







## Correlation between quality of life and burden of family caregivers of infants with cleft lip and palate\*

Correlação entre qualidade de vida e sobrecarga em cuidadores familiares de bebês com fissura labiopalatina

Correlación entre calidad de vida y sobrecarga en cuidadores familiares de bebés con fisura labiopalatina

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### ABSTRACT

**Objective:** To evaluate the correlation between measures of quality of life and burden in family caregivers of infants with cleft lip and palate and to analyze possible associations between quality of life and sociodemographic variables. **Method:** Exploratory, cross-sectional study conducted in hospital specialized in the treatment of craniofacial anomalies, with caregivers who answered the following data collection instruments: sociodemographic characterization form, World Health Organization Quality of Life – BREF questionnaire and the Burden Interview Scale. The statistical analysis was conducted using the Pearson's Correlation test, the Student's t-test and the ANOVA test with a level of significance of 0.05. **Results:** 77 caregivers participated in the study. There was an inverse correlation between quality of life and burden in the Physical Health, Psychological, Social Relationships and Environment domains. There was a positive correlation between quality of life and family income in the Environment domain. **Conclusion:** The greater the burden on the caregiver, the lower was their perception of quality of life. Caregivers with higher family income and greater level of education presented a better perception quality of life in the Environment domain.

### DESCRIPTORS

Quality of Life; Caregivers; Cleft Lip; Cleft Palate.

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## INTRODUCTION

Cleft lip and palate are a malformation that occurs to the baby between the fourth and twelfth week of pregnancy. In Brazil, its prevalence is one in every 650 births. This malformation involves functional, aesthetic and psychosocial aspects, and demands treatment and rehabilitation that must be performed by a multidisciplinary team<sup>(1)</sup>.

The family is essential in the rehabilitation of patients with cleft lip and palate, and they must consider making changes in their daily life<sup>(2)</sup>. The diagnosis, birth and stages of the treatment of the child with cleft lip and palate require and enable the family to learn and make adaptations<sup>(3)</sup>. To this end, care must be specialized, comprehensive, humanized, and performed by a multidisciplinary team<sup>(1,4)</sup>. Therefore, it is essential to support the family during the entire rehabilitation treatment of the child with cleft lip and palate<sup>(5)</sup>. In this context, nursing professionals have a fundamental role<sup>(3)</sup>.

The continuous demands imposed on the caregiver can be a burden and generate changes in their daily life, compromising their perception of quality of life<sup>(5)</sup>.

The rehabilitative treatment of cleft lip and palate comprises numerous interventions, which are initially related to feeding and, later, to functional implications, dental management, craniofacial growth, and speech disorders, in addition to aesthetics<sup>(1)</sup>.

Guidance for parents and caregivers is essential and must include: feeding, hygiene, and comfort techniques; and, in the next moment, the pre and postoperative care of the restorative surgeries<sup>(1,5-7)</sup>.

Quality of life assessment can help healthcare teams to improve care services and planning of clinical interventions, favoring the development of innovative health promotion activities<sup>(8)</sup>. Caregivers may face health issues, reduction in quality of life and overload, which can compromise the assistance provided and lead the caregiver to a state of illness<sup>(9)</sup>.

Educational interventions focused on guidance for family caregivers and promotion of their well-being require special attention from health professionals. Nurses play a key role in planning, implementing and evaluating educational interventions for caregivers, which provide guidelines for care according to individual needs, aiming at continuity in home care, and guidance on the adaptations and accessibility of residences<sup>(10)</sup>. Knowing the reality of patients and their relatives and understanding their questions, longings, and experiences is indispensable for an adequate care<sup>(5,11)</sup>.

Considering that caring for a child with cleft lip and palate can lead to a worse perception of quality of life<sup>(12)</sup>, and that the burden can negatively influence this perception, it is essential to assess the correlation between these variables. A situational analysis allows planning and implementing actions to minimize the burden, favoring the health and well-being of caregivers. In this context, a research question is proposed: is there a correlation between the burden and the perception of quality of life of family caregivers of infants with cleft lip and palate? The hypothesis is that there is a correlation between measures of quality of life and burden in these caregivers.

Thus, the objectives of this study were: to evaluate the correlation between measures of quality of life and burden in family caregivers of infants with cleft lip and palate and to analyze possible associations between quality of life and socio-demographic variables.

## METHOD

### STUDY DESIGN

This is an exploratory, cross-sectional study carried out in an institution specialized in the treatment and rehabilitation of patients with craniofacial anomalies and related syndromes.

### DATA COLLECTION

Considering the mean number of first repair surgeries of the cleft lip and palate (13 per month) and the period stipulated for the data collection, the consecutive non-probability sampling consisted of 77 family caregivers. Inclusion criteria were: being 18 years of age and older, being literate and the primary caregiver of infants aged 3 to 6 months with cleft lip and palate<sup>(1)</sup> who were not operated and had no neurological disorders. Family caregivers who reported using psychoactive drugs were excluded. Data was collected from March to September 2015, exclusively by the researcher, through an individual interview, which occurred in a private room in the outpatient clinic of the hospital, before the nursing consultation, with an estimated time of 15-20 minutes. Medical records were consulted to verify the inclusion criteria before the interview.

Three data collection instruments were used: a sociodemographic characterization form, the World Health Organization Quality of Life – BREF (WHOQOL – BREF)<sup>(13)</sup> and the Burden Interview Scale<sup>(14)</sup>.

The sociodemographic characterization of the family caregiver considered the age, gender, level of education, degree of kinship with the baby, family income and city where he/she lives.

The perception of quality of life was evaluated through the World Health Organization Quality of Life – BREF (WHOQOL – BREF)<sup>(13)</sup>. The questionnaire contains 26 questions, two related to general quality of life and 24 distributed in four domains: Physical Health, Psychological, Social Relationships and Environment. Each domain has a score ranging from zero to 100, in which zero corresponds to the worst quality of life, and 100 to the best quality of life<sup>(13)</sup>.

The perception of burden of family caregivers was evaluated by the Portuguese version of the Burden Interview Scale<sup>(14)</sup>. The scale is composed of 22 items, each with a five-point ordinal scale (from zero to four). The total scale score can range from zero to 88. Higher the scores indicate greater the burden<sup>(14)</sup>.

### DATA ANALYSIS

Data were analyzed using the software IBM Statistical Package for Social Sciences (SPSS), version 21.0 for Windows. The Pearson's correlation test was used to verify the correlations between the measures of interest (quality of life, burden, age and family income).

The linear correlation coefficients between the variables were classified in three levels: values smaller than 0.30 indicate weak correlation and little clinical applicability, even when statistically significant; values between 0.30 and 0.50 indicate moderate correlation, and above 0.50, strong correlation<sup>(15)</sup>.

The mean scores of the WHOQOL – BREF domains were compared using the Student's t-test (according to the city where they lived) and the ANOVA (level of education). The significance level was set at 0.05.

## ETHICAL ASPECTS

The study began after obtaining approval from the Research Ethics Committee of the proposing institution, under protocol no. 960.936/2015, and agreement of the cooperating institution, under protocol no. 976.019/2015. The study was conducted according to the ethical standards required and in accordance with Resolution 466/2012 of the National Health Council.

Individuals who met the inclusion criteria were invited to participate in the research, and the objectives of the research were clarified in verbal and written form. All participants formalized their participation signing the Informed Consent Form.

## RESULTS

The participants of the study were 77 family caregivers, of which 74 (96.1%) were mothers. Participants had a mean age of 28.8 years (ranging from 18 to 48), secondary education (27.3%; n=21), and were predominantly from the state of São Paulo (54.5%; n=42) (Table 1).

**Table 1** – Socio-demographic characterization of family caregivers of infants with cleft lip and palate – Bauru, SP, Brazil, 2015.

Variables	Mean (SD) or % (N)
<b>Age (years)/Mean (SD)</b>	28.8 (7.1)
<b>Level of education</b>	
Complete elementary education	6.5 (05)
Incomplete elementary education	18.2 (14)
Complete secondary education	27.3 (21)
Incomplete secondary education	18.2 (14)
Complete higher education	20.8 (16)
Incomplete higher education	9.0 (07)
<b>Kinship</b>	
Mother	96.1 (74)
Other relatives	3.9 (03)
<b>Family income in MW*/Mean (SD)</b>	
Up to 2 MW	42.8 (33)
+ 2 to 4 MW	32.5 (25)
+ 4 to 9 MW	14.3 (11)
+ 9 to 15 MW	5.2 (4)
+ 15 MW	5.2 (4)
<b>Place of living</b>	
State of São Paulo	54.5 (42)
Other states	45.5 (35)

\*MW = Minimum wage (788.00 BRL, valid in the period of data collection).

The correlation between the measures of quality of life and the measures of burden showed an inverse association between the variables, indicating that, with the reduction of burden, the quality of life increased or vice versa. This correlation was observed in all quality of life domains: Physical Health ( $r=-0.283$ ;  $p=0.013$ ), Psychological ( $r=-0.498$ ;  $p<0.001$ ), Social Relationships ( $r=-0.434$ ;  $p<0.001$ ) and Environment ( $r=-0.344$ ;  $p=0.002$ ). The intensity of the correlation obtained was weak for the Physical Health domain, and moderate for the Psychological, Social Relationships and Environment domains. Regarding family income, there was a positive correlation of moderate intensity only with the Environment domain ( $r=0.419$ ;  $p<0.001$ ) (Table 2).

**Table 2** – Correlations between quality of life (WHOQOL – BREF domains) and burden (Burden Interview Scale), age and income of family caregivers of infants with cleft lip and palate – Bauru, SP, Brazil, 2015.

Domains / Variables	r	p*
<b>Domains / Burden</b>		
Physical HHhealth	<b>-0.283</b>	<b>0.013*</b>
Psychological	<b>-0.498</b>	<b>&lt;0.001*</b>
Social Relationships	<b>-0.434</b>	<b>&lt;0.001*</b>
Environment	<b>-0.344</b>	<b>0.002*</b>
<b>Domains / Age (years)</b>		
Physical Health	0.094	0.414
Psychological	-0.004	0.971
Social Relationships	-0.029	0.804
Environment	0.132	0.253
<b>Domains / Family income</b>		
Physical Health	-0.007	0.954
Psychological	-0.082	0.483
Social Relationships	-0.125	0.280
Environment	<b>0.419</b>	<b>&lt;0.001*</b>

\*Pearson's correlation coefficient.

There was no statistically significant relationship between the domains: Physical Health ( $p=0.78$ ), Psychological ( $p=0.64$ ), Social Relationships ( $p=0.89$ ) and Environment ( $p=0.58$ ) and the caregivers' place of living. Regarding the level of education, there was a difference only in the Environment Domain ( $p=0.019$ ), with mean values ranging from 56.5 (SD±16.7) to 72.8 (SD±8.8) for those caregivers who had incomplete secondary education and complete higher education, respectively.

## DISCUSSION

The results evidenced that the mother is the main provider of care, which is in accordance with the literature<sup>(2,5-6,11,16)</sup>. This demonstrates the importance of the family environment in the process of rehabilitation of the individual born with a malformation, since the perception of this process and the coping capacity are influenced by parents' expectations, attitudes and support<sup>(2)</sup>. Personal coping strategies

and the history of the relationship between the patient and the caregiver should be considered<sup>(17)</sup>.

The mean age found was 28 years, therefore the caregivers were young. Due to the several care measures required by infants with cleft lip and palate, family members have to exercise responsible roles, even at a young age. A stronger mother-child bond<sup>(18)</sup> may also justify this finding.

Regarding level of education, 45.5% (35) of the participants attended secondary school and 27.3% (21) concluded it. The prevalence of secondary education and low family income are corroborated in the literature<sup>(2,5-6,11,16)</sup>.

Low levels of education and unfavorable socioeconomic contexts can lead to caregiver overload and predispose them to stress<sup>(5)</sup>.

The correlation between quality of life and sociodemographic variables showed that caregivers who had incomplete secondary education and higher education presented a better perception of their quality of life in the Environment Domain. This domain also includes feelings of security, the home environment, availability and quality of health care, new information and skills and opportunities to acquire them, among other aspects<sup>(13)</sup>.

The majority of participants reported a family income of up to two minimum wage. Studies performed at the same institution showed that most families belonged to the low<sup>(11,19)</sup> and lower middle classes, reflecting the Brazilian reality<sup>(2)</sup>.

Most caregivers were from cities in São Paulo state. This result is probably related to the location of the institution in that state. It is a public hospital recognized by the World Health Organization as a center of excellence for the treatment of craniofacial anomalies and related syndromes and a national and international reference<sup>(1,20)</sup>.

The correlation between the measures of quality of life (WHOQOL – Bref domains) and the measures of burden (Burden Interview Scale) showed an inverse relationship between the variables, indicating that, with the reduction of the burden, the quality of life increased or vice versa, in all areas of the WHOQOL - BREF. The negative correlation with the burden was stronger in the Psychological domain than in the other domains, that is, this correlation was more evident in the Psychological domain and less evident in the Physical Health domain. However, all the four quality of life domains were correlated with burden.

A comparative study on the quality of life of families with children born with cleft lip and palate before and after the surgical treatment showed that caring for children with cleft lip and palate significantly reduces the quality of life of family caregivers in all the domains, before the surgery. The most pronounced impacts, which most affected quality of life, were in the financial and social domains. Caregivers of children with cleft lip and palate need support from society, health professionals, friends and relatives<sup>(12)</sup>.

A study pointed out the need to support families of children with cleft lip and palate beyond the support from the health system, which should provide quality care, including guidance and training to parents and caregivers. The study also pointed out the need for education and training

of health professionals outside specialized centers, for public awareness-raising activities on birth defects and for social support programs<sup>(21)</sup>.

The family caregiver is usually unprepared for the care and its inherent burden. It is commonly a new and sudden situation that requires some preparation. Accepting, supporting and clarifying questions are essential for the caregiver to acquire new knowledge and skills<sup>(22)</sup>.

Counseling sessions should be organized soon after birth to improve the quality of life of family caregivers. This will provide an opportunity to discuss the plans established and to support their care<sup>(23)</sup>. Caring for a loved one can be more meaningful and rewarding than the social losses caused by the overburden. However, caring for a dependent family member at home can bring changes in the physical, psychological and social aspects of the caregiver<sup>(18)</sup>.

A research revealed a significant association between caregiver overload and quality of life among family caregivers of patients with schizophrenia and pointed out predictors of quality of life, such as overburden, social support and professional support<sup>(24)</sup>.

Therefore, a better support leads to a faster and better adaptation of the family of the child with cleft lip and palate<sup>(3)</sup>. Including the strengthening of the bond between mother and child<sup>(19)</sup> to these factors, it is inferred that the findings of the present study explain the greater correlation with the Psychological domain and the smaller correlation with the Physical Health domain, as well as the inverse relationship between burden and quality of life.

The explanatory factors associated with increased caregiver burden and poorer perception of quality of life are relevant for identifying families at risk and for developing interventions<sup>(25)</sup>. Parents, like many other caregivers, are very dedicated to provide well-being to their children, but their own well-being and health are often neglected<sup>(25)</sup>.

Regarding age, negative correlations were identified in a study with family caregivers of individuals with spinal cord injury. A worse health-related quality of life was associated with age, that is, the older the family caregiver, the worse their quality of life<sup>(10)</sup>.

In contrast, a study with family caregivers of people with special needs pointed out that the age of the caregiver did not affect quality of life. The primary caregiver is the person who spends more time caring for the person with special needs. Therefore, this caregiver is subject to physical, psychological or emotional fatigue related to their overburden<sup>(26)</sup>.

Rarer and more complex diseases require more specialist advice. Lack of information about the patient and resource deficits in some centers may have adverse impacts on the patients' quality of life and on the heavy economic and social burden borne by patients and their families<sup>(27)</sup>.

Overburden can be associated with physical, emotional, social and financial suffering<sup>(5)</sup>. Programs to prevent overburden and negative emotional impact can positively affect the health and quality of life of dependent individuals and their caregivers. Educational interventions for preparing caregivers and promoting well-being deserve special attention from health professionals. In the care context, nurses

are responsible for planning care, considering the individual needs of each patient and the family caregiver. This includes the preparation of educational interventions aiming at the continuity of care<sup>(10)</sup>.

It is believed that the present study contributed to the evaluation of quality of life and overburden of family caregivers of infants with cleft lip and palate. This will allow the multidisciplinary team to plan and implement actions that address the self-care and quality of life of these informal caregivers, since patients, family members and caregivers must be integrated in the same care context.

Cleft lip and palate are among the most frequent congenital malformations, and healthcare guidance is fundamental for the construction of knowledge among mothers<sup>(28)</sup>. Therefore, identifying the areas with the greatest deficiency allows for a review of the intervention proposals, with the aim of improving the quality of care and, consequently, promoting health<sup>(29)</sup>.

It is important to conduct periodic evaluations of the quality of life and the burden of family caregivers of infants with cleft lip and palate, with the purpose of reducing their overburden and improving their quality of life.

Thus, the hypothesis of the present study was confirmed. It is possible to affirm, according to the results, that there is an inverse correlation between measures of quality of life and burden of family caregivers of infants with cleft lip and palate.

## CONCLUSION

The study found positive results regarding quality of life and burden of family caregivers of infants with non-operated cleft lip and palate. However, the age criteria and the research within a single institution can be considered limitations in the present study, since they do not allow the generalization of the results. In this context, multicenter studies with caregiver of children with cleft lip and palate in different age groups should be conducted.

The evaluation of quality of life and burden of family caregivers of infants with cleft lip and palate showed an inverse correlation between quality of life and burden, i.e., the greater the burden on the caregiver, the lower was their perception of quality of life. Caregivers with higher family income and greater level of education presented a better perception of the quality of life in the Environment domain.

## RESUMO

**Objetivo:** Avaliar a correlação entre as medidas de qualidade de vida e sobrecarga em cuidadores familiares de bebês com fissura labiopalatina, e analisar possíveis relações entre a qualidade de vida e as variáveis sociodemográficas. **Método:** Estudo exploratório, transversal, realizado em um hospital de referência no tratamento de anomalias craneofaciais, com cuidadores que responderam aos seguintes instrumentos de coleta dos dados: formulário para caracterização sociodemográfica, questionário *World Health Organization Quality of Life – Bref* e escala *Burden Interview*. Para a análise estatística foram utilizados os testes de Correlação de Pearson, t de Student e Anova, com nível de significância de 0,05. **Resultados:** Participaram 77 cuidadores. Constatou-se correlação inversa entre as medidas de qualidade de vida e sobrecarga nos domínios Físico, Psicológico, Relações Sociais e Meio Ambiente. Entre qualidade de vida e renda familiar, verificou-se correlação positiva com o domínio Meio Ambiente. **Conclusão:** No grupo estudado, quanto maior era a sobrecarga da cuidadora, menor era a sua percepção da qualidade de vida. Cuidadores com maior renda familiar e maior escolaridade apresentaram melhor percepção da qualidade de vida referente ao domínio Meio Ambiente.

## DESCRIPTORIOS

Qualidade de Vida; Cuidadores; Fenda Labial; Fissura Palatina.

## RESUMEN

**Objetivo:** Evaluar la correlación entre las medidas de calidad de vida y sobrecarga en cuidadores familiares de bebés con fisura labiopalatina y analizar posibles relaciones entre la calidad de vida y las variables sociodemográficas. **Método:** Estudio exploratorio, transversal, realizado en un hospital de referencia en el tratamiento de anomalías craneofaciales, con cuidadores que respondieron a los siguientes instrumentos de recolección de datos: formulario para caracterización sociodemográfica, cuestionario *World Health Organization Quality of Life – Bref* y escala *Burden Interview*. Para el análisis estadístico se utilizaron las pruebas de Correlación de Pearson, t de Student y Anova, con nivel de significación de 0,05. **Resultados:** Participaron 77 cuidadores. Se constató correlación inversa entre las medidas de calidad de vida y sobrecarga en los dominios Físico, Psicológico, Relaciones Sociales y Medio Ambiente. Entre calidad de vida e ingresos familiares, se verificó correlación positiva con el dominio Medio Ambiente. **Conclusión:** En el grupo estudiado, cuanto mayor era la sobrecarga de la cuidadora, tanto menor era su percepción de la calidad de vida. Cuidadores con mayores ingresos familiares y mayor estabilidad presentaron mejor percepción de la calidad de vida referente al dominio Medio Ambiente.

## DESCRIPTORIOS

Calidad de Vida; Cuidadores; Labio Leporino; Fissura del Paladar.

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