RESEARCH PAPER (ORIGINAL) ARTÍCULO DE INVESTIGACIÓN (ORIGINAL)

Sleep quality in informal caregivers of children with invasive and non-invasive mechanical ventilation

Calidad del sueño en cuidadores informales de niños con ventilación mecánica invasiva v no invasiva

Qualidade do sono em cuidadores informais de crianças com ventilação mecânica invasiva e não invasiva

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Abstract

Background: Sleep disturbances are one of the symptoms that have the highest correlation with caregiving. Among the population of Chile, 63.2% reports having sleep disturbances.

Objective: To identify sleep characteristics and habits in the caregivers of children belonging to the National Program of Invasive and Non-Invasive Ventilatory Assistance at Home of the Ministry of Health of Chile.

Methodology: A quantitative, descriptive, cross-sectional study with 82 family caregivers. The Pittsburgh Scale is applied, as well as a questionnaire about habits, nutrition, exercise, and stimulant intake. Results: Age 41.5 (SD = 9.4) years; mean number of hours of sleep of 6.29 hours; 52.4% are short sleepers; according to the Pittsburgh scale, 81.7% have sleeping problems. The higher the educational level and the scheduled physical activity, the lower the risk of presenting sleeping problems. Living alone with children without any other supportive family member presents additional problems. Conclusion: The care for the child with high technological dependence at home must have a multidisciplinary approach, considering the satisfaction of basic needs of caregivers, such as sleep.

Keywords: caregivers; nursing care; respiration, artificial; ventilators, mechanical; sleep wake disorders; sleep hygiene

Resumen

Marco contextual: Las alteraciones del sueño son uno de los síntomas que tiene la más alta correlación con el cuidar. En la población chilena el 63,2% refiere presentarla.

Objetivo: Identificar características y hábitos del sueño en los cuidadores de niños pertenecientes al Programa Nacional de Asistencia Ventilatoria Invasiva y No Invasiva en domicilio del Ministerio de Salud de Chile.

Metodología: Estudio cuantitativo, descriptivo, transversal, con 82 cuidadores familiares. Se aplica la Escala de Pittsburg y el cuestionario sobre hábitos,

alimentación, ejercicios e ingesta de estimulantes. **Resultados:** Edad 41,5 (SD = 9,4) años; promedio horas de sueño 6,29 horas; el 52,4% es dormidor corto; según la escala de Pittsburg, el 81,7% presenta problemas para dormir; a mayor nivel educacional y actividad física programada, menor es el riesgo de presentar problemas para dormir. Vivir solo con los hijos, sin otro familiar de apoyo, presenta más problemas. Conclusiones: El cuidado al niño con alta dependencia tecnológica en domicilio debe tener un abordaje multidisciplinario, y considerar la satisfacción de necesidades básicas como el sueño del cuidador.

Palabras clave: cuidadores; atención de enfermería; respiración artificial; ventiladores mecánicos; trastornos del sueño-vigilia; higiene del sueño

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phical research.

Resumo

Enquadramento: Os distúrbios do sono são um dos sintomas que tem a maior correlação com o cuidado, na população chilena 63,2% relatam apresentá-lo.

Objetivo: Identificar características e hábitos do sono em cuidadores de crianças pertencentes ao Programa Nacional de Assistência Ventilatória Invasiva e Não Invasiva da residência do Ministério da Saúde do Chile.

Metodologia: Estudo quantitativo, descritivo, transversal, com 82 familiares cuidadores. É aplicada a escala de Pittsburgh e um questionário sobre hábitos, nutrição, exercício e ingestão de estimulantes.

Resultados: Idade 41,5 (DP = 9,4) anos; horas médias de sono 6,29 horas; 52,4% dormem curtos períodos; de acordo com a escala de Pittsburgh, 81,7% têm problemas para dormir; quanto maior o nível educacional e a atividade física programada, menor o risco de apresentar problemas de sono. Viver sozinho com crianças sem outro membro da família de apoio representa mais problemas. Conclusão: O cuidado no domicílio à criança com alta dependência tecnológica deve ter uma abordagem multidiscilplinar, considerando a satisfação das necessidades básicas do cuidador, como o sono.

Palavras-chave: cuidadores; cuidados de enfermagem; respiração artificial; ventiladores mecánicos; transtornos do sono-vigília; higiene do sono

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Introduction

Sleep is a vital necessity that occupies one-third of life, it brings to the functional organic and psychological repair of the person, becoming the basis of well-being. It is also responsible for establishing the cognitive processes and memory, allowing hormonal secretions, neurotransmitters and amino acids essential for survival in all stages of the life cycle. (Masalan, Araya, Del Rio, & Yáñez, 2014, p. 46)

According to the 2016-2017 National Health Survey, there is a high prevalence of suspicion of sleep disorders, such as insomnia 5.6% (4.6% - 6.8%), in people over 15 years old, and 28.8% declares to have also poor sleep (Ministerio de Salud, 2018). Especially in people who carry out care activities within a family, the literature reports that the caregivers perceive their quality of life with a tendency to the negativity, given the care to a chronic patient for long periods, which has an impact on demands that exceed their capacities and affect the physical, psychological, social and spiritual well-being dimensions (Galvis-López, Aponte-Garzón, & Pinzón-Rocha, 2016).

In light of the foregoing, a high prevalence of sleep disorders in the general population and especially in people in charge of taking care of others, it becomes necessary to investigate the quality of sleep in caregivers of children belonging to the National Program of Invasive and Non-Invasive Ventilatory Assistance at home of the Ministry of Health of Chile, to determine strategies that allow a multidisciplinary approach to improve the quality of sleep and therefore the quality of life for caregivers.

Background

In this research, the informal caregiver is the person responsible for the care of the child or adolescents with invasive ventilatory assistance (IVA) and non-invasive ventilatory assistance (NIVA) at home.

The non-invasive mechanical ventilation (NIMV) uses continuous positive airway pressure (CPAP) or different levels of pressure (BIPAP), without intubation, which allows

children to keep their airways permeable by contributing to the decrease of the respiratory work.

It is generally used in children with moderate to severe acute hypoxemic respiratory failure, obstructive diseases such as chronic obstructive pulmonary disease and cystic fibrosis, among others (Parga, Zambrano, Valdebenito, & Prado, 2017).

Some studies in informal primary caregivers of patients with limitation in the activity reveal sleep disorders over 66%. In these same caregivers a positive correlation between the variables of sleep disorders in the caregiver and the limitation in the activity of patients was found (Buenfil Díaz, Hijuelos Garcia, Pineda, Salgado Burgos, & Pérez Padilla, 2016).

Predictors of poor quality of life in mothers are described, such as a sleep time inferior to their needs; little or no perception of self-efficacy for the care of the sick child; lack of perceived social support; limitations of the maternal role; little vitality; mental health affected with high levels of depression and anxiety; functional compromise; low capacity of confrontation; no adaptation to the situation of chronic illness in the family and overload of care (Macedo, Rangel da Silva, Paiva, & Pereira Ramos, 2015). Moreover, the existence of overload of the caregiver as one of the impacts of chronic disease of children and adolescents is compounded by the absence of a partner; low educational level; insufficient income; unemployment; alteration of the professional life; decrease of social coexistence; increased number of children; depressive symptoms and anxiety and high tensions in daily life. In addition, the perception of the severity of the pathology, the nights of lost or interrupted sleep due to the acute manifestations of the disease and the disappointment of not being able to meet the needs of the children also influence it. Grandmothers and other women of the family are also associated with the caring activities, being mothers the main people involved in this process (Macedo et al., 2015).

Likewise, it is known that caregivers face immediately the stress, leading to some functions to deteriorate, affecting their physical, social and psychological capacities, which impacts the care and their own quality of life (Silva Fhon, Gonzales Janampa, Mas Huaman, Marques, & Partezani Rodrigues, 2016).

Despite this, little is known about the influence of the quality of sleep, stress, and wear of the caregiver in the quality of life. Feeley et al. (2014) studied 61 mothers of children with bronchopulmonary dysplasia, who had an average of 5.8 hours of sleep, and a significant correlation between quality of sleep, depressive symptoms and stress was found, noting that the quality of sleep is the most significant predictor of quality of life.

Research Question

What is the quality of sleep of caregivers of children belonging to the National Program of IVA and NIVA at home of the Ministry of Health of Chile?

Methodology

It is a quantitative, descriptive, and cross-sectional study, whose sample is composed of 82 family caregivers belonging to the National Programs of IVA and NIVA of the metropolitan region, during the year 2014 (53.6% of the corresponds to the universe). The caregivers were invited to participate through their nurses of the respective programs and the inclusion criteria were: caregivers of children with IMV and NIMV belonging to National Programs of IVA and NIVA in the metropolitan region. We used the Pittsburgh Sleep Quality Index (PSQI; Lomeli et al., 2008), which allows measuring the presence of sleep disturbances and percentage of efficiency through a score that ranges from 0 to 21, corresponding results over 5 to bad sleepers.

The PSQI is validated for Spanish-Speaking countries showing indexes of internal consistency in such assessments (reliability coefficient 0.83 and 0.81 in the Spanish population and 0.77 in the Colombian population. Due to the lack of validations for the Chilean population, the scale translated into Spanish and validated in Colombia was used (Escobar-Cordoba &

Eslava-Schmalbach, 2005).

In addition, some questions about habits related to daily feeding routines, exercises, and stimulants intake were incorporated. It was applied by the nursing team of the program, through an interview conducted at home.

The research involved with the approval of the National Programs of IVA and NIVA at Home of valid total Ministry of Health of Chile homecare, also, was approved by the Ethics Committee of the Faculty of Medicine at the Pontificia Universidad Católica de Chile.

The study does not present a risk, because it does not intervene on people and it respects the freedom of right to participation, through the signing of an informed consent, given by the nurses in charge of visiting the children in each home.

A descriptive analysis is performed for the relevant variables of the study, tests to observe an association between some variables and the quality of sleep. For the descriptive aspects, frequencies and percentages were used in the categorical variables and averages and standard deviations for the numeric variables. For the relational analysis, contingency tables, risk statistics (*Odds Ratio - OR*) and logistic regressions were used. In all cases, a probability of type 1 error of 0.05 was considered as a criterion for rejecting the null hypothesis.

Results

In total 82 people were surveyed (79 women and 3 men). Mean age of 41.5 years old (*SD* = 9.4), minimum age of 22 years old and a maximum of 73 years old. In relation to the socio-demographic characteristics, it is observed that most caregivers reported being in a couple (77.8%) and living with the family, in addition to their other children (86.8%). With regard to the educational level, the majority has finished the secondary education (63%), 24.7% the basic level and 12.3% the higher level. With respect to the working activity, 24.4% work outside their homes (Table 1).

Table 1 Sociodemographic characteristics of the sample

Variable	Category	n	%
With couple	Yes	63	77.8
	No	18	22.2
	Valid total	81	100
	Basic	20	24.7
Educational level	Secondary	51	63.0
	Higher	10	12.3
	Valid total	81	100
Activity	Outside home	20	24.4
	No activity outside of the home	62	75.6
	Valid total	82	100
Co-habiting	Family	66	86.8
	Only children	10	13.2
	Valid total	76	100

With regard to the variables related to health and lifestyle, it is observed in general terms that they do not practice scheduled physical activity beyond their daily activities (80.5%); 67.1%

stated that they did not consume alcohol, and 84.1% do not take sleep medications. With regard to cigarette consumption, 46.3% of the sample stated that they consumed cigarettes (Table 2).

Table 2
Frequencies for Health and Lifestyle Variables

Variable	Category	n	%
Exercises	Yes	16	19.5
	No	66	80.5
	Valid total	82	100
	Yes	38 44	46.3
Smokes cigarettes	No	44	53.7
	Valid total	38	100
	Yes	44 82 27 55	32.9
Consumes alcohol	No	55	67.1
	Valid total	16 66 82 38 44 82 27 55	100
Yes Sleep medications No Valid total	Yes	13	15.9
	69	84.1	
	Valid total	82	100

With regard to the general sleep characteristics, caregivers have an average of 6.29 hours of sleep (SD = 1.47), 52.4% is classified with short sleep. Despite this, the majority considers that sleep is restful (64.2%). However, it is

important to stress that 35.8% does not regard it as such. With respect to the quality of sleep, measured with the scale of Pittsburg, 81.7% of the group in study presents a sleeping problem, only 18.3% does not present any problem.

We compared the presence of sleep problems with various socio-demographic and lifestyle factors and observed that none of the evaluated associations is significant from a statistical point of view. However, some relevant trends can be analyzed. The higher the educational level, the lower the risk of sleep problems compared with the group with lower levels of education (OR = 0.259 higher/basic education; OR secondary/

basic 0.455). In addition, caregivers who live only with the children present a double risk of sleep problems than those living with other family members (OR only children/family = 2). At the same time, people who do not make exercise are more at risk than those who make it (OR = 2.545), and also that alcohol behaves in the sample as a protective factor for the sleep problems (OR = 0.486; Table 3).

Table 3
Frequencies, percentages, and OR with 95% confidence interval for sleep problems according to sociodemographic and lifestyle variables

Variable		Sleep problems			IC 050/
	Category	Yes % (n)	No % (n)	- OR	IC 95%
Couple	WITH	82.5 (52)	17.5 (11)	0.945	[0.233 - 3.834]
	WITHOUT (ref)	83.3 (15)	16.7 (3)	-	
Educational level	Higher	70 (7)	30 (3)	0.259	[0.035 - 1.898]
	Secondary	80.3 (41)	19.7 (10)	0.455	[0.091 - 2.293]
	Basic (ref)	90 (18)	10 (2)	-	
Activity outside home	No	82.2 (51)	17.8 (11)	1.159	[0.324 - 4.147]
	Yes (ref)	80 &	20 (4)	-	
Co-habiting	Only children	90 (9)	10 (1)	2	[0.231 - 17.318]
	Family (ref)	81.8 (54)	18.2 (12)	-	
Exercising	No	84.8 (56)	15.2 (10)	2.545	[0.727 - 8.912]
	Yes (ref)	68.8 (11)	31.2 (5)	-	
Smoking	Yes	78.9 (30)	21.1 (8)	0.709	[0.231 - 2.181]
	No (ref)	84.1 (37)	15.9 (7)	-	
Alcohol consumption	Yes	74.1 (20)	25.9 (7)	0.486	[0.155 - 1.523]
	No (ref)	85.5 (47)	14.5 (8)	-	
Sleep medications	Yes	84.6 (11)	15.4 (2)	1.277	[0.252 - 6.471]
	No (ref)	81.2 (56)	18.8 (13)	-	

There was no significant association between the age of the caregivers and the sleep problems (Mann Whitney U = 431.5; p > 0.05), although those who do have sleep problems were older.

Discussion

Little is known about the influence of the quality of sleep in the quality of life of caregivers of children with chronic respiratory problems. A study of 61 mothers of children with bronchopulmonary dysplasia, with an average age

of 29.6 years old and their children aged 14 months, reported an average of 5.8 hours of sleep (SD = 1.46), which coincides with the results (6.3 hours) of this investigation. In this study, the rate of Pittsburgh was deficient (Feeley et al., 2014). Some studies reveal that excessive or insufficient duration of sleep may be associated with an increased risk of breast cancer (Mansano-Schlosser & Ceolim, 2017). Different studies coincide in that the maintenance of care for a prolonged period of time is directly related to the load perceived by caregivers and the decline in the quality of life (Guer-

ra-Martín, Amador-Marín, & Martínez-Montilla, 2015). This generates health problems such as fatigue, depressive symptoms, sleep disorders, among others (Çelik, Annagur, Yılmaz, Demir, & Kara, 2012).

On the other hand, sleep disorders among caregivers in this study can be explained due to the fact that the caregiver remains a large part of the night paying attention to the night activities of the child. This situation ends up becoming an everyday activity, which translates into a habit for the caregiver, explaining the results that reveal that 55.2% is a short sleeper. The lack of restful sleep impacts in the lack of energy to do the next day's activities, deteriorating their quality of life. The duration and quality of sleep have a direct and indirect effect on mood, as well as in the psychological and physical health (Vargas Escobar & Pinto Afanador, 2010). Some studies have shown that the duration and quality of sleep could predict the proper functioning during the day, as well as the negative mood and anxiety (Wong et al., 2013). The quality of sleep is an indicator associated with the well-being, health, and quality of life (Polo-Kantola et al., 2014).

In relation to sleep and exercise, in this study we found that 80.5% declared not to make any type of exercise, however, the review of the literature shows that exercise is an activity that enhances the quality of sleep. Practice some exercise preferably in the morning improves the quality of sleep. This has been proven in the sedentary and obese population, as well as in postmenopausal women (Arcos-Carmona et al., 2011; Cervelló et al., 2014; Subirats Bayego, Subirats Vila, & Soteras Martínez, 2012).

Some studies have found a direct correlation between the psychological and affective well-being with the quality of sleep. They have also pointed to the importance of the quality of sleep as a history of emotional, physical and psychological problems at different stages in the life cycle (Cervelló et al., 2014; Polo-Kantola et al., 2014; Wong et al., 2013).

The results of this study reveal a component similar to those found in other studies with regard to age, relationship, and educational level. However, the majority of the sample has a partner and takes care of the children, in addition to living with other people, becoming a protective factor for the caregiver. It should

be noted that only 24% of caregivers have a job outside their homes, which is consistent with other research (Flores, Rivas, & Seguel Palma, 2012).

Finally, the results with respect to the consumption of cigarettes (46.3%) are higher than the prevalence in the general population in Chile (33.3%), as well as the consumption of alcohol for this sample, which is 32.9%, and for the general population, which is 11.7%. In relation to the consumption of sleep medicines, it is reported a 16% of intake, concordant with the statistics of the country, where the sleep problems are perceived, but not treated with medications (Ministerio de Salud, 2018).

Within the limitations of the study, it is to highlight that the sample size is small, so the power is relatively low, making it difficult to find significant associations. However, the trends found are theoretically plausible and are consistent with previous studies. Therefore, it is possible to think that the results give an account of a reality that health teams and society will have to face with the implementation of complementary strategies to the technical aspects.

On the other hand, most caregivers are female, which makes it difficult to determine the differences between men and women.

Finally, it is necessary to conduct more studies that allow increasing the potential and precision of results to support decision-making on public policy implementation.

Conclusion

In the development of this research, few studies that address the health problems of family caregivers of patients with IMV and NIMV at home have been found, so this document provides relevant information about the quality of sleep of caregivers, revealing that those family caregivers who do not have social support have a poor Pittsburg index.

It is important to highlight that in a care program for chronically ill patients at home and especially of National Programs of NIVA-IVA, where children have a high degree of dependence on technology support, a multidisciplinary approach is necessary, where the *care of the caregiver* is one of the axes of the intervention. In this context, it is also necessary to

consider the satisfaction of basic needs such as leisure, recreation, and sleep, which are not recognized and relieved by the caregivers but are important for the maintenance of the care of their children at home. The support given to the caregiver goes beyond the technology used in caring for children. As long as public policies that focus specifically on the caregivers and consider the factors of health risk are not put in place, the quality of life of this group will continue to be affected.

These results show that there is an ethical imperative for the multidisciplinary team to take care of those who care for people requiring constant attention with specialized technology at home. In this case, sleep, as a basic necessity, must be satisfied, because it provides elements for the repair and daily operation of the organism, which allows quality care.

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