

Perceived Burden of Care among Parents of Children with Sickle Cell Disease

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ABSTRACT

Background: Children affected with Sickle Cell Disease mostly depend on their parents for assistance which creates physical, emotional, social, and financial burdens among the parents. The objective of this study was to find out the level of perceived burden of care among parents of children with sickle cell disease in a hospital.

Methods: A descriptive cross-sectional research design was used with a quantitative approach. The data were collected using a structured interview schedule using the Zarit Burden Interview scale among 152 parents attending the social service unit of Bheri Hospital, Nepalgunj. A nonprobability purposive sampling technique was used. Data were analyzed using Statistical Package for Social Science (SPSS), version 20. The Chi-square test was used to measure the association between the level of burden of care and selected variables.

Results: One hundred and fifty-two parents were included in the study, among which more than half (58.6%) were fathers. More than half (52.0%) of parents perceived mild to moderate burden with a Mean \pm SD score of level of burden is 1.26 ± 0.44 . A significant statistical association was found between the level of burden of care and the relationship to the child ($p=0.002$), and the type of family ($p=0.04$).

Conclusions: The study showed that the majority of the parents' perceived a mild to moderate burden.

Keywords: Burden of care; parents; sickle cell disease; zarit burden interview

INTRODUCTION

Sickle cell disease (SCD) refers to a group of hereditary disorders, all of which are related to the presence of abnormal sickle hemoglobin (HbS).¹ SCD is more common in sub-Saharan Africa, World Health Organization (WHO) stated that approximately 5.0% of the world's population carries trait genes for hemoglobin disorders, mainly, sickle-cell disease and thalassemia; and over 3, 00, 000 babies are born with severe hemoglobin disorders each year.^{2,3} A retrospective study in Nepal reported the high prevalence of sickle cell disease in provinces 5, 6, and 7. The highest incidence rate (41.0%) for positive cases of hemoglobinopathy was found at Bheri Hospital, Nepalgunj where sickling disorder was more common (24.8%) among Tharu ethnic groups (58.3%).⁴

Caregiver burden can be defined as “the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time”.⁵ It consists of subjective and objective dimensions. Subjective burden primarily involves the personal feelings of caregivers generated while performing the caring function, while objective burden is defined as events or activities related to negative caring experiences.⁶ Parents are the first and the most important caregivers of children with SCD who suffer from various financial, family, social, mental, and psychological problems.⁷ Parents of chronically ill children experience poorer mental health (more anxiety and depression) than parents of unaffected children.⁸ Thus, the aims of the study were to assess the level of perceived burden of care among parents of children with sickle cell disease.

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METHODS

A descriptive cross-sectional study was done to find out the level of perceived burden of care among parents of children with sickle cell disease who attended the social service unit of Bheri Hospital. Bheri Hospital is the referral center for Sickle Cell Disease from all over Nepal and is located in Lumbini Province. This study setting was selected purposively. The calculated sample size using Cochran's formula⁹ was 385 assuming a 50.0% prevalence of burden of care among children with sickle cell disease, 5.0% absolute allowable error, and 95.0% confidence interval (CI). The total pediatric population registered with sickle cell disease (N) was 249. After adjusting the sample size in an infinite population using the formula; the final required sample size was 152. The parents were selected by non-probability purposive sampling technique.

The parents were enrolled in the study from the records of Bheri Hospital who were registered social service unit of Bheri Hospital, Banke district. The parents included in the study were either fathers or mothers of the SCD-affected children who had at least one child affected with Sickle Cell Disease and were providing care for at least six months to the affected children. Those parents who were known for cases of mental illness and intellectual disability and relatives other than the parents were excluded from the study. Data were collected by using the structured interview schedule and direct face-to-face interview technique. Zarit Burden Interview schedule (ZBI)¹⁰ was used to assess the burden among parents. It is a standardized validated tool developed by Zarit, Reever, and Bach-Peterson in 1980 consisting of 22-item questionnaires that assess the parent's perceptions of burdens that may inadvertently affect their health, personal, financial, and social well-being. All the items of the questionnaire possess 5-point Likert scale ranging from 0 to 4. The levels of burden as described by the Zarit Burden Interview such as little or no burden (0-21), mild to moderate burden (21 - 40), moderate to severe burden (41 - 60, and severe burden (61 - 88). The Zarit Burden Interview tool measured the burden in five domains such as burden in the relationship (Items 1,8,11,14,18,20); emotional wellbeing (Items 2,4,5,9,10,21,22); social and family life (Items 3,6,12,13); finances (Item 15) and loss of control over one's life (Items 7, 16,17,19). The content validity of the research instruments was maintained by the review of the literature and consultation with a group of experts such as pediatricians and pediatric nurses working with sickle cell disease children; psychologists and psychiatric nurses. Cronbach's alpha coefficient

for internal consistency of the Zarit Burden Interview was 0.82 in this study. Pretesting of the instrument was done in 10% of the sample size i.e., 16 parents at Bheri Hospital meeting the inclusion criteria. The parents involved in pretesting were excluded from the final study. The scale has also been used in various Nepalese research studies.^{11, 12} The Nepali version of the ZBI scale was used in the study with permission taken from Mapi Research Trust, France.

Ethical approval was obtained from the Institutional Review Committee (IRC) of the Institute of Medicine, Tribhuvan University. Written permission was taken from the administration of Bheri Hospital, Nepalgunj prior to data collection. Parents were explained the purpose of data collection and written informed consent was obtained before data collection. They were also assured about the confidentiality of the information by not sharing it with other people and the information was solely used for the purpose of research only. At the end of data collection, queries of parents related to sickle cell disease were addressed and health education was given as per their needs. Parents exhibiting moderate to severe burdens were provided with appropriate counselling by the researcher. Data was collected from 2nd February to 5th March 2021.

Data were recorded and coded and analyzed using SPSS version 20. Frequency, percentage, mean, median, and standard deviation. as used to illustrate socio-demographic characteristics and perceived care burdens. The Chi-square test was used to measure the association between the level of burden of care and selected sociodemographic characteristics of parents.

RESULTS

A total of 152 parents having at least a child with SCD and providing care for at least six months to the affected children were enrolled in the study. The socio-demographic characteristics of the 152 parents who participated in the study and their children with SCD are shown in Table 1.

Table 1. Socio-demographic characteristics of parents and children (n=152).

Characteristics	Number	Percent
Age of parents in completed years		
>40	77	50.7
≤40	75	49.3
Mean±SD=41.57±8.12 years		
Relationship to child		

Father	89	58.6
Mother	63	41.4
Ethnicity		
Tharu	151	99.3
Brahmin/Chhetri	1	0.7
Educational status		
Not able to read and write	57	37.5
Informal education	18	11.8
Basic level (8 grades)	44	28.9
Secondary level (9-12 grades)	29	19.1
Higher education (Bachelors and above)	4	2.6
Occupation of parents		
Farming	96	63.1
Labor	34	22.4
Business	15	9.9
Type of family		
Nuclear	81	53.3
Joint	71	46.7
Age of children in completed years		
15-19	110	72.4
10-14	27	17.8
5-9	14	9.2
≤ 4	1	0.7
Mean± S.D.= 15.78±3.78 years		
Sex of children		
Male	88	57.9
Female	64	42.1

Regarding the clinical profile of the children with SC, most of the children (77.1%) were hospitalized at least five times, and among them, the majority (78.4%) had received blood transfusions for up to 4 pints due to SCD (Table 2).

Table 2. Disease related characteristics of children with sickle cell disease (n=152).

Variables	Number	Percent
Duration of disease		
≤ 3 years	93	61.2
> 3 years	59	38.8
Median=3 (Q1=2, Q3=4)		
Hospitalization due to SCD		
Yes	96	63.1
No	56	36.8

Frequency of hospitalizations (n=96)

≤ 5 times	74	77.1
> 5 times	22	22.9

Median=2 (Q1=1, Q3=5)

Blood Transfusions done due to SCD

Yes	74	48.6
No	78	51.3

Number of blood Transfusions (n= 74)

≤ 4 pints	58	78.4
> 4 pints	16	21.6

Median=2 (Q1=1, Q3=4)

Regarding the burden of care, more than half (52.0%) of the parents perceived mild to moderate burden (Mean±S.D.= 1.26 ± 0.44) and 2.6% had severe burden while caring for their child with sickle cell disease (Table 3).

Table 3. Perceived level of burden among respondents (n =152).

Level of burden	Number	Percent	Mean ± SD
Little or No burden (0-20)	13	8.6	1.26 ± 0.44
Mild to Moderate burden (21-40)	79	52	
Moderate to Severe burden (41-60)	56	36.8	
Severe burden (61-88)	4	2.6	

more than half (52.0%) of parents nearly always felt that they should be doing more for their child and about half (48.7%) of parents nearly always felt that they could do a better job in caring for their child. Likewise, again nearly half (48.0%) of parents were always afraid regarding the future of their child in this study (Table 4).

Table 4. Top 5 items contributing to parent's burden ranked in descending order of ZBI (n=152).

ZBI Items	NA No. (%)	Mean ±S.D.
Do you feel you should be doing more for child	79 (52.0)	3.11 ±1.10
Do you feel you could do a better job in caring for your child	74 (48.7)	3 ±1.15
Are you afraid of what future holds for your child	73 (48.0)	3.02 ±1.21
Do you feel uncertain about what to do about your child	64 (42.1)	2.79 ±1.37
Do you feel that you don't have enough money to take care of your child, in addition to the rest of your responses	39 (25.7)	2.74± 1.07

A significant statistical association was found between the level of burden of care and relationship to child ($p=0.002$) and type of family ($p= 0.04$) as shown in Table 5.

Table 5. Association between perceived level of burden and socio-demographic characteristics of parents (n=152).

Character-istics	Level of burden		Chi-square value	p-value
	Little to moderate burden No. (%)	Moderate to severe burden no. (%)		
Age of parent (in years)				
≤40	44 (58.7)	31 (41.3)	0.21	0.64
41 and above	48 (62.3)	29 (37.7)		
Relation to Child				
Father	63 (70.8)	26 (29.2)		
Mother	29 (46.0)	34 (54.0)	9.46	0.002*
Education				
Literate	60 (63.2)	35 (36.8)		
Illiterate	32 (56.1)	25 (43.9)	0.73	0.39
Type of Family				
Nuclear	55 (67.9)	26 (32.1)	3.94	0.04*
Joint	37 (52.1)	34 (47.9)		
Occupation				
Farming	58 (63.0)	34 (37.0)	0.61	0.43
Others	34 (56.7)	26 (43.3)		

*Level of significance $p<0.05$

DISCUSSION

Regarding the level of burden, the present study revealed that more than half (52.0%) of parents perceived mild to moderate burden. This finding is found to be similar to the findings of the study done in Jamaica where the overall mean burden score was 27.2 indicating mild to moderate burden.¹³ However, the findings of this study were higher than the findings of a similar study done in Grenada where 53.8% of parents perceived no to little burden.¹⁴ This variation might be due to the cultural differences and socioeconomic characteristics of the study population, sample size, and place variation.

Regarding the financial burden, more than one-third (37.5%) of parents frequently and less than one-third (25.7%) of parents nearly always experienced financial burden in this study which is consistent with the findings of the study done in Jamaica where a majority

(73.0%) indicated that they often did not have enough money to care for the child.¹³ Similar findings were also reported in another study done in Lagos, Nigeria where above half (53.0%) of the parents had to take loans to meet the hospital expenditure of SCD, thus creating a significant impact on the financial status of the family.¹⁵ Likewise, findings are also similar to other studies done in Southwest, Nigeria showing parents often spent 0.38% to 34.4% of their family income on the treatment of their child with sickle cell disease and thus creating a significant financial burden in the households with SCD.¹⁶ Similarly, the findings are also consistent with the findings of a study done in Nigeria which showed financial stress was evident in 58.2% of the families,¹⁷ and in Kenya showing over half (52%) of caregivers facing financial hardships.¹⁸

Regarding burden in the family and social life, in this study, nearly half (45.4%) of parents never felt that their relationships with family members and friends were affected in a negative way while caring for their child, and only (38.8%) rarely felt that their social life has suffered because of caring for their child. These findings were inconsistent with the findings in other similar studies done in Iraq where a majority (66.9%) of the caregivers had not enough time for other family members when caring for their sick child and 43.8% of the caregivers experienced occasional disagreement among family members.¹⁹ These findings were also found to contrast with the findings of a study done in Lushaka which showed the majority (98%) of the parents indicated that living with a child affected with SCD affected the interrelationship within the home environment as well as with other people outside the home.²⁰ The findings of this study were also dissimilar to the findings of the study done in Cameroon which reported majority (56.3%) of caregivers have difficulty living with SCD-affected children.²¹ This difference might be due to the availability of social support, cultural differences, and awareness about SCD among parents in Nepal.

Regarding the emotional well-being of the parents, this study showed the majority (66.5%) of parents felt of doing a better job in caring for their child and more than one-third (40.8%) of the parents felt strained. This finding was similar to the findings of a study done in Nigeria where 43.8% of the parents had emotional distress.²² The emotion dimension was also found to be most affected in another study done in Saudi Arabia (median [75th centile])=44.44 [66.67]) making it consistent with the findings of this study.²³

Regarding loss of control over the life domain, the findings of this study showed most (72.3%) of the parents

were afraid about the future of their child with Mean \pm S. D. (3.02 \pm 1.21). This study also showed nearly half (45.4%) of the parents never felt being unable to take care of their child longer with Mean \pm S.D. (0.95 \pm 1.02) and the majority (53.3%) of the parents never felt the loss of control over the life due to child's illness with Mean \pm S.D (0.80 \pm 0.94). This was found to be consistent with the findings of the study done in Jamaica where caregivers being afraid about the future of their child had a mean score of 2.2 indicating a high burden, while, caregivers' feeling of being unable to take care of their child longer had mean score 0.4 and caregivers' feeling of loss of control over life due to child's illness was 0.5, respectively indicating less burden.⁸

The study was conducted in only one hospital and a non-probability sampling technique was used so the findings of the study cannot be generalized to the larger population.

CONCLUSIONS

More than half of the parents have perceived a mild to moderate burden while caring for their child with SCD. Most of the parents perceived a burden emotionally and financially. This study also showed that the level of burden was associated with the relationship of parents to their child and the type of family.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

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