ORIGINAL ARTICLE

Home Mechanical Ventilation in Children: Impact on the Sleep Quality of Caregivers

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Abstract

Introduction: The role played by caregivers of children with complex chronic diseases may be influenced by sleep disturbances. This situation may affect long-term quality care for children. This study aimed to evaluate the sleep quality of caregivers of children with complex chronic diseases under home mechanical ventilation.

Methods: This analytical observational study was carried out from October 2018 to January 2019. We assessed the caregivers of children/adolescents with complex chronic disease under home mechanical ventilation for three months or more, followed in the pneumology clinic of a tertiary pediatric hospital in Coimbra, Portugal. The evaluation instrument included the Portuguese version of the Pittsburgh sleep quality index.

Results: This study was conducted on 33 caregivers. The mean global score obtained by the sample evaluated using the Pittsburgh sleep quality index was higher than the one attained from the healthy Portuguese population sample (8 *vs* 1.20). Global scores ≥ 5 were obtained for 72.4% of the study sample, indicating a high risk of sleep disturbance. Caregivers of children / adolescents with respiratory disease attained the worst scores in sleep quality (mean Pittsburgh sleep quality index score = 11), followed by neuromuscular disease and central hypoventilation (mean Pittsburgh sleep quality index score = 8). There was no statistically significant difference between the three diagnostic groups.

Discussion: There was a discrepancy between the subjective sleep quality (good in 64%) and the Pittsburgh sleep quality index score (poor in 72%), with significant percentage of daytime sleepiness/dysfunction (75%). Half of the study sample showed sleep efficiency indices below 85%. It is essential to raise awareness among professionals regarding the importance of evaluating the sleep quality of caregivers of children with complex chronic diseases, since the importance of the matter may be missed by them.

Keywords: Caregiver Burden/diagnosis; Caregivers; Disabled Children; Home Nursing; Respiration, Artificial; Sleep Deprivation; Sleep Quality

Keypoints

What is known:
- The caregivers of children who depend on medical technology at home, experience numerous negative outcomes, including sleep disturbance.
- Chronic sleep disturbance may threaten the ability of caregivers to provide long-term quality care for their children.

What is added:
- The sleep quality of the caregivers of children under home mechanical ventilation is lower than that recorded in the healthy Portuguese population.
- The caregivers of children with respiratory disease and of Association for Children with Life-threatening or Terminal Conditions and their Families group 2 had the worst values in sleep quality.

Introduction

In the last few decades, there has been a substantial rise in the number of children and adolescents depending on home mechanical ventilation, due to an increase in the number of patients surviving critical illness, thanks to technological advances.[1-4] Home mechanical ventilation has allowed a prolongation of life, palliation

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of symptoms, and an improvement in the quality of life.[1] Accordingly, the responsibility for the care of many of these children has shifted from professionals in the hospital to parents in the family, and society has increasingly relied on the caregivers of dependent children to provide highly skilled and vigilant care in their homes 24 hours a day.[2,3]

The caregivers of children who depend on medical technology at home have been found to experience numerous negative outcomes, including high levels of physical, emotional, financial, and family stress.[5] The extraordinary responsibility that caregivers undertake may be linked to chronic sleep disturbance, which may threaten their ability to provide long-term quality care for these children.[2]

Sleep is recognized as a complex biobehavioral process described as a reversible behavioral state of perceptual disengagement from, and unresponsiveness to the environment.[6] The adequate quantity and quality of sleep is considered necessary for the overall health and optimal daytime performance of each person. Shorter sleep duration and higher nocturnal awakenings have been reported in caregivers of children with physical disabilities, compared to those of typically developing children.[2] Chronic sleep deprivation is considered a major public health concern and has been associated with caregiver stress and depression. Furthermore, sleep disruptions may increase the risk of accidents and provide a mechanism that contributes to the acquirement of neurological and other organic diseases. On the other hand, the dependence of caregivers on sleep medication can also be a problem.[2,7]

In 1993, a home mechanical ventilation program for children and adolescents with chronic respiratory failure began in our hospital. It has already supported hundreds of patients with a positive impact on patients and caregivers lives.[4]

Methods

This analytical observational study was performed between October 2018 and January 2019. The study sample was selected through convenience sampling of parents / caregivers of children / adolescents (0-17 years) with complex chronic diseases followed in the pneumology clinic of our hospital (Hospital Pediátrico de Coimbra, Portugal). The inclusion criteria were consent of the parents / caregivers of children / adolescents with complex chronic disease with history of home mechanical ventilation for at least three months. Parents / caregivers who could not read and/or write in Portuguese were excluded from the study. In this study the main person responsible for most of the care of the patient was defined as a caregiver. Home mechanical ventilation included invasive ventilation by tracheostomy and non-invasive ventilation provided at the child home.

Complex chronic disease was defined as any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or one organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center[8] and updated according to the international classification of diseases (ICD-10) diagnostic codes.[9]

The diagnoses were classified according to the diagnostic group into neuromuscular disease, respiratory disease, metabolic / neurodegenerative disease, central hypoventilation, and other congenital or genetic defects (namely all the congenital / genetic defects, except for central hypoventilation, which constitutes a different group). They were also grouped according to the trajectory of the classification of the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT), reflecting the trajectory of diseases requiring palliative care in a pediatric context. The groups included:

- Group 1: life-threatening conditions for which curative treatment may be feasible but can fail;
- Group 2: conditions in which premature death is inevitable, but long periods of intensive treatment is aimed at prolonging life and allows participation in normal activities;
- Group 3: progressive conditions without curative treatment options, where treatment is exclusively palliative and may extend over many years;
- Group 4: irreversible but non-progressive conditions with severe disability that are susceptible to health complications and premature death.

The Pittsburgh sleep quality index (PSQI), validated for the Portuguese population, was used as the evaluation instrument.

The PSQI is a generic instrument that subjectively measures the sleep quality of a subject over a one-month time interval. It consists of 19 questions, grouped into seven clinical domains related to sleep quality (subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medication, and daytime dysfunction). Each component is evaluated on a scale from 0-3. The seven components are combined to obtain the overall value of sleep quality on a scale from 0-21, which helps distinguish between

good sleep quality and poor sleep quality. A global value ≥ 5 indicates a poor sleeper, with major difficulties in at least two components, or moderate difficulties in over three components. A higher overall value reflects a worse sleep quality.[10-12]

The information obtained was complemented by a questionnaire which included other variables, including demographic variables (gender, age, academic qualifications, marital status, relationship to the child / adolescent) and clinical variables (presence of sleep disorder) of the caregivers and demographic, clinical and social variables of the child / adolescent (gender, age, diagnosis, attendance of a place of learning quantified in hours, average of daily hours of ventilation and type of interface of ventilation). The informed written consent was obtained from the caregivers, and they completed the questionnaire anonymously.

Statistical analysis was performed using IBM SPPS Statistics® version 25. A significance level of 5% was adopted in this study.

Results

Group of caregivers and patients

The total number of 29 (87.9%) mothers and four (12.1%) fathers completed the PSQI, with no other type of caregivers included. The sociodemographic details are presented in Table 1. Of the 33 caregivers included in the study, 24.2% suffered from some type of pathology or sleep disorder.

Regarding the gender of children / adolescents included in the study, 23 (69.7%) and 10 (30.3%) were male and female, respectively, in the age range of 1-5 years old (n = 6, 18.2%), 6-10 years (n = 8, 24.2%), and 11-18 years (n = 19, 57.6%).

In total, 81.8% of the children / adolescents in this group were attending school daily. The patients were mainly categorized into a diagnostic and an ACT group, as presented in Table 2.

The types of ventilation interface included face mask, nasal mask, and tracheostomy in 27 (81.8%), five (15.2%), and one (3%) patient, respectively. The average daily hours of home mechanical ventilation was eight hours (minimum four and maximum 12 hours). However, 48.5% of patients were using ventilation for no more than eight hours, 51.5% between 9-15 hours, and no patient required ventilation for 16 hours or more.

Table 1. Sociodemographic details of caregivers

	Median (min-max)
Age (years)	40 (30-53)
Academic degree	**n (%)**
Primary school	3 (9.1%)
Middle School	10 (30.3%)
High school	13 (39.4%)
Bachelor / Master	7 (21.2%)
Marital Status	**n (%)**
Single	3 (9.1%)
Married / non-marital partnership	25 (75.8%)
Divorced / separated	5 (15.2%)

max - maximum; min - minimum.

Sleep quality

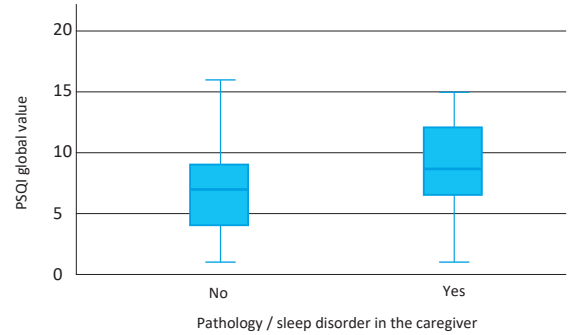
The values obtained in each of the components of the PSQI and its global value are presented in Table 3. The PSQI global scores are presented in Table 4 by diagnostic and ACT groups, characteristics of home mechanical ventilation, and attendance in the place of learning. There was no statistically significant difference in the diagnostic and ACT groups in terms of the PSQI global scores.

Moreover, there was no statistically significant correlation between the number of hours a day of home mechanical ventilation use and the global scores of sleep quality ($r = 0.074$, $p = 0.669$).

The relationship between the global score of sleep quality and the presence of pathology / sleep disorder in the caregiver was studied using extreme diagrams and quartiles (Fig. 1).

Discussion

Sleep disturbance is a highly common problem with multiple contributing factors, which is experienced by family caregivers of children who transition from specialized pediatric facilities to their homes.[2] Whereas



PSQI - Pittsburgh sleep quality index.
No: 7 ± 4 (mean ± standard deviation).
Yes: 9 ± 4 (mean ± standard deviation).

Figure 1. Presence of pathology / sleep disorder in the caregiver and the global value of Pittsburgh sleep quality index.

short-term sporadic exposure to sleep deprivation over the course of a lifetime most probably will not have serious long-term consequences on neural functions, a relatively long and constant period of sleep deprivation, chronic sleep restriction, or fragmentation can lead to serious acute and chronic damage to neural functioning.[10]

The mean PSQI global score for the study sample was much higher than that obtained for a healthy normalized Portuguese population, for whom the mean global score was 1.20 with a standard deviation (SD) of 0.46, indicating a significantly impaired sleep quality.[11] However, this value is similar to the results of other populations of caregivers of patients with severe psychomotor development (mean ± SD of PSQI global score = 8 ± 4)[12] and caregivers of adolescents with neuromuscular diseases under home mechanical ventilation (mean ± SD PSQI global score = 7.4 ± 4.7).[13]

The majority (72.4%) of the sample obtained global scores ≥ 5, indicating the presence of difficulties in, at least, two components of the questionnaire and a higher risk of sleep disturbance.[11] The literature associates sleep disruption with short and long-term health consequences for the caregivers.[5] Sleep disruption is also associated with a disruption in the activities and duties of the caregiver, as well as the patient care.[14]

More than half (63.6%) of the caregivers perceived their own quality of sleep as good, despite the global score

Table 2. Diagnostic group and association for children with life-threatening or terminal conditions and their families group of the children / adolescents under home mechanical ventilation

Diagnostic group	**n (%)**
Other congenital or genetic defect	15 (45.5%)
Neuromuscular disease	8 (24.2%)
Respiratory disease	7 (21.2%)
Central hypoventilation	2 (6.1%)
Metabolic / neurodegenerative disease	1 (3%)
ACT group	**n (%)**
1	0 (0%)
2	17 (51.5%)
3	1 (3%)
4	15 (45.5%)

ACT - Association for Children with Life-threatening or Terminal Conditions and their Families.

Table 3. Sleep quality of the caregivers (Pittsburgh sleep quality index)

Component 1 - subjective sleep quality			**%**
Good			63.6%
Fairly bad / very bad			36.4%
Component 2 - sleep latency			**%**
Mild to moderate changes			50.0%
Few or no changes			50.0%
Component 3 - sleep duration			**%**
> 7 hours			48.4%
6-7 hours			19.4%
< 6 hours			32.3%
Component 4 - sleep efficiency			**%**
≥ 85%			50%
75% - 84%			25.0%
≤ 74%			25.0%
Component 5 - sleep disturbance			**%**
Mild to moderate			75.0%
Severe			25.0%
Component 6 - use of sleep medication			**%**
No			72.7%
Yes, once or twice a week			9.1%
Yes, three or more times a week			18.2%
Component 7 - daytime dysfunction			**%**
Mild			25.0%
Moderate to severe			75.0%
	Mean	**SD**	**%**
Global PSQI score	8	4	
Global score ≥ 5 - poor sleep quality			72.4%
Global score < 5 - good sleep quality			27.3%

PSQI - Pittsburgh sleep quality index; SD - standard deviation.

Table 4. Pittsburgh sleep quality index global values according to patients characteristics

	PSQI value Mean (SD)
Diagnostic group	
Other congenital or genetic defect	6 (4)
Neuromuscular disease	8 (4)
Respiratory disease	11 (4)
Central hypoventilation	8 (5)
Metabolic / neurodegenerative disease	7 (NA)
ACT group	
2	9 (4)
3	7 (NA)
4	7 (4)
Type of interface of home mechanical ventilation	
Face mask	7 (5)
Nasal mask	7 (4)
Tracheostomy	9 (NA)
Daily hours of home mechanical ventilation	
≤ 8 hours	6 (1)
9 - 15 hours	8 (4)
Attendance of a place of learning	
Yes	8 (4)
No	8 (4)

ACT - Association for Children with Life-threatening or Terminal Conditions and their Families; NA - not applicable; PSQI - Pittsburgh sleep quality index; SD - standard deviation.

obtained in the PSQI test indicating a good sleep quality in only 27.3% of the caregivers. This may be explained by the fact that the caregiver gets accustomed to their sleeping condition.[13]

Caregivers of children / adolescents with respiratory disease were the ones with the worst scores of sleep quality (mean PSQI value = 11), followed by neuromuscular disease and central hypoventilation (mean PSQI value = 8). In previous studies, caregivers of children ventilated due to respiratory pathology, caregivers of young people with neuromuscular diseases under home mechanical ventilation, and mothers of children with congenital central hypoventilation syndrome presented mean PSQI scores of 8.69, 7.4, and 7.5, respectively.[13-15] An accentuated difference can be observed in the mean PSQI score in the respiratory group, compared to the present study.

Caregivers of ACT group 2 presented the worst sleep quality (mean PSQI value = 9). Although no reports were found in the literature to compare ACT groups, we can hypothesize an association to the longer trajectory of the disease.

Half of the study sample had sleep efficiency indices below 85% (the normal value being 80%), which may be associated with drowsiness and diurnal dysfunction. The results of another study suggested a significant difference in sleep efficiency between the caregivers of ventilated and healthy children.[16]

A very significant percentage of caregivers reported sleep disturbance and/or daytime dysfunction. However, this might not be directly related to the need for providing care to the child / adolescent. It was described that 52% of caregivers of ventilated children reported waking at least once a week to perform nighttime caregiving duties, compared to 9% of caregivers of healthy children.[16] Furthermore, in families of technology-dependent children, a large proportion of families (22 out of 36) experienced regular sleep disruption (where parents reported getting up in the night at least twice a week).[17]

Approximately 25% of the caregivers needed sleep medication, at least once a week, similar to what was recorded for a population of caregivers of ventilated children (24.1%).[16] This can be potentially a safety issue, since caregivers may fail to wake if necessary.

The type of interface and the daily hours of using home mechanical ventilation did not seem to interfere with sleep quality. The duration of home mechanical ventilation and the time of the day when it was performed were identified as important factors for sleep disruption, with a greater negative impact associated with the increase in daily hours of home mechanical ventilation.[17] However, the longer-term use of non-invasive ventilation appears to result in an adjustment by the caregiver, with consequent improvement in sleep quality.[18]

Regarding the limitations of the study, one can refer to the relatively sample small size, which can make it difficult to find significant associations.

Pittsburgh sleep quality index does not provide detailed information on specific factors, which may vary depending on the underlying pathology and influence the sleep quality of caregivers accordingly. The study was based on a subjective self-completion tool that can lead the caregiver to underestimate / overestimate the quality of the measured parameters. The fact that about 25% of the sample presented a sleep disorder may constitute a bias to the obtained results.

Sleep may be influenced by other variables not considered in this study, such as environmental issues, sleep hygiene habits, presence of one or more caregivers, and child / adolescent disease stage.

It would be useful to carry out a prospective and longitudinal study, which would allow the questionnaires to be applied immediately before the onset of home mechanical ventilation and after a period of 3-6 months to determine the impact of home mechanical ventilation on the sleep quality of the caregivers and reduce the interference of other external factors.

Based on the obtained results, the sleep quality of caregivers of children / adolescents under home mechanical ventilation was lower than that recorded for the healthy Portuguese population and presented values similar to those described in particular groups in the literature. The caregivers of children / adolescents with respiratory disease and those of the ACT group 2 had the worst sleep quality values.

Based on the data obtained, it is essential to sensitize health professionals to assess the sleep quality of the caregivers of patients with complex chronic disease, given the relevance, not only for performing their duties but also for their own health and quality of life. Therefore, taking care of the caregivers should be one of the axes of medical intervention.

Author Contribuitions

RG, CM, NM and CC participated in the study conception or design. RG, CM and AB participated in acquisition of data. RG, CM and CC participated in the analysis or interpretation of data. RG, CM and CC participated in the drafting of the manuscript. RG, NM and CC participated in the critical revision of the manuscript. All authors approved the final manuscript and are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Conflicts of Interest

The authors declare that there were no conflicts of interest in conducting this work.

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Protection of human and animal subjects

The authors declare that the procedures followed were in accordance with the regulations of the relevant clinical research ethics committee and with those of the Code of Ethics of the World Medical Association (Declaration of Helsinki 2013).

Provenance and peer review

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Confidentiality of data

The authors declare that they have followed the protocols of their work centre on the publication of patient data.

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Ventilação Mecânica Domiciliária em Crianças: Impacto na Qualidade do Sono dos Cuidadores

Introdução: O papel desempenhado por cuidadores de crianças com doença crónica complexa pode ser influenciado por problemas do sono, o que pode afetar a longo prazo a qualidade dos cuidados prestados à criança. O objetivo deste estudo foi avaliar a qualidade do sono dos cuidadores de crianças com doença crónica complexa sob ventilação mecânica domiciliária.

Métodos: Estudo observacional e analítico realizado entre outubro 2018 e janeiro 2019. Incluímos cuidadores de crianças / adolescentes com doença crónica complexa sob ventilação mecânica domiciliária há três meses ou mais, seguidos em consulta de pneumologia de um hospital pediátrico terciário. O instrumento de avaliação foi o Pittsburgh *sleep quality index* (versão portuguesa).

Resultados: Incluímos 33 cuidadores. O valor global médio obtido pela nossa amostra no Pittsburgh *sleep quality index* foi superior ao de uma amostra de população portuguesa saudável (8 *vs* 1,20). Obtiveram um valor global ≥ 5 72,4%, traduzindo um maior risco de problemas do sono. Os cuidadores de crianças / adolescentes com doença respiratória obtiveram os piores valores de qualidade do sono (valor Pittsburgh *sleep quality index* médio = 11), seguidos pela doença neuromuscular e hipoventilação central (valor Pittsburgh *sleep quality index* médio = 8). Não se observou diferença estatisticamente significativa entre os três grupos diagnósticos.

Discussão: Houve uma discrepância entre a qualidade subjetiva do sono (boa em 64%) e o valor de Pittsburgh *sleep quality index* (má em 72%), com uma percentagem significativa de sonolência / disfunção diurna (75%). Metade da amostra demonstrou índices de eficiência do sono inferiores a 85%. É essencial alertar os profissionais para a avaliação da qualidade do sono dos cuidadores de crianças com doença crónica complexa, uma vez que esta pode não ser adequadamente percecionada.

Palavras-Chave: Assistência Domiciliar; Crianças com Deficiência; Cuidadores; Fardo do Cuidador/diagnóstico; Privação do Sono; Qualidade do Sono; Respiração Artificial