

Burdens and predictors of the Burden experienced by Family Caregivers of Patients with Oral and Maxillofacial Tumours

Abstract

Aim: There is a dearth of knowledge on the burden of family caregivers of patients with maxillofacial tumours in Nigeria. This burden may be influenced by racial peculiarities and the disease entity of the patient. The aim of this study is to assess and document the burdens and predictors of burdens experienced by family caregivers of patients with oral maxillofacial tumours presenting at a tertiary health facility in South Western Nigeria. **Materials and Methods:** A descriptive cross-sectional study that included 110 consenting family caregivers of patients diagnosed with oral and maxillofacial tumours. A semi-structured questionnaire was used to collect information on their sociodemographic characteristics and caregiving burden using the Zarit burden interview tool. Data were analysed using descriptive and inferential statistics with Statistical Package for Social Sciences version 21.0. **Result:** The most frequent group of caregivers was patients' children (32.0%), aged 30–39 years (28.2%), females (54.5%), with secondary education (41.8%), and traders (38.2%), who earned less than national minimum wage (55.5%). Majority (42.7%) experienced mild-to-moderate burden; coping strategy was mainly prayers (76.4%), while the greatest need expressed was financial assistance (93.6%). The significant predictors of caregiver burden were the presence of pain (adjusted odds ratio [AOR] = 2.961; 95% confidence interval [CI] = 1.165–7.526; $P = 0.023$) and severe clinical condition (AOR = 3.342; 95% CI = 1.133–9.853; $P = 0.029$). **Conclusion:** The most common category of the burden of family caregivers of patients with maxillofacial tumours was the mild-to-moderate category, and the most significant predictors were the presence of pain and severity of clinical condition. The greatest need expressed was financial assistance. Therefore, an emphasis on adequate pain control and alternate sources of funding may appreciably relieve the burden of family caregivers of patients with maxillofacial tumours.

Keywords: Burden, caregivers, maxillofacial, predictors of burden, tumours

Introduction

Chronic and disabling conditions can affect the daily functions of patients to varying degrees, and most of them may eventually require the assistance of a family caregiver. Caring for an ill family member can be a source of burden both physically and emotionally as the care can pose lifestyle restrictions for the family caregiver, depending on the degree of the patient's incapacitation. The peculiarity of maxillofacial tumours is such that they occur in a rather conspicuous region and, by virtue of their site, may affect essential life-sustaining functions such as breathing and eating. Therefore, the patient's social interaction and daily functions can be immediately threatened by the presence of these tumours, and reliance on family and friends may become pertinent. Factors that can affect the degree of burden on a caregiver include the disease type and burden of the disease on the patient, ethnicity,

religion, gender, age, and socioeconomic factors.^[1,2] Even among a disease cluster, factors such as the region of body affected and degree of functional and aesthetic disability can further modify the burden. Drentea^[3] opined that caregiving is best studied within a certain disease cluster or category because each cluster will bring about specific issues surrounding the cluster of the problem.^[3]

Oral and maxillofacial tumours may result in functional challenges such as pain, difficulty with swallowing, and mastication, which may lead to the alteration in frequency and duration of eating as well as altered or restricted diet.^[4] In order to ensure adequate nutritional needs, enteral feeding via orogastric, nasogastric, or gastrostomy tube or even hyperalimentation may have to be introduced.^[5] There may be long enduring pain from the tumour or the side effect of the treatment. Speech and aesthetics may also be affected with devastating impact in terms of psychosocial

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functioning and job.^[6] Patients with oral and maxillofacial tumours may have to undergo various treatment modalities with possible prolonged treatment periods, side effects, and complications. Some may even experience recurrence within a short interval of treatment, and sometimes there is a need for multiple or repeated surgeries.^[7,8] During advanced stages of illness, some patients may become debilitated with the impairment of activities of daily living. Additional supports are often provided by relatives and friends who see it as a part of their responsibilities to the patient. These caregivers who render assistance and support to family members or acquaintances who have physical or psychological needs are referred to as family caregivers.^[3] Family caregivers have been shown to form the foundation of the healthcare system in some countries especially in long-term service and support system where they also function to support advances in patient management.^[9,10]

Growing body of research on tumour care has shown that caregivers of patients with tumours undergo varying degrees of silent suffering.^[11,12] Most caregivers of patients with oral and maxillofacial tumours have to cope with emotional stress of diagnosis and prognosis. They have to invest time and energy, learn to support varying degree of functional disability of the patient, spend time to accompany the patient for treatments at health facilities, support the patient physically, emotionally, spiritually, and financially, albeit with no previous training in caregiving. Most times, the caregiving demands, which may come suddenly and they are least prepared for, may exceed available resources of the caregiver and lead to stressful situations.^[13] Data documenting the impact of oral and maxillofacial tumours on family caregivers in the Nigerian context are still very limited. This study aims to assess the burden of caregivers of patients with oral and maxillofacial tumours presenting for the treatment in a tertiary health facility in South Western Nigeria.

Materials and Methods

The study was approved as a descriptive, cross-sectional, hospital-based design by the institutional Ethical Review Committee with ethical approval number UI/EC/17/0272. Eligible subjects were consecutive consenting adult (18 years and above) and informal primary caregivers (family members or friends) that accompanied patients diagnosed with tumours of the oral and maxillofacial region to the Department of Oral and Maxillofacial Surgery for management. The inclusion criteria were willingness of the patient and caregiver to participate in the study and the ability to understand the instrument that was used for the measurement of burden. Those that did not consent were excluded from the study.

Sample size calculation

The minimum sample size of 110 was calculated using an appropriate statistical formula for descriptive health studies, $n = Z^2pq/d^2$ with the use of 92.5% of caregivers of oral cancer patients that had caregiver burden from a previous study.^[12]

Data collection tools and technique

A semi-structured questionnaire designed for the purpose was used to collect relevant data to assess the background characteristics of patients and caregivers. Data collected from patients include: age, gender, diagnosis, the presence of aesthetic and/or functional impairment, clinical condition, educational level, and the length of hospital admission. Data on the sociodemographics, family setting, relationship to patient, number of children, duration of caregiving, coping strategies, caregiver need, time spent with patient per day, and coping with job during the period of caregiving were obtained from the caregivers.

The level of caregiver's burden was assessed using the Zarit burden interview score. The Zarit burden index is widely accepted as a reliable and valid scale for measuring caregivers' burden and has been used extensively. Previous studies in Nigeria have validated the Zarit burden index.^[14,15] The index is a 22-item index with scores ranging from 0 to 88. The score is interpreted as little or no burden: 0–20, mild-to-moderate burden: 21–40, moderate-to-severe burden: 41–60, and severe burden: 61–88. 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 documented by 0.91 internal consistency and 0.71 test-retest reliability.^[16] Clinical conditions were classified as "severe" for malignant tumours and "not severe" for benign tumours.

Data analysis

The data obtained were manually cleaned and recoded. Data were entered into the computer and analysed using the Statistical Package for Social Sciences (SPSS 21.0 Microsoft Inc., 2016). Simple descriptive and inferential statistics were carried out. Descriptive statistics were presented as frequencies, proportions, mean, and standard deviations. Bivariate chi-square test was used to test associations between sociodemographic characteristics, other variables, and burden experienced. The criterion for the inclusion of variables in the logistics regression model was a $P < 0.2$ in the bivariate analysis. Odd ratio and 95% confidence interval (CI) were presented and used as measures of the strength of association. Variables achieving a $P < 0.05$ were considered statistically significant.

Results

A total of 110 primary caregiver–oral and maxillofacial surgical patient pairs were recruited into the study. The mean age of the patients was 44.3 (± 19.4) years ranging from 10 to 85 years. Majority were 60 years and above (23.6%), males (51.8%), had secondary education (40.0%), monogamous (73.6%), residents outside Ibadan (56.4%), unemployed (39.1%), and Christians (63.6%). The mean age of the caregivers was 42.2 (± 12.9) years ranging from 20 to 68 years.

Most of the caregivers were aged 30–39 years (28.2%), females (54.5%), with secondary education (41.8%), traders (38.2%),

Table 1: Distribution of sociodemographic variables among maxillofacial patients and caregivers

Variable	Patients		Caregivers	
	Frequency (N = 110)	%	Frequency (N = 110)	%
Age group (years)				
10–19	12	10.9	-	-
20–29	17	15.5	24	21.8
30–39	18	16.4	31	28.2
40–49	23	20.9	28	25.5
50–59	14	12.7	13	11.8
≥60	26	23.6	14	12.7
Sex				
Male	57	51.8	50	45.5
Female	53	48.2	60	54.5
Level of education				
None	9	8.2	8	7.3
Primary	22	20.0	11	10.0
Secondary	44	40.0	46	41.8
Tertiary	35	31.8	45	40.9
Occupation				
None	43	39.1	17	15.5
Trader	27	24.5	42	38.2
Artisan	23	20.9	21	19.1
Civil servant	17	15.5	30	27.3

Table 2: Care variables of maxillofacial patients

Variable	Patients	
	Frequency (N = 110)	%
Hospital admission		
Yes	64	58.2
No	46	41.8
Length of admission (days) (n = 64)		
1–7	30	46.9
>7	34	53.1
Patient's clinical condition		
Severe	40	36.4
Not severe	70	63.6
Presence of pain		
Yes	62	56.4
No	48	43.6
Support group membership		
No	110	100.0
Yes	0	0
National Health Insurance Scheme		
No	109	99.1
Yes	1	0.9
Presence of disability (n = 82)		
Yes	79	96.3
No	3	3.7

and Christians (58.2%), and their care variables showed that 58.2% of the patients were on admission with majority spending longer than 7 days (53.1%) and 56.4% of the patients had pain [Tables 1 and 2]. Caregivers having more than two children (85.5%), who earned less than national minimum wage (55.5%), and with a self-dependent source of income (85.4%) were in the majority [Table 3]. Majority (32.0%) of the caregivers were the patients' children [Figure 1].

Table 3: Socioeconomic characteristics of family caregivers

Variable	Caregivers	
	Frequency (N = 110)	%
Caregivers' number of children		
None	2	1.8
1–2	14	12.7
>2	94	85.5
Monthly income (Naira)		
None	17	15.5
≤30,000 (≈US\$73)	43	39.0
>30,000 (≈US\$73)	50	45.5
Sources of income (n = 93)		
Self	79	85.4
Others*	14	14.6

*Children, siblings, spouse, relatives

The most common diagnosis was benign mandibular lesion (57.0%). Other diagnosis included malignant maxillary lesion (21.0%), benign maxillary lesion (10.0%), malignant mandibular lesion (10.0%), malignant salivary gland lesion (6.0%), and benign salivary gland lesion (3.0%). Figure 2 showed that the highest number of patients with disabilities were those with a combined disability of function, pain, and aesthetics (35; 32.7%). There was no form of disability in 2.8% of family caregivers. The greatest need of 94.5% of the patients was to get well; in 3.0%, it was financial support, whereas in 1.0%, each was to get a job, continue with education, and have children, respectively. On the other hand, financial support (93.6%) was the caregivers' major need [Figure 3].

Table 4 shows the caregiving burden, needs, and coping strategies of caregivers of the patients. Only 6.4% of the caregivers experienced severe burden, whereas 21.8% were

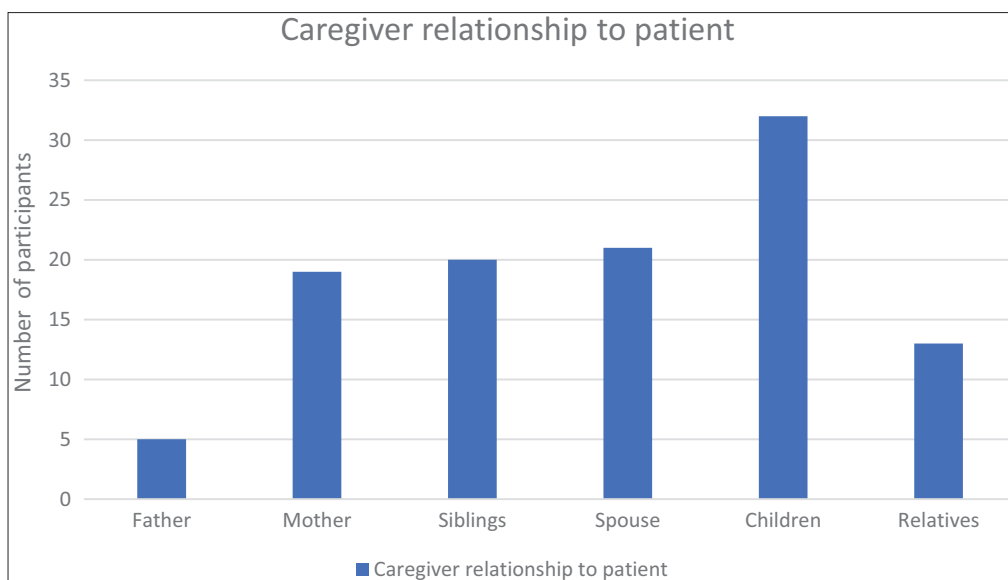


Figure 1: Caregivers' relationship to patients

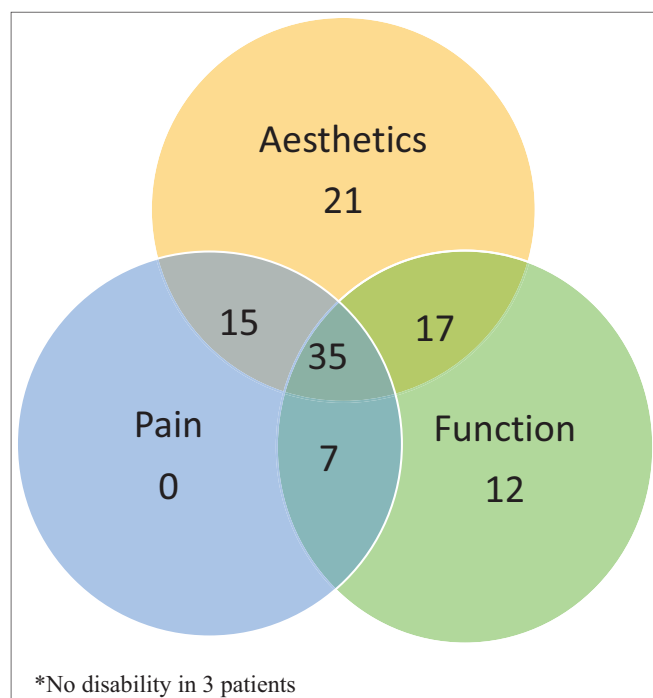


Figure 2: Disabilities seen in patients; no disability in three patients

in the category of moderate-to-severe burden. Prayer (76.4%) was their major coping strategy. Majority spent all day caring for the patient (76.4%) and often got tired (78.2%) but were satisfied with the care their relatives received from the hospital (87.3%). Almost all the caregivers and the patients did not register for National Health Insurance Scheme (NHIS) as they paid hospital bills out of pocket (99.1%).

Table 5 shows the factors associated with burden among these caregivers. The significant predictors were the presence of pain (adjusted odds ratio [AOR] = 2.961; 95% CI = 1.165–7.526;

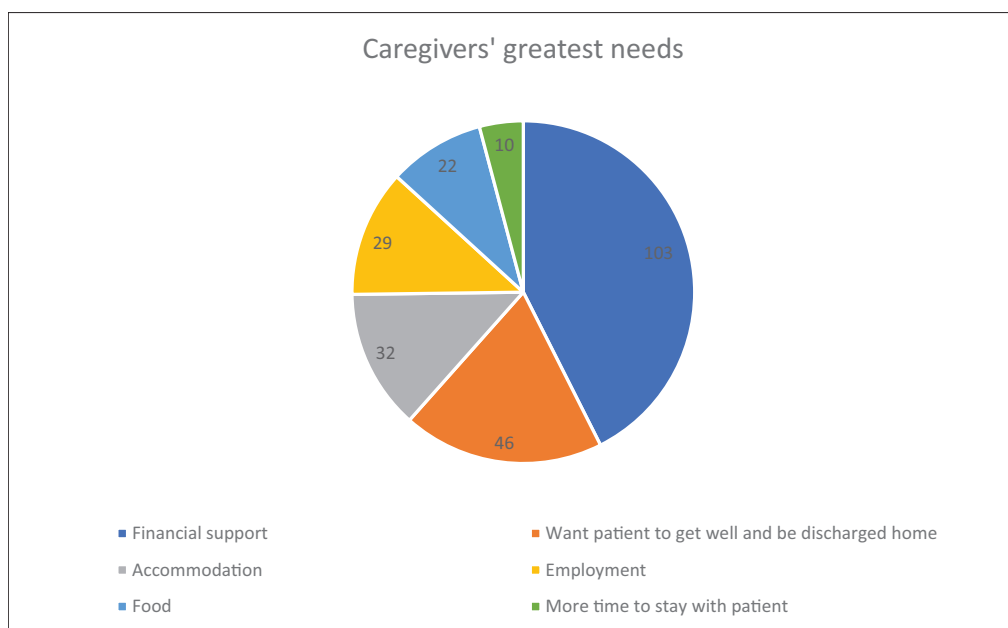
$P = 0.023$) and severe clinical condition (AOR = 3.342; 95% CI = 1.133–9.853; $P = 0.029$).

Discussion

This study examined the burden and predictors of burden experienced by caregivers of patients with oral and maxillofacial tumours presenting for the treatment in a tertiary health facility. The concept of burden involves two different domains: the objective and subjective aspects.^[17] The objective aspect has to do with activities of daily living such as feeding and personal hygiene, which is impaired in patients with maxillofacial tumours, whereas the subjective aspect is related to the feelings and concerns with the present and future of the patient.^[17] The interplay between the objective and subjective aspects eventually determines the effect and the eventual psychological reactions by the caregiver. Those with positive feelings usually feel less burdened, whereas others with a contrary appraisal may feel more burdened and stressed.^[18,19]

The analysis revealed that the majority of the caregivers experienced mild-to-moderate burden, whereas only few experienced severe burden. In the Western part of Nigeria where this study was carried out, close family ties and communal living are still relatively common. Family members see it as an obligation to take care of the sick or incapacitated ones, and despite the presence of stressors, they still derive a sense of satisfaction and fulfilment at being able to contribute to the care and well-being of a suffering relative without feeling burdened. However, severe burden^[12,20] and moderate-to-severe burden^[11,21] have been documented from other similar studies. The observed relatively lower burden in the present study could be a reflection of the different ways in which people from different cultures respond to stressful situations.

A majority of the caregivers in our study were immediate family members and mostly females in agreement with



*Some caregivers gave multiple responses as their greatest needs.

Figure 3: Caregivers' greatest needs

Table 4: Caregiving burden, needs, and coping strategies of caregivers of maxillofacial patients

Variable	Frequency (N = 110)	%
Caregiver burden		
Severe	7	6.4
Moderate to severe	24	21.8
Mild to moderate	47	42.7
Little or none	32	29.1
Caregiving time (hour/day)		
<8	14	12.7
8-<24	12	10.9
24	84	76.4
Effect of caregiving*		
Gets tired	86	78.2
Leave from work	65	59.1
Had to stop working	33	30.0
Coping strategies*		
Prayers	84	76.4
Psychological and financial support from family	14	12.7
Believe in medical/surgical care	12	10.9
Encourage self	9	8.2
Self-medication	4	3.6
Music/films/radio	3	2.7
Payment of hospital bill		
Out of pocket	109	99.1
National Health Insurance Scheme	1	0.9
Satisfaction with care received by patient		
Satisfied	96	87.3
Not satisfied	14	12.7

*Multiple responses

previous studies that reported caring role in terms of family responsibility to be imposed on women by the society.^[11,22] In contrast, Nguyen and Dan found more of the caregivers of cancer patients in her study to be males.^[20]

The male caregivers experienced more caregiver burden than female caregivers, contrary to the findings in the study of Kim and Schulz.^[13] In Nigeria, males, by virtue of the societal role, are expected to source for family income and may have to negotiate between caregiving, job, and other life events, which may place more burden on them unlike women whose primary role and responsibility is more of caring for the home front. Most of the female caregivers in the study of Kim *et al.*^[15] were employed in full-time or part-time jobs,^[15] unlike our study where a majority of the female caregivers were either unemployed or self-employed. Nguyen and Dan^[20] in a similar study also reported higher caregiver burden among females and cited postmenopausal stress and tendency of women to experience greater depression in response to life pressure than men as plausible reasons.^[20]

A majority of the caregivers in our study were the patients' children unlike an earlier study where the spouses were reported to form the majority of the caregivers.^[20] The possible reason for this finding could be family role distribution where the parents are mostly the breadwinners, and as the parent that is healthy plays this role, the children are left to take care of the ill parent. The emotional attachment of children to parents could also play a role, and in addition, caregiving period may be seen as payback time where the children feel obliged to reciprocate the care the parents gave to them at one time or the other. Our study was hospital-based unlike the study of Nguyen and Dan that included both the care at

Table 5: Logistic regression analysis of factors associated with caregiver burden among caregivers of maxillofacial patients

Variable	Caregiver burden		Test statistics, X ² ; P value	AOR; 95% CI; P value
	Low (%)	High (%)		
Sex of patient				
Male (ref.)	13 (22.8)	44 (77.2)	2.265; 0.132	2.286; 0.911–5.739; 0.078
Female	19 (35.8)	34 (64.2)		
Caregiving duration (months)				
<6 (ref.)	12 (38.7)	19 (61.3)	1.936; 0.164	0.217; 0.024–1983; 0.176
≥6	20 (25.3)	59 (74.7)		
Caregiving time (hours)				
<8 (ref.)	7 (50.0)	7 (50.0)	3.407; 0.182	1.382; 0.127–15.055; 0.790
8–23	3 (25.0)	9 (75.0)		
24	22 (26.2)	62 (73.8)		
Patient has pain				
Yes	13 (21.0)	49 (79.0)	4.545; 0.033	2.961; 1.165–7.526; 0.023
No (ref.)	19 (39.6)	29 (60.4)		
Patient's clinical condition				
Not severe (ref.)	26 (37.1)	44 (62.9)	6.050; 0.014	3.342; 1.133–9.853; 0.029
Severe	6 (15.0)	34 (85.0)		

AOR = adjusted odds ratio, CI = confidence interval

home and hospital.^[20] This may explain why they found more spouses than children as caregivers, since most spouses live together and most times will have to look after each other for the mutual support role when at home.

Caregiving duration or number of hours spent caring for the patient was not associated with caregiver burden. This is at variance with earlier studies that reported caregiver burden to be associated with a number of hours of caregiving.^[11,23] Cultural norms may be responsible for the observed difference. In most parts of Western Nigeria, family ties are strong and taking care of an ill member of the family is seen as a duty and when the need arises may be taken up as full-time responsibility unlike other climes where other responsibilities such as work schedule are still on the caregivers.^[11] Although as opined by Kim *et al.*, a large amount of caregiving time can lead to higher caregiving demand and burnout for the caregiver, which could be a stressor for caregiver burden.^[11] However, when the caregiver sees it as a responsibility and call of duty to a loved one, it may allow for a positive appraisal and makes it feel less burdensome.

In contrast to an earlier work,^[21] the present study did not demonstrate any significant relationship between gainful employment and caregiver burden. Gainful employment has been reported to be associated with higher caregiver burden, premised on the fact that caregivers may have to negotiate between caregiving and their employers and other responsibilities.^[21] However, in the present study, a majority of the caregivers were self-employed, and this allowed more flexibility of planning their schedules without having to seek for permissions from employers. Also, most of these caregivers by the nature of their jobs such as petty trading had people

around that could look after their businesses during the periods they had to be away to take care of their ill family member.

Almost all our subjects accessed care through out of pocket payment, and only very few utilised other means such as NHIS. A majority of the caregivers are without gainful employment or engaged in petty trading and earned below the recommended national minimum wage. Financial implication of tumour management could be quite huge and caring for such patients in an environment where poverty level is high and having to pay out of pocket could place a huge burden on individuals and households. The burden on the caregivers can adversely affect the caregiving services rendered and may ultimately contribute to the poor outcome of tumour management. Huge financial burden of cancer from direct and indirect causes has been previously reported to affect the outcome of cancer case management.^[24] It is therefore not surprising that the greatest need expressed by the caregivers in this study was financial support.

The factors that were statistically associated with caregivers' burden in the present study were pain and severe clinical condition of the patient. When patients are in pain or the illness becomes severe, it may aggravate both emotional and physical burdens on the caregiver. The emotional burden might be as a result of watching a relative go through the agony of pain or distress, the feeling that the illness is getting worse, the feeling of helplessness and anxiety as well as the fear of losing the relative. Also, the physical demand to handle the patients' need might become more intense, and an untrained caregiver might get more confused on what to do to relieve the patient of the distress. There is also the tendency for the patients at the point of undergoing pain or worsening condition to be less cooperative, more demanding, and difficult to satisfy.

This finding, however, is contrary to the finding in the study of Caning *et al.* that reported no association between disease severity and burden.^[25]

Coping strategy employed in this study was mainly spiritual support (prayers) followed by family support. According to Lazarus and Folkman, coping is defined as cognitive and behavioural efforts to manage demands perceived as tasking or exceeding the resources of an individual.^[26] Coping strategies play a role in modulating the psychological impact of stressful events and have been broadly grouped into problem-focused (active) and emotional-focused (passive) coping.^[26] In the present study, diverse emotional coping strategy was employed among all the study participants similar to earlier studies carried out in the same environment on coping strategies by caregivers.^[27,28] The findings in this study could be a reflection of the cultural beliefs and high level of spirituality in the environment where the study was carried out.^[27,28]

Conclusion

This study has assessed the burden and predictors of burden of family caregivers of patients with maxillofacial tumours in South Western Nigeria. We found the burden level to be mainly in the mild-to-moderate category and significant predictors to be the presence of pain and disease severity, whereas the greatest need expressed by caregivers was financial support. Coping strategy was mainly in the form of spiritual and family support. Our study showed that despite the availability of NHIS, it was poorly accessed. There was a high rate of unemployment and poverty.

Our findings have implications for clinicians, healthcare planners, and government. It is recommended that emphasis should be on adequate pain control and better implementation of alternate sources of health funding such as the NHIS to make it more effective and more inclusive. This will relieve the family and the caregivers of the high financial burden necessary to manage maxillofacial tumours. Faith-based strategies should be readily available to caregivers to improve their coping ability. The government should also look at means of reducing the high unemployment rate and empowering the citizenry financially.

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Conflicts of interest

There are no conflicts of interest.

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