

## Burden of Childhood Sickle Cell Disease on Caregivers at the Sickle Cell Unit of Chantal Biya's Foundation in Yaounde, Cameroon

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### ABSTRACT

**Background:** Sickle cell disease is a very common inherited blood disorder. It is characterized by several chronic manifestations, which becomes burdensome for the patients, and the caregivers (parents). Identifying and understanding the factors associated with burden among caregivers of children with sickle cell disease will allow us to improve their quality of life and in turn, the care given to the sick children. Thus, this study aimed at evaluating the level of burden among caregivers of children with sickle cell disease and determining the factors influencing this state.

**Methods:** A hospital based cross-sectional analytic study was carried out from March 2022- April 2022 at the 'Centre Mere et Enfant' (CME) of the 'Foundation Chantal Biya' (FCB) in Yaounde. Data was collected using the Zarit Burden Interview (ZBI). Data were entered and analyzed using Epi Info version 7.2.2.6 Statistical significance was set at  $p$ -value  $<0.05$  while bivariate and multivariate analysis was used to test for associations.

**Results:** One hundred and seventy-four caregivers (174) were included in the study among which more than half (77.6%) were females. Almost half (49.4%) respondents perceived moderate to severe burden with Mean score of level of burden being 42.8. Significant statistical associations were found between moderate to severe caregiver burden and job loss ( $p=0.01$ ;  $OR=1.09-7.34$ ) and social stigmatization ( $p=0.0003$ ;  $OR=1.45-5.51$ ).

**Conclusions:** The study revealed that majority of the caregivers perceived a moderate to severe burden and that this level of burden was associated with social stigmatization and job loss.

### Keywords

Sickle cell disease, Caregiver, Caregiver burden, Zarit Burden Interview.

### Introduction

Sickle cell disease (SCD), an inherited blood disorder, caused by a genetic mutation characterized by the replacement of glutamic acid by valine at position 6 of beta globin chain leading to an abnormality in Red Blood Cells (RBC) affecting the blood carrying capacity of hemoglobin. Pioneering studies established that SCD

results from a defect in the hemoglobin molecule [1] leading to a propensity for the cells to assume an abnormal, rigid, sickle like shape under certain circumstances (oxygen deprivation). Sickle cell disorders, with exception made for the hemoglobin A and hemoglobin S heterozygous coexistence, also called sickle cell trait (SCT) are usually associated with severe clinical manifestations. The most common form of SCD in Africans is the homozygous disease (HbSS), an autosomal recessive disorder first described by Africanus Horton in 1874, in the article "the diseases of tropical climates and their treatment" 36 years before James Herrick in 1910 [2]. An estimated 300000 babies are born each year with

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SCD worldwide, with 75% of the births occurring in Sub-Saharan Africa[3] with Cameroon being the 6<sup>th</sup> African country with the highest number of SCD births per year (7,172 births) after Nigeria, Democratic Republic of Congo, Tanzania, Uganda and Angola[4]. Its prevalence in 2014 in Cameroon was 21.6% [5].

It is a chronic condition whose hallmark feature remains the frequent and unpredictable pain termed vaso-occlusive crisis (VOCs) which accounts for approximately 25% of hospital visits in SCD children[6] first manifesting as dactylitis also known as “hand foot syndrome” (a painful swelling of the hands and feet with the highest incidence between 6 months and 2 years). Other manifestations of SCD are less common than VOCs, including “acute chest syndrome” (pneumonia or pulmonary infarction), anemia, bone or joint necrosis, priapism, renal failure, or cerebrovascular accident.

SCD and its multifaced clinical presentations, especially the pain episodes, can have widespread impact on both the affected children and their families. The empirical findings suggest that the risk factors for caregiver burden include socio-demographic and psychological aspects. Specifically, SCD has been associated with several indicators of psychological maladjustment including emotional and behavioral problems and poor academic performance[7]. Numerous studies have documented an association between SCD and depression [8].

With respect to the family, caregivers of children with SCD are overwhelmed with work absenteeism, increase family financial burden, and increase care demand which is partly due to the unpredictability of pain crisis care in SCD. Taking care of a child with SCD is a challenging experience for both the caregiver and the other family members[9]. 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 (quality of life) [9]. Not surprisingly, caregivers of children with SCD experience psychological symptoms, including symptoms of depression and anxiety [10] so, parenting children with chronic diseases is highly demanding and has practical and emotional consequences leading to decrease quality of care given to SCD patients. A previous study indicated that the caregiver burden results in burnout, acute and chronic physical disorders, depression, social isolation, and financial concerns. It has also been revealed that parents of children with chronic disease experience moderate to severe burden[11]. Reason why caregivers of chronic and severely ill patients are sometimes called hidden patients [12]. It is therefore important to address the caregivers’ well-being and to identify the need for additional support for the health of both caregiver and affected children. Specifically, this study aimed to determine the level of burden among caregivers of SCD affected children and to identify the associated factors to caregiver burden among caregivers of SCD affected children in our local setting, where the disease is still seen as a taboo.

## Materials and Methods

This study was a hospital based cross sectional study carried out over a period of 2 months, from March to April 2022. The study took place at the CME (Centre Mère et Enfant) of the FCB (Fondation Chantal Biya) Yaounde, created on 23<sup>rd</sup> February 1999; it is part of a large group called “FCB”. The CME is a health facility unlike any other which provides specific care for sickle cell affected children in a special unit called “moyen standing”, here they are hospitalized and routine visits are programmed for every Wednesday of the week. New cases are managed at emergency unit and sent to the ward which has a capacity of 11 beds. Nevertheless, in case of a full ward, there is a possibility of admitting more patients in other services. The staff is made up of general practitioner, residents, nurses, and assistant nurses.

We included all caregivers aged 21 years old and above who gave their consent and excluded all parents or other caregivers with any known psychological disorder and whose consent was not given. The estimated sample size was 160 participants, calculated using the Cochran’s formula and an estimated prevalence of burden among parents with SCD children in Cameroon at 88.3% [5] and these participants were selected by a non-probabilistic consecutive and purposive sampling method. Ethical approval was obtained from the Institutional Review Board of the Faculty of Health Sciences University of Buea (IRB FHS-UB), followed by authorization from the director of FCB-CME. Recruitment of participants and collection of data was facility-based, participants were approached with the informed consent document which explained the study design, risks, benefits, and what was required from them.

Parents who accepted to be part of the study were verified for eligibility, wherein if eligible they gave their consent. The structured questionnaire was administered by the principal investigator according to the participant’s first language and it included: demographic data (patient’s information: age, gender, region of origin, address, phone number, occupation, income, educational status, marital status, tribe, religion), income was assessed using SMIG (Salaire Minimum Interprofessionnel Garanti) in Cameroon. Low income was defined as < 36,270fcfa and high income >36,270fcfa. The Zarit Burden Interview (ZBI) is a self-administered tool, first developed by Zarit et al. in 1985, to determine the difficulties of care among caregivers of people with cognitive and chronic diseases. It is a 22-item instrument designed for evaluation of the caregiver burden. It assesses the caregiver’s stressors in physical, emotional, social, and financial aspects. These items are answered on a five-point Likert scale from ‘0=never’ to ‘4=always’ with a total score from 0 to 88. Scores 61-88, 41-60, 21-40, and lower than 21 on the scale stand for severe, moderate, mild and no burden, respectively [13].

To meet the objectives of the study and to address the context of the guiding literature, additional questions were formulated to capture necessary data such as financial hardship and social support. Data collected was keyed in and analyzed using Epi Info version 7.2.2.6. Quantitative variables were represented in tables and pie-

chart. Bivariate and multivariate analyses were used to identify factors related to moderate to severe burden using a P-value of  $P < 0.05$  at a CI of 95%.

## Results

A total of 104 caregivers were extracted from hospitalization and emergency unit while, 79 participants were approached during routine visits giving a total of 174 participants, of which 9 were excluded due to refusal to participate. Caregivers aged 26-35 years represented the largest age group 68 (39.1%), with the mean age being 37 ( $\pm 9$ ) years. 135 (77.6%) were female, and 39 (22.4%) were male with a sex ratio of 3:1. Among these females, 122 (90.4%) were mothers. Almost half 85 (48.9%) had at least secondary level education, whilst 77 (44.3%) admitted having reached the tertiary level. Most participants were married 117 (67.2%), employed 128 (73.6%) with a monthly income  $>36270$  FCFA accounting for 135 (77.6%) (Table 1).

The pedigree analysis of participants' families revealed that, 145 (83.3%) had one child while 29 (16.7%) of families had two living children who had SCD. One-fifth of participants 35 (20.1%) revealed that one or more of their children had died due to causes believed to be related to SCD. Most affected children were between 1 to 5 years old with the median age being 6 years (Range: 3–10). Many SCD-affected children 56 (32.18%) were diagnosed between 7-12 months of age and the median age at diagnosis was 6 months. Clinically, about half 88 (50.0 %) of the SCD-affected children were reported to have experienced 2 to 3 hospital admissions per year with the main reason of hospitalization being VOCs 98 (56.3%). The median number of hospital admissions per year was 2 (Range: 0–3). One hundred and fifty-six (89.7%) children of caregivers involved in this study experienced blood transfusion with more than half of them who had experienced  $<5$  transfusions since the diagnosis. Most of the caregivers 102 (58.6%) spend more than 10hrs per day providing care to their sick children. One hundred and twenty-four (71.3%) ran out of money for care and 17 (9.8%) caregivers reported to have lost their job due to caregiving role. Sixty-six (37.9%) mentioned that they have experienced stigmatization and 76 (43.7%) belonged to support groups.

Out of 174 participants, 86-experienced moderate to severe burden accounting for 49.4% and 72 experienced mild to moderate burden accounting for 42.4% (Figure 1). Caregiver burden scores were calculated with an average total score of 42.8, which reflects that the average caregiver burden was moderate to severe among our participants. An itemized analysis of participants' responses to ZBI questions was done which revealed the top 5 items that contributed to most caregiver's burden and their degree of impact ranked in descending order (Table 2). None of the explored socio-demographic factors was associated with moderate to severe burden. Blood transfusion ( $p$ -value=0.03) was the only clinical variable which was statistically significantly associated with moderate to severe burden. With respect to financial and social support, job loss ( $p$ -value=0.01) and stigmatization ( $p$ -value=0.0003) were statistically significantly associated with moderate to severe burden. On multivariate analysis of factors

associated with moderate to severe burden, social stigmatization ( $p$ -value=0.0022; adjusted OR=2.83) and job loss ( $p$ -value=0.03; adjusted OR= 2.21) were associated with moderate to severe burden (Table 3).

**Table 1:** Socio-demographic data of participants.

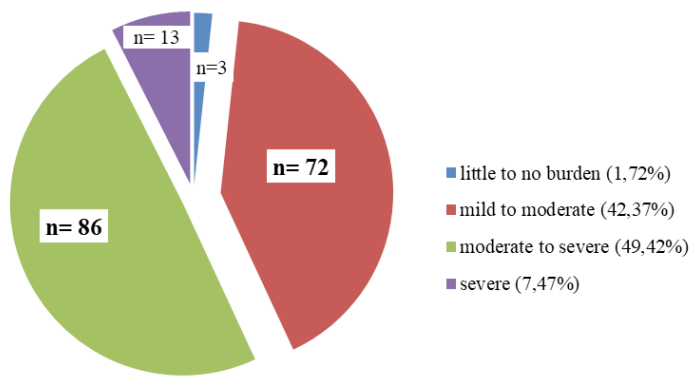
Variables	Frequency(n)	Percentages (%)
<b>Gender (N=174)</b>		
Female	135	77.6
Male	39	22.4
<b>Total</b>	174	100.0
<b>Age (N=174)</b>		
[21-25]	14	8.1
[26-35]	68	39.1
[36-45]	66	37.9
[46-55]	20	11.5
$>55$	6	3.5
Mean Age	37.37 $\pm$ 9.59	
<b>Total</b>	174	100.0
<b>Nationality (N=174)</b>		
Cameroonians	170	97.7
Foreigners	04	2.3
<b>Total</b>	174	100.0
<b>Occupation (N=174)</b>		
Unemployed	46	26.4
Employed	128	73.6
<b>Total</b>	174	100.0
<b>Monthly income (N=174)</b>		
$\leq 36270$	39	22.4
$>36270$	135	77.6
<b>Total</b>	174	100.0
<b>Level of education (N=174)</b>		
Primary	12	6.9
Secondary	85	48.9
Higher Education	77	44.3
<b>Total</b>	174	100.0
<b>Marital status (N=174)</b>		
Single	57	32.8
Married	117	67.2
<b>Total</b>	174	100.0
<b>Relation with child (N=174)</b>		
Mother	122	70.1
Father	32	18.4
Other Relatives	20	11.5
<b>Total</b>	174	100.0

**Table 2:** Top 5 items contributing to caregiver's burden ranked in descending order with respect to the ZBI.

Questions	Mean response	Type of burden
1) Are you afraid of what the future holds for your child?	3.1	emotional
2) Do you feel your health has suffered because of your involvement with this child?	2.8	physical
3) Do you feel you should be doing more for this child?	2.5	emotional
4) How much burdened do you feel in caring for your child?	2.3	emotional
5) Do you feel that you don't have enough money to care for your child?	2.2	financial

**Table 3:** Multivariate analysis of associated factors.

Variables	aOR	CI	p-Value
Social Stigmatization	2.83	1.45-5.51	0.0022
Job loss	2.21	1.09-7.34	0.03
Blood transfusion	1.45	0.89-2.89	0.41



**Figure 1:** Pie chart showing ZBI classification and distribution of caregiver burden.

## Discussion

Wonkam et al. in 2014 revealed that 88.3% had moderate to severe difficulty in coping with living with a SCD affected child [5]. This reveals a large gap between caregivers of SCD affected children and their psychological wellbeing in our setting. This study was designed to assess the level and risk factors of burden of childhood SCD among caregivers. Our findings revealed that, out of 174 participants, almost half (49.4%) experienced moderate to severe burden, whilst 42.4 % experienced mild to moderate burden. These findings were lower when compared to that of Wonkam et al. which showed that 88.3% had moderate to severe difficulty in coping with sickle cell disease [5]. This could be explained by the fact that our study took place in a hospital setting that provides a special ward devoted to sickle cell disease, with many doctors to ensure the wellbeing of patients as well as caregivers. It could also be explained by the shorter duration of the study. The findings of this study were also lower than the findings of a similar study done in Nepalgunj where 52.0% of the respondents perceived mild to moderate burden [14]. This variation may be due to the cultural differences and socioeconomic characteristics of the study population, sample size and place variation. Majority of caregivers in this study were females, which is in line with many other studies [15]. In our analysis, none of the socioeconomic factors (level of education, marital status, occupation, and income) were associated with moderate to severe burden. Single caregivers were however more likely to develop moderate to severe burden. This probably reflects that patients with stable family relationships might have a more promising condition (partner support, more finances...) to take care of a SCD affected child. This is in line with the findings of Wonkam and colleagues conducted in 2014 showing that high risk caregivers' groups are singles, especially single females, unemployed, and caregivers with a low level of formal education [5].

None of the child's characteristics were significantly associated with moderate to severe burden. Majority of SCD affected children were between 1-5 years which was however negatively associated with moderate to severe burden, meaning that caregivers of younger children were more prone to milder forms of burden. Similar studies

found that hospital, financial and child life stressors increased with the age of the children [5]. Child's age was associated with daily activities, indicating potentially more difficulties for caregivers of older children [16]. There was a statistical significance between blood transfusion and moderate to severe burden. The number of blood transfusion did not have a significant impact but the history of blood transfusion was important enough to induce moderate to severe burden ( $P = 0.03$ ;  $OR = 1.36$ ). Patients requiring blood transfusion might have a more severe clinical condition and manifestation of SCD promoting financial hardship as most participants reported spending more when blood transfusion was part of the management plan. Wonkam et al. provided additional evidence that vaso-occlusive painful events ( $>3$  per year) are the disease-related stressors that undermine the coping ability of caregivers. The unpredictable nature of sickle cell disease may also be the reason why it is feared by parents [5]. Among those who reported that they had ever ran out of money to care for their child 75 experienced moderate to severe burden. As mentioned by participants, this was related to the severity of disease, causing repeated hospital admissions and blood transfusion which increase the daily expenditures. It was also related to the time spent caring for the child which had a direct impact on income as some caregivers reported to have lost their jobs following their absence from workplace due to their role of caregiver. This finding is in line with a similar study conducted by Adegoke et al who revealed that job loss, underemployment and/or unemployment arising from time spent caring for a child with SCD, will significantly contribute to the financial burden experienced by caregivers and their family [17]. Concerning social support, stigmatization was statistically and positively associated with moderate to severe burden ( $p=0.0003$ ;  $OR=2.98$ ). Adegoke et al. [17] also found that about half of the caregivers in their study reported the existence of stigmatization. According to existing literature, caregivers of chronically ill children including those suffering from SCD are at higher risk of developing signs and symptoms of depression and anxiety. This is due to the stress and pressure related to such conditions, most of them reported that they feel responsible for the child's illness. Reason why the creation of support groups plays a big role in helping these caregivers in managing their burdens. In this study, support group was negatively associated with moderate to severe burden. Meaning that caregivers who were in support groups, were less likely to develop moderate to severe burden. This is in line with other studies wherein support groups for caregivers of children with chronic illness have shown shared social identity, resulting in a sense of belonging, support, and empowerment, as well as improvements in family functioning and psychological health. The study carried out by Tameka Duncan and colleagues in Jamaica justified the low level of burden among caregivers of SCD affected children by the existence of specialized clinics which provide a strong support system to the client (social worker, outreach programs, teen camps, and excellent partnership with ministry of health to provide National Health Funds benefits for clients) [18].

On multivariate analysis, only social stigmatization ( $p$ -value =



0.0022; OR = 2.83) and job loss (p-value = 0.03; OR = 2.21) were predictors of moderate to severe burden. This was in line with the study conducted by Kuerten et al., which indicated significant financial hardship related to having a child with SCD, most often reported as losing revenue due to job loss and working fewer hours [19]. This is in contrast with a study in Nigeria which indicated that families of individuals with sickle cell disorders deny any evidence of stigmatization. One reason for this difference could be the fact that most parents hide their child's condition and sometimes cover up frequent episodes of crises and hospitalization from other people [20].

### Strength

To the best of our knowledge, this is the second study in Cameroon, evaluating the level of burden perceived by caregivers of SCD affected children which could help tailor policy agendas with respect to the management of SCD children and their families.

### Limitation

A limitation to this study was our reliance on the caregiver's ability to recall some information and events, and their ability to objectively quantify emotional stress.

### Conclusion

Based on the findings of the study, almost half of the caregivers bore a lot of weight due to the disease of their children with 49.4% seen to have moderate to severe burden. The financial burden (characterized by job loss), blood transfusion and social stigmatization contributed significantly more than other measured factors to the burden of the caregivers. Better psychosocial and financial support may be needed to improve the quality of life of both children with SCD and their caregivers and ensure easy access to healthcare at affordable costs to SCD-affected families. Adherence to support groups is a better way of communicating; sharing of feelings and experiences but family's support remains the best.

### Acknowledgement

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## Appendix: QUESTIONNAIRE

### A- Identification

CODE: AGE:	GENDER:	
REGION OF ORIGIN:	ADDRESS:	
PHONE NUMBER:	OCCUPATION:	
INCOME:	<input type="checkbox"/> Low Income ( ≤36.270 FCFA)	<input type="checkbox"/> High Income ( >36.270 FCFA)
LEVEL OF EDUCATION: MARITAL STATUS:		
RELATIONSHIP WITH THE CHILD:		

### A- Past history information

1.	How old is this child?	
2.	At what age was the diagnosis made?	
3.	How many children are in this family?	
4.	Among them, how many have been diagnosed with sickle cell disease?	
5.	Has there ever been a death among those with sickle cell?	<input type="checkbox"/> Yes <input type="checkbox"/> No
6.	If yes, how many?	
7.	How many hospital admissions can your child have per year?	
8.	Most common reason for hospital admissions	<input type="checkbox"/> Vaso-occlusive( pain) crisis <input type="checkbox"/> Anemia ( shortage of blood) <input type="checkbox"/> Infections <input type="checkbox"/> others
9.	Has any of your children ever experienced blood transfusion?	<input type="checkbox"/> Yes <input type="checkbox"/> No
10.	If yes, how many?	
11.	Have you ever run out of money for hospital care?	<input type="checkbox"/> Yes <input type="checkbox"/> No
12.	How often do you provide care per day?	<input type="checkbox"/> Less than 1h <input type="checkbox"/> 1-4h <input type="checkbox"/> 4-7 <input type="checkbox"/> 7-10 <input type="checkbox"/> >10h
13.	Have you ever missed days of work because you were caring for your child?	<input type="checkbox"/> Yes <input type="checkbox"/> No
14.	Have you ever lost your job because of this condition?	<input type="checkbox"/> Yes <input type="checkbox"/> No
15.	Have you ever felt stigmatized because of your child's illness?	<input type="checkbox"/> Yes <input type="checkbox"/> No
16.	Have you ever felt responsible for your child's illness?	<input type="checkbox"/> Yes <input type="checkbox"/> No
17.	Do you take part in support groups?	<input type="checkbox"/> Yes <input type="checkbox"/> No

**B– Questionnaire (ZARIT BURDEN INVENTORY)**

Instructions: Read each statement and rate it on a scale from 0 (never) to 4 (nearly always).

	Never (0)	Rarely (1)	Sometimes (2)	Quite frequently (3)	Nearly always (4)
1. Do you feel that this child asks for more help than he/she needs?					
2. Do you feel that because of the time you spend with this child that you don't have enough time for yourself?					
3. Do you feel stressed between caring for this child and trying to meet other responsibilities for your family or work?					
4. Do you feel embarrassed over this child's behaviour?					
5. Do you feel angry when you are around your child?					
6. Do you feel that this child currently affects our relationships with other family members or friends in a negative way?					
7. Are you afraid what the future holds for this child?					
8. Do you feel this child is dependent on you?					
9. Do you feel strained when you are around this child?					
10. Do you feel your health has suffered because of your involvement with this child?					
11. Do you feel that you don't have as much privacy as you would like because of this child?					
12. Do you feel that your social life has suffered because you are caring for this child?					
13. Do you feel uncomfortable about having friends over because of this child?					
14. Do you feel that this child seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
15. Do you feel that you don't have enough money to take care of this child in addition to the rest of your expenses?					
16. Do you feel that you will be unable to take care of this child much longer?					
17. Do you feel you have lost control of your life since this child's illness?					
18. Do you wish you could leave the care of this child to someone else?					
19. Do you feel uncertain about what to do about this child?					
20. Do you feel you should be doing more for this child?					
21. Do you feel you could do a better job in caring for this child?					
22. Overall, how burdened do you feel in caring for your relative?					