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The Burden and Perceived Stress on Family Caregivers of Patients With Orofacial Cleft Deformities in The Perioperative Period of Cleft Repair

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Abstract

Different stages along the trajectory of cleft care may present with different and peculiar challenges that may negatively impact family caregivers, leading to considerable stress and burden. This study aims to evaluate the family caregiver burden and perceived stress of caring for patients with cleft deformities. Contributing factors to family caregivers' burden in the perioperative period of cleft repair was also identified. A cross-sectional design that included 90 adult caregiver–patient pairs was employed. Semi-structured questionnaire was used to collect necessary information. The level of caregiver's burden was assessed using the Zarit burden interview score. The results demonstrated the levels of caregiver burden as severe (4.4%), moderate to severe (21.1%), mild to moderate (40%), and little or none (34.5%). The only significant and independent predictor of caregiver burden was earning less than US$50/month (odds ratio = 2.30, 95% CI = 0.95-5.61, $P = .066$). Coping strategy was mainly family support (98.9%), while the greatest need expressed was financial assistance (66.7%). Our findings suggests that efforts geared at reducing direct and indirect cost of cleft care may help in reducing caregivers' burden.

Keywords

orofacial cleft, caregivers, burden, perceived stress, perioperative period, cleft repair

Introduction

Orofacial clefts (OFC) are congenital deformities that can be seen, felt, and heard (1), with significant impact on function and aesthetics. Most family caregivers of patients with OFC have to cope with the emotional stress of a child or relative with deformity or disability and learn to support varying degree of functional disability and aesthetic challenge of the patient (2,3). They also regularly need to spend time to accompany the patient for treatments, support the patient physically, emotionally, spiritually, and financially (2-4). In many occasions, the caregiving demands, which often comes suddenly, may exceed available resources, thereby putting the caregiver under varying degrees of stress and burden (2). A family caregiver is a family member that lives with the patients and is closely involved in their activities of daily living, health care, and relates socially with them (5).

The concept of burden however involves 2 different domains, the objective and subjective aspects (6). The objective aspect has to do with concrete demands like activities of daily living such as feeding which to different extent is adversely affected by most types of clefts, while the subjective aspect has to do with emotions like feelings, concerns with the present and future of patient (6). The interplay between the objective and subjective aspects of the burden eventually determines the effect and the eventual psychological reactions by the caregiver. Those with positive feelings

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who report more benefit and meaning from the caregiving experience usually feel less burdened, while others with a contrary appraisal of a similar experience may feel more burdened and stressed (7–9).

Previous studies have shown caregiver burden to be affected by a complex interplay of factors (9–11). For those having surgical repair of the cleft, the perioperative period may further modify the caregiving experience either positively or negatively. The expectations and uncertainties of the outcome of surgery on restoration of form and function, possible complications of surgery as well as the additional demand of caregiving during the perioperative period are possible factors capable of modifying the objective and subjective aspects of caregiving experience (12). Ethnicity, cultural norms, and practices also influence to a large extent the subjective domain of caregiving (10–13).

Each stage of cleft care may be associated with specific issues that aggravate the burden or the perceived stress by the family caregivers. It is therefore paramount to identify the dynamics of the burden and stress as it pertains to specific aspects of cleft care, so as to design effective interventions that ensure family caregivers continue to perform their role effectively and are compliant with the treatment protocols without jeopardizing their own health and the outcomes of care.

Caregiving is best studied within a specified disease cluster or category and situation since each cluster or situation usually engages unique problems (4). There is still a dearth of knowledge of the enormity of caring for a child with cleft lip and palate (CL/P) and the effects on the family caregiver (14). This study therefore sets out to assess the burden and perceived stress of family caregivers of patients with OFC during the perioperative period of cleft repair in a suburban health facility.

Method

Study Design and Location

This descriptive, cross-sectional, hospital-based study was carried out between October 2017 and October 2019 at the cleft unit of Sacred Heart Hospital, Lantoro, Abeokuta, southwest Nigeria.

Study Population

The study population consisted of patients with cleft deformities and their adult (18 years and above) family caregivers. These family caregivers provided unpaid care for patients with OFC deformities during the perioperative period of cleft repair surgery.

Inclusion Criteria

Included were adult family caregivers who rendered care without any form of payment and were responsible for care on a daily basis and who consented to participating in the study.

Exclusion Criteria

Excluded were family caregivers of patients with comorbidities that needed special care like those with associated neurological deficit.

Sample Size Calculation

The minimum sample size of 80 was calculated using an appropriate statistical formula for descriptive health studies ($n = Z^2pq/d^2$) with 7% of family caregivers having severe caregivers' burden and nonresponders taken into consideration (15).

Data Collection

A semi-structured questionnaire designed for the purpose was used to collect relevant data to assess the background characteristics of patients and family caregivers. Information collected from patients were age, gender, diagnosis, presence of aesthetic or functional impairment, educational level, length of hospital admission, and type of surgical treatment received. Data collected from family caregivers were the sociodemographics, family setting, relationship to patient, number of children, duration of caregiving, coping strategies, caregiver need, the time spent with patient per day, and coping with job during the period of caregiving. Also, information on income was collected from the caregivers and then classified using the Nigerian minimum wage of 18 000 Naira, which was approximately US$50US per month at the beginning of the study. The caregivers earning less than the Nigerian minimum wage were classified as low income earners.

The level of caregiver's burden was assessed using the Zarit burden interview score (16). The Zarit burden index is widely accepted as a reliable and valid scale for measuring caregivers' burden and has been used extensively. The index is a 22-item index with scores ranging from 0 to 88, and the score grow proportional to the severity of the burden perceived by the caregiver. The score is interpreted as little or no burden 0 to 21, mild to moderate burden 21 to 40, moderate to severe burden 41 to 60, and severe burden 61 to 88. Scores of 0 to 21 are taken as low burden and above 21 as high burden. It is unique as it measures various aspects of caregivers' burden, such as caregivers' health, psychological well-being, finances, social life, and the relationship between the caregiver and the patient. This scale is highly reliable as it has 0.91 internal consistency and 0.71 test–retest reliability (16).

Data Analysis

Data were entered into the computer and analyzed using the Statistical Package for Social Sciences (SPSS 21.0;

Table 1. Sociodemographic Characteristics of the Primary Caregivers of Cleft Patients.

Variable	Frequency	%
Primary caregivers		
Father	4	4.4
Mother	84	93.4
Grand father	1	1.1
Grand mother	1	1.1
Age group (years)		
18-29	42	46.7
30-39	37	41.1
40 and above	11	12.2
Gender of the primary caregivers		
Male	5	5.6
Female	85	94.4
Level of education of the primary caregivers		
None	9	10.0
Primary	20	22.2
Secondary	29	32.2
Tertiary	32	35.6
Occupation of the primary caregivers		
None	6	6.7
Trading	42	46.7
Civil servant	19	21.1
Artisan	23	25.5
Religion of the primary caregivers		
Christianity	57	63.3
Islam	33	36.7
Monthly income (Naira) of the primary caregivers		
<18000 Naira (US$50)	55	61.1
≥18000 Naira (US$50)	35	38.9

Microsoft Inc., 2016) to present descriptive and inferential statistics. Descriptive statistics were presented with frequencies, proportions, mean, and SD. χ^2 test was used to test associations between primary caregiver characteristics and burden experienced. Logistics regression analysis was performed to evaluate sociodemographic variables and other variables that are independently associated with the caregivers' burden. Odds ratio (OR) and 95% CI were presented for measures of the strength of association. Variables achieving a P value of $< .05$ was considered statistically significant.

Results

A total of 90 caregiver–patient pairs were included in the study. The primary caregivers' mean age was 32.4 (SD, 7.0) years (range 18-60). The primary caregivers were mostly the mothers (93.4%), traders (46.7%), Christians (63.3%), had tertiary education (35.6%), and earned less than US$50 per month (61.1%; Table 1).

Table 2 shows the sociodemographics, diagnosis, admission, clinical conditions, and surgical treatment of the cleft patients. Most cleft patients were less than 12 months old (57.8%; range 1-252 months; mean age 23.6 [SD 41.5] months), females (63.3%), and from monogamous family setting (87.8%). Feeding and aesthetic problems (46.7%) were the commonest type of disability. All the patients had primary repair surgery with cheiloplasty (72.2%) being the commonest type of surgery performed on them. None of the patients had revision surgery.

Table 2. Sociodemographics, Diagnosis, Admission and Clinical Conditions of Cleft Patients.

Variable	Frequency	%
Age group (months)		
<12	52	57.8
12 and above	38	42.2
Gender		
Male	33	36.7
Female	57	63.3
Level of education		
None	77	85.6
Primary	10	11.1
Secondary	3	3.3
Family setting		
Monogamous	79	87.8
Polygamous	11	12.2
Diagnosis		
Unilateral cleft lip	29	32.2
Isolated cleft palate	25	27.8
Unilateral cleft lip and palate	22	24.4
Bilateral cleft lip and palate	8	8.9
Bilateral cleft lip	3	3.3
Tessier 7 cleft	3	3.3
Type of disability		
Feeding and aesthetic problems	42	46.7
Aesthetic problems	23	25.6
Speech problems	13	14.4
Feeding problems	12	13.3
Treatment received		
Surgery	90	100
Type of surgical procedure		
Cheiloplasty	65	72.2
Palatoplasty	25	27.8
Hospital Admission		
Yes	90	100
Duration of admission (days)		
≤4	54	60
>4	36	40

Table 3 reported caregiving burden, needs, and coping strategies. Caregiver burden shows that 4.4% experienced severe burden while 21.1% experienced moderate to severe burden. Financial support (66.7%) was the major caregiver need with family support (98.9%) as the coping strategy.

Table 4 shows the factors associated with caregiver burden among cleft patients. Caregiver age, level of education, and employment status were not significantly associated with caregiver burden (with $P = .26$, $P = .639$, $P = 1.00$, respectively). Likewise, no statistical significance was found when caregiver burden was associated with cleft patient's variables: age ($P = .682$), gender ($P = .452$), duration of admission ($P = .659$), type of cleft ($P = .355$), type of disability ($P = .497$), and type of surgery performed ($P = .492$). The only statistically significant factor responsible for higher caregiver burden was earning less than US$50 ($P = .066$).

The employment status of caregivers, type of disability, and type of surgery performed on the cleft patients did not show any statistical significant relationship with caregiver burden. The only significant and independent predictor of caregiver burden was earning less than US$50/month (OR = 2.30, 95% CI = 0.95-5.61, $P = .066$).

Table 3. Caregiving Burden, Needs, and Coping Strategies of Caregivers of Cleft Patients.

Variable	Frequency	%
Caregiving burden		
Severe	4	4.4
Moderate to severe	19	21.1
Mild to moderate	36	40.0
Little or none	31	34.5
Caregiver needs		
Financial support	60	66.7
Clothing	4	4.4
Societal acceptance	4	4.4
Job	2	2.2
Friendly crèche service	1	1.1
Food	1	1.1
Money and clothing	1	1.1
None	17	18.9
Effect of caregiving		
Stopped working	36	39.6
Get tired	17	18.7
On leave of absence	6	6.6
None	31	35.1
[a]Coping strategy		
Family support	90	98.9
Self-encouragement	35	38.5
Prayer	34	37.4
Discuss challenges with other caregivers	13	14.3
Substance use (alcohol/smoking)	12	13.2
Self-medication (analgesics)	11	12.1

[a] Multiple response.

Discussion

This study has demonstrated that the overall caregiver burden among family caregivers of cleft patients was mainly moderate with about 34.5% experiencing little or no burden, 40% experiencing mild to moderate burden, while 21.1% had experienced moderate to severe burden, and only 4.4% had experienced severe burden. A similar study earlier carried out in Brazil also reported a similar finding in which 57% of family caregivers did not show any evidence of burden while only 7% experienced severe burden (15). This similar finding may be due to the similarity in African and Brazilian family structure as well as similar supports received for cleft care from different agencies and organizations like smile train that support free cleft surgeries globally.

A number of previously documented studies have looked at the burden of caregiving on the family caregivers of cleft patients and have shown inconsistent results which varied

Table 4. Logistic Regression Analysis of Factors Associated With Caregiver Burden Among Caregivers of Cleft Patients.

	Caregiver burden			
Variable	Low (%)	High (%)	Test statistics, χ^2, P value	OR, 95% CI, P value
Caregiver age (years)				
18-29 (Ref.)	17 (40.5)	25 (59.5)	1.269, 0.260	1
≥30	14 (28.6)	34 (71.4)		1.70, 0.71-4.07, 0.234
Caregiver education				
None/primary	9 (30)	20 (70)	0.220, 0.639	1.32, 0.51-3.37, 0.567
Secondary/tertiary (Ref.)	22 (36.1)	39 (63.9)		1
Income (Naira)				
<18000 (US$50)	15 (26.8)	40 (73.2)	3.221, 0.073	2.30, 0.95-5.61, 0.066
≥18000 (US$50) (Ref.)	16 (45.7)	19 (54.3)		1
Age of cleft patient (months)				
<12	17 (32.1)	35 (67.9)	0.167, 0.682	1.24, 0.52-2.97, 0.636
≥12 (Ref.)	14 (36.8)	24 (63.2)		1
Gender of cleft patient				
Male	13 (39.4)	20 (60.6)	0.565, 0.452	0.69, 0.28-1.69, 0.419
Female (Ref.)	18 (31)	39 (69)		1
Duration of admission (days)				
≤4	4 (40)	6 (60)	0.154, 0.659	0.75, 0.20-2.88, 0.675
>4 (Ref.)	27 (33.3)	53 (66.7)		1
Type of surgery				
Cheiloplasty	21 (32.3)	44 (67.7)	0.473, 0.492	1.40, 0.54-3.63, 0.492
Palatoplasty (Ref.)	10 (40)	15 (60)		1

Abbreviation: OR, odds ratio.

between no burden and low burden (14,17,18). Several reasons may account for the noted discrepancies and these may include methodology, period in the cleft care trajectory, instrument used for assessment of burden and perceived stress, setting of patient, and whether home, hospital inpatient, perioperative period or outpatient, as well as age of the patient.

In the methodology, while some authors have looked mainly at the objective domain, other authors have looked at both the objective and subjective domain, and expression of stress and burden is a complex interplay of factors involving these 2 domains. Both the objective and subjective domains were assessed in the present study.

The different periods in cleft care, such as before or after surgery and settings of care such as home or hospital admission, may present different challenges to the caregivers and as previously hypothesized; care burden may differ along the care trajectory (19), and this was reflected in the study of Emeka et al that reported significant difference in the quality of life of family caregivers before and after cleft repair (20). The present study was carried out among family caregivers of cleft patients in the perioperative period, and this period may be associated with peculiar subjective and objective demands. The demand and care for surgical patients, the psychological impact, expectations and anxieties associated with repair of cleft under general anesthesia, as well as increase in financial and care demands. Family caregivers have to be in the hospital, with disruptions in their daily routines, responsibilities have to be reprioritized, there may be more involvement in nursing care, and other activities which are sometimes more complex than they are used to, all which may negatively affect the family caregivers. However, despite the presence of all these stressors, the pleasure and joy derived from caring for and being able to relieve the challenges of a loved one as well as the hope that the condition is about to be remedied and problem-solved generally gives the family caregivers a better appraisal making them express little or no burden. This may explain the moderate level of burden reported in the majority of the family caregivers in our study which is in agreement with the findings in a similar study (15).

When compared to other caregiving for patients with other chronic conditions, cleft caregivers appear to be associated with lower burden, and this may be attributable to the severity of the condition and its demand on the family caregivers (21,22). Cleft is a condition which although affects form and function, it rather is less functionally disabling, has excellent outcomes and better prognosis with treatment, and less care demand on the family caregivers compared to some other neurological and more debilitating conditions (12).

In the present study, majority of the family caregivers were the mothers, in consonant with previously documented studies (23,24). Mothers are known to have strong emotional bond to their babies and derive joy in doing anything to be able to give the best possible care for the babies (12). Previous studies have also reported women to take responsibility for most physical tasks related to caring for children's health and spend more time caring for the child in comparison with men (25,26).

Higher education levels have been reported to be associated with lower caregiving burden in previous reports (27,28); however, we found no correlation between family caregiver's education level and burden among our study participants in agreement with the study of Pegah et al. Education is expected to be an important ability capable of positively affecting the perception of family caregivers of stressful factors and promote their problem-solving ability and mental flexibility, which results in better handling and positive appraisal of stressful situations (23,28). A plausible explanation for our finding is that the enlightenment and educational aspect of cleft care by the cleft team arms the family caregivers with necessary information to empower them to handle effectively all the required aspects of the cleft care with positive appraisal of the situations irrespective of educational level.

Most of our patients were less than 12 months with majority having cheiloplasty. This is in agreement with the findings of Gbolahan et al that reported the commonest reason for seeking treatment by caregivers of cleft patients to be the obvious cosmetic challenge (29), and at this age, majority were likely having primary lip repair. In terms of perioperative care, the demand for CP tends to be more than for CL as related to diet and wound care; in addition, the less visible change associated with palatoplasty may not be well appreciated by the caregivers. Despite these, this study failed to demonstrate any significant association of age and type of cleft repair with caregiver burden. We feel this may have been due to the short period involved in the perioperative cleft care. The caregiver burden varies with different periods of cleft care, and this short perioperative period has its peculiarities including anxiety of surgery, expectations, and joy of having the cleft problem solved, which possibly allows for positive appraisal that will overshadow any form of stress associated with this period of cleft care.

The only factor that was statistically associated with caregivers' burden in the present study is low earning in agreement with the study of Canning et al that reported lower family income as a predictor of caregiver distress independent of other variables (22). Although the cleft surgeries for the patients in this study were done free of fees; however, transportation, accommodation, and feeding expenses were the responsibility of the family caregivers. As opined by Canning et al, family caregivers of chronically ill children may be particularly vulnerable to fluctuations in economic resources due to variations in direct and indirect costs associated with treatment (22). This is likely more pronounced in a society like our own where there is high level of poverty among the majority of the populace (29).

Many previous studies have reported gainful employment to be associated with overall caregiver stress, and this has been attributed to the ways family caregivers have to negotiate between caregiving and the employers and other responsibilities (30). The present study, however, did not demonstrate any significant relationship between employment and caregiver stress. The fact that the majority of the family caregivers in our study were either artisans or engaged in a form of personal trade may mean that they do not need to seek for permission from any employer to care for their loved ones. In addition, the short period of hospitalization (4-7days) and elective nature of cleft surgery could allow for a measure of flexibility and scheduling that suit the family caregivers' time in such a way that it will not significantly affect their occupation. This explains the lower burden noted in comparison to conditions that might necessitate more prolonged period of care during the treatment period (21).

Coping strategies play a role in modulating the psychological impact of stressful events and published report have shown that the way family caregivers cope with their child's condition affects their stress level (31). Coping strategies can be problem-focused or emotion-focused (32). The finding from the present study revealed that all participants employed diverse emotion-focused coping strategies at variance with the finding in the study of Sischo et al that reported the family caregivers to have employed both problem-focused and emotion-focused coping strategies (31). Most of the family caregivers in the study of Sischo et al, used problem-focused coping strategies by learning about cleft and cleft treatment through sources like the internet and cleft team (31). The study of Sischo et al was carried out in the United States where majority of the citizens are educated (relative to our setting) and have access to health care facilities, different resources, and information unlike our own study in a suburban region in Nigeria where level of education is comparably lower and access to resources and information is poor.

The coping strategies in our study was mainly family support, followed by self-encouragement, spiritual supports like prayers, discussing, and comparing "notes" with other family caregivers of cleft patients. In the study of Sischo et al, emotion-focused coping strategies documented included social support like having discussions with cleft team and other caregivers and self-encouragement (31). The pattern of the coping strategies in this study appears to be a reflection of the cultural beliefs and the level of spirituality of the society where the study was carried out. Family ties and communal living play a strong role in the culture, and the level of spirituality is high which are the areas commonly explored during challenging times to find "succor" or "solution to the challenges." A previous study from the same environment also reported spirituality as the main coping strategy for family caregivers (5).

The greatest need expressed by the family caregivers was financial support. This is not surprising as the majority of the family caregivers in our study earned less than the recommended minimum wage in Nigeria, and caring for chronically ill children puts a lot of financial burden on the family caregivers (22).

Study Limitation

This study was limited by being self-reported, having a cross-sectional design, and from a hospital. These make the study findings prone to bias; however, efforts were made by the researchers to explain the study purpose to the study participants.

Conclusion

Family caregivers of cleft patients have low to moderate level of burden during the perioperative cleft repair period. The only factor that was significantly associated with burden in this study was low earnings. Emotion-focused coping strategies were adopted by all the caregivers while the greatest need expressed by the caregivers was financial support. Since burden is capable of affecting the health and performance of caregivers, this may lead to disruption in compliance with the planned protocol of cleft care pathway and ultimately outcome of management may be suboptimal.

Caregivers form a major part of the cleft team; therefore, in order to have a better and improved outcome of cleft care, there is need for a care plan that will address the need of both care partners. Improving access to health facilities for cleft care by way of use of outpost or other facilities situated closer to the community where cleft surgeries can be safely carried out will reduce some indirect costs and financial burdens on the caregivers. The information that the local community can easily access about cleft and its management may help in the use of problem-solving coping strategies to which the caregivers will have a better appraisal, more adequately prepared and more involved in the management of cleft. Need for the decision makers to look for ways of improving the socioeconomic status of the suburban and rural populace in terms of improving earnings and better access to resources and information like ease of access to the internet.

Authors' Note

Ethical approval for this study was obtained from the hospital ethics committee and informed consent obtained from the caregivers of the cleft patients.

Declaration of Conflicting Interests

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