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ORIGINAL ARTICLE

STRESS AND OVERLOAD IN INFORMATIVE CARE OF CHILDREN WITH ISOLATED ROBIN SEQUENCE

ESTRESSE E SOBRECARGA EM CUIDADORES INFORMAIS DE CRIANÇAS COM SEQUÊNCIA DE ROBIN ISOLADA

ESTRÉS Y SOBRECARGA EN CUIDADORES INFORMALES DE NIÑOS CON SECUENCIA DE ROBIN AISLADA

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ABSTRACT

Objective: to investigate the association between stress and overload in informal caregivers of infants with Isolated Robin Sequence. **Method:** cross-sectional study, developed at the Hospital for Rehabilitation of Craniofacial Anomalies. The sample consisted of 20 caregivers. The Lipp Adult Stress and Symptom Scale and the Burden Interview Scale were used for evaluation. **Results:** 45% had stress and 45% had overload. Among those who presented stress, 45% were in the resistance phase, with a predominance of psychological symptoms (30%). As for the overload, 40% presented moderate level. It was evidenced that 67% of the caregivers presented an association between overload and stress. **Conclusion:** most caregivers presented no stress or overload. However, it was observed an association between stress and overload, demonstrating the need for interventions that minimize this phenomenon. **Descriptors:** Nursing; Caregiver; Overload; Stress.

RESUMO

Objetivo: investigar a associação estresse e sobrecarga em cuidadores informais de lactentes com Sequência de Robin Isolada. **Método:** estudo transversal desenvolvido no Hospital de Reabilitação de Anomalias Craniofaciais. A amostra constou de 20 cuidadores. Para a avaliação, foram utilizadas a Escala de Sintomas e Estresse em Adultos de Lipp e a Escala de *Burden Interview*. **Resultados:** dos participantes, 45% apresentaram estresse e 45%, sobrecarga. Dentre os que apresentaram estresse, 45% encontraram-se na fase de resistência, com predomínio dos sintomas psicológicos (30%). Quanto à sobrecarga, 40% apresentaram nível moderado. Evidenciou-se que 67% dos cuidadores apresentaram associação entre sobrecarga e estresse. **Conclusão:** a maioria dos cuidadores não apresentou estresse e tampouco sobrecarga. No entanto, observou-se associação entre estresse e sobrecarga, demonstrando a necessidade de intervenções que minimizem esse fenômeno. **Descritores:** Enfermagem; Cuidador; Sobrecarga; Estresse.

RESUMEN

Objetivo: investigar la asociación de estrés y sobrecarga en cuidadores informales de lactantes con Secuencia de Robin Aislada. **Método:** Estudio transversal, desarrollado en el Hospital de Rehabilitación de Anomalias Craneofaciales. La muestra constó de 20 cuidadores. Para la evaluación se utilizaron la Escala de Síntomas y el estrés en los adultos de Lipp y la escala de *Burden Interview*. **Resultados:** de los participantes, 45% presentó estrés y el 45% sobrecarga. Entre los que presentaron estrés, el 45% se encontró en la fase de resistencia, con predominio de los síntomas psicológicos (30%). En cuanto a la sobrecarga, el 40% presentó un nivel moderado. Se evidenció que el 67% de los cuidadores presentaron asociación entre sobrecarga y estrés. **Conclusión:** la mayoría de los cuidadores no presentó estrés ni tampoco sobrecarga. Sin embargo, se observó asociación entre estrés y sobrecarga, demostrando la necesidad de intervenciones que minimicen ese fenómeno. **Descriptores:** Enfermería; Cuidador; Sobrecarga; Strés.

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INTRODUCTION

The Robin Sequence is defined as a triad of symptoms including retromicrognathia, glossoptosis and cleft palate (in 90% of cases), and may be present in isolation or in association with syndromes and other clinical comorbidities.¹⁻²

Infants with Isolated Robin Sequence (IRS) present respiratory problems, ranging from mild dyspnea to severe choking attacks, in addition to feeding problems, requiring specific and systematized care, with constant clinical observation. Usually, infants use artifacts, including nasopharyngeal intubation and feeding probe.¹

Nursing care for infants with IRS requires multiple care, that is performed by the entire Nursing team, while caregivers are trained to care for the child after discharge from hospital.²⁻³ Although these infants are discharged from hospital When, in addition to having favorable clinical conditions, their caregivers are able to maintain care at home, because they do not feel supported by the health team present during hospitalization, parents and caregivers experience different feelings that can result in stress.⁴ It is important to note that, and the maintenance of care, as well as their quality, influence the prognosis of the child, and may lead to complications that include death.²

Caregivers who present a higher level of anxiety and stress need differentiated support and acceptance by the interdisciplinary team, especially Nursing, who will promote their training regarding child care for continuity in the home environment.⁵⁻⁶ It is emphasized that In the home environment caregivers may present, through the context of care, other problems that include reduced attention to other children, lack of leisure, financial difficulties, family conflicts, exhaustion and isolation.⁷

The child with a diagnosis of congenital deficiency or anomaly, in the family, requires a great deal of care and demands that, for the parents, usually the main caregivers, presents in their daily life changes related to well-being and quality of life, which can lead to high levels of overload And vulnerability to stress, which consequently leads to feelings of depression, sadness, devaluation, guilt, post-traumatic stress disorder and stress, fatigue, exhaustion, decreased leisure activities, changes in family and economic relations.^{4,7}

The act of caring for a child in an atypical situation exposes the caregiver to a stress and / or overload scenario, which can be detrimental to health and well-being, since this

caregiver dedicates himself full-time, not having time for leisure and even rest.⁸

Overloading may be associated with physical, emotional, social, and financial distress related to care for a patient or family member. The caregiver's overload adds objective and subjective components, and in the objective component are activities provided to care, and in the subjective component is the way in which the caregiver perceives its role, and can add feelings of anguish, guilt or shame, increasing the risk of physical and mental impairment.⁹⁻¹⁰

Parents or caregivers perform activities of great importance in providing care to the child with craniofacial malformation, making it possible to affect stress in caregivers associated with care.

In view of the above, the question is: do informal caregivers of infants with isolated Robin's Sequence present overload and stress? Is there an association between overload and stress?

This study will contribute to formalizing a situational diagnosis in relation to stress and overload in these informal caregivers, contributing to the planning and implementation of strategies that minimize these phenomena that can negatively influence the rehabilitation process.

OBJECTIVE

- To investigate the association of stress and overload in informal caregivers of infants with Isolated Robin Sequence.

METHOD

A descriptive and cross-sectional study of a quantitative design, developed in a public and reference hospital in the treatment of patients with cleft lip and palate and related anomalies, more precisely in the Semi-Intensive Care Unit known as the Special Care Unit. This unit is composed of eight beds intended for the care of children up to two years of age, who usually develop with respiratory disorders and dysphagia. At the same time, this unit is dedicated to the promotion and training of caregivers (promotion of self-care) to maintain care after hospital discharge.

The population was composed of informal caregivers of infants with IRS, who followed the infants from the second hospitalization in the SCU.

Backing up the occupancy rate and time period for the research, the sample consisted of 20 caregivers. Informal caregivers of infants with IRS were included, that is, they presented the classic signs (micrognathia, glossoptosis

and cleft palate), besides the need for nasopharyngeal intubation, nasogastric tube and feeding facilitating techniques, and that they did not present other alterations or comorbidities associated.

The research began after approval of the Ethics in Research Committee involving Human Subjects of the Institution, through opinion number 939.806 and CAAE: 39218414.7.0000.5441, obeying the precepts of CNS Resolution 466/12.

The Stress Symptom Inventory for Adults (SSIA) was used to assess stress, and the Burden Interview (BI) Scale was used for evaluation of the overload.¹²⁻³

SSIA aims to identify the symptomatology of stress, the psychological or somatic types and the phase (alertness, resistance, near-exhaustion and exhaustion). It is an instrument validated and approved by the Federal Council of Psychology, being used in research and clinical activities for the diagnosis of stress in adults; is composed of three pictures with questions regarding the symptoms observed in the four phases of stress, where the subject indicates which symptoms he has experienced in the last 24 hours, in the last week and in the last month.¹²

The BI was developed to evaluate the overload of parents or caregivers, being translated and validated for the Brazilian population. It contains 22 questions encompassing the areas of health, social and

personal life, financial situation, well-being, emotional behavior and interpersonal relationship. The response score for each item ranges from zero to four, in which ZERO - never; one - rarely; two - sometimes; three - often and four - always. The last item of the scale evaluates, in a global way, how much the relative feels overwhelmed in the care with the patient. For this item, the response alternatives are: zero - not at all, one - slightly, two - moderately, three - very, four - extremely. The final BI score is obtained by the sum total of all responses, ranging from zero to 88. The higher the final score, the greater the caregiver's overload.¹³

The data collection was performed in a private environment, outside the hours of stay in the UCE, aiming not to interfere in the norms and routines of the unit, in February and July 2015. The results were submitted to descriptive statistical analysis, including relative, absolute frequency, mean and standard deviation.

RESULTS

Regarding the characterization of the sample, it was observed that 100% of the participants were mothers. The mean age was 28 years (± 6). Regarding marital status, 80% reported a stable union. In relation to schooling, high school education prevailed (60%) (Table 1).

Table 1. Distribution of participants according to sociodemographic data. Bauru (SP), Brazil, 2015.

| Variables | Characteristics | n | % |
|-------------------|-----------------------------|----|-----|
| Education | Graduated | 5 | 25 |
| | Incomplete higher education | 2 | 10 |
| | Complete Highschool | 7 | 35 |
| | Incomplete Highschool | 5 | 25 |
| | Complete Basic education | 1 | 5 |
| Marital status | Married / stable union | 16 | 80 |
| | Single | 1 | 5 |
| | Others | 3 | 15 |
| Degree of kinship | Mother | 20 | 100 |
| Age | 19 - 23 | 5 | 25 |
| | 23 - 27 | 4 | 20 |
| | 27 - 31 | 2 | 10 |
| | 31 - 35 | 8 | 40 |
| | 35 - 37 | 1 | 5 |

In the evaluation of the caregivers' overload, a minimum score of 11 and a maximum of 41

(22 \pm 9) were found, revealing moderate overload in 40% of the participants (Table 2).

Table 2. Distribution of participants according to the evaluation of overload. Bauru (SP), Brazil, 2015.

| Overload | n | % |
|--------------------|----|----|
| Absent | 11 | 55 |
| Moderate | 8 | 40 |
| Moderate to severe | 1 | 5 |

Regarding stress, 45% of the participants presented, predominantly in the resistance

phase (45%) and with psychological symptoms (30%) (Table 3).

Table 3. Distribution of participants according to the stress evaluation. Bauru (SP), Brazil, 2015.

| Stress | Characteristics | n | % |
|----------|----------------------------|----|----|
| Yes | | 9 | 45 |
| No | | 11 | 55 |
| Phase | Alert | -- | -- |
| | Resistance | 9 | 45 |
| | Almost-exhaustion | -- | -- |
| | Exhaustion | -- | -- |
| Symptoms | Physical | 2 | 10 |
| | Psychological | 6 | 30 |
| | Physical and psychological | 1 | 5 |

When associating stress with overload, it was observed that 67% of the participants who

presented an overload also presented stress (Table 4).

Table 4. Association between stress and overload of participants. Bauru (SP), Brazil, 2015.

| Overload | Stress | | Total |
|----------|---------|--------|----------|
| | Yes (%) | No (%) | |
| Yes (%) | 6 (67) | 3 (33) | 9 (100) |
| No (%) | 3 (27) | 8 (73) | 11 (100) |

DISCUSSION

In this study, the infant with IRS requires multiple care, both in the hospital environment and in his / her home, because upon discharge, his / her primary caregiver should be able to perform the care with safety and efficiency, including manipulation of the gastric tube for alimentary support, use of feeding facilitation techniques, nasopharyngeal intubation with systematic observation of the respiratory pattern and postural treatment.² In this context, it is evident the importance of the nurses and their staff in the training of the caregivers during the hospitalization of the child, aiming at the maintenance of the after hospital discharge.

Caregivers perform different and multiple tasks, associated with the reduction of the patient's functional capacity related to participation in care, and may result in overload.¹⁴ The concept of overload is predisposed as multidimensional, encompassing the biopsychosocial sphere, resulting in a balance between the following variables: Time available for care; financial resources, psychological, physical and social conditions, and assignments and delegation of roles related to the act of caring. That is, the emotional impact experienced by caregivers may interfere with the care provided to the patient, which may lead to hospitalizations and greater morbidity and mortality among caregivers.¹⁴

Parents and family members, faced with the birth of unimagined children, experience various negative feelings, including mourning, guilt, frustration, and failure over protection, which often result in emotional overload.¹⁵

A study carried out to compare the burden of formal and informal caregivers showed

prevalence in informal caregivers, associating this result with lack of skill and lacking technical and scientific knowledge. It also pointed out the difficulty of situational coping by informal caregivers.¹⁶ This result infers on the great challenge of Nursing regarding the training of caregivers.

In this study, it was observed that all the caregivers were composed of mothers, demonstrating the affective bond between mother and child. This relationship was evidenced in other studies.^{5,14,17} The maternal figure is culturally related to care, including caring for children and the family, as well as frequently carrying out other activities as employment bonds, which, if somatized, can result in overload. The literature points out emotional overload in caregiver parents as one of the main challenges faced by families, especially mothers.¹⁸

A study evaluating the prevalence of anxiety and depression symptoms in caregivers of children with chronic neurological diseases included in a home enteral nutrition program showed that all caregivers were mothers. The authors found a high predisposition for anxiety and depression symptoms, as well as the perception of psychic overload and distress, highlighting the need for emotional support and support.¹⁹

Another investigation about the emotional overload and the perception of the quality of life in mothers of children with inborn errors of metabolism showed that the care given to the child interfered negatively in the quality of life of mothers, especially in the field of social relations , In addition to showing emotional overload, which was associated with low perception about the quality of life.²⁰

As for marital status, stable union prevailed. It is agreed that well-structured families

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facilitate the rehabilitation process, since the environment is conducive to the division of labor between the spouses. On the other hand, they may cause a spouse to be overloaded in cases where there is no division of labor.¹⁴ Parental involvement in the child's recovery process strengthens the affective bond.²¹

Regarding age, the mean was 28 years (± 6), therefore young, contrary to the findings of other studies with caregivers of children with different pathologies.^{14,17} One study evaluated stress and anxiety in mothers who accompanied their infants with Robin Sequence during hospitalization, evidenced maternal age between the ages of 22 and 43, a more advanced age when compared to the current study.⁴

It is worth noting that, although young, these caregivers play roles that denote great responsibility, considering the specific care that infants with IRS need, ie, there is a need for high availability linked to care, and may generate overload, considering the unavailability in performing activities related to youth. In contrast to this hypothesis, other authors did not show an association between the caregiver's age and the overload.¹⁴ Studies in caregivers of infants with SRI also showed no correlation between age and levels of stress and anxiety.^{5,22}

The low level of schooling may be related to unfavorable socioeconomic factors, which may result in overloading the caregiver, in addition to predisposing stress.²³ In contrast, the presence of stress to families with higher purchasing power and belonging to the high social class, linked this result to greater access to information and treatment, triggering intense searches for care and increasing internal collections, and even influencing the process of adaptation.¹⁵

When assessing the informal caregivers of infants with SRI, it was observed that the majority did not present overload. This result is inferred from the link between mother and child, as well as emotional aspects related to motherhood. Thus, a study concluded that the low overload index portrayed the difficulty of recognition and verbalization, since, due to cultural factors, it is complex for the mother to admit that a child is a burden, that is, it represents an overload.²⁰

Among the caregivers who presented an overload, the moderate level prevailed. Moderate overload may indicate the need to support the care process, providing subsidies to the actions of the tasks performed, as well as clarifying the signs of doubts that may be present among caregivers.²⁴ Regarding the result obtained, it can be described that the

moderate level of overload present in the mothers participating in this study is defined as the satisfaction experienced by them in caring for their children, who in turn are totally dependent, not only for being infants and being common to the need for care due to the range to the multiple care and interventions inherent in IRS.

Caregivers need interventions that strengthen and promote their well-being in the physical, psychological and social spheres.²² In this context, it is imperative that the interdisciplinary team, especially Nursing, work directly and continuously with patients and caregivers. In the present study, when assessing the prevalence of stress among caregivers of infants with IRS, it was observed that the majority did not present, corroborating the literature.⁵ This result may be associated to the fact that the stress evaluation occurred after the second hospitalization, That is, period in the home considered as adaptive, however, the caregiver is blamed for the illness of the child and thus feels responsible for the child's illness, causing negative influences, including manifestations of stress.¹⁵

Another factor that may justify the result evidenced in this study is that infants with IRS whose treatment is effective present a very favorable clinical evolution, that is, approximately 60 days after the interventions, they constantly evolve to nasopharyngeal extubation and oral feeding, Conditions that are considered common to infants without IRS.

The use of the hypercaloric diet and craniofacial growth favors tongue and mandible anteriorization and maturation of the laryngeal structures, demonstrating the efficacy of the protocol established for the treatment.¹ It is evident that this is not an unfavorable prognosis, since That treatment is early and appropriate, compared to other diseases, including cancer, innate errors of metabolism, neurological diseases, among others, whose prognoses are usually unfavorable or little evolutionary. Thus, these factors contribute to the minimization of stress among these caregivers, emphasizing the need for multidisciplinary intervention to the infant with IRS at birth, considering that the critical period refers to the first months of life.

This study showed that among the mothers who presented the stress, all were in the resistance phase. In this phase, the caregiver is able to obtain control through the situation in which he or she is inserted.⁵ The resistance phase is described as an intermediary, where the individual's body seeks equilibrium, occurring a period of adaptation where stress

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factors can be eliminated, obtaining Internal balance of the person or its evolution to the next stage, due to the lack of the adaptive process and the non-elimination of the stress factors.¹²

Strategies to minimize stress factors are imperative, especially for individuals who are constantly involved in the caring process. In this way, the importance of health professionals in knowing the reality of each family, and with that, to provide support to the planning and implementation of public policies, including programs of social support to the caregivers and their relatives, stands out. Influence of caregivers in the rehabilitation process.^{15,17,25}

When associating stress to the overload among caregivers, it was observed that 30% presented. However, other authors have associated stress to high overload in informal caregivers of the elderly.¹⁷

There is evidence of the need to consider these informal caregivers as strategic in the success of the rehabilitation process, including their sanity and well-being, and should be inserted in the context of Nursing care.²⁶ Still, the relevance of greater participation of the family so that care for the child with cleft lip and palate is shared, avoiding possible deleterious effects on caregivers' health.²⁷

The scarcity of studies on stress and overload in children, particularly with malformations, limited the comparison of our results. The transversal and single-center methodology make it impossible to generalize the results of this study. Thus, longitudinal and multicenter studies are encouraged. It is believed that the results of this study may contribute to the formalization of a situational diagnosis about stress and overload in these caregivers.

CONCLUSION

Most caregivers of infants with IRS had no stress or overload. This result is associated to the fact that caregivers are mothers, and to different coping mechanisms. However, it was observed an association between stress and overload, demonstrating the need for interventions that minimize this phenomenon.

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