

Correlation between burden and sleep quality in informal caregivers of infants with orofacial cleft

Correlação entre sobrecarga e qualidade do sono em cuidadores informais de lactentes com fissura orofacial

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ABSTRACT

Objective: To evaluate the correlation between burden and sleep quality in caregivers of infants with cleft lip and/or palate.

Methods: This descriptive cross-sectional study was carried out in a Brazilian tertiary public hospital between March and September 2020. The sample included the main informal, literate caregivers of infants with cleft lip and/or palate, aged 18 years or older. The instruments used were the Burden Interview Scale and the Pittsburgh Sleep Quality Index. Data were collected during the infants' hospitalization. Statistical analysis adopted Pearson and Spearman correlations, with a 5% significance level.

Results: A total of 31 informal caregivers participated in the study, most of them mothers (n=28; 90%), with a mean age of 30 years (standard deviation – SD=7.5), low socioeconomic status (n=20; 64%), who completed high school (n=19; 61%), were married (58%), had two children (n=15; 48%), and no employment relationship (n=18; 58%). A moderate correlation was found between sleep quality and burden (r=0.39; p=0.032) and between burden and subjective sleep quality (r=0.39; p=0.029), sleep latency (r=0.43; p=0.017), and daytime dysfunction (r=0.49; p<0.001).

Conclusions: The study showed that the higher the burden, the lower the sleep quality. The findings indicate the need to plan and implement interventions to minimize the burden experienced by these informal caregivers in order to improve their sleep quality.

Keywords: Caregivers; Sleep; Stress, psychological; Nursing; Cleft lip; Cleft palate.

RESUMO

Objetivo: Avaliar a correlação entre a sobrecarga e a qualidade do sono em cuidadores de lactentes com fissura de lábio e/ou palato.

Métodos: Estudo descritivo e transversal, realizado em um hospital público e terciário brasileiro entre março e setembro de 2020. Foram incluídos cuidadores informais principais de lactentes com fissura de lábio e/ou palato, alfabetizados e com idade igual ou superior a 18 anos. Utilizaram-se a Escala de Burden Interview e o Índice da Qualidade de Sono de Pittsburgh. A coleta de dados aconteceu durante a internação dos lactentes. Para a análise estatística, utilizaram-se as Correlações de Pearson e de Spearman, com nível de significância de 5%.

Resultados: Participaram do estudo 31 cuidadores informais, dos quais prevaleceram as mães (n=28; 90%), com média de idade de 30 anos (desvio padrão — DP=7,5), pertencentes à classificação socioeconômica baixa (n=20; 64%), com ensino médio completo (n=19; 61%), casadas (58%), com dois filhos (n=15; 48%) e sem vínculo empregatício (n=18; 58%). Observou-se correlação moderada entre a qualidade do sono e a sobrecarga (r=0,39; p=0,032), e entre a sobrecarga e a qualidade subjetiva do sono (r=0,39; p=0,029), a latência do sono (r=0,43; p=0,017) e a disfunção durante o dia (r=0,49; p<0,001).

Conclusões: Evidenciou-se que quanto maior a sobrecarga, menor foi a qualidade do sono. Os achados apontam a necessidade de planejar e implementar intervenções que minimizem a sobrecarga vivenciada por esses cuidadores informais, a fim de promover a qualidade do sono deles.

Palavras-chave: Cuidadores; Sono; Estresse psicológico; Enfermagem; Fenda labial; Fissura palatina.

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INTRODUCTION

Orofacial clefts, which include lip and/or palate, are prevalent among facial malformations and can manifest alone or associated with syndromes and other deformities. Its etiology is multifactorial, and the incidence in Brazil is 1:650 live births.^{1,2}

These clefts are related not only to esthetic but functional and psychosocial impairments, requiring a series of readjustments from parents/guardians and/or caregivers. The rehabilitating process should be performed by a multidisciplinary team, aiming to fully meet the countless needs of these individuals, starting with surgical procedures called primary surgeries, including cheiloplasty and palatoplasty.^{3,4}

In addition, orthodontic interventions, secondary surgeries, esthetic and functional adaptations, and facial growth monitoring are necessary. The association of all these factors requires a prospective treatment.^{3,5}

Often, the child's parents or close relatives, such as grandparents, uncles/aunts, or godparents, assume responsibility for the care needs, and since they lack the necessary training, they are called informal caregivers. The inherent responsibilities of the care process can result in burden on these informal caregivers, which is defined as the perceived physical, emotional, social, and financial suffering related to the care of a patient and/or a family member.^{5,6} Care centralization is potentially associated with the caregiver's exhaustion and negligence of their own health and self-care, considering that they often prioritize the infant's care. These actions can trigger stress, burden, and anxiety in the short- and medium-term.^{7,8} Thus, sleep quality is regarded as one of the determinants of quality of life and the level of stress experienced.^{9,10}

Sleep has the function of reestablishing, restoring, and conserving energy, and when impaired, either quantitatively or qualitatively, the individual can suffer a series of short- and long-term losses, including social and occupational interaction, as well as psychological and/or cognitive aspects.^{10,11}

Considering the factors above, we sought to answer the following questions: Are informal caregivers of children with cleft lip and/or palate burdened? How is the sleep quality of these caregivers? Are burden and sleep quality correlated? In short, identifying burden levels and their correlation with sleep quality in informal caregivers of children with cleft lip and/or palate becomes paramount since the quality of the care provided by them depends on their physical and mental well-being. Therefore, this research aimed to evaluate the correlation between burden and sleep quality in caregivers of infants with cleft lip and/or palate.

METHOD

This quantitative descriptive cross-sectional study was carried out in a tertiary public hospital located in the inland of the state

of São Paulo, Brazil. This facility is a national and international reference for the care of patients with craniofacial anomalies and related syndromes. It is managed by a public university and funded by its own resources and the Brazilian public health system (*Sistema Único de Saúde* — SUS). Its practice is targeted at care, teaching, and research. The care is multi- and interdisciplinary.

The study population consisted of informal caregivers of infants with cleft lip and/or palate who were accompanying the children during hospitalization for primary surgeries. The inclusion criteria were: being the infant's main informal caregiver, being aged 18 years or older, and being literate.

Sampling was consecutive and non-probabilistic. For sample calculation, we conducted a pilot study with a standard deviation (SD) of 0.5 points. Based on this study, we considered a sampling error of 0.2 and a 95% confidence level. Thus, the number of participants estimated was 25. Lastly, the sample comprised 31 caregivers.

Data were collected between March and September 2020, in a private environment, during the infants' hospitalization, using three self-administrated instruments: a sociodemographic questionnaire, the Burden Interview (BI) Scale,¹² and the Pittsburgh Sleep Quality Index (PSQI).¹³

The sociodemographic questionnaire was used to characterize the participants according to the variables: age, gender, marital status, schooling, social class, number of children, and employment relationship. The BI Scale was adopted to assess the burden, while the PSQI evaluated the subjective sleep quality.¹²⁻¹⁴

The BI scale was developed to assess the burden on parents or caregivers and was translated and validated for the Brazilian population. It has 22 questions covering the domains: health, social and personal life, financial situation, well-being, emotional behavior, and interpersonal relationship. The response score for each item ranges from 0 to 4, and the last question of the scale evaluates how burdened the family member feels overall in caring for the patient. The final score is obtained through the total sum of all answers, ranging from 0 to 88. The level of burden is classified as follows: <20 points indicate no burden; 21–40 points, moderate burden; 41–60 points, moderate to severe burden; and ≥61 points, severe burden.¹²

PSQI evaluates sleep quality and disorders over a period of one month. It was developed by Buysse et al.¹³ in 1989 and was translated and validated for the Brazilian context.¹⁴ It has 19 questions divided into seven evaluation components: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. The global score ranges from 0 to 21 points: 0–4 points — good sleep quality; 5–10 points — poor sleep quality; and >10 points — sleep disorder/terrible sleep quality.¹³

Data were tabulated and organized in Microsoft Office Excel 2018. Categorical variables were submitted to descriptive statistical analysis. We used the Pearson correlation test to correlate burden and sleep quality with the total scores of both questionnaires. Spearman correlation was used to correlate the total burden score with PSQI components. The significance level adopted for both tests was 5% ($p \leq 0.05$). In addition, we analyzed the strength of the linear correlation, with values lower than 0.30 indicating weak correlation; between 0.30 and 0.50, moderate correlation; and above 0.50, strong correlation.¹⁵

The research started after approval by the Research Ethics Committee of the facility (official report 3,823,675 and CAAE: 26673319.7.0000.5441) and complied with all principles of Resolution no. 466/2012 of the Brazilian National Health Council.

RESULTS

Initially, 35 caregivers were invited to participate in the study. Among them, three did not meet the general research criteria, and one refused to participate. Therefore, the sample consisted of 31 participants, most of them mothers ($n=28$; 90%), with a mean age of 30 years ($SD=7.5$; ranging from 18 to 50 years). Most participants had a low socioeconomic status ($n=20$; 64%), completed high school ($n=19$; 61%), were married (58%), had two children ($n=15$; 48%), and no employment relationship ($n=18$; 58%). The children's mean age was 11 months ($SD=2.5$).

Nine participants (29%) had moderate burden, and one had moderate to severe burden (3%) — that is, 32% of the participants experienced burden. The variables that contributed most to burden were: the perceived dependence of the infant upon the caregiver ($mean=2.9$; $SD=1.2$) and the feeling that the caregiver could be doing more for the infant ($mean=1.8$; $SD=1.3$). On the other hand, the variables that contributed least were the caregiver's perception that the infant negatively affects their relationships ($mean=0.1$; $SD=0.3$), followed by the desire to leave the care to someone else ($mean=0.2$; $SD=0.5$).

Regarding sleep quality, 15 caregivers (48%) were classified as having poor sleep quality and seven (22%) as terrible — that is, 70% of the participants presented impaired sleep quality. The time between laying down and falling asleep was, on average, 30 minutes, while the sleep duration was 7 hours.

The prevalent variables related to sleep quality evaluation were sleep disturbances ($mean=1.3$; $SD=0.7$), followed by subjective sleep quality ($mean=1.1$; $SD=0.7$) and sleep latency ($mean=1.1$; $SD=1.0$). On the other hand, the variable with the lowest score was the use of sleeping medication ($mean=0.3$; $SD=0.2$) (Table 1).

The variables “burden” and “sleep quality” showed a moderate correlation ($r=0.39$; $p=0.032$). Regarding the variables

related to sleep quality, burden presented a moderate correlation with subjective sleep quality ($r=0.39$; $p=0.029$), sleep latency ($r=0.43$; $p=0.017$), and daytime dysfunction ($r=0.49$; $p<0.001$) (Table 2).

DISCUSSION

Among the study participants who experienced burden, most showed moderate burden, considering subjective and objective aspects. Subjective factors are related to the caregiver's response to emotional demands regarding their role, manifested by the discomfort associated with care routine and the adequacy to permanent life changes, whether in the personal, social, or professional domains, in addition to negative feelings, such as shame, helplessness, and vulnerability.¹⁶

Table 1. Distribution of sleep quality assessment components according to the Pittsburgh Sleep Quality Index.¹³

	Mean	SD
Sleep disturbances	1.3	0.7
Subjective sleep quality	1.1	0.7
Sleep latency	1.1	1.0
Sleep duration	1.0	1.1
Daytime dysfunction	1.0	0.8
Sleep efficiency	0.6	1.1
Use of sleeping medication	0.3	0.8

SD: standard deviation.

Table 2. Correlations between burden and sleep quality in informal caregivers of infants with cleft lip and/or palate.

	r	Correlation	p-value
Burden × sleep quality*	0.39	Moderate	0.032 [‡]
Burden × subjective sleep quality [†]	0.39	Moderate	0.029 [‡]
Burden × sleep latency [†]	0.43	Moderate	0.017 [‡]
Burden × sleep duration [†]	0.06	Weak	0.762
Burden × sleep efficiency [†]	0.01	Weak	0.977
Burden × sleep disturbances [†]	0.20	Weak	0.287
Burden × use of sleeping medication [†]	0.34	Weak	0.064
Burden × daytime dysfunction [†]	0.49	Moderate	<0.001 [‡]

*Pearson correlation; [†]Spearman correlation; [‡]5% significance level ($p \leq 0.05$).

On the other hand, the objective aspects of burden are associated with concrete demands, such as a large number of daily tasks to be performed with the infant and the supervision and attention required by the child, including impairment to social, professional, and even financial life. As a result, the informal caregiver of the infant with cleft lip and/or palate is at risk of going through changes that might interfere with their social life due to their increased responsibilities.¹⁶

In fact, the feeling of being able to do more for the infant was evident, pointing to a sense of weakness related to the care provided since burden is associated with perceived physical, psychological, financial, and social suffering.⁷ These circumstances might sometimes lead the caregiver to believe they could do more, despite some other issues related to previous domains preventing them from doing so.

This study showed mothers as the main caregivers, corroborating the literature.^{7,9,17,18} This is an important factor associated with burden because, most often, the maternal figure not only provides care for the infant but performs professional and domestic activities, in addition to caring for her other children. In this research, most mothers had two children, followed by those who had more than two.

Burden was associated with unemployment rates and low socioeconomic status.¹⁹ A large part of the participants belonged to the low class, which relates to financial difficulties in managing care with the infant's needs and home demands and can even justify the feeling of being able and wanting to do more.

The infant's mean age was 11 months. During this period, children go through a significant process of psychomotor development, acquiring motor skills, understanding, and discovering the environment in which they live, in a free and unrestricted manner, demanding more attention and care. Thus, we can note a correlation between burden and the infant's age.²⁰ Moreover, the caregiver can manifest, over time, feelings of frustration and non-acceptance, which may be present from the discovery of the cleft to the occasional emergence of feeding difficulties that lead to weight loss, anemia, and growth deficit, associated with the whole context.²¹

Also, it is in this age group that cleft palate repair surgery is performed, certainly influencing the stress level of these caregiver parents, with consequent repercussions on burden and sleep quality, which may be exacerbated by doubts and the need to learn new care related to the postoperative period, in addition to monitoring the child during this convalescence period.^{5,21}

Concerning sleep, the mean duration was 7 hours, in line with recommendations from the Brazilian Sleep Association, which recommends at least 7 and at most 9 hours of sleep, aiming at preserving baseline health conditions associated with sleep quality for people aged 18 to 60 years.²² A similar result

was found in another study that included caregiver parents of children without comorbidities.¹⁹

However, although the mean sleep duration was adequate, 70% of the participants presented poor or terrible sleep quality. We can infer that this result is once again related to the children's age group, as they demand more time dedicated to feeding, hygiene, safety, and other care.

In fact, recurrent crying episodes, the increase and readjustment in frequent nocturnal feeding needs, as well as other care and changes, are predisposing factors for lower sleep quality.¹⁹ In addition to age-related issues, children with orofacial cleft have some particularities that include: higher risk of aspiration, regurgitation of milk from the nostrils, increased occurrence of otitis, feeding difficulties, and issues related to the social, functional, and esthetic domains.²⁰

The components that contributed most to reducing sleep quality were related to sleep disturbances, that is, during the past month, how often this caregiver needed to interrupt their sleep and why, including waking up in the middle of the night, breathing problems, needing to use the bathroom, feeling too hot, having pain, among other reasons.¹³

Thus, most caregivers marked the item "other reasons to wake up," usually to take care of the infant. We emphasize that subjective sleep quality reflects how the caregiver perceives their sleep quality, while latency refers to the time it takes to sleep after lying down.¹³

Furthermore, based on the study participants' verbal reports, the influence of technologies in this process, including the constant use of mobile phones and other electronic devices, may increase physical and emotional euphoria, in addition to heightening the state of alertness due to the light intensity, which can lower sleep quality and the production of melatonin.^{23,24}

On the other hand, the component that least contributed to reducing sleep quality was the use of sleeping medication. The use of sleep-inducing drugs and/or sedatives decreases attention and alertness, preventing the caregiver from responding to the care demands of these children. Thus, poor or terrible sleep quality can influence the life of caregivers, with short-to-long-term losses associated with daily activities, social and professional interactions, and cognitive and psychological disorders.¹⁰

Physiological mechanisms of energy conservation and cyclic ones related to sleep, insomnia, and impaired sleep quality can cause disorders linked to neuroendocrine functions, with negative repercussions on the quality of life, as they are directly interconnected.^{10,11}

When assessing the correlation between burden and sleep quality, we found that the higher the burden, the worse the sleep quality. Although related studies of informal caregivers of children are incipient, a similar result was identified among

informal caregivers of dependent relatives and individuals with Alzheimer's disease.^{25,26}

The more exhausted and burdened the caregiver, the greater the negative repercussions on sleep quality. Actually, the sleep dysfunction and burden generated by infant care persist up to the school age.²⁷

Caring for infants with cleft lip and/or palate goes beyond physiological issues. There are also primary surgeries, which take time and require postoperative care related to feeding, hygiene, and care and create a financial burden due to traveling, medications, and lodgings for treatments outside the home, which can exacerbate the burden since these tasks are usually performed by the main caregiver.²⁰

We underline that the quality of care provided to the child strongly depends on the health and well-being of their caregivers.¹⁷ In this sense, measures aimed at preventing and identifying burden are necessary in all care spheres, as well as the detection of sleep-related disorders. These variables are closely connected to the quality of life and health of the caregiver and the patient who receives the care provided by them.

Identifying factors that can protect and improve sleep quality and satisfaction, as well as measures to help detect the burden on these caregivers, is necessary. Moreover, the creation of family-oriented care models is essential to support them in their activities and monitor those involved in all health spheres: physical, mental, and spiritual.²⁸⁻³⁰

In short, to invest in the caregiver's health is to promote the rehabilitation process since, besides being responsible for the child's care, they have needs and roles that go beyond the act of caring.

Lastly, we highlight that although the BI Scale, in its validation process for the Brazilian population, evaluated 82 caregivers — aged 60 to 85 years — of patients with depression and followed at the outpatient level, in the present study, the Cronbach's alpha coefficient resulted in an index of 0.84, showing appropriate reliability also for informal caregivers of infants with orofacial cleft. With respect to the PSQI validation, the authors considered some of the participants' data that could interfere with sleep quality, such as obesity and previous diagnosis

of diseases, including obstructive sleep apnea, which were not evaluated in this study, representing a limitation. In addition, we emphasize that data were collected during the infant's hospitalization for surgery, which may have somehow influenced both the burden and sleep quality, even if this information is based on the previous 30 days, since surgical procedures are a moment of high stress for caregivers, involving pre-, intra-, and postoperative care.⁵ Thus, further research is necessary to consolidate and expand these findings. However, the benefits of this research are evident, pointing to a moderate correlation between burden and sleep quality, allowing us to reflect on interventions to minimize this problem, especially when considering that care quality is closely related to the health and well-being of caregivers.

In conclusion, we found that the higher the burden, the lower the sleep quality. Therefore, the results show the need to plan and implement interventions to minimize the burden experienced by informal caregivers of children with cleft lip and/or palate in order to improve the sleep quality of this population.

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Conflict of interests

The authors declare there is no conflict of interests.

Authors' contribution

Study design: Batista NT, Trettene AS. *Data collection:* Batista NT, Martinez AF. *Data analysis:* Batista NT, Farinha FT, Trettene AS. *Manuscript writing:* Batista NT, Farinha FT. *Manuscript revision:* Bom GC, Trettene AS. *Study supervision:* Trettene AS.

Declaration

The database that originated the article is available with the corresponding author.

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