British Journal of Education
Vol.13, Issue 6, 17-25, 2025
Online ISSN: 2054-636X (Online)
Print ISSN: 2054-6351(Print)
Website: https://www.eajournals.org/
Publication of the European Centre for Research Training and Development-UK

Health Education Intervention and Burden of Sickle-Cell Condition Among Primary Caregivers in Osun State

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doi: https://doi.org/10.37745/bje.2013/vol13n61725 Published April 26, 2025

Citation: Oladeji M.O., Erezitome D.O., and Igodo C. (2023) Health Education Intervention and Burden of Sickle-Cell Condition Among Primary Caregivers in Osun State, *British Journal of Education* , Vol.13, Issue 6, 17-25

Abstract: *Sickle cell disorder is a global health challenge which overtime have defy most medical efforts for treatment and the best remedy lie in its prevention. Therefore, managing a life-long chronic illness such as sickle cell disease (SCD) can be burdensome, specifically to caregivers. More so, if these burdens are not well managed, it may be detrimental to quality of life (QOL) of caregivers. Therefore, introducing health education to caregivers could enhance self-management of stress. This study therefore investigates Health education intervention and burden of sickle-cell condition among primary caregivers in Osun State. This study adopted quasi-experimental designed. The total sample size for this study was 208 participants, who were selected using Two stages sampling techniques: while systematic sampling technique was used in selection of PHCs, Purposive sampling technique was used in selection of participants. A primary sourced data collection instrument (structured questionnaire) with close ended items was adopted for collection of data. Data collected were Sorted, Edited and Coded, respectively before processed into Statistical Package for Social Science (SPSS) edition 27 for analysis. Data were analyzed using frequency and valid percent aspect of descriptive Statistics. Finding revealed an increase in the rate of participant with good knowledge between pre-intervention and post-intervention (48.8%<79.6%). Finding also revealed a reduction in the overall financial high burden from pre-intervention and post-intervention (70.5%<44.6%). Finding also revealed a reduction in the level of psychological burden from pre-intervention to post-intervention (56.2%<30.8%). The study concluded that, majority of the respondents' experienced financial and psychological burden, which becomes reduced significantly during post intervention. This study therefore recommended that, government should institute strict policies on premarital genotype screening to ensure that individuals going into marriage knows their status before marriage.*

Keyword*:* health education, intervention, burden, sickle-cell condition, primary caregivers

INTRODUCTION

Sickle cell disorder is a global health challenge which overtime have defy most medical efforts for treatment and the best remedy lie in the prevention. Sickle cell disorder (SCD) is the commonest inherited disorder

of hemoglobin in children resulting from the inheritance of abnormal hemoglobin genes from both parents (Willard, et al., 2023). The course of the disorder varies with severe manifestations, requiring frequent hospitalization visits such that, its present new challenges to wealthy families and complicates the existing challenges among poor families. This implies that, the challenges encountered in care of children with sickle cell are not peculiar to any social economic status or hierarchy. The fact that, caregivers of children with sickle cell disorder are always in and out of hospital, explains the level of physical stress, trauma, financial stress and sometimes confusion, their caregivers are subjected to. Ajeh and Isaac (2024) noted that, confronting the problem of care for people living with sickle cell disease is becoming an enormous task and a huge social problem due to the magnitude of the problem. This ranges from large number of people that are involved, to the huge sum of money that is lost, time lost on constant care and most importantly, emotional trauma those patients and their parents have to pass through on a daily basis (Obimakinde et al., 2020).

Sickle cell disease (SCD) is one of the commonest but preventable inherited diseases. It is a disease of the red blood cells and is a lifelong ailment which has been with man since the existence of man. Managing a life-long chronic illness such as sickle cell disease (SCD) is burdensome on those affected and has been correlated with the well-being of the sufferers (Oyeyemi & Atulomah, 2022). Therefore, physical burden, psychological burden, financial burden and trauma all constitute the burden of caring for children living with sickle cell disease. Physical burden include the body aches, pains, fatigue, sleeplessness and sometimes burnouts could be experienced by parents of sufferers. The physical burden results from the daily routine care such as feeding, washing of clothes, bathing of the sick, feeding them and accompanying them to clinics that parents render to patients living with this disease (Kanma-Okafor etl al., 2022). The financial burden is mainly the money spent by parents on paying for drugs, hospital bills/beds, and transportation from hospitals and money spent on extra foods and vegetables given to people living with sickle cell disease so as to beef up their general health (Muoghalu, 2016). However, if these burden are not coped with, it may be detrimental to health such has it may actually affect the quality of life (QOL) among caregivers by manifesting in severe complication. Therefore, health education for this group is important towards educating them on proper way to reduce their stress.

Since, the management of SCD should be family-centered, besides the total dependence of the afflicted child on his/her caregiver for general care and treatment, parents, or caregivers, are subjected to continuous pressure; which may, in return, affect the patient's QoL (Willard et al., 2023). Consequently, caregivers are developing psychological disorders such as depression and anxiety (Piel, 2016; Badawy, et al., 2017). Several studies have described the association between parenting a child with SCD and physical, financial or psychological distress; approximately 30 to 40% of caregivers had symptoms of psychological distress (Olatunya et al., 2017; Wonkam et al., 2014). It has been established that Nigeria bears the greatest burden of sickle cell disease in the world. There are forty million carriers of the gene in the country making it a significant public health concern in Nigeria (Erusiafe & Awunor, 2023). Owing to the fact that sickle cell disease is very symptomatic and requires constant care, parents or care givers of people living with sickle cell disease suffer untold hardship in the course of taking care of them (Muoghalu 2016). Families who have children with sickle cell disease (SCD) endure numerous potentially stressful experiences and daily hassles related to the biological complications of SCD. These ordeals can cause difficulties with finances, work, transportation and changes to daily routines and therefore, health education is required. It

is against these backdrop, the study investigates Health Education Intervention and burden of Sickle-Cell Condition among primary caregivers in Osun State.

Objectives of the Study

1. Assess caregivers' knowledge of sickle cell disease and the management of children with Sickle cell diseases(Pre and Post) in selected hospitals inOsogbo Osun State, Nigeria.
2. Identify the magnitude of financial burden experience (Pre and Post) among caregivers of children with Sickle cell diseases in selected hospitals in Osogbo Osun State, Nigeria.
3. Examine the degree of psychological burden experience (Pre and Post) among caregivers of children with Sickle cell diseases in selected hospitals in Osogbo Osun State, Nigeria.

Research Questions

1. Do caregivers' have adequate knowledge of sickle cell disease and the management of children with Sickle cell diseasesin selected hospitals in Osogbo Osun State, Nigeria?
2. What is the magnitude of financial burden experienceamong caregivers of children with Sickle cell diseases in selected hospitals in Osogbo Osun State, Nigeria?
3. What is the degree of psychological burden experience among caregivers of children with Sickle cell diseases in selected hospitals in Osogbo Osun State, Nigeria?

METHODOLOGY

This study will adopt quasi-experimental designed. This is a type of design that established a relationship between cause and effect. This designed will be adopted in this study because the study will sought to look at the effect of health education as a tool for burden alleviation. The population of this study constitutes all caregivers of children with Sickle cell condition attending UNIOSUN Teaching Hospital and State Specialist Hospital, Asubiaro Osogbo, Osun State. The need to pick this hospital is due to the fact that, these two hospital are the main hospital with sickle cell patients in Osogbo. Only one care giver will be permitted to represent each child with sickle cell and the representative can be either a parent or other family members serving as caregivers. More so, only care givers who are willing to participate will be included in this study. while, other care givers whose child or children attend any other clinic, aside from sickle cell clinic will be excluded. More so, care giver(s) who is/are not physically, mentally or emotionally stable will be excluded. The total sample size for this study was 211 participants, who were selected using Two stages sampling techniques: purposive sampling techniques for selection of two health facilities from Osogbo and Olorunda local government respectively, while systematic sampling technique was used in selection of Participants. A primary sourced data collection instrument (structured questionnaire) with close ended items was adopted for collection of data. Data collected were Sorted, Edited and Coded, respectively before processed into Statistical Package for Social Science (SPSS) edition 27 for analysis. Data were analyzed using frequency and valid percent aspect of descriptive Statistics.

RESULT

Table 1: Demographic Characteristics of Respondents

Items	**Frequency**	**Percentage**
Gender		
Male	78	37.5
Female	130	62.5
Total	**208**	**100.0**
Age		
18-27 years	24	11.5
28-37 years	30	14.4
38-47 years	68	32.7
48-57 years	64	30.8
58 years or above	22	10.6
Total	**208**	**100.0**
Level of education		
No formal Education	14	6.7
Primary Education	46	22.1
Secondary Education	85	40.9
Tertiary Education	63	30.3
Total	**208**	**100.0**
Ethnicity		
Yoruba	130	62.9
Igbo and affiliates	66	31.3
Hausa and affiliates	12	5.8
Total	**208**	**100.0**
Relationship with patients		
Father	11	5.3
Mother	102	49.0
Siblings	68	32.7
Others	27	13.0
Total	**208**	**100.0**
Marital Status		
Single	58	27.4
Married	200	72.6
Total	**208**	**100.0**
Job condition		
Employed	26	12.5
Unemployed	66	31.3
Self employed	116	56.2
Total	**208**	**100.0**

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Table 1 above present demographic characteristics of respondents. On gender majority (62.5%) were female, while over a third (37.5%) were male. Results on age shows that, 11.5% were 18-27 years, 14.4% were within 28-37 years, 32.7% of the respondents falls between 38-47 years, 30.8% of the respondents' falls within 48-57 years and 10.6% were 58 years or above. On level of education, majority 40.9% had secondary education, 30.3% had tertiary education, 22.1% had primary education and 6.7% had no formal education. On Ethnicity, majority (62.2%) were Yoruba, 31.3% were Igbo and affiliates, while 5.8% were Hausa and affiliates. On relationship with patients, a significant percent (49.0%) were mothers as well as siblings (32.7%), while 5.3% were fathers and 13.0% were others such as friends or relatives among others. On marital status, majority (72.6%) were married, while 27.4% were still single. On Job condition, majority (56.2%) were self-employed, close to a third (31.3%) were unemployed and 12.5% were employed.

Caregivers' Pre and Post-intervention knowledge of primary caregiver on management of sickle cell disease

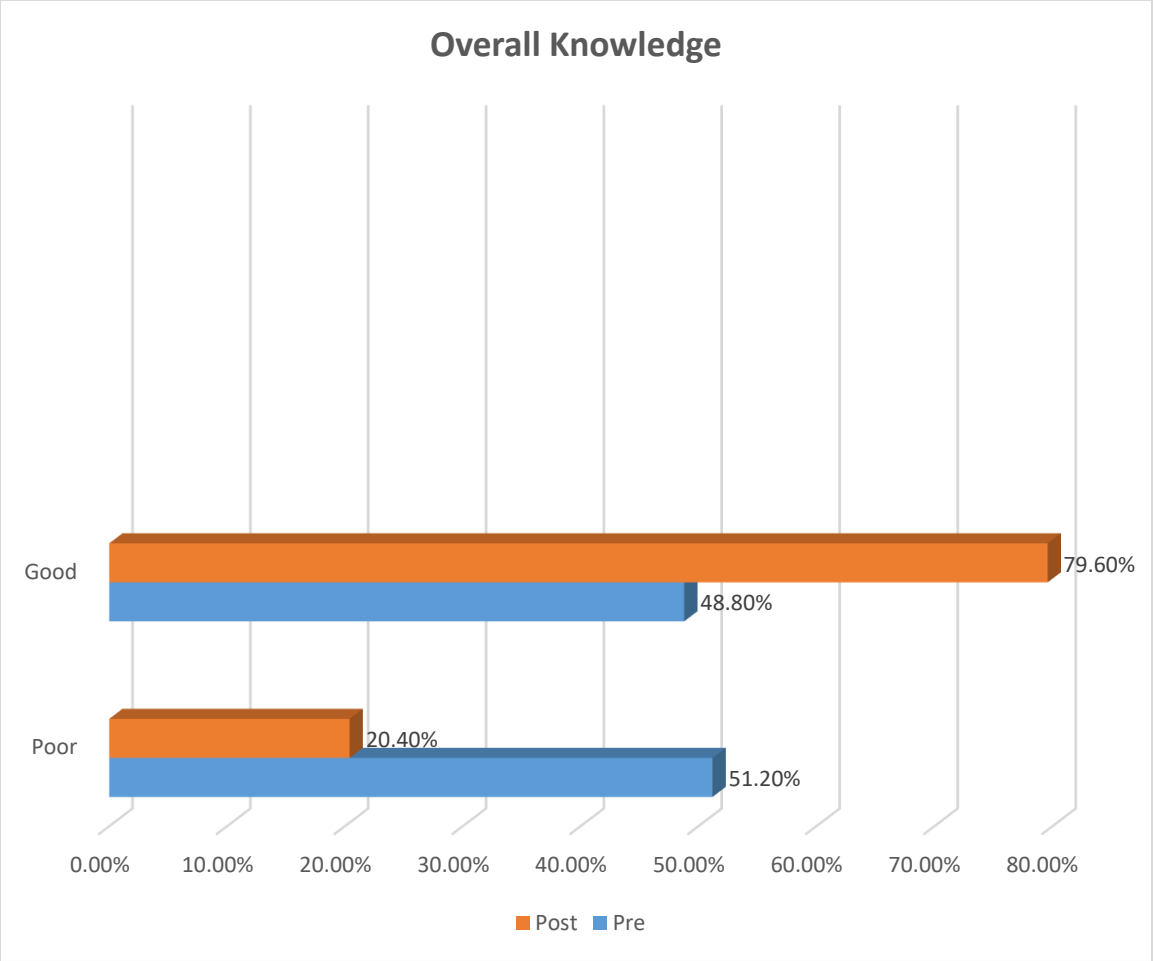

Figure 1: Overall Caregivers' Pre and Post-intervention knowledge of primary caregiver on management of sickle cell disease

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Figure above show a higher post-intervention knowledge (79.6%) compare to the pre -intervention knowledge (48.8%).

Pre and Post magnitude of financial burden experience among caregivers of children with Sickle cell diseases

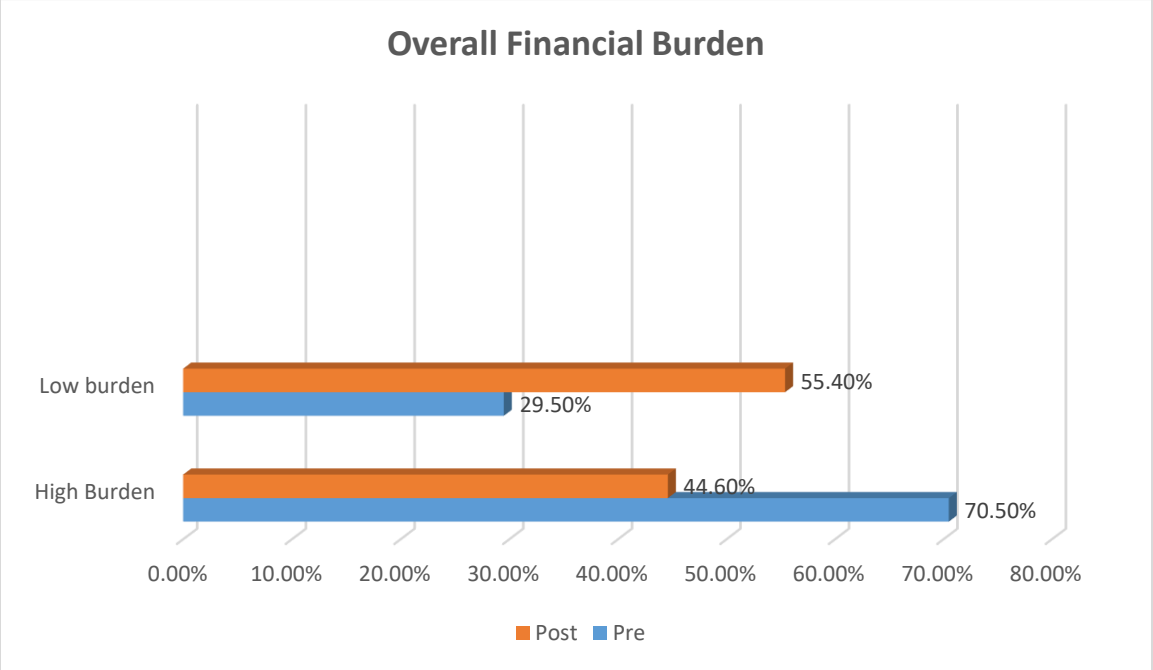

Figure 2: Overall Caregivers' Pre and Post-intervention financial burden experience by primary caregiver in management of sickle cell disease

Figure above show a reduction in the percent of primary caregiver experiencing high post-intervention financial burden (44.6%) compare to those experiencing high pre -intervention financial burden experience (70.5%).

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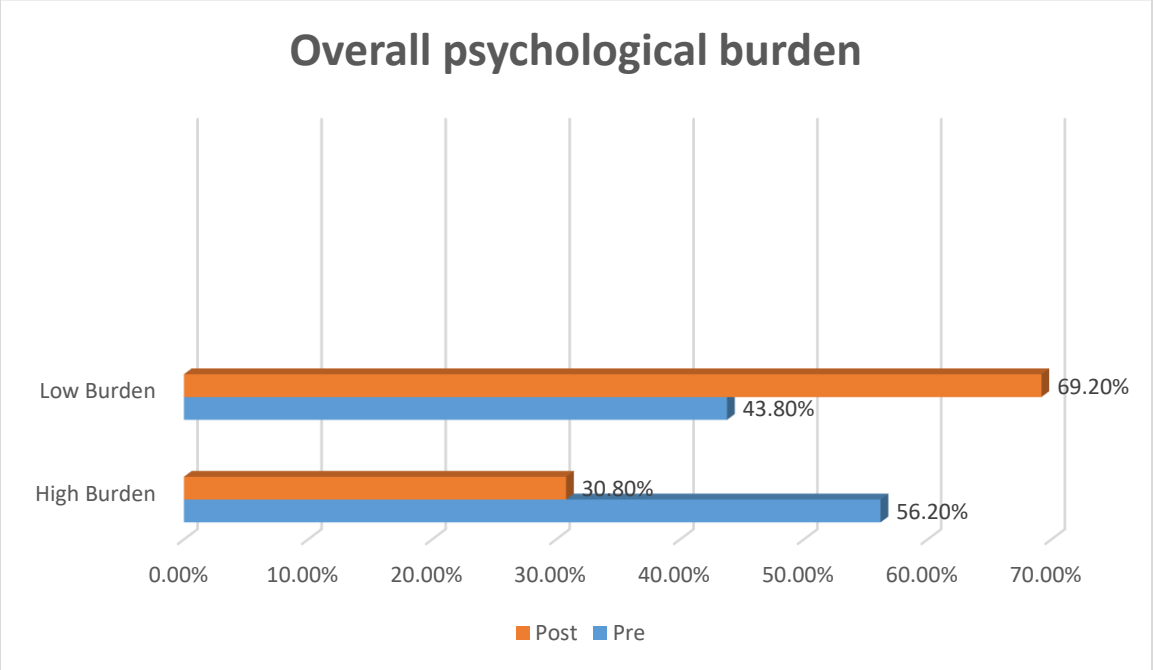

Figure 3: Overall Caregivers' Pre and Post-intervention psychological burden experience by primary caregiver in management of sickle cell disease

Figure above show a reduction in the percent of primary caregiver experiencing high post-intervention psychological burden (30.8%) compare to those experiencing high pre -intervention psychological burden experience (56.2%).

DISCUSSION

Findings revealed that, majority of the respondents were female. This corroborate the general view in this part of the world that, women are major carrier in the home. Also, having majority of the respondents to be over 20 years is an indication that, most respondents were adult as specified in the inclusion criteria. More findings revealed that, majority were educated and this is an indication that, information would be provided with high precision. Similarly Nnanchi et al. (2022) in a study conducted in Ebonyi **S**tate, Nigeria found major participants to be between aged 25-34 and well-educated. The fact that, Yoruba dominated the respondent is because the study was conducted in Yoruba territory. Findings also revealed that, majority of the respondents were family of caregivers such as mothers and siblings. This guarantee high support for the patients. More so, majority were married and were self employed. More finding revealed that, only below half of the respondents have adequate knowledge of sickle cell disease and the management during pre-intervention. However during post intervention, majority already had good knowledge of sickle cell disease and the management. Uche et al. (2017) highlighed the gap between awareness and comprehensive knowledge of SCD, suggesting the need for education intervention centered towards reducing the burden. This finding is evidence in the results presented above, where there was an appreciable difference in the knowledge of respondent between pre and post-intervention. The plausible reason to this is because

majority of the respondents are learned and easily understand teachings. Ajibade et al (2017) also reported that the level of understanding and knowledge of respondents to psychosocial impact of Sickle Cell Disease and the management/treatment strategies was adequate.

More so, finding revealed that, there is high financial burden experienced in the pre-intervention compare to post intervention. Findings agrees with Muoghalu (2016) who found that many parents with people living with sickle cell disease experience financial burden in the form of financial cost for treatment and also in the form of loss of income due to the time spent on routine day to day care for people living with the disease. This findings exposed that, participants confessed that, cost of treatment/drugs for sickle cell disease is unbearable, obtain loan during crisis, basic needs can't be met often due to treatment financing among others. However, there were a significant change in the financial burden experience among respondents between pre and post-intervention. Finding also revealed that, there is high psychological burden experienced in the pre-intervention compare to post intervention. This findings revealed that, during pre-intervention, majority of the participants confessed to becoming traumatic, experience tension, stress, sorrow among others during crisis. Finding is in line with Olatunya et al., (2017) who found that, over 30% of caregivers or parent of children with SCD had symptoms of psychological distress However, there were a significant change in the psychological burden experience among respondents between pre and post-intervention.

CONCLUSION

The major role of a nurse precede just administering care using appropriate procedures, their major include, prevention of likelihood of illness, such as among care givers of patients. This helps to reduce the level of congestion experience in the hospitals, thereby reducing the task of nurses. The implication of the findings of this study to community nurses to ensure, the perform holistic role of care; while caring for children with sickle cell, they should also help prevent exhaustion of caregivers in all areas and as well prevent short reoccurrence of crisis, through impactation of knowledge. This study concluded that, below half of the respondents during pre-intervention have low knowledge on sickle cell disease and its management, however a significant increase in knowledge was experienced duirng post-intervention. The study also concluded that, majority of the respondents experienced financial and psychological burden, which becomes reduced significantly during post intervention. This study therefore recommended that, Government should institute strict policies on premarital genotype screening to ensure that individuals going into marriage knows their status before marriage. Also, genotype screening equipment should be made available and affordable in all primary health centers. Also it is imperative that, Health workers especially nurses should intensify their public enlightenment campaign to address the issue of stigma and discrimination among people living with sickle cell diseases. Nurses also need to increase the rate of counseling caregivers of sickle cell patients to ensure that, they have adequate knowledge of sickle cell and management to reduce rate of crisis among their children.

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