

## Psychosocial Factors Influencing Informal Care Givers Burden of People Living with Sickle Cell Disease (SCD) In Cross, River State, Nigeria

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doi: <https://doi.org/10.37745/ijphpp.15/vol9n32336>

Published June 02, 2024

Citation: Ella R.E., Asuquo E.F., and Gbobbo J.(2024) Psychosocial Factors Influencing Informal Care Givers Burden of People Living with Sickle Cell Disease (SCD) In Cross, River State, Nigeria, *International Journal of Public Health, Pharmacy and Pharmacology*, 9 (3), 23-36

**ABSTRACT:** *Sickle cell disease (SCD) is a global health concern with 10 million people affected and about 300,000 newly diagnosed children born worldwide. Africa bears the brunt of SCD, sub-Saharan Africa accounting for 75%. Nigeria accounts for 33% of the global burden of PLWSCD in CRS. The study aimed to investigate Psychosocial Factors Influencing Informal Care Givers Burden of People Living with Sickle Cell Disease (SCD) In Cross, River State, Nigeria. Two specific objectives were used in the study. The study employed a cross-sectional research design. Questionnaire, elicited data from 385 respondents. Face and content validity and test-retest method with a reliability coefficient of 0.83 was obtained. The result revealed that 49(12.7%) respondents experienced "Little or no Burden", 112(29.1%) "Mild to Moderate Burden", 216(56.1%) "Moderate to Severe Burden", 8(2.1%) "Severe Burden". 273(70.9%) did not receive any form of support. The study concludes that recognizing and addressing care givers burden by health care providers, policy makers, advocacy organizations can better support and improve the well-being of affected families. Therefore, implementation of robust support programs for caregivers is crucial to address their multifaceted challenges.*

**KEYWORDS:** sickle cell disease, caregiver, burden, psychosocial factors.

### INTRODUCTION

Sickle cell disease (SCD) is a global health concern affecting a significant number of individuals with an estimated prevalence of 100 million people worldwide (Piel et al., 2017). It is particularly

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prevalent among populations of African, European, and American descent, as well as individuals of Arab and Asian ancestry. Africa disproportionately bears the brunt of this disease. Yearly about 300,000 newly diagnosed children are born worldwide, but Sub-Saharan Africa accounts for 75% of this number (Nwabuko et al., 2022). Nigeria is identified as the epicenter center for SCD with 100,000-150,000 new-born living with Sickle cell disease yearly, accounting for 33% of the global burden of SCD. From the statistics about four to six million people are living with the disease in Nigeria, which approximately accounts for 1 in every 4 Nigerians living with sickle cell trait (Aygün et al. 2012).

According to Alabiand & Adebowale-Tambe (2021) Nigeria occupies a strategic position in SCD epidemiology in the global perspective, but remains a black sheep among the comity of nations due to lack of strategic vision in reducing the national and global diseases burden. They added that SCD prevalence within the states in Nigeria ranges from 1%-3% with Hb-SS as the predominant hemoglobin variant found in Nigeria. With the above prevalence many Nigerians will be affected and a lot more serve as family /Informal caregivers.

Nigeria has one of the highest prevalence rates of SCD in the world, and Cross River State is among the regions most affected by this condition. The high prevalence of SCD in the region is influenced by the genetic component of the disorder, as well as other factors specific to the area (Sahoo, 2020). Cross River State in Nigeria has a significant burden of sickle cell disease (SCD) due to a combination of factors. SCD is an inherited blood disorder, and in areas with a high prevalence of carriers, the likelihood of two carriers having a child with SCD is increased.

According to Nnodu et al., (2021), the burden of child mortality from sickle cell disease in Nigeria had been on the increase and disproportionately higher than the burden of mortality of children without sickle cell disease. However, the author added that most of these deaths could be prevented if adequate resources were allocated and caregivers equipped for appropriate intervention (Nnodu, et al., 2021). The authors further revealed that the estimated national average of under-5 mortality with sickle cell disease born between 2003 and 2013 was 490 per 1000 live births 4.0 times higher than children with HbAA. Moreover 4.2% of national under-5 mortality is attributable to excess mortality from sickle cell disease. Many families in Nigeria are familiar with high mortality with SCD and affirmed it as a repeated decimal which is imperative in SCD. Caring for a child with sickle cell disease (SCD) has been described by several studies across the world as burdensome most especially for parents or caregivers of these children (Kilorizi et al., 2022). Caring for a child with SCD places extra demands on parents, both physically and psychologically, which may harm their quality of life. Parents have to face the reality of the illness after their children are diagnosed with SCD and to manage everyday life while caring for their children with SCD. Families of children with SCD most especially experience financial difficulties, and are unable to make quality time for their other children resulting in deteriorated social lives. Hardship, struggle and difficulty become the normal way of life for those parents (Yawson et al., 2016; Muoghalu 2016; Ali & Razeg 2017). The high morbidity with periods of exacerbation s and remissions coupled with

mortality associated with this condition affect parents and family members who accept caregiving role with little or no preparation for their expected role. The psycho-social impact of sickle cell disease is devastating and worrisome to parents' families and even to the individuals affected by the disorder (Nnodu, et.al. 2021). Children with sickle cell disease are at risk for maladjustment in almost every area of functioning. Individuals with sickle cell disease experience severe, episodic and chronic pain, multi-system organ failure, stroke and life-threatening infections. In addition, patients experience lower academic achievement compared to healthy children with similar demographic characteristics. They have lower chances of meaningful employment in adulthood, face trouble in attention and concentration; score lower on measures of intelligence, and also have increased school absenteeism, and are more likely to repeat grades. For children with sickle cell disease in households of parents without higher education, the disease's impacts are exacerbated. On the family, the psycho-social challenges of sickle cell are worrisome with financial burden, inability to get support with nonchalant attitude and inadequate support to parents of children with sickle cell disease (Fergeus et al., 2017). Caregivers of individuals with SCD often experience reduced quality of life, psychological distress, and financial hardship in association to adopted role, although many remain oblivious of the enormous significance of this role to the family and the nation as a whole (Li & Dong, 2017).

Informal caregivers play a crucial role in managing chronic illnesses such as sickle cell disease (SCD). They provide support and assistance to individuals affected by SCD, but this responsibility can be physically and emotionally taxing, leading to significant caregiver burden. They often experience strain in various forms, including physical, emotional, and financial demands. Galiatsatos et al., (2017), opined that the burden of caring for individuals with SCD involves taking responsibility especially for the young and vulnerable; the responsibility involves follow-up caring, caregiving tasks, financial distress, patient support, external support, and caregiving strategy.

Providing care to children, whether full-time or part-time, formal or informal, can have a significant impact on caregivers, both physically and emotionally. Caregivers provide a wide range of assistance, including helping with daily tasks, emotional support, and companionship. These caregiving responsibilities can be time-consuming with emotional, , physical , and psychological draining, leading to high levels of stress and caregiver burden. This stress can have negative effects on the health and well-being of the caregivers, including poor health and increased risk of depression (Rotberg et al., 2019). Literature suggests that care-giving can result in significant caregiver's burden and stress, which could contribute to poor health and depression among caregivers (Fergeus et al., 2017). Caregivers are at a greater health risk than the care receivers because they often neglect their own needs while caring for others. This can lead to physical and mental health issues, including stress, depression, and insomnia. The stress of caregiving could also result in physical and verbal aggression towards the care receiver. Additionally, caregiver stress has been linked to child sickness, abuse and neglect (Li & Dong, 2017). Losada (2018) found that caregiver stress is a contributing factor to child sickness, abuse, and neglect. In addition to

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stress-related health concerns, caregivers may experience other challenges such as financial, social, and psychological outcomes. Similarly he stated that the impact of caregiving varies depending on the relationship between the caregiver and care recipient, with spousal and child caregiving often being more stressful for women (Losada, 2018). Caregivers of children with SCD in some jurisdictions have reported negative emotional and personal life impacts of the disease, and others showing difficulty in maintaining family relationships and meeting the needs of other family members (Najart et al., 2023)

There is a need for interventions to support caregivers and improve their well-being, with psycho-therapeutic and psych educational interventions showing positive effects (Losada, et al., 2022). The region of Cross River State in southern Nigeria offers a distinctive setting for examining the psycho-social factors that contribute to caregiver burden within the context of Sickle Cell Disease (SCD). Understanding of the specific psycho social factors influencing caregivers' burden in Cross River State is a necessity. There is need for continuous enlightenment and premarital counseling on the pattern of inheritance of SCD. Further research is needed to comprehensively explore and document these factors in order to develop interventions and support programs to help caregivers and improve the quality of life for children with SCD. It is therefore necessary to conduct specific studies that focus on psychosocial dynamics of care givers burden within Cross River State, Nigeria.

#### AIM AND OBJECTIVES OF THE STUDY

To assess the psycho-social factors that influence the burden experienced by informal caregivers of individuals living with Sickle Cell Disease (SCD) in Cross River State, Nigeria, and to inform the development of targeted interventions and support mechanisms.

#### OBJECTIVES OF THE STUDY

1. To determine level of burden among informal caregivers of children with sickle cell disease in Cross River State, Nigeria.
2. To examine the availability of support to informal caregivers of children with sickle cell disease in Cross River State, Nigeria.

#### METHODOLOGY (MATERIALS AND METHODS)

This study used the cross-sectional research approaches. The accessible population was made up of all 384 caregivers of people with SCD living in Calabar, the Southern senatorial district. The total sample size for this study was 424. The instrument for data collection was a self- developed questionnaire with questions emanating from variables reviewed in the study. The questionnaire spread into three (3) sections; A-C to assess the Psychosocial factors influencing informal care givers burden of people living with Sickle Cell Disease (SCD) in Cross River State, Nigeria.

A - Socio-demographic data of respondents.

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- B - Level of burden among informal caregivers of children with sickle cell disease.  
 C - The availability of support to informal caregivers of children with sickle cell Disease.

The self-administered instrument composed of 22 items scored on a Likert-type scale with 5 response options: never (0 points), rarely (1 point), sometimes (2 points), quite often (3 points), and almost always (4 points). The data was analysed using the Statistical Package for Social Sciences (SPSS) vision 20.0 and the result was resented in percentages, tables, figures and bar charts.

## DATA ANALYSIS AND RESULTS

Table1.0: Socio-demographic data

<b>Variables</b>		<b>Frequency</b>	<b>%</b>
<b>Age in years</b>	20 -29years	119	30.9%
	30 -39years	152	39.5%
	40 -49years	85	22.1%
	50years and above	29	7.5%
<b>Gender</b>	Male	136	35.3%
	Female	249	64.7%
<b>State of Origin</b>	Cross River State	178	46.2%
	Akwa Ibom	108	28.1%
	Others specify	99	25.7%
<b>Religion</b>	Christianity	346	89.9%
	Islam	39	10.1%
	Others specify	0	0.0%
<b>Marital status</b>	Single	134	34.8%
	Married	235	61.0%
	Divorce	16	4.2%
<b>Level of education</b>	Primary	6	1.6%
	secondary	58	15.1%
	Tertiary	321	83.4%
<b>Occupation</b>	Self employed	155	40.3%
	Civil servant	126	32.7%
	Full time housewife	36	9.4%
	Others specify	68	17.7%
<b>Relationship to care recipient</b>	mother	79	20.5%
	Father	48	12.5%
	Siblings	68	17.7%

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	Relatives	117	30.4%
	Spouse	17	4.4%
	Parent	10	2.6%
	Child	10	2.6%
	Others specify	36	9.4%
<b>Are you a care giver</b>	Yes	34	8.8%
	No	351	91.2%
<b>How long have you been a caregiver</b>	1 - 5 years	216	56.1%
	6 -10years	79	20.5%
	11-15 years	60	15.6%
	16- 20 years	20	5.2%
	21 years and above	10	2.6%

Among the 385 respondents, 119 (30.9%) were in the age range of 20-29 years, 152 (39.5%) were in the age range of 30-39 years, 85 (22.1%) were in the age range of 40-49 years, and 29 (7.5%) were 50 years and above. 136 (35.3%) were male, and 249 (64.7%) were female. 178 (46.2%) were from Cross River State, 108 (28.1%) were from Akwa Ibom, and 99 (25.7%) were from other specified states. 346 (89.9%) identified as Christians, 39 (10.1%) identified as Muslims, and none specified another religion. 134 (34.8%) were single, 235 (61.0%) were married, and 16 (4.2%) were divorced. 6 (1.6%) had a primary education, 58 (15.1%) had a secondary education, and 321 (83.4%) had tertiary education. 155 (40.3%) were self-employed, 126 (32.7%) were civil servants, 36 (9.4%) were full-time housewives, and 68 (17.7%) had other specified occupations. 79 (20.5%) were mothers, 48 (12.5%) were fathers, 68 (17.7%) were siblings, 117 (30.4%) were relatives, 17 (4.4%) were spouses, 10 (2.6%) were parents, 10 (2.6%) were children, and 36 (9.4%) specified other relationships. 34 (8.8%) identified as caregivers, and 351 (91.2%) did not identify as caregivers. 216 (56.1%) had been caregivers for 1-5 years, 79 (20.5%) for 6-10 years, 60 (15.6%) for 11-15 years, 20 (5.2%) for 16-20 years, and 10 (2.6%) for 21 years and above.

Table 2: the level of burden among informal caregivers of children with sickle cell disease in Cross River State, Nigeria.

S/N	Items	N (%)	R (%)	S (%)	QO (%)	AA (%)	mean	σ	Decision
1	I feel [care recipient] asks for more help than needed	32 (8.3)	50 (13.0)	212 (55.1)	69 (17.9)	22 (5.7)	2.997	0.934	High burden
2	I don't have not enough time for oneself	4 (1.0)	93 (24.2)	177 (46.0)	81 (21.0)	30 (7.8)	3.104	0.893	High burden
3	I feel stressed when caring and trying to meet other responsibilities	12 (3.1)	79 (20.5)	168 (43.6)	114 (29.6)	12 (3.1)	3.091	0.863	High burden
4	I feel embarrassed	56 (14.5)	145 (37.7)	114 (29.6)	65 (16.9)	5 (1.3)	2.527	0.979	Low burden

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5	I feel angry	62 (16.1)	119 (30.9)	157 (40.8)	38 (9.9)	9 (2.3)	2.514	0.955	Low burden
6	I feel [care recipient] my affects relationships with other family members/friends in a negative way	55 (14.3)	87 (22.6)	200 (51.9)	40 (10.3)	3 (0.8)	2.608	0.884	Low burden
7	I am afraid what the future holds [for care recipient]	11 (2.9)	76 (19.7)	158 (41.0)	127 (33.0)	13 (3.4)	3.143	0.871	High burden
8	I feel [care recipient] is dependent	17 (4.4)	95 (24.7)	186 (48.3)	70 (18.2)	17 (4.4)	2.935	0.883	High burden
9	I feel strained when around [care recipient]	30 (7.8)	98 (25.5)	187 (48.6)	58 (15.1)	12 (3.1)	2.803	0.897	Low burden
10	I feel my health has suffered [because of involvement with care recipient]	45 (11.7)	80 (20.8)	195 (50.6)	59 (15.3)	6 (1.6)	2.743	0.909	Low burden
11	I feel I don't have as much privacy	38 (9.9)	97 (25.2)	168 (43.6)	74 (19.2)	8 (2.1)	2.784	0.937	Low burden
12	I feel my social life has suffered because of caregiving	31 (8.1)	81 (21.0)	214 (55.6)	46 (11.9)	13 (3.4)	2.816	0.869	Low burden
13	I feel uncomfortable having friends over	44 (11.4)	120 (31.2)	163 (42.3)	52 (13.5)	6 (1.6)	2.626	0.915	Low burden
14	I feel that [care recipient] expects me to be taken care as if there is no one else	31 (8.1)	70 (18.2)	216 (56.1)	60 (15.6)	8 (2.1)	2.855	0.851	Low burden
15	I feel I don't have enough money	31 (8.1)	75 (19.5)	169 (43.9)	88 (22.9)	22 (5.7)	2.987	0.988	High burden
16	I feel unable to care for much longer	40 (10.4)	78 (20.3)	191 (49.6)	66 (17.1)	10 (2.6)	2.813	0.928	Low burden
17	I feel I have lost control of life since caring role	41 (10.6)	85 (22.1)	181 (47.0)	72 (18.7)	6 (1.6)	2.784	0.923	Low burden
18	I wish that I could leave the caring role to someone else	61 (15.8)	91 (23.6)	154 (40.0)	67 (17.4)	12 (3.1)	2.683	1.035	Low burden
19	I feel uncertain about what to do [with care recipient]	26 (6.8)	86 (22.3)	182 (47.3)	81 (21.0)	10 (2.6)	2.904	0.895	High burden
20	I feel I should be doing more [for care recipient]	4 (1.0)	47 (12.2)	182 (47.3)	112 (29.1)	40 (10.4)	3.356	0.863	High burden
21	I feel I do a better job at caring	23 (6.0)	32 (8.3)	201 (52.2)	106 (27.5)	23 (6.0)	3.192	0.895	High burden
22	Overall, how burdened in caring role	45 (11.7)	55 (14.3)	196 (50.9)	69 (17.9)	20 (5.2)	2.906	0.996	High burden

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Note: N=385, N=Never, R=Rarely, S=Sometimes, QO=Quite often, AA=Almost always.  
Weighted mean = 2.871

Among the identified challenges, a considerable proportion of caregivers reported high levels of burden in aspects such as feeling that the care recipient asks for more help than needed (8.3%, mean =  $2.997 \pm 0.934$ ), not having enough time for oneself (1.0%, mean =  $3.104 \pm 0.893$ ), and feeling stressed when balancing caregiving with other responsibilities (3.1%, mean =  $3.091 \pm 0.863$ ). These findings suggest a significant emotional and time-related strain on this subset of caregivers.

Conversely, certain aspects were associated with lower reported burden. For instance, feeling embarrassed (14.5%, mean =  $2.527 \pm 0.979$ ), feeling angry (16.1%, mean =  $2.514 \pm 0.955$ ), and perceiving that the care recipient affects relationships negatively (14.3%, mean =  $2.608 \pm 0.884$ ) were linked to lower burden levels.

Additionally, caregivers expressed concerns about the future for the care recipient (2.9%, mean =  $3.143 \pm 0.871$ ), a sense of dependence of the care recipient (4.4%, mean =  $2.935 \pm 0.883$ ), and uncertainty about what to do with the care recipient (6.8%, mean =  $2.904 \pm 0.895$ ), contributing to a perception of higher burden.

Overall, the weighted mean for the caregivers' burden across all items was 2.871, providing a comprehensive overview of the challenges faced by informal caregivers of children with sickle cell disease in Cross River State, Nigeria. These findings underscore the need for targeted support and interventions to alleviate the burden experienced by this caregiving population. Categorizing this level of burden according to (Zarit et al., 1985) is seen in table 3.

Table 3: Level of burden

Level of burden	Frequency	%	mean	SD
Little or no burden	49	12.7%	2.4753	0.7395
Mild to Moderate burden	112	29.1%		
Moderate to Severe burden	216	56.1%		
Severe burden	8	2.1%		

N = 385

Level of Burden

0 – 20: Little or no burden

21 – 40: Mild to Moderate burden

41 – 60: Moderate to Severe burden

61 – 88: Severe burden

Among the 385 respondents, 49(12.7%) respondents reported experiencing "Little or No Burden." A total of 112 respondents (29.1%) expressed "Mild to Moderate Burden," while 216 respondents



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(56.1%) indicated "Moderate to Severe Burden." Additionally, 8 respondents (2.1%) reported experiencing the most intense burden, categorized as "Severe Burden." The mean burden level for the "Mild to Moderate Burden" category was 2.4753, with a standard deviation of 0.7395. This analysis provides a detailed breakdown of the distribution and intensity of burden levels within the surveyed population, highlighting the prevalence of different burden categories and their associated statistical measures. The level of burden is illustrated in figure 1.

Figure 1: Illustrating the level of burden among informal caregivers of children with sickle cell disease in Cross River State, Nigeria

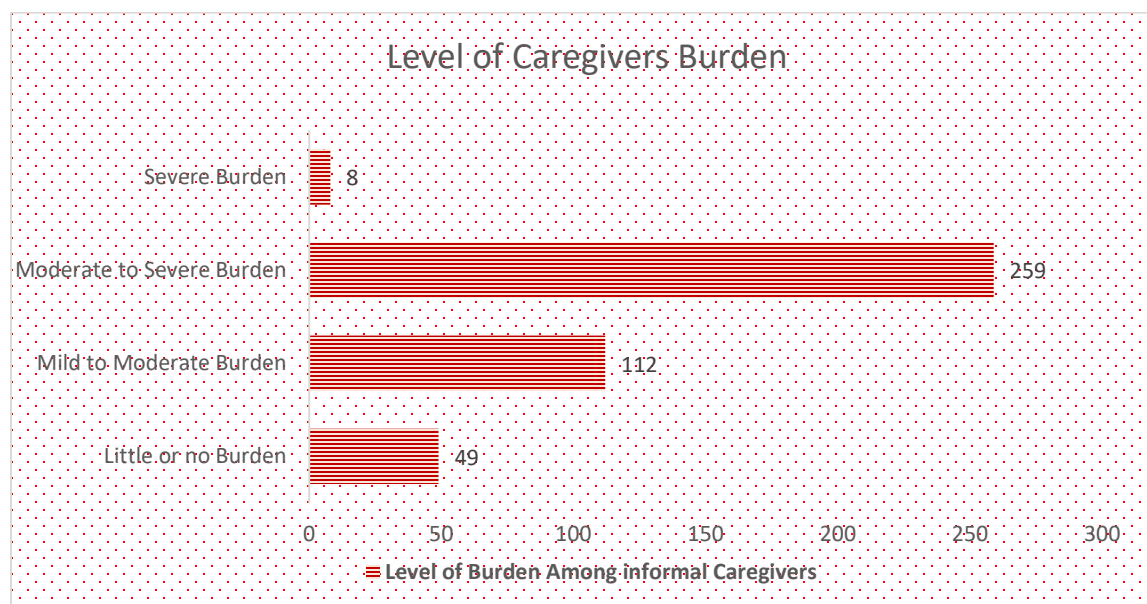


Table 3: the availability of support to informal caregivers of children with sickle cell disease in Cross River State, Nigeria.

S/N	STATEMENTS	Yes	(%)	No	(%)	mean	S.D	Grand Total
1	Have you received any formal training or education to help you in your caregiving role?	91	23.6	294	76.4	192.5	143.54	
2	As a caregiver have you ever receive any form of support?	100	26.0	285	74.0	192.5	130.81	
3	Have you received emotional support (e.g., understanding, empathy, and listening)	102	26.5	283	73.5	192.5	127.97	

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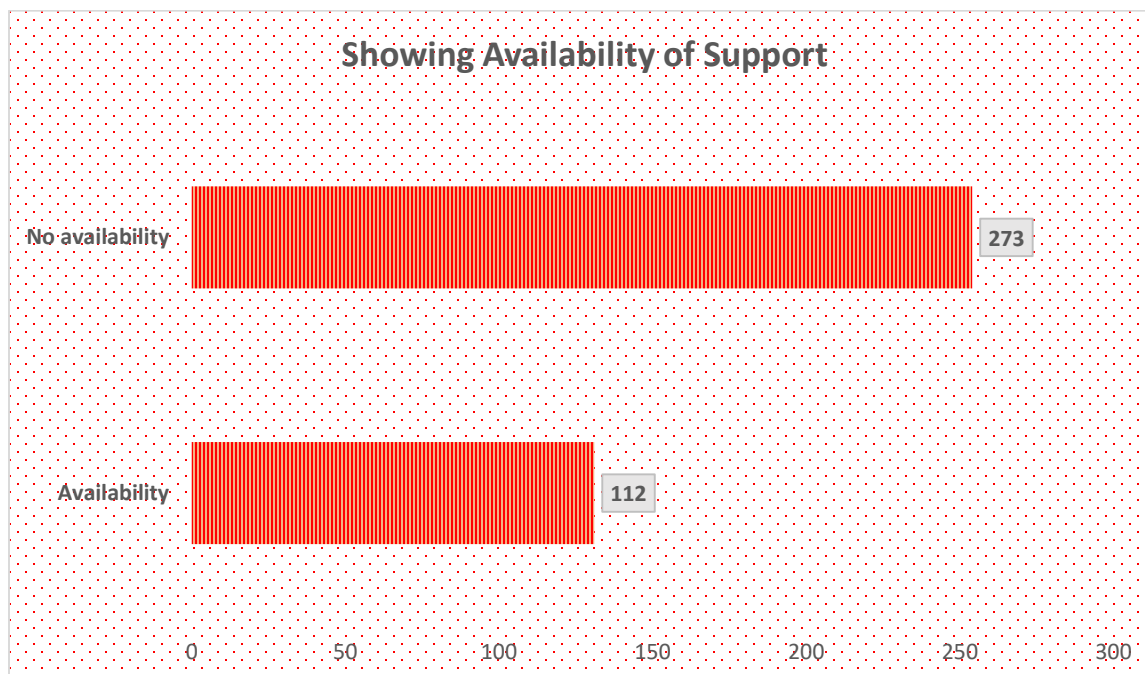
4	Have you received practical support (e.g., assistance with caregiving tasks)	109	28.3	276	71.7	192.5	118.09	
5	Have you received Informational support (e.g., access to educational resources)	117	30.4	268	69.6	192.5	106.77	
6	Have you received financial support (e.g., assistance with caregiving-related expenses)	156	40.5	229	59.5	192.5	51.62	
Data transformation		675/2310x385 =112		1635/2310 x 385=273				2310

Among the 385 respondents, 91 (23.6%) had received formal training or educational help, while 294 (76.4%) had not. The mean and standard deviation for this statement were 192.5 and 143.54, respectively. For the statement "As a caregiver have you ever received any form of support?" 100 (26.0%) respondents answered affirmatively, while 285 (74.0%) had not. The mean and standard deviation for this statement were 192.5 and 130.81, respectively. Regarding "Emotional support (e.g., understanding, empathy, and listening)," 102 (26.5%) respondents indicated they received it, while 283 (73.5%) did not. The mean and standard deviation for this statement were 192.5 and 127.97, respectively.

For "Practical support (e.g., assistance with caregiving tasks)," 109 (28.3%) respondents reported receiving such support, while 276 (71.7%) did not. The mean and standard deviation for this statement were 192.5 and 118.09, respectively. Concerning "Informational support (e.g., access to educational resources)," 117 (30.4%) respondents acknowledged receiving it, while 268 (69.6%) did not. The mean and standard deviation for this statement were 192.5 and 106.77, respectively. In terms of "Financial support (e.g., assistance with caregiving-related expenses)," 156 (40.5%) respondents affirmed receiving support, while 229 (59.5%) did not. The mean and standard deviation for this statement were 192.5 and 51.62, respectively. Data transformation revealed 112 (29.1%) had some form of support, while the majority 273 (70.9%) did not received any form of support.

The availability of support to informal caregivers of children with sickle cell disease in Cross River State, is illustrated in figure 2.

Figure 2: Bar chart showing availability of support to informal caregivers of children with sickle cell disease in Cross River State, Nigeria.



The study shows that among the 385 respondents, the majority 273(70.9%) did not receive any form of support, while 112 (29.1%) did received some forms of support

## DISCUSSION

Level of Burden Among Informal Caregivers of Children with Sickle Cell Disease in Cross River State, Nigeria.

The study findings show that most of the respondents had high to severe burden with sickle cell disease as informal caregivers. This maybe secondary to the demanding nature of caregiving, coupled with concerns about the child's health, treatment adherence, and long-term outcomes, these contributes to elevated levels of emotional strain among caregivers. Moreover, financial implication associated with frequent hospitalization and unpredictable nature of the disease may induce strain and limited support may impact quality of life as well as strain family relationships and dynamics. The high morbidity and mortality rates of sickle cell disease, coupled with the lack of comprehensive support systems, may contribute to the perceived burden among informal caregivers. Additionally, limited access to healthcare resources and cultural factors might exacerbate the challenges faced by caregivers, intensifying the burden associated with caring for individuals with sickle cell disease. This findings corroborates with Adeniran et al., (2020) who asserted that caregiving is demanding activities affecting physical wellbeing and financial burden is further exacerbated by the high cost of hospitalization and the lack of affordable health insurance options (Adeniran et al., 2020). Poku et al.,(2018) asserted that burden on caregivers of children with sickle cell anaemia is multifaceted and transcend, physical, emotional and psychological wellbeing of the care receiver as well as quality of life. The further revealed that the psychological

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distress experienced by caregivers is much which can manifest as physical and mental ill health if not alleviated through family counselling which has been shown to improve the quality of care for children with sickle cell anaemia as well as quality of life of the care giver (Poku et al., 2018). This study also aligns with Ohaeri and Shokunbi's (2002) cross-sectional study in Nigeria, which assessed the psycho-social burden among caregivers of sickle cell disease (SCD) patients. Their findings revealed that objective burden indices were considerably higher for SCD patients in crisis, indicating a substantial burden on caregivers.

#### Availability Of Support to Informal Caregivers of Children With Sickle Cell Disease in Cross River State, Nigeria.

The study findings reveal that most of the respondents affirmed to no availability of support to informal caregivers. The lack of support for informal caregivers could be attributed to several factors. It's possible that there is insufficient awareness or acknowledgment of the challenges faced by informal caregivers in the context of the study. Additionally, there may be a lack of established support systems or programs tailored to address the specific needs of informal caregivers. Financial constraints, limited resources, or gaps in healthcare policies might contribute to the absence of structured support mechanisms. Cultural attitudes and societal perceptions towards caregiving roles may also play a role, potentially overlooking the essential contributions and needs of informal caregivers. This aligns with the findings of Anie & Egunjobi (2018) on the psycho-social dimensions of Sickle Cell Disorder among adolescents and adults in Lagos, Nigeria, emphasizing the societal perceptions and attitudes towards the disorder, which could influence the support available to caregivers.

#### CONCLUSION

In conclusion, this study sheds light on the significant burden faced by caregivers of individuals with sickle cell disease (SCD) in Cross River State, Nigeria. The findings underscore the complex interplay of psycho-social challenges, financial strain, and inadequate support structures, contributing to caregiver burden. The prevalence of SCD in the region, coupled with high mortality rates and limited resources, amplifies the challenges faced by families. It is evident that caregivers, often informal and family members, play a vital role in managing SCD, necessitating targeted interventions to alleviate their burden. The study emphasizes the need for tailored support programs, education, and advocacy to enhance the well-being of caregivers and, consequently, improve the overall care landscape for individuals with SCD. Addressing these challenges requires a comprehensive approach involving healthcare professionals, policymakers, and the community to create a supportive environment that recognizes and addresses the unique needs of caregivers in the context of SCD.

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