



# Impact of emotional distress on caregivers burden among Nigerian children with Obstructive Adenotonsillar hypertrophy



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## ABSTRACT

**Background:** Despite the significance of the role of caregivers among children with Obstructive Adenotonsillar hypertrophy (OAT), their caregiving experience and emotional well-being are given poor attention in research, policy and service design. This study represents a novel effort sought to investigate the burden experienced by caregivers of children with OAT and the impact of emotional distress on their caregiving burden.

**Methodology:** A total of one hundred consecutive caregivers of children with OAT were interviewed with designed socio-demographic questionnaire. This was subsequently followed by administration of General Health Questionnaire-12 (GHQ-12) to ascertain emotional distress using cut-off score  $\geq 3$  and Zarit Caregivers Burden of care scale was used to characterize the pattern of burden experienced by these caregivers.

**Results:** In this study, the mean ages of children with OAT and their caregivers were 36.7( $\pm 21.8$ ) months and 34.4( $\pm 5.4$ ) years, respectively. The affected children were mainly males (68%), while their caregivers were predominantly females (84%). Fifty-seven percent of children with OAT were schooling but 13% of them had academic delay. Majority of the caregivers (66%) had a tertiary level of education. Of the total participants, up to 43% reported various degrees of burden of care, with majority (34%) of them reporting mild to moderate burden of care. In the same vein, 48% were emotionally distressed. Following regression analyses, emotional distress was independently associated with burden of care among participants (Odds ratio [OR] = 0.108; 95% Confidence Interval [95% CI] = 0.043–0.272;  $p < 0.001$ ).

**Conclusion:** Caregivers of children with OAT reported the experience of various degrees of burden, and worse among caregivers with emotional distress. Overall, the level of distress and burden observed in this study were many-fold what has been reported among caregivers of other populations of children. The results of this study support the proposal of proactive measures to address the psychosocial needs of caregivers as integral to the care of children with OAT. Further research on the well-being of caregivers is also justified.

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## 1. Introduction

Enlargement of adenoids and tonsils with significant obstruction to upper airways, otherwise known as Obstructive Adenotonsillar hypertrophy (OAT) is a common condition among children with known indication for surgical procedure called

adenotonsillectomy (surgical removal of adenoids and tonsils) [1,2]. In particular, OAT with its attendant complications is frequently associated with striking negative impacts on the affected children and their caregivers [3–5]. Such adverse consequences on the affected children include breathing difficulty, obstructive sleep apnea, snoring, poor sleep, behavioral problems, developmental delay, and in extreme cases could result in failure-to-thrive among others [6,7]. With regard to caregivers of children with OAT, their physical health, psychosocial well-being and productivity can be impaired [3].

Compared to other groups of patients, caregivers play vital roles in the care of children and contribute immensely to outcome in

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those with OAT. For instance, important decisions and treatment related activities spanning the peri-operative period are commonly carried out by caregivers. Consequently, these roles might constitute significant sources of frustration as well as stress and place burdensome demands on caregivers; thereby leading to “caregiver burden” [7]. Again, caregivers may have to cope with disruptions in their daily routines [1], and deal with the need to provide socioeconomic, emotional and other support to their patients [8] as well as other family members.

Existing literature has linked caregiving with dire physical and psychological consequences [9–11], which are often related to the burden experienced by the caregivers. Examples of common psychological consequences of caregiving include distress, anxiety, anger, and depression among others [12–14]. Specifically, studies have identified a bi-directional relationship between caregiving burden and psychological distress among patients with various chronic medical illnesses [13,15,16]. Unfortunately, while caregiver burden has been extensively examined in relation to many chronic illnesses [15–19], there appears to be none among caregivers of children with OAT. Similar scenarios have been reported in the developed world [15] as caregivers have often been referred to as the hidden patients [16].

Knowledge about burden of care and emotional distress among caregivers of children with OAT is important to the well-being of both the caregivers and the affected children. Especially because the quality of care and life of the affected children are adversely affected when caregivers emotional concerns are neglected. Additionally, information on caregivers' well-being can inform policy and development of health services for children with OAT and their caregivers. To this end, this study aims to investigate the burden of care, and the influence of emotional distress on caregiving among children with OAT. It is postulated that caregiving among children with OAT would be burdensome to varied degrees and emotional distress with other identifiable factors would constitute important determinants.

## 2. Methodology

### 2.1. Study setting

This is a cross sectional, multicenter study carried out among caregivers of children with OAT attending health facilities in Lagos. These centers receive referred patients from all parts of the densely populated Lagos metropolis and the surrounding states. The patients load is appreciably large because broad clinical services are rendered to patients by specialists in Ear, Nose and Throat. These study centers are secondary and tertiary centers with specialized otolaryngology services and therefore receive referrals from other private and public hospitals.

The diagnosis of OAT was made by specialists in Ear, Nose and throat based on nocturnal symptoms of snoring, pauses in breathing, gasping for breath, increased respiratory effort (nasal flaring and supraclavicular, suprasternal, and intercostal retractions), and recurrent/persistent rhinorrhea and mouth breathing. Obstructive Adenoid was ascertained with a radiograph showing either  $\geq 50\%$  narrowing of the postnasal space or obliteration of the postnasal air column with soft tissue shadow. This was confirmed using Fujioka [20] formula to determine the adenoidal-nasopharyngeal ratio (A–N ratio). While Grade III–IV tonsil enlargement on oropharyngeal examination based on Brodsky [21] classification was confirmatory of obstructive tonsillar enlargement.

### 2.2. Study participants and ethical considerations

The study participants were made up of one hundred informal caregivers of children with OAT in the study locations. Eligible

participants were recruited consecutively over a period of 3 months, made up of consenting adults that are directly involved in the care of children with OAT (all participants were made up of parents in this study) and not currently considered to be a primary caregiver for anyone else.

Ethical approval was gotten before commencement of the study by sending a copy of the study protocol to the Health Research Ethics committee of the Lagos University Teaching Hospital. Again, informed consent of each participant was secure and participants were assured of their freedom to opt out of the study at any time without any negative consequence. All the participants found with psychological distress or significant burden in the course of the study were counseled and/or referred for management if indicated.

### 2.3. Study instruments and procedure

The study was carried out following institutional and ethical approval from the Health Research Ethics Committee of the hospital. Instruments for the study were administered on the eligible participants on the confirmation of the diagnosis of OAT before the commencement of the treatment. The eligible participants were subjected to designed questionnaire to elicit socio-demographic variables of the caregivers and their children. Such variables include: age, sex, employment, marital status, religion, number of children and their ages of caregivers. Data from the children include age, gender, school and academic delay.

This was followed by administration of the General Health Questionnaire-12 (GHQ-12) [22] to measure emotional distress among caregivers. GHQ-12 is the shortest version of the General Health Questionnaire. It consists of 60 items in its original form but shorter versions of 30, 28, 20 and 12 are available. Both original and shorter versions have cross cultural validity and reliability. Using bimodal scoring scale (0, 0, 1, 1), the maximum obtainable score was 12; and scores  $>3$  were regarded as positive screen on the GHQ-12. It has been validated and well used across multiple settings including Nigeria [23–27].

Lastly, the Zarit's Caregiver Burden Scale (ZCBS) [28] was administered to the participants to elicit the pattern of burden of care experienced among them. ZCBS is a 22-item questionnaire with a 5-item response set ranging from ‘never’ to ‘nearly always’. Each item is rated from 0 to 4 (higher scores denoting higher burden for a particular item). Zero to twenty points mean little or no burden, 21–40 points mean mild-to-moderate burden, 41–60 points mean moderate-to-severe burden, 61–88 points mean severe burden. The test–retest reliability and face validity of ZCBS has been established; and has been extensively used in studies conducted in Nigeria [29,30]. Further classification of the scores into significant burden for those scoring above 40 and no significant burden for those scoring 40 and below was done in line with previous categorization [30]. The instruments were administered either in English or Yoruba for those who were not literate. Participants were assisted in the completion of the questionnaire as much as indicated to ensure that the answers were reliable. Overall, three participants declined consent.

### 2.4. Data analyses

Data were analyzed using the 17th version of Statistical Package for the Social Sciences (SPSS-17) [31]. Normally distributed data were summarized using mean ( $\pm$ SD), while categorical data were represented as proportions. Descriptive statistics like means, frequencies and percentages were used to analyze the data. Chi square, Fisher's exact test and logistic regression analyses were used to ascertain the association and correlation between the variables. A  $p$ -value  $<0.05$  in two-tail was considered statistically significant.

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