



# International Journal of Multidisciplinary Research and Growth Evaluation.

## Psychosocial Problem and Counselling Needs of Sickle Cell Patients in Nigeria

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### Article Info

**ISSN (online):** 2582-7138

**Volume:** 06

**Issue:** 01

**January-February 2025**

**Received:** 20-11-2024

**Accepted:** 23-12-2024

**Page No:** 995-998

### Abstract

Sickle cell disease (SCD) is a chronic genetic disorder that affects millions of people worldwide, with Nigeria having the highest burden. Despite the availability of government hospitals, SCD patients in Nigeria face significant psychosocial challenges that affect their healthcare-seeking behavior that received much attention is the counselling of people affected by the disease.

This study review to explore the psychosocial behavior of SCD patients in Nigeria. It started by conceptualizing the psychosocial problems, counselling and Sickle Cell Disease before delving into the psychosocial impacts of an SCD Diagnosis, psychological needs of Sickle Cell patients in Nigeria and counselling Needs of Sickle Cell Disease Patients in Nigeria. The paper also presented the problems of Sickle Cell Disease Counselling in Nigeria and finally provided the suggestions.

**Keywords:** Sickle cell disorder, psychosocial behavior, Counseling Needs of sickle cell Patients in Nigeria and Sickle Cell Counselling

### Introduction

Sickle cell disease (SCD) is a genetic disorder that affects millions of people worldwide, with Nigeria having the highest burden of the disease globally. The condition is characterized by recurring episodes of acute pain, chronic anemia, and increased susceptibility to infections, which significantly impact the quality of life of affected individuals.

In Nigeria, the majority of sickle cell patients rely on government hospitals for their healthcare needs. However, these hospitals often face challenges such as inadequate funding, insufficient healthcare personnel, and lack of specialized care for sickle cell patients. These challenges can lead to poor health outcomes, increased morbidity, and mortality among sickle cell patients.

Beyond the physical symptoms of the disease, sickle cell patients in Nigeria also face significant psychosocial challenges, including stigma, discrimination, anxiety, depression, and social isolation. These psychosocial factors can affect their behavior and attitudes towards attending government hospitals, ultimately influencing their healthcare-seeking behavior and adherence to treatment.

This study aims to explore the psychosocial behavior of sickle cell patients in attending government hospitals in Nigeria, with a focus on understanding the factors that influence their healthcare-seeking behavior and adherence to treatment. By examining the psychosocial aspects of sickle cell disease in the Nigerian context, this study seeks to contribute to the development of effective interventions that improve the health outcomes and quality of life of sickle cell patients in Nigeria.

### Conceptual Clarification

The following keys are clarified. They are namely: *Psychosocial Disorder, Counselling, Sickle Cell and Sickle Cell Counselling*

### Psychosocial Behavior

Psychosocial Behavior include the broad spectrum of all complaints which are not strictly medical or somatic. They affect the patient's functioning in daily life, his or her environment and/or life events. On the one hand, it concerns various psychological problems such as: anxiousness, nervousness, tenseness, (posttraumatic or acute) stress, depression and feeling depressed, burn out, loneliness, irritability, sleep disorder, sexual problems, tics, alcohol abuse, tobacco abuse, drug abuse, memory problems.

behavior problems, learning difficulties, phase-of-life problems, fear of mental illness, psychoses, schizophrenia, anxiety (disorder), somatization disorder, suicide/suicidality, neurasthenia/ surmenage, phobia/obsessive compulsive disorder, personality disorder or identity problem, hyperkinetic disorder, intellectual disabilities, relational problems (with friend, family and/or partner), medically unexplained symptoms and eating disorders.

### Counselling

Counselling as a concept, as observed by Bor has many interpretations. Whatever its goals, counselling is directed towards assisting people to take decisions, to effect a change, to prevent problems or crises or to manage them when they arise. Hopson cited Irinoye thus, from a problem-solving perspective, saw counselling as helping people to explore problems and clarify conflicting issues, and to discover alternative ways of dealing with the problems by taking appropriate decisions and action.

### Sickle Cell Disorder

Sickle cell disease (SCD) is a genetic disorder that affects millions of people worldwide, with Nigeria having the highest burden of the disease globally. The condition is characterized by recurring episodes of acute pain, chronic anemia, and increased susceptibility to infections, which significantly impact the quality of life of affected individuals. In Nigeria, the majority of sickle cell patients rely on government hospitals for their healthcare needs. However, these hospitals often face challenges such as inadequate funding, insufficient healthcare personnel, and lack of specialized care for sickle cell patients. These challenges can lead to poor health outcomes, increased morbidity, and mortality among sickle cell patients.

### Sickle Cell Counseling

#### Genetic Counseling

1. Risk Assessment: Assess the risk of sickle cell disease in offspring, considering the genotype of both parents (National Society of Genetic Counselors, 2019) <sup>[15]</sup>.
2. Genetic Testing: Offer genetic testing to identify carriers of sickle cell trait and diagnose sickle cell disease (American College of Medical Genetics and Genomics, 2013) <sup>[3]</sup>.

#### Psychosocial Counseling

1. Emotional Support: Provide emotional support and counseling to help individuals cope with the diagnosis and management of sickle cell disease (Anie *et al.*, 2010) <sup>[4]</sup>.
2. Pain Management: Educate patients on effective pain management strategies, including pharmacological and non-pharmacological interventions (Ballas, 2010) <sup>[6]</sup>.

#### Reproductive Counseling

1. Family Planning: Discuss family planning options with individuals with sickle cell disease, including the risks and benefits of pregnancy (Royal College of Obstetricians and Gynaecologists, 2011) <sup>[19]</sup>.
2. Preimplantation Genetic Diagnosis: Offer preimplantation genetic diagnosis (PGD) as an option for individuals with sickle cell disease who wish to avoid passing the condition to their offspring (American Society for Reproductive Medicine, 2018) <sup>[5]</sup>.

### Psychosocial Impacts of a Sickle cell Diagnosis

#### Emotional Impacts

1. Anxiety and Depression: A diagnosis of sickle cell disease can lead to increased anxiety and depression in patients and their families (Jenerette & Murdaugh, 2008) <sup>[11]</sup>.
2. Fear and Uncertainty: The unpredictable nature of sickle cell disease can create fear and uncertainty, leading to emotional distress (Anie *et al.*, 2010) <sup>[4]</sup>.
3. Grief and Loss: Patients and families may experience grief and loss due to the impact of the disease on daily life and future plans (Kasar *et al.*, 2017) <sup>[13]</sup>.

#### Social Impacts

1. Stigma and Discrimination: Sickle cell disease patients may face stigma and discrimination, leading to social isolation and decreased self-esteem (Afolabi *et al.*, 2015) <sup>[2]</sup>.
2. Social Withdrawal: Patients may withdraw from social activities due to pain, fatigue, or fear of stigma, leading to decreased social support (Hood *et al.*, 2017) <sup>[8]</sup>.
3. Strained Relationships: The chronic nature of sickle cell disease can strain relationships with family and friends, leading to emotional distress (Barakat *et al.*, 2010) <sup>[7]</sup>.

#### Cognitive Impacts

1. Cognitive Impairment: Sickle cell disease can affect cognitive function, particularly in areas such as attention, memory, and executive function (Schatz *et al.*, 2015) <sup>[20]</sup>.
2. Body Image Disturbances: Patients may experience body image disturbances due to the physical effects of the disease, such as jaundice, ulcers, or avascular necrosis (Isichei *et al.*, 2018) <sup>[9]</sup>.

#### Behavioral Impacts

1. Non-Adherence: The complexity of sickle cell disease management can lead to non-adherence to treatment regimens, exacerbating physical and emotional symptoms (Lemanek *et al.*, 2018) <sup>[14]</sup>.
2. Substance Abuse: Patients may turn to substance abuse as a coping mechanism for chronic pain and emotional distress (Ballas, 2010) <sup>[6]</sup>.

#### Psychological Needs of sickle cell Patients in Nigeria

Sickle cell patients in Nigeria face significant psychological challenges that impact their quality of life. Emotional Support is crucial, as patients often experience anxiety, depression, and fear due to the unpredictable nature of the disease (Barakat *et al.*, 2010) <sup>[7]</sup>.

Psychological Interventions are necessary to address these challenges. This can include counseling, cognitive-behavioral therapy, and support groups to help patients cope with their condition (Isichei *et al.*, 2018) <sup>[9]</sup>.

Caregiver Support is also essential, as caregivers often experience emotional burden and stress when caring for sickle cell patients (Barakat *et al.*, 2010) <sup>[7]</sup>. Policies and interventions should be implemented to support caregivers and provide them with adequate psychological support.

Social Support from family, friends, and community is vital for sickle cell patients in Nigeria. Social support can help patients feel less isolated, reduce stress, and improve their overall well-being (Isichei *et al.*, 2018) <sup>[9]</sup>.

### Counseling Needs of sickle cell Patients in Nigeria

Given the complex psychosocial needs of individuals with sickle cell infection, counseling is essential to promote coping strategies, enhance quality of life, and improve mental health outcomes (Anie *et al.*, 2010) <sup>[4]</sup>. Counseling can also help individuals develop resilience and adapt to the challenges posed by the condition.

Moreover, counseling can address the specific needs of caregivers and family members, providing them with emotional support, stress management techniques, and guidance on how to care for their loved ones effectively (Anie *et al.*, 2010) <sup>[4]</sup>.

### Key Considerations for Counseling

1. Holistic approach: Counseling should adopt a holistic approach, addressing the physical, emotional, and social needs of individuals with sickle cell infection (Anie *et al.*, 2010) <sup>[4]</sup>.
2. Cultural sensitivity: Counseling should be culturally sensitive, taking into account the unique experiences and challenges faced by individuals from diverse backgrounds (Barakat *et al.*, 2010) <sup>[7]</sup>.
3. Family involvement: Counseling should involve family members and caregivers, providing them with support and guidance on how to care for their loved ones effectively (Barakat *et al.*, 2010) <sup>[7]</sup>.

### Problems of sickle cell counseling in Nigeria

Here are some problems of sickle cell counseling in Nigeria

Inadequate Trained Counselors: There is a shortage of trained genetic counselors in Nigeria, making it difficult for patients to access accurate and reliable counseling services (Afolabi *et al.*, 2015) <sup>[2]</sup>.

Limited Awareness: Many Nigerians are unaware of the importance of sickle cell counseling, leading to low uptake of counseling services (Ibrahim *et al.*, 2013) <sup>[10]</sup>.

Cultural and Social Barriers: Cultural and social barriers, such as stigma and discrimination, can prevent individuals from seeking sickle cell counseling (Afolabi *et al.*, 2015) <sup>[2]</sup>.

Inadequate Funding: Sickle cell counseling services in Nigeria are often underfunded, making it difficult to provide comprehensive counseling services (Ibrahim *et al.*, 2013) <sup>[10]</sup>.

Limited Access to Testing: Limited access to genetic testing and screening can make it difficult for counselors to provide accurate and reliable counseling services (Afolabi *et al.*, 2015) <sup>[2]</sup>.

Poor Healthcare Infrastructure: The poor state of healthcare infrastructure in Nigeria can make it difficult for counselors to provide counseling services, particularly in rural areas (Ibrahim *et al.*, 2013) <sup>[10]</sup>.

### Psychosocial habits and counseling interventions for sickle cell anemia patients

#### Psychosocial Challenges

1. Anxiety and Depression: Sickle cell anemia patients often experience anxiety and depression due to the chronic nature of the illness and its impact on daily life (Jenerette & Murdaugh, 2008) <sup>[11]</sup>.
2. Pain Management: Pain is a significant issue for sickle cell anemia patients, and inadequate pain management can lead to increased anxiety and depression (Ballas, 2010) <sup>[6]</sup>.
3. Social Isolation: Sickle cell anemia patients often experience social isolation due to the stigma associated

with the illness and the need to avoid certain social situations that may trigger pain episodes (Hood *et al.*, 2017) <sup>[8]</sup>.

### Counseling Interventions

1. Cognitive-Behavioral Therapy (CBT): CBT has been shown to be effective in reducing anxiety and depression in sickle cell anemia patients (Kaslow *et al.*, 2013) <sup>[12]</sup>.
2. Family Psycho-Education: Family psycho-education can help improve coping skills and family dynamics, leading to better outcomes for sickle cell anemia patients (Barakat *et al.*, 2010) <sup>[7]</sup>.
3. Support Groups: Support groups can provide sickle cell anemia patients with a sense of community and connection, helping to reduce social isolation and improve mental health outcomes (Thompson *et al.*, 2018) <sup>[18]</sup>.

### Nursing Interventions

1. Pain Management: Nurses play a critical role in managing pain in sickle cell anemia patients, using a multimodal approach that incorporates pharmacological and non-pharmacological interventions (Ballas, 2010) <sup>[6]</sup>.
2. Promoting Coping Skills: Nurses can promote coping skills in sickle cell anemia patients by teaching relaxation techniques, breathing exercises, and distraction (Jenerette & Murdaugh, 2008) <sup>[11]</sup>.
3. Enhancing Self-Esteem: Nurses can enhance self-esteem in sickle cell anemia patients by focusing on individual strengths and promoting independence (Hood *et al.*, 2017) <sup>[8]</sup>.

### Conclusion

Sickle Cell counselling is the skill of helping people to take important decisions about life, relationships. When the skill is well learnt it is adaptable to managing all health-related problems. The health and illness patterns of the world's population are changing, especially with the emergence of ageing populations and increasing life expectancy. There are changes in the patterns and forms of existing diseases as well as the emergence of new ones. The orientation to health and illness has gone beyond thinking of cure as the only major motive of caring. Life involves accepting limitations and living positively within them. Counselling is caring that goes beyond curing. The issues brought to light by the needs of people with HIV and AIDS, and the people affected by their relationship to those infected, go beyond the disease itself. We are all affected, otherwise the whole world would not be talking about it.

Ultimately, this study's conclusions have implications for the development of effective strategies to improve the health outcomes and quality of life of sickle cell patients in Nigeria. By addressing the psychosocial challenges faced by these patients, healthcare providers and policymakers can work towards reducing the burden of sickle cell disease in Nigeria and improving the lives of those affected by this condition.

### Recommendations

1. Healthcare providers should prioritize the psychosocial needs of sickle cell patients, including providing education, Skill, counseling, and social support in Nigeria.
2. Policymakers should develop targeted interventions to

reduce stigma, improve social support, and promote mental health among sickle cell patients in Nigeria.

3. Further research is needed to explore more on psychosocial challenges faced by sickle cell patients in Nigeria and to develop effective strategies to address these challenges.

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