Original Article

TEXTO & CONTEXTO ENFERMAGEM
TEXT & CONTEXT NURSING TEXTO & CONTEXTO ENFERMERÍA

STRESS, OVERLOAD AND QUALITY OF LIFE IN CAREGIVERS OF CHILDREN WITH/WITHOUT OROFACIAL CLEFT AND DYSPHAGIA

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ABSTRACT

Objective: to analyze the correlation between stress, overload and quality of life of informal caregivers of children with and without orofacial cleft and dysphagia.
Method: a cross-sectional, case-control study carried out in a public and tertiary hospital, located in the inland of São Paulo, Brazil, which encompassed two groups: case and comparative. The case group consisted of 30 informal caregivers of children with orofacial cleft and dysphagia, using a feeding tube, while the comparative group consisted of 30 informal caregivers of children without orofacial cleft, fed orally. For data collection, the Bourden Interview Scale, Inventory of Stress Symptoms for Adults and the World Health Organization Quality of Life Bref were used. For statistical analysis, the following tests were used: chi-square, Student's t, Mann-Whitney and Pearson's correlation, all with a 5% significance level. Analysis of the linear correlation forces was also used.
Results: in the case group, stress presented a moderate correlation with the overall quality of life (r=-0.41; p=0.025) and satisfaction with health (r=-0.42; p=0.021). Also in the case group, referring to quality of life, the Physical and Psychological domains presented a strong correlation with overload (r=-0.54, p=0.002; r=-0.55, p=0.002, respectively). In the comparative group, no correlations were identified.
Conclusion: among the informal caregivers of children with orofacial cleft and dysphagia, there was a correlation between stress and the perception of global quality of life and satisfaction with health, as well as between overload and quality of life, in the physical and psychological dimensions.

DESCRIPTORS: Psychological stress. Overload. Quality of life. Caregivers. Cleft lip. Cleft palate. Swallowing disorders. Nursing.

HOW CITED: Bom GC, Prado PC, Farinha FT, Manso MMFG, Dutka, Trettene AS. Stress, overload and quality of life in caregivers of children with/without orofacial cleft and dysphagia. Texto Contexto Enferm [Internet]. 2021 [cited YEAR MONTH DAY]; 30:e20200165. Available from: https://doi.org/10.1590/1980-265X-TCE-2020-0165

ESTRESSE, SOBRECARGA E QUALIDADE DE VIDA EM CUIDADORES DE CRIANÇAS COM/SEM FISSURA OROFACIAL E DISFAGIA

RESUMO

Objetivo: analisar a correlação entre o estresse, a sobrecarga e a qualidade de vida de cuidadores informais de crianças com e sem fissura orofacial e disfagia.
Método: estudo transversal, do tipo caso-controle, realizado em um hospital público e terciário, situado no interior de São Paulo, Brasil, que englobou dois grupos: caso e comparativo. O grupo-caso constou de 30 cuidadores informais de crianças com fissura orofacial e disfagia, em uso de sonda alimentadora, enquanto o comparativo foi composto por 30 cuidadores informais de crianças sem fissura orofacial, alimentadas por via oral. Para a coleta de dados, utilizou-se a Escala de Bourden Interview, Inventário de Sintomas de Stress para Adultos e o *World Health Organization Quality of Life Bref*. Para a análise estatística, utilizaram-se os testes: qui-quadrado, *t* de Student, Mann-Whitney e de correlação de Pearson, todos com nível de significância de 5%. Usou-se, ainda, a análise das forças de correlação linear.
Resultados: no grupo-caso, o estresse apresentou moderada correlação com a qualidade de vida global (r=-0,41; p=0,025) e satisfação com a saúde (r=-0,42; p=0,021). Ainda no grupo-caso, referente à qualidade de vida, os domínios Físico e Psicológico apresentaram forte correlação com a sobrecarga (r=-0,54, p=0,002; r=-0,55, p=0,002 respectivamente). No grupo comparativo, não foram identificadas correlações.
Conclusão: entre os cuidadores informais de crianças com fissura orofacial e disfagia, evidenciou-se correlação entre o estresse e a percepção da qualidade de vida global e da satisfação com a saúde, bem como entre a sobrecarga e a qualidade de vida, nas dimensões física e psicológica.

DESCRITORES: Estresse psicológico. Sobrecarga. Qualidade de vida. Cuidadores. Fenda labial.
Fissura palatina. Transtornos de deglutição. Enfermagem.

ESTRÉS, SOBRECARGA Y CALIDAD DE VIDA DE CUIDADORES DE NIÑOS CON/SIN HENDIDURA OROFACIAL Y DISFAGIA

RESUMEN

Objetivo: analizar la correlación entre estrés, sobrecarga y calidad de vida de cuidadores informales de niños con y sin hendidura orofacial y disfagia.
Método: estudio transversal, de tipo caso-control, realizado en un hospital público terciario, ubicado en el interior de São Paulo, Brasil, que abarcó dos grupos: caso y control. El grupo de casos estaba compuesto por 30 cuidadores informales de niños con hendidura orofacial y disfagia, que utilizaban una sonda de alimentación, mientras que el grupo control se conformó por 30 cuidadores informales de niños sin hendidura orofacial, alimentados por vía oral. Para la recolección de datos se utilizó la Escala Bourden *Interview*, el Inventario de Síntomas de Estrés para Adultos y el Cuestionario de Calidad de Vida de la Organización Mundial de la Salud (WHOQOL-BREF). Para el análisis estadístico se utilizaron las siguientes pruebas: chi-cuadrado, t de Student, pruebas de correlación de Mann-Whitney y Pearson, todas con un nivel de significancia del 5%. También se utilizó el análisis de fuerzas de correlación lineal.
Resultados: en el grupo de casos, el estrés presentó una correlación moderada con la calidad de vida global (r = -0,41; p = 0,025) y la satisfacción con la salud (r = -0,42; p = 0,021). En el grupo de casos, en relación a la calidad de vida, los dominios Físico y Psicológico mostraron una fuerte correlación con la sobrecarga (r = -0,54, p = 0,002; r = -0,55, p = 0,002 respectivamente). En el grupo control, no se identificaron correlaciones.
Conclusión: entre los cuidadores informales de niños con hendidura orofacial y disfagia, hubo correlación entre el estrés y la percepción de calidad de vida global y satisfacción con la salud, así como entre sobrecarga y calidad de vida, en las dimensiones física y psicológica.

DESCRIPTORES: Estrés psicológico. Sobrecarga. Calidad de vida. Cuidadores. Labio leporino.
Fisura palatina. Trastornos de la deglución. Enfermería.

INTRODUCTION

Orofacial fissures are the most common non-syndromic malformations of craniofacial involvement. With a multifactorial etiology, the incidence of 1:650 live births is admitted in Brazil. They can lead to functional, aesthetic and psychosocial problems[1–2].

In newborns and infants, the implications are related to functional difficulties, in particular those related to feeding, which include ineffective lip sealing, insufficient sucking due to the absence of intraoral pressure, nasal reflux of food and prolonged feeding time[3–4].

Although oral feeding is not contraindicated due to the sucking and swallowing reflexes being preserved, in some cases, especially those associated with genetic syndromes and/or clinical problems, these children can present oropharyngeal dysphagia, whose symptomatology includes from cough and choking to bronchoaspirations and low weight gain[1,3]. Thus, the feeding process becomes difficult for these children and frustrating for their parents and/or caregivers.

Associated with this, it is frequently necessary to use feeding tubes, which will allow children to have a clinical condition compatible with their recovery and survival[3–4]. Their use does not contraindicate hospital discharge; however, caregivers must receive training to ensure care continuity at the residence, which includes the child's upright positioning continuously, preparation and administration of the diet, maintenance of the permeability of the probe, proper fixation of the probe, nasal and oral hygiene, and monitoring of complications such as nausea, vomiting, diarrhea, bloating and gastroesophageal reflux, among others[5–6].

In general, the responsibility for the care of the child is assumed by the parents or family members who do not have scientific training to do so. Faced with this new reality, the caregiver is in front of a universe that goes beyond the care demands, being able to experience negative feelings and difficulties related to new responsibilities[7–9].

Thus, the act of caring, with the responsibilities that are inherent to it, can represent an exhaustive task. Added to this is the fact that caregivers sometimes neglect their own health and self-care to care for their children. These factors in association can cause, in the short and medium term, overload and/or stress that will influence the quality of care provided and the perception of quality of life[10–11].

In short, family-centered care models are needed to support the family unit in caring for a child with dysphagia and/or with eating difficulties. The parents and the informal caregivers must be included in the process and receive monitoring of their physical and mental well-being[12–13].

However, it is emphasized that the act of caring for a child, even without comorbidities, such as orofacial cleft and dysphagia, demands time and responsibility, that is, these caregivers are also susceptible to developing stress and overload, with negative influences in their quality of life[14]. Thus, aiming at more reliable and independent results, in this study it was decided to compare informal caregivers of children with orofacial cleft and dysphagia to caregivers of children without these alterations.

In view of the above, it was sought to answer the following questions: do informal caregivers of children with and without orofacial cleft and dysphagia suffer from stress and overload? Do overload and stress influence the perception of quality of life? Comparatively, is there a difference between these variables in caregivers of children with and without orofacial cleft and dysphagia?

Considering the vulnerability of these informal caregivers, as well as their exposure to stressors and overload factors, it is relevant to understand the influence of these variables on the perception of their quality of life. In this sense, the importance of covering caregivers in the context of Nursing care is emphasized, since their health and well-being directly influence the quality of care provided and, in turn, the rehabilitation process.

Thus, the aim of this study was to analyze the correlation between stress, overload and quality of life for informal caregivers of children with and without orofacial cleft and dysphagia.

METHOD

A cross-sectional, case-control study carried out in a public and tertiary hospital, a reference in the care of patients with craniofacial anomalies and related syndromes, located in the inland of the state of São Paulo, Brazil.

As previously mentioned, for the purpose of comparison, two groups were listed: case and comparative. The population of the case group comprised informal caregivers aged 18 years or older of children aged 0 to 1 year, 11 months and 29 days old, fed exclusively by a feeding tube and who had necessarily been discharged to their homes before the research, characterizing the provision of home care by the caregiver and enabling the assessment of overload, stress and quality of life.

In contrast, the comparative group comprised informal caregivers aged 18 years or older, of children aged 0 to 1 year, 11 months and 29 days old, who did not have orofacial cleft or other clinical comorbidities and genetic syndromes, accompanied in a childcare program of a municipality in the inland of the state of São Paulo, Brazil. This choice was due to the population presenting similar sociodemographic characteristics to the case group, which made the comparison between groups possible and viable.

In both groups, informal caregivers using psychiatric drugs (such as antidepressants, anxiolytics, antipsychotics and mood stabilizers) and caregivers of children with neuropsychomotor impairment were excluded.

For sample calculation, the following was considered: percentage of overload and stress to be detected of 45%[15], test power of 90%, and error of 5%. Thus, 30 participants were estimated, that is, the sample consisted of 60 caregivers, 30 for the case group and 30 for the comparative group.

Data collection was initiated after approval by the Committee of Ethics in Research involving human beings of the institution. All the participants formalized their adherence to the study by signing the Free and Informed Consent Form, in line with Resolution 466/12 of the National Health Council.

For data collection, four instruments were used, namely: Sociodemographic Questionnaire, LIPP's Stress Symptoms Inventory for Adults (LSSI), Bourden Interview Scale to assess overload and the World Health Organization Quality of Life - WHOQOL-Bref to assess quality of life[16–18].

The Sociodemographic Questionnaire was used to characterize the participants according to the following variables: age, gender, schooling, socioeconomic classification[19], number of children and marital/emotional status.

The perception of quality of life was assessed using the WHOQOL-Bref. It consists of 26 questions, the first of which refers to quality of life in general; and the second, to satisfaction with the participants' own health. The other 24 questions are divided into four domains: Physical, Psychological, Social Relations and Environment. Each domain has a score ranging from 0 to 100, where 0 corresponds to the worst quality of life; and 100, to the best quality of life[18].

LIPP's Stress Symptoms Inventory for Adults aims to identify, in an objective manner, the stress symptoms, the psychological or somatic types, and the stage in which the participant is (alertness, resistance, near-exhaustion and exhaustion). It consists of three charts with questions regarding the symptoms observed in the four phases of stress, in which the subjects will indicate which symptoms they have experienced in the last 24 hours, in the last week and in the last month[16].

Finally, to evaluate overload, the Bourden Interview Scale was used. Developed for the purpose of assessing the overload of informal caregivers, it has been translated and validated for the Brazilian population. It consists in 22 items, with answers scored in a range from 0 to 4 points. The classification occurs as follows: 0 to 21 points, no overload; valuesbetween 21 and 40 points indicate moderate overload; between 41 and 60, moderate to severe overload; and equal to or above 61 points, severe overload[17].

For the case group, the information regarding the inclusion and exclusion criteria was obtained by consulting the medical records, as well as that relating to the sociodemographic characterization. For the comparative group, the information was obtained through an interview conducted individually and in a private environment.

Data collection was carried out between the months of January and June 2017, with the participants of the case group during the hospitalization period of the children, individually, and outside the hours when the caregivers were in the hospital. For the comparative group, the approach took place in a private room, and data collection was conducted before the medical appointment with the pediatrician. Data collection lasted a mean of 40 minutes.

The data were analyzed using the IBM Statistical Package for Social Sciences (SPSS) program®, version 21.0 for Windows. For the statistical analysis of the sociodemographic variables, gender and age, the chi-square and Student's t tests were used. In order to compare stress, overload and quality of life between the groups, the Mann-Whitney test was used. In order to correlate stress and overload with quality of life, Pearson's correlation was used. The significance level adopted for all tests was 5% ($p \leq 0.05$). In addition, the analysis of linear correlation forces was used, in which a correlation below 0.30 indicates weak correlation, from 0.30 to 0.50, moderate correlation; and above 0.50, strong correlation[20].

RESULTS

Regarding the characterization of the groups, there was no statistically significant difference between them, indicating homogeneity (Table 1).

Table 1 – Sociodemographic characteristics of the participants in the case group and comparative group. Bauru, SP, Brazil, 2017. (n=60)

Variables		**Case**		**Comparative**		***p*-value**
		n	**%**	**n**	**%**	
Gender	Male	–	–	02	7	0.472[*]
	Female	30	100	28	93	
Age	25 years old (±1.8)	30	100	–	–	
	26 years old (±2.2)	–	–	30	100	
	Complete higher education	9	30	8	27	0.177[*]
Schooling	Incomplete high school	03	10	0	0	
	Complete high school	18	60	22	73	
Marital status	Single	05	16	03	10	0.704[*]
	Stable union	25	83	27	90	
Social classification	Lower low	09	30	06	20	
	Upper low	16	53	16	54	
	Lower mid	05	17	3	10	0.475[*]
	Mid	–	–	2	6	
	Upper mid	–	–	3	10	

[*] Chi-square test; [†] Student's *t* test; Significance level adopted: 5% ($p \leq 0.05$).

Stress was significantly higher in the case group (p=0.001), with predominance of the resistance phase (80%; n=20) and psychological symptoms (72%; n=28). As for overload, although present in both groups (case and comparative) at a moderate level, there was no statistically significant difference between them (p=0.147) (Table 2).

Table 2 – Analysis and comparison of stress and overload in the case group and comparative group. Bauru, SP, Brazil, 2017. (n=60)

Variables	Groups	n	Median	Q1	Q3	Mean	SD§	*p*-value
Stress	Case	30	4.1	2.8	6.2	4.7	2.3	< 0.001*
	Comparative	30	2.4	1.7	3.4	2.8	1.8	
Overload	Case	30	25.0	23.0	29.3	25.1	6.4	0.147
	Comparative	30	22.0	13.5	28.0	22.2	10.7	

§SD: Standard Deviation; *Mann-Whitney test, with a significance level adopted at 5% (p ≤ 0.05).

When assessing the global perception of quality of life and satisfaction with health, it was observed that the case group presented lower median values whencompared to the comparative group (p=0.005 and p=0.026, respectively). Regarding quality of life, it was verified that the case group presented lower median valuesin the Psychological (p=0.016), Social Relations (p=0.017) and Environment (p<0.001) domains (Table 3).

Table 3 – Analysis of quality of life in the case group and in the comparative group. Bauru, SP, Brazil, 2017. (n=60)

Domains	Groups	n	Median	Q1	Q3	Mean	Standard deviation	p-value
Physical	Case	30	63.0	38.8	75.0	59.8	19.1	0.057
	Comparative	30	69.0	54.5	81.0	68.9	16.8	
Psychological	Case	30	56.0	44.0	70.5	56.5	17.3	0.016*
	Comparative	30	69.0	56.0	75.0	67.8	12.1	
Social Relations	Case	30	62.5	50.0	69.0	58.0	19.0	0.017*
	Comparative	40	75.0	56.0	81.0	67.6	19.9	
Environment	Case	30	50.0	44.0	56.0	52.0	12.8	< 0.001*
	Comparative	30	66.0	54.5	75.0	64.3	12.4	
Global quality of life	Case	30	4.0	3.0	4.0	3.6	0.8	0.005*
	Comparative	30	4.0	4.0	4.3	4.1	0.6	
General perception of health	Case	30	3.5	2.0	4.0	3.3	1.1	0.026*
	Comparative	30	4.0	3.0	4.0	3.9	0.9	

*Mann-Whitney test, with a significance level adopted at 5% (p ≤ 0.05).

When correlating stress and overload with quality of life in the case group, there was a weak correlation between them (r=0.21; p=0.269). Stress showed a moderate correlation with global quality of life (r=-0.41; p=0.025) and satisfaction with health (r=-0.42; p=0.021). The Physical and Psychological domains presented a strong correlation with overload (r=-0,54, p=0,002; r=-0,55, p=0,002 respectively) (Table 4).

Table 4 – Correlation between stress, overload and quality of life in the case group. Bauru, SP, Brazil, 2017. (n=60)

Correlation variables	r[†]	Correlation[‡]	p-value§
Stress/Overload	0.21	Weak	< 0.269
QoL domains*/Stress			
Physical	0.10	Weak	0.269
Psychological	-0.13	Weak	0.582
Social Relations	0.16	Weak	0.479
Environment	0.26	Weak	0.399
Global quality of life	-0.41	Moderate	0.025§
General perception of health	-0.42	Moderate	0.021§
QoL domains*/Overload			
Physical	-0.54	Strong	0.002§
Psychological	-0.55	Strong	0.002§
Social Relations	-0.31	Moderate	0.094
Environment	-0.28	Weak	0.136
Global quality of life	-0.22	Weak	0.233
General perception of health	-0.22	Weak	0.248

*QoL: Quality of life; [†]Spearman' correlation; [‡]Analysis of linear correlation forces; [§]Significance level adopted at 5% ($p \leq 0.05$).

DISCUSSION

When correlating stress with quality of life, a moderate correlation was noticed with the individual's perception of their overall quality of life, as well as with the individual's satisfaction with their health. These results reinforce the hypothesis that the care demands required by the condition of the child with orofacial cleft and dysphagia, using a feeding tube, is a stressor for the informal caregivers, with a negative influence on the perception of quality of life.

In this sense, a study carried out in South Africa pointed out that the burden of caring for a child with orofacial cleft was mainly related to the dietary difficulties experienced and to the need for countless returns or visits to the hospital, with consequent stress on the caregivers[4].

It is noteworthy that the accidental exit or displacement of the feeding tube is an important concern in the context of care for dysphagic children, with the need for medical and/or nursing care for their recovery. In fact, frequent visits to hospitals increased the family's stress and anxiety[21]. Thus, the training of caregivers aiming at their preparation for hospital discharge, that is, for care continuity at the residence, must be established as a priority, since the level of care ability, among other factors, influences the overload and stress levels[22].

Another research study that included informal caregivers of infants with orofacial cleft, dysphagia and who were fed by tube indicated that the mothers, for assuming the integral care of these children, either because they do not receive support or because they do not trust the provision of care provided by other people, felt overloaded and stressed[13].

Another study carried out with informal caregivers of infants with a Robin sequence, which is characterized by micrognathia, glossoptosis and cleft palate in 90% of the cases, pointed out that 45% of them presented stress, with a predominance of the resistance phase and psychological symptoms. It is noteworthy that these infants, especially in the first months of life, use a feeding tube[6]. In addition to that, different studies have pointed out high stress levels among informal caregivers of children, including those with cancer and sickle cell disease[23–24].

The resistance phase, prevalent among the participants of this study, indicates that the individual is chronically exposed to a stressor and has not developed compensatory mechanisms, presenting a tendency to tiredness, declining disposition and memory failures[16]. Therefore, it is necessary to develop and implement actions that favor welcoming, address the needs of the families, and include the psychological assessment of these informal caregivers[25].

Although it was not the object of this study, it is inferred that the participants' sociodemographic characteristics can be related to the results herein evidenced, such as the fact that all the informal caregivers in this study were mothers.

They, whose children have special needs, sometimes feel guilty and, as a result, have difficulty dividing tasks related to care, preferring to centralize and manage them, which certainly contributes to the development of stress and overload, with an influence on the perception of their quality of life. Added to this, the fact that the woman performs several activities, which, in the case of mothers, in addition to managing the house, obligations with other children and with the spouse, sometimes need to perform work activities to ensure the provision necessary for the family[3,6].

A study carried out with parents of children diagnosed with congenital anomalies evidenced that the mothers presented more difficulties in emotional adjustment compared to the fathers, with a worse perception of quality of life, as they fully assume the care of their child. They also felt overloaded, often depriving themselves of social life[26].

In this sense, the active participation of the family in relation to the care of the child, in association with psychological monitoring at the family level, emerge as alternatives to reduce stress and favor the physical and mental health of the caregivers[27].

Other results that draw the attention refer to the mean age of the participants, which was 25 years old, and to the low socioeconomic class, prevalent among the participants. Although young, these caregivers play roles that show great responsibility and need for full dedication, causing lack of time to perform routine activities, including recreational and self-care, with implications for family and social life[3,6,13].

An unfavorable socioeconomic condition can influence care quality and maintenance in the home environment since, to provide it, specific materials, diets and other supplies are necessary, which are costly to the families. In fact, difficulties related to the acquisition of materials, as well as financial, frequently contribute to increased stress and overload[6,13].

Thus, Nursing, together with the health team, must act and interact in favor of an effective articulation and integration between the family and all the health professionals and/or institutions involved in care, aiming to guarantee the conditions for its continuity[28].

Also referring to stress, psychological symptoms prevailed, indicating that caregivers could be experiencing feelings such as excessive irritability, excessive tiredness, anguish, anxiety and emotional hypersensitivity[16]. It is at this stage that people can present a fixed idea regarding some subject matter, which in this study refers to the condition of the child with the malformation associated with feeding difficulties and use of the feeding tube.

Therefore, it is believed that these conditions may alter the individual's perceptual capacity, including that of their own health and overall quality of life, since the fact that informal caregivers present psychological symptoms can negatively influence both their quality of life and their ability to offer welcoming and answering to the care demands required by the children, which may compromise their ability to cope with situations[10,29].

In fact, the care provided to the child using a feeding tube is a condition that enables feelings and emotional reactions of fears, uncertainties and concerns[6,13].

When the relationship between overload and quality of life was made, a strong correlation was verified with the Physical and Psychological domains. A similar result was observed in another study carried out with informal caregivers who are part of a family health program, pointing out that the greater the overload, the lower the caregiver's satisfaction with their own health and quality of life, that is, individuals more overloaded by the task have a worse perception of their quality of life[30]. Another research study that included 224 informal female caregivers demonstrated that overload was negatively correlated with quality of life[31]. In addition, a research study pointed out that high levels of anxiety, depression and overload negatively influence the quality of life scores of informal caregivers[32].

The Physical and Psychological domains include satisfaction with sleep, with the development of daily activities, willingness to self-care and the ability to work[18]. In this sense, it is emphasized that the care of the dysphagic child requires constant surveillance from the caregiver, that is, there is a need, for example, to prepare and install the diet during the night, which affects sleep quality and, chronically, affects the activities of daily living, such as self-care. It is frequently observed that informal caregivers stop exercising professional activities, devoting themselves almost exclusively to providing care[3,6,13].

In addition, in this study, it was evidenced that the caregivers presented a moderate level of overload, which can indicate the need for support in the care process, whether from the family or from society, or be related to the need, not always expressed, for clarifications about the care the child needs. It is noteworthy that this result was observed among caregivers in the case and comparative groups, pointing out that the act of caring for the child, even without comorbidities, can generate overload.

High levels of overload can be associated with exhaustive care demands, lack of time to perform recreational activities and social interaction, which can cause family conflicts, loneliness and exclusion, which will have an impact on the physical and psychological conditions of those who provide care[15,17].

In fact, informal caregivers present higher levels of overload when compared to formal caregivers because they do not have the experiences, knowledge and skills acquired in professional training[33]. They also tend to isolate themselves socially, reducing the support they could receive from society.

Although the entire family is affected by the disease, disability or limitation of one of its members, in most cases the primary caregiver takes care of the patient in the physical and emotional sphere. Thus, the inherent overload experienced in a chronic way can manifest itself through physical and psychological problems, with the possibility of influencing the type of care that the patient starts to receive. Therefore, special attention must be paid to the caregivers, who can sometimes become ill when faced with the care demand imposed on them[34].

In this sense, some actions have shown to be promising. Among them, family-centered care, which consists of a care model in which the main focus of attention is the individuals and their family, and not merely the disease. In other words, the family is the essential source of support[35].

In addition, another health care practice refers to long-term therapeutic relationships between health professionals and users, based on the creation of bonds from the perspective of longitudinal care[36].

Finally, since this research includes a single center and a cross-sectional design, cause and effect relationships are not allowed, nor is the generalization of results, constituting limitations of this study. Thus, the performance of multicenter and prospective studies is encouraged, aiming to consolidate the results herein signed.

However, the contributions of this research to the clinical practice are evident and include the strengthening of the hypothesis that informal caregivers present stress and overload in view of the care burden imposed on them; and that these variables influence the perception of their quality of life and their health in general. It is noteworthy that this situation can have a negative impact on the quality of care provided and, in turn, on the children's rehabilitation process.

Thus, turning the attention to the caregivers by understanding the physical, social and emotional barriers involved in the act of caring becomes essential to provide them with better quality of life, as well as to provide quality results in the care they provide. In summary, family-centered Nursing care is urgent and indispensable.

CONCLUSION

Among the informal caregivers of children with orofacial cleft and dysphagia, compared to informal caregivers of children without these alterations, there was a moderate correlation between stress, the perception of global quality of life and satisfaction with health and overload with the perception of quality of life, in the physical and psychological dimensions.

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NOTES

ORIGIN OF THE ARTICLE

Extracted from the dissertation - Informal caregivers of children with cleft lip and palate, dysphagia, using a feeding tube: correlation between stress, overload and quality of life, presented to the Graduate Program in Rehabilitation Sciences of the Hospital for the Rehabilitation of Craniofacial Anomalies, *Universidade de São Paulo*, in 2018

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APPROVAL OF ETHICS COMMITTEE IN RESEARCH

Approved in the Research Ethics Committee of the Hospital for the Rehabilitation of Craniofacial Anomalies, opinion No.1,867,446/2017, Certificate of Presentation for Ethical Appreciation: 62380016.0.0000.5441.

CONFLICT OF INTEREST

There is no conflict of interest.

EDITORS

Associated Editors: Selma Regina de Andrade, Gisele Cristina Manfrini, Elisiane Lorenzini, Monica Motta Lino.
Editor-in-chief: Roberta Costa.

HISTORICAL

Received: May 11, 2020.
Approved: August 12, 2020.

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