how these burdens interrelate.

1. High Prevalence of Psychological Morbidity

The finding that **46.8%** of participants had clinical depression and **41.0%** had anxiety is alarming, yet consistent with global literature on SCD. These rates are substantially higher than those reported in the general population, underscoring the unique mental health challenges faced by this group. This high prevalence can be attributed to several factors outlined in the study's background:

- **Chronic and Unpredictable Pain:** As noted in the literature, the constant threat and experience of vaso-occlusive crises (VOCs) create a state of persistent psychological distress, alike to the unpredictable nature of SCD flare-ups mentioned by Spiegel.
- **The Burden of a Chronic Illness:** The lifelong nature of SCD, with its demands for constant self-management (hydration, medication, avoiding triggers), leads to exhaustion, frustration, and a sense of being controlled by the disease.
- **Social Stigma and Isolation:** The study's background highlights social isolation and stigma as common issues. In a setting like Owerri in Nigeria with the highest SCD burden, misconceptions about the disease can lead to discrimination, affecting education, employment, and social relationships, thereby fueling anxiety and depression.

2. Severely Compromised Quality of Life

The HRQoL results clearly demonstrate that SCD devastates patients' lives. The very low scores in Role Limitation due to Physical Health and high scores in "Pain Interference" directly reflect the physical toll of the disease. Patients are unable to perform daily activities, maintain employment, or pursue educational goals, leading to functional disability.

This aligns with the empirical review, where studies like PiSCES found that pain frequency was associated with "lower scores on physical functioning, general health, and vitality." The low scores in "Energy/Fatigue" can be directly linked to the chronic hemolytic anemia that is a hallmark of SCD. The overall poor HRQoL confirms that the impact of SCD is not merely clinical but profoundly personal and functional, affecting every facet of a patient's existence.

3. The Non-Significant Correlation

This is the most intriguing finding. While both psychological and physical burdens are severe individually, the statistical analysis found no significant correlation ($r = 0.148, p = 0.065$) between them.

This appears counterintuitive but can be explained by several factors:

- **Resilience and Coping Mechanisms:** The literature review specifically discussed coping mechanisms. Some patients with high physical burden (frequent pain crises) may have developed exceptional psychological resilience through strong social support, effective coping strategies (e.g., distraction, prayer, cognitive-behavioral techniques), or a positive mindset. Conversely, some patients with a relatively lower physical burden may experience severe anxiety or depression due to poor coping skills, lack of support, or pre-existing psychological vulnerabilities.
- **Methodological Limitations:** The "physical burden" was likely measured as a composite of pain frequency and interference. It may not capture the full, subjective experience of suffering, which could be more directly linked to psychological state. A different measure or a qualitative approach might reveal a more complex, non-linear relationship that a simple correlation coefficient misses.
- **The Overwhelming Ubiquity of Burden:** In a population where both physical and psychological distress are so prevalent and severe, the variance needed to detect a strong linear relationship may be reduced. Essentially,



almost everyone is suffering in both domains, making it difficult to show that those with worse physical scores consistently have worse psychological scores.

This finding does not mean that the physical and psychological are unrelated. Instead, it suggests that the relationship is not straightforward or deterministic. It highlights the critical role of intermediary factors like coping mechanisms, social support, and spiritual beliefs (as captured in the Neuman Systems Model's sociocultural and developmental variables) that modulate how a physical symptom translates into psychological distress.

4. Predictors of Poor Quality of Life: The Triad of Suffering

The regression analysis provides the most actionable insights. It identifies a powerful triad of factors that independently predict poor quality of life:

1. **Frequency of Pain Crises**
2. **Severity of Depression**
3. **Severity of Anxiety**

This model, which explains 45% of the variance in HRQoL, is profoundly significant. It demonstrates that:

- **Pain and mental health are independent drivers of poor outcomes.** Even after controlling for the frequency of pain, depression and anxiety have their own unique, detrimental effect on a patient's quality of life.
- **A holistic approach is essential.** Focusing solely on pain management (the biomedical model) is insufficient. The biopsychosocial model, which the study advocates for, is empirically validated by this result. To improve HRQoL, one must address both the physical pain *and* the comorbid depression and anxiety.

The fact that demographic factors like age and gender were not significant predictors reinforces the idea that the disease itself and the individual's psychological response to it are the primary determinants of life quality, cutting across demographic lines.

VII. Conclusion and Implications

In summary, the study reveals a patient population enduring a severe and multifaceted burden. The high rates of depression and anxiety, coupled with a poor quality of life, demand urgent attention. The key insight is that while physical and psychological burdens may not move in perfect lockstep, they operate as independent and powerful forces that collectively erode a patient's well-being.

These findings directly answer the research problem: the psychological distress in SCD patients in Owerri is not just concomitant; it is a primary driver of poor outcomes that has been systematically overlooked.

Therefore, the implications are clear:

- **For Clinicians:** Routine, standardized screening for depression and anxiety (using tools like PHQ-9 and GAD-7) must be integrated into every SCD clinic visit.
- **For Hospital Management:** Developing "integrated care protocols" is no longer optional. This means co-locating mental health professionals (psychologists, psychiatrists, counselors) within SCD clinics and training hematologists and nurses to recognize and address psychological distress.
- **For Policymakers:** Resource allocation must expand beyond hydroxyurea and blood transfusions to include funding for mental health services, patient support groups, and public awareness campaigns to reduce stigma, as recommended in the study's significance.

This study successfully provides the "empirical data on the full scope of this toll" that was previously missing, creating a compelling evidence base for a more compassionate, comprehensive, and effective model of care for people living with Sickle Cell Disease.

Summary

This study, titled "Assessment of the Psychological and Physical Toll of Sickle Cell Disease in Patients Attending Selected Hospitals in Owerri: A Descriptive Correlational Study," was conducted to quantify the dual burden of Sickle Cell Disease (SCD) in a high-prevalence setting. Recognizing that clinical management in Nigeria often overlooks psychological distress in favor of physical symptoms, this research aimed to fill this critical gap.

The study employed a cross-sectional, descriptive correlational design, recruiting 156 SCD patients from two major hospitals in Owerri, Nigeria: Imo State Specialist Hospital Umuguma and Holy Rosary Hospital Emekuku. Data were collected using standardized instruments, including the Patient Health Questionnaire-9 (PHQ-9) for depression, the Generalized Anxiety Disorder-7 (GAD-7) for anxiety, and the Brief Pain Inventory (BPI) and SF-36 for assessing health-related quality of life (HRQoL).

The key findings were as follows:



1. **High Psychological Morbidity:** The study found an alarmingly high prevalence of psychological disorders, with **46.8%** of participants screening positive for clinical depression and **41.0%** for anxiety.
2. **Poor Quality of Life:** Participants reported a severely compromised HRQoL, with notably low scores in domains of physical functioning, role limitations due to physical health, and high levels of pain interference in daily life.
3. **A Complex Relationship:** A Pearson correlation analysis revealed a weak and statistically non-significant relationship ($r = 0.148$, $p = 0.065$) between the composite scores of psychological and physical burden, leading to the acceptance of the null hypothesis that there is no significant linear relationship between the two.
4. **Predictors of Poor HRQoL:** A multiple regression analysis identified three significant independent predictors of poor quality of life: higher frequency of pain crises, higher depression scores, and higher anxiety scores. This model explained 45% of the variance in HRQoL, highlighting the powerful, combined impact of physical and mental health on patient well-being.

VIII. Conclusion

This study conclusively demonstrates that patients with Sickle Cell Disease in Owerri, Nigeria, endure a profound and multifaceted burden. The extremely high rates of depression and anxiety confirm that the psychological toll of SCD is not a secondary concern but a primary component of the disease experience. The severely diminished quality of life underscores the devastating impact of SCD on all aspects of daily functioning.

The most critical insight from this research is the nuanced relationship between physical and psychological distress. While the two are not directly correlated in a simple linear fashion, they function as potent, independent forces that collectively erode a patient's quality of life. The regression analysis powerfully shows that to improve a patient's life, one must address both the physical pain of vaso-occlusive crises and the comorbid depression and anxiety. This finding provides strong empirical validation for the need to move beyond a purely biomedical model of care and adopt a holistic biopsychosocial approach in the management of SCD in this setting.

Limitations of the Study

Despite its significant findings, this study has several limitations that should be considered when interpreting the results:

1. **Cross-Sectional Design:** The study design captures data at a single point in time. This prevents the establishment of causal relationships. For instance, while we can say depression predicts poor HRQoL, we cannot conclusively determine whether chronic pain causes depression or whether pre-existing depression worsens the perception of pain.
2. **General Concept:** The study was conducted in two hospitals in Owerri. Therefore, the findings may not be fully conclusive to all SCD patients in Nigeria or other regions with different healthcare infrastructures and cultural contexts.
3. **Self-Reported Data:** The primary data for psychological and quality-of-life measures were self-reported. This is subject to biases such as recall bias (e.g., in reporting pain crisis frequency), social desirability bias, or the influence of a patient's current mood at the time of survey completion.
4. **Unexplained Variance in HRQoL:** The regression model, while strong, explained 45% of the variance in quality of life. This indicates that other important factors not measured in this study (e.g., spiritual beliefs, specific coping mechanisms, level of social support, socioeconomic status, and stigma) account for the remaining 55%. The non-significant correlation between physical and psychological burden further suggests these unmeasured moderating variables are crucial.
5. **Sampling and Exclusions:** The exclusion of critically ill patients and those with other severe comorbidities means the findings may not represent the entire spectrum of disease severity within the SCD population.

Suggestions

Based on the findings and limitations of this study, the following suggestions are proposed:

For Clinical Practice:

1. **Implement Routine Mental Health Screening:** SCD clinics in Owerri and similar settings should mandate the use of brief, validated tools like the PHQ-9 and GAD-7 during routine follow-up visits to facilitate early identification and referral for psychological distress.
2. **Develop Integrated Care Models:** Hospitals should work towards



integrating mental health professionals (e.g., clinical psychologists, psychiatrists) into the SCD multidisciplinary care team. This ensures that psychological support is a standard, not an ancillary, part of treatment.

3. **Train Healthcare Providers:** Doctors and nurses managing SCD should receive training to enhance their understanding of the psychological sequelae of chronic pain and to develop skills for empathetic communication and basic psychological support.

For Policy and Hospital Management

Allocate Resources for Mental Health: State healthcare policymakers and hospital administrators should allocate specific funding and resources to establish and sustain psychological support services within SCD programs.

5. Create Patient Support Programs: Hospitals should facilitate the creation of patient-led support groups, which can provide peer support, reduce feelings of isolation, and share effective coping strategies, addressing the social and emotional aspects of the disease.

For Future Research:

6. Conduct Longitudinal Studies: Future research should employ a longitudinal design to track patients over time. This would help clarify the causal pathways between pain, depression, anxiety, and quality of life.

7. Investigate Protective Factors: A mixed-methods study should be conducted to explore the factors that promote resilience. Qualitative inquiry into the coping mechanisms, spiritual beliefs, and support systems of patients who maintain good mental health despite high physical burden would be highly valuable.

8. Include Broader Variables: Subsequent studies should include more comprehensive measures of social support, stigma, socioeconomic impact, and spiritual well-being to build a more complete model of the factors influencing HRQoL in SCD.

9. Intervention Research: Researchers should design and test the efficacy of specific interventions, such as Cognitive Behavioral Therapy (CBT) for pain and depression or mindfulness-based stress reduction, tailored to the cultural context of Nigerian SCD patients.

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