

# **Adjusting to Psychosocial Impacts of Sickle Cell Disease through Mindfulness Training Among Selected Patients at Lagos State General Hospital, Odan Lagos**

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## **ABSTRACT**

**Background:** Sickle cell disease (SCD) patients experience significant psychosocial impacts that affect their quality of life. While many studies have examined SCD in Nigeria, few have explored coping strategies, particularly mindfulness training, for managing these psychosocial challenges. This study investigated the effectiveness of mindfulness training for managing psychosocial impacts among SCD patients.

**Methods:** A descriptive cross-sectional study was conducted among 80 SCD patients at Lagos State General Hospital, Odan Lagos. Data were collected using structured questionnaires from patients who received mindfulness training intervention. Inclusion criteria were trained SCD patients aged 18 years or older receiving hospital treatment. The response rate was 96.25% (77/80). Data were analyzed using frequency tables, percentages, and correlation analysis.

**Results:** Most respondents (62.3%, n=48) reported experiencing psychosocial issues in the previous two years. Stigmatization (19.5%, n=15) and mental health issues (15.6%, n=12) were the most common challenges. Mindfulness training showed positive impacts on patients' lifestyle (79.2% reported improvement). Common coping strategies included believing in God (22.1%, n=17) and maintaining positive thinking (20.8%, n=16). A significant positive correlation was found between psychological therapy and patient wellbeing ( $r=0.960$ ,  $p<0.01$ ). Psychosocial factors showed negative correlation with patient outcomes ( $r=-0.224$ ).

**Discussion:** The findings demonstrate that mindfulness training can be an effective intervention for managing psychosocial impacts among SCD patients. Religious coping and positive thinking emerged as important complementary strategies. Healthcare providers should consider incorporating mindfulness training and supporting various coping mechanisms to help SCD patients manage psychosocial challenges.

## **INTRODUCTION**

Sickle cell disease is the most common monogenic ailment in the world, and it is a deadly hematologic condition caused by a single nucleotide mutation that leads to the synthesis of defective hemoglobin S, which has the potential to polymerize and induce sickling of erythrocytes.<sup>1</sup> Several patients have this chronic, genetic illness, which is characterized by an abnormal hemoglobin level.

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Chronic and very disabling sickle cell disease gets worse over time. Organ dysfunction, frequent, excruciatingly painful vaso-occlusive episodes, persistent hemolytic anemia, and, if untreated, early death are its hallmarks.<sup>2</sup> Many incapacitating symptoms, including organ and tissue damage, exhaustion, immunodeficiency, and acute and chronic pain, may be present in SCD patients.<sup>3</sup>

In contrast to healthy individuals with normal hemoglobin, sickle cell disease patients who are in a "steady-state" exhibit chronic coagulation activation. The thrombin and fibrin formation markers prothrombin fragment 1.2, fibrinopeptide A, thrombin-antithrombin complexes (TAT), D-dimers, and plasmin-antiplasmin complexes (PAP), as well as increased production of these molecules, are commonly raised in the plasma of these patients. Sickle cell illness places a significant psychosocial burden on those living with the condition, their families, and careers.<sup>4</sup>

Patients and families impacted by sickle cell disease frequently endure severe psychosocial impacts and associated complications. Managing the condition and its repercussions can occasionally be challenging for patients, their families, and medical professionals. One of the risk factors for psychological problems is the adjustment to sickle cell disease symptoms, its complications, restrictions on daily functioning, anxiety and stress brought on by unforeseen events, and neurocognitive deficits. The social relationships, educational success, and employment of sickle cell disease sufferers may also be significantly impacted by the condition and its therapies. Prior research has confirmed that chronic illness in general and sickle cell disease, in particular, are risk factors for patient adjustment.

Sickle cell illness may harm a patient's social life, academic performance, physical and mental health, and job. For instance, sickle cell disease patients may have psychological health issues like melancholy, fear of dying, and sickness denial. Patients and their families must regularly deal with psychosocial issues because of how pain and other symptoms affect sickle cell disease patients' daily lives and because of how society perceives sickle cell illness and those who are affected.

A sickle cell disease patient personally experiences many stages of anxiety regression, including depression, GAD-General anxiety disorder, panic disorder, phobias, particularly Thanatophobia, hypochondriasis, and other related anxiety disorders. Over time, sickle cell patients have been stigmatized and viewed differently from the perspective of the public. Estimates indicate that one-to-two thirds of children with SCD experience substantial psychosocial symptoms and have a lower quality of life in terms of their physical health.<sup>5</sup> SCD can result in physical, mental, and psychological comorbidities, such as chronic and severe anemias, infections, strokes, intense pain episodes, postponed puberty, and academic underachievement.<sup>6</sup>

Mindfulness training is one of many adjustment strategies used by sickle cell disease patients to deal with the psychological implications of their condition. A mental activity known as mindfulness training teaches patients how to slow down their breathing, quiet their racing thoughts, and let go of their negative emotions. Reflection is incorporated

into mindfulness training, an intervention that encourages people to nurture awareness of both bodily and mental sensations. Mindfulness is defined as a mental state involving being fully focused on present reality to acknowledge and accept one's thoughts, feelings, and sensations without passing judgment.

Studies on sickle cell disease in Nigeria often generalize about the cause of the condition, but there has not been a thorough investigation of how sickle cell disease patients can adjust to its psychosocial effects and do so through mindfulness training. Due to this knowledge gap, this study will examine how chosen patients at Lagos State General Hospital, Odan, are adjusting to the psychosocial effects of sickle cell disease through mindfulness training.

The following are the specific objectives of the study:

1. To highlight the various psychosocial issues often experienced by sickle cell disease patients;
2. To find out the influence of psychological therapy on the lives of sickle cell disease patients;
3. To scrutinize the psychosocial impact of sickle cell disease among selected patients; and
4. To establish the mindfulness training strategy adopted on SCD patients.

## **METHODS**

### **Study Design and Setting**

This descriptive cross-sectional study was conducted at Lagos State General Hospital, Odan Lagos, Nigeria. The study received ethical approval from the Health Research and Ethical Committee at Lagos State University Teaching Hospital.

### **Participants**

The study population consisted of male and female individuals diagnosed with sickle cell disease (SCD), aged 18 years and above, who were registered patients at the designated study hospital. Eligibility for participation was based on the following inclusion criteria: a confirmed diagnosis of SCD, age 18 years or older, prior participation in a mindfulness training program, and active registration at the study hospital. A total of 80 participants were recruited using purposive sampling, allowing the selection of individuals who met the specified criteria and could provide rich, relevant data for the study.

## **Data Collection**

Data were gathered using a structured, pre-tested questionnaire organized into four key sections. The first section captured socio-demographic information such as age, gender, and educational background. The second section assessed participants' psychosocial experiences in relation to living with SCD. The third section explored their experiences with mindfulness training, while the fourth examined the coping strategies they employed in managing the challenges associated with the condition. The questionnaire was pilot-tested to ensure clarity and reliability prior to its full deployment. Of the 80 individuals approached, 77 completed the questionnaire, resulting in a high response rate of 96.25%.

## **Data Analysis**

Quantitative data were analyzed using descriptive statistical methods, including frequencies and percentages, to summarize participants' characteristics and responses. In addition, correlation analysis was conducted to examine potential relationships between key variables. Statistical significance was determined at a p-value of less than 0.01.

## **RESULTS**

The findings of the study on the gender of respondents is indicated in table 1 above. It shows that 41.6% (32) of the respondents were males, while 58.4% (45) were females. This gender taxonomy avers that the majority of the respondents were females. The findings of the study on the age category of respondents also shows that 39.0% (30) were between ages 18-23 years, 23.4% (18) were between ages 24-29 years, 22.1% (17) were between 30-35 years while 15.6% (12) above 35 years in age. The result above shows that most of the respondents were between the ages of 18 and 23.

The table above revealed that 9.1% (7) of the respondents had attained primary education, 49.4% (38) had attained secondary education, 35.1% (27) had attained tertiary education, while 6.5% (5) had other educational attainments such as vocational and informal education. This is a pointer that a good number of the respondents had attained secondary education. In addition, the table above showed that 63.6% (49) of the respondents were Christians, 35.1% (27) were Muslims and 1.3% (1) belonged to an undisclosed religion. By implication, most of the respondents were Christians.

The finding of the study as revealed in the table above showed that 72.7% (56) of the respondents were Yorubas, 16.9% (13) were Igbos and 10.4% (8) belonged to other tribes in Nigeria. This implies that a larger percentage of the respondents belonged to the Yoruba ethnic group. The table above also revealed that 55.8% (43) of the respondents were living with their parents, while 44.2% (34) were not living with their parents. This is an indication that most of the respondents still live with their parents.

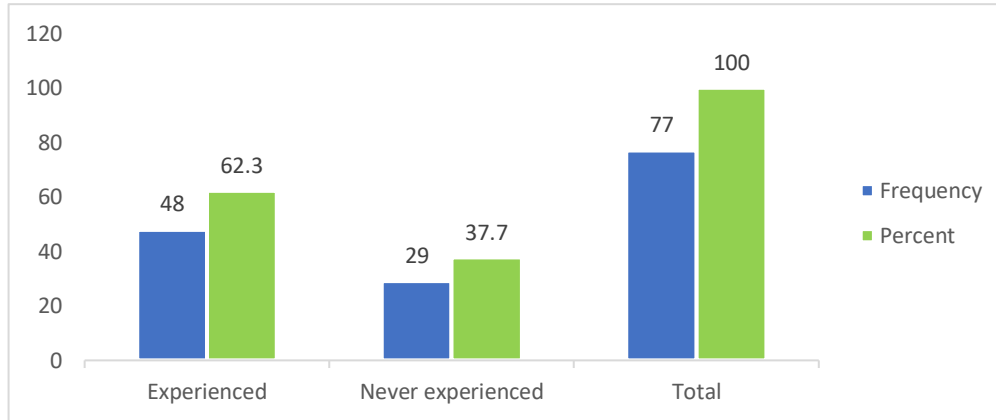
Conclusively, the report of findings in the table above showed that 40.3% (31) of the respondents belonged to a monogamous family, 2.6% (2) belonged to a polygamous

family, 13.0% (10) came from a single-parent family type, and the question did not apply to 44.2% (34) of the respondents. This implies that the majority of the respondents belonged to a monogamous family.

**Table 1: Socio-demographic Profile of Respondents**

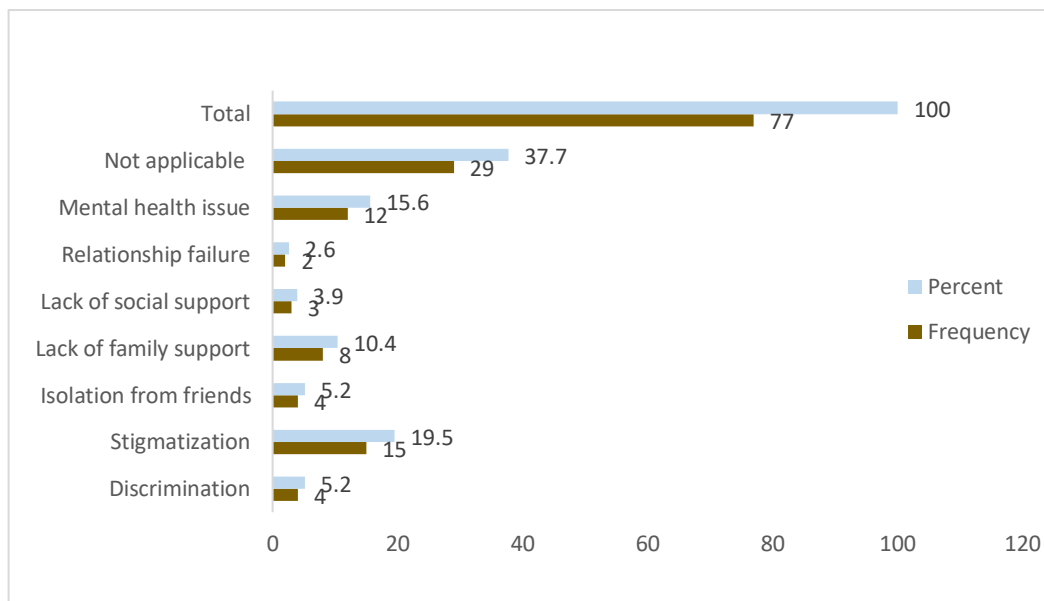
<b>Socio-demographic Characteristics</b>	<b>Frequency</b>	<b>Percent</b>
<b>Gender</b>		
Male	32	41.6
Female	45	58.4
<b>Age Grades</b>		
18-23years	30	38.9
24-29years	18	23.4
30-35years	17	22.1
35years and above	12	15.6
<b>Religious Affiliation</b>		
Christianity	49	63.6
Islam	27	35.1
Others	1	1.3
<b>Educational Attainment</b>		
Primary Education	7	9.1
Secondary Education	38	49.3
Tertiary Education	27	35.1
Others	5	6.5
<b>Ethnic Group</b>		
Yoruba	56	72.7
Igbo	13	16.9
Other tribes	8	10.4
<b>Living with parents</b>		
Living	43	55.8
Not living	34	44.2
<b>Family Types</b>		
Monogamy	31	40.2
Polygamy	2	2.6
Single Parenthood	10	13.0
Not applicable	34	44.2

Findings on respondents' experience of any social or psychological issues is presented in Figure 1 above showing that 62.3% (48) of the respondents have experienced social or psychological issues in the last two years, whereas 37.7% (29) of the respondents have never experienced any social or psychological issues in the last two years. Derivatives from the foregoing are that a larger percentage of the respondents have experienced social or psychological issues in the last two years.



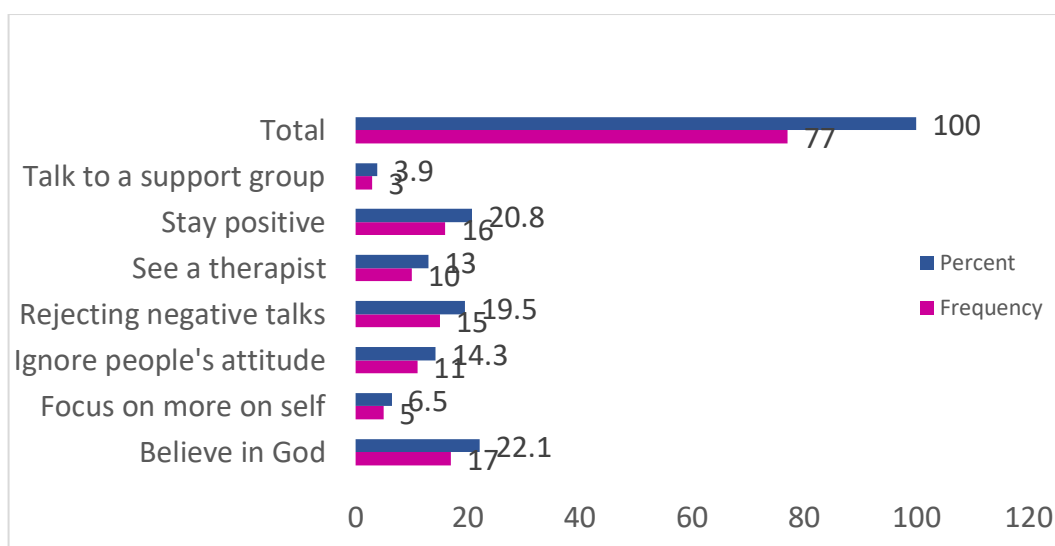
**Figure 1: The Social or Psychological Issues ever experienced in Two Years**

Findings on the type of psychosocial issues experienced by the respondents are indicated in figure 2, which shows that 5.2% (4) of the respondents had experienced discrimination the most, 19.5% (15) have experienced stigmatization the most, 5.2% (4) have experienced isolation from friends the most, 10.4% (8) have experienced lack of family support the most, 3.9% (3) have experienced lack of social support the most, 2.6% (2) have experienced relationship failure the most, 15.6% (12) have experienced mental health issues the most, and the question did not apply to 37.7% (29) of the respondents. It can be deduced from the preceding analysis that most SCD patients have experienced stigmatization and mental health issues the most.



**Figure 2: Type of psychosocial issues experienced**

The findings of the study as revealed in Figure 3 show that 22.1% (17) of the respondents reported that believing in God is the strategy they often adopted to stay calm and relaxed when people irritated them or said unpleasant things about their SCD condition, 6.5% (5) focused more on themselves, 14.3% (11) ignored people's attitude, 19.5% (15) usually rejected the negative talks, 13.0% (10) talked to a therapist, 20.8% (16) stayed positive, and 3.9% (3) talked to a support group. Derivative from this analysis is that most of the respondents usually adopted either the strategy of believing in God or staying positive to stay calm and relaxed when people irritated them or said unpleasant things about their SCD condition.



**Figure 3: Strategy adopted to stay calm and relaxed when people say unpleasant things about their SCD**

### Correlation Analysis

The results presented in Table 2 indicate a **strong positive correlation** between psychological therapy and the livelihoods of patients with sickle cell disease (SCD), with a correlation coefficient of  $r = 0.960$  and a  $p$ -value less than 0.01. This statistically significant relationship suggests that as engagement with psychological therapy increases, the overall livelihood and quality of life of SCD patients also improve substantially.

The strength of the correlation, being very close to 1 demonstrates a strong and direct association. This implies that therapeutic sessions contribute meaningfully to patients' emotional resilience and social functioning, helping them navigate societal pressures, reduce internalized stigma, and maintain a more stable and productive life. In essence, access to psychological support plays a crucial role in safeguarding the livelihoods of individuals living with SCD.

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**Table 2: Correlation analysis for psychological therapy and livelihoods of SCD patients**

Variables Correlated	Correlation Coefficient (r)	p-value	Strength & Direction	Statistical Significance
Psychological Therapy & Livelihoods of SCD Patients	0.96	< 0.01	Strong Positive	Significant

\*\*. Correlation is significant at the 0.01 level (2-tailed)

The results of the correlation analysis are presented in Table 3. A strong positive correlation was found between psychological therapy and patient well-being ( $r = 0.960$ ,  $p < 0.01$ ). This statistically significant relationship indicates that as access to or engagement in psychological therapy increased, patients' perceived quality of life also improved substantially. The high correlation coefficient reflects a strong association, suggesting that psychological interventions play a critical role in enhancing the well-being of individuals living with sickle cell disease (SCD).

In contrast, a weak negative correlation was observed between psychosocial factors and patient outcomes ( $r = -0.224$ ,  $p > 0.01$ ). Although not statistically significant, the negative direction of the correlation suggests that as the burden of psychosocial challenges (e.g., stigma, isolation, emotional distress) increases, there tends to be a decline in patients' ability to function effectively in society. The weak strength of the relationship reflects limited but adverse influence, implying that psychosocial issues may contribute negatively to the lived experiences and social integration of SCD patients.

**Table 3: Correlation analysis for psychosocial factors and impact on SCD patients**

Variables Correlated	Correlation Coefficient (r)	p-value	Strength & Direction	Statistical Significance
Psychological Therapy and Patient Well-being	0.96	< 0.01	Strong Positive	Significant
Psychosocial Factors and Patient Outcomes	-0.224	> 0.01	Weak Negative	Not Significant

## DISCUSSION

Findings from the study revealed that a larger percentage of the respondents were females. This is supported by the research study conducted by Ilesanmi who reported that, gender role socialization and anticipation may have been responsible for more females reporting SCD and its associated problems.<sup>7</sup> In Nigeria, males are expected to show bravery, forte, and fortitude during times of crisis and are expected to be the main source of income, to be the head in their families, and to tolerate pain. This is validated by the fact that females



normally account for or complain more than males when they are suffering from various kinds of illnesses.

A good number of the respondents in this study had attained secondary education or less, this is in line with the empirical study conducted by Amaral et al., who reported that, the reason lower levels of education are associated with higher numbers of sickle cell disease may be because education provides the knowledge and information needed in the management of the treatment for and effectively coping with sickle cell disease.<sup>8</sup>

Findings from the study also revealed that about eighty percent (79.2%) of the respondents strongly believed that mindfulness training had brought about a positive change in their lifestyle. This agrees with the research carried out by Rasmussen and Pidgeon, and Bowlin and Baer who confirmed in their report that, mindfulness is linked to improved psychosocial functioning, specifically higher levels of life satisfaction, self-esteem, positive affect, empathy, and optimism.<sup>9-10</sup>

Also, it can be deduced from the findings of the study that most SCD patients had experienced stigmatization and mental health issues the most. This is in concord with the research findings of Fetuga et al., (2020) who reinforced that stigmatization is common among those with sickle cell disease in Africa because of the perceived cultural and spiritual views of the population about the disorder. This research findings is further strengthened by Ola et al who reported in their findings that people's willingness to disclose their SCD status is impacted by stigma from loved ones, and romantic partners because they worry about being pitied, treated unfairly, or discriminated against.<sup>11, 12</sup>

The correlation analysis of the study revealed that psychosocial factors and impact on SCD patients, were correlated in the negative direction (-0.224), and the weak negative correlation between social and psychological issues, and impact on SCD patients, indicated that the various psychosocial issues experienced by SCD patients usually had a negative impact on their lives, and affected their proper functioning in the society in a damaging way. This finding is in tandem with the research report submitted by Brown et al., that sickle cell disease, a condition that poses a serious risk of death, has been linked to numerous studies' findings that it has negative psychosocial effects on patients.<sup>13</sup> Consequently, individuals with chronic illnesses such as SCD are three to four times more likely to experience a variety of mental health complaints. Anie and Akinyan (2018) also confirm that the primary causes of psychosocial problems for individuals with sickle cell disease and their families are the ways in which society perceives the disease and its victims, as well as the effects of the disease's symptoms and pain.<sup>14</sup>

Findings from the study revealed that most of the respondents usually adopt the mindfulness strategy of believing in God, and staying positive to stay calm and relaxed when people irritate them or say unpleasant things about their SCD condition. This is also supported by the findings of the study conducted by Anie, and Akinyan who reported that people with sickle cell disease in Nigeria frequently used praying and hoping as an effective coping strategy, in contrast to those in the United Kingdom.<sup>14</sup> They emphasized

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that the coping strategy appears to be influenced by outside factors like religion, belief in God, superstitions, and stigma. To buttress these findings, Clayton-Jones et al., and Foster and Ellis, reported in their empirical findings that religion and/or spirituality serve as a significant coping mechanism for people with SCD, increasing their sense of meaning and trust in God as well as their faith.<sup>15, 16</sup>

## **CONCLUSION**

Mindfulness training shows promise as an intervention for managing psychosocial impacts among SCD patients. The integration of spiritual coping mechanisms and positive thinking strategies appears particularly effective in the Nigerian context. Healthcare providers should consider implementing comprehensive support programs that incorporate mindfulness training while acknowledging the role of religious and cultural factors in patient coping strategies.

## **Implications for Practice**

1. Healthcare providers should screen SCD patients for psychosocial challenges and provide appropriate support.
2. Mindfulness training programs should be integrated into routine care for SCD patients.
3. Cultural and religious coping mechanisms should be acknowledged and supported within treatment programs.
4. Community education programs are needed to reduce stigmatization and improve social support.

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