Residência RP Pediátrica
Publicação Oficial da Sociedade Brasileira de Pediatria

Submitted on: March 20, 2020
Approved on: April 15, 2020

ORIGINAL ARTICLE

Subjective evaluation of the quality of sleep of the main caregiver of a child or a teenager with cerebral palsy

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Keywords:
Cerebral Palsy,
Sleep,
Caregivers,
Child,
Adolescent.

Abstract

Objective: Subjectively evaluate the quality of sleep of a main caregiver of a child or a teenager with cerebral palsy. **Methods:** Prospective transversal study, with sample of 55 main caregivers of children or teenagers diagnosed with cerebral palsy. Socioeconomic data was collected through a general data record and quality of sleep data through Pittsburgh sleep quality index. Caregivers of 18 years old or less were deleted of the study. The data was tabulated in Excel® spreadsheet and analyzed by StatSoft Statistica software, version 10, to identify the frequencies and descriptive statistics obtained through the questionnaires. **Results:** Most of main caregivers consider their sleep quality good (50.9%). However, just 21 sleep the appropriate number of hours for the effective performance of daily adult functions, while 85.44% have sleep latency greater than 15 minutes and only 27.27% do not have daytime drowsiness. Sleep efficiency was greater than 85% for 67.27% of the sample and 47.26% feel moderate or much unwillingness or lack of enthusiasm for daily activities. **Conclusions:** The obtained results allow us to identify changes in the quality of sleep of the main caregivers of children or adolescents with cerebral palsy, which questions the individual perception of most participants as to the presence of good quality of sleep. Therefore, evaluation of those participants with polysomnography is indicated in order to complement the analysis of sleep quality

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Residência Pediátrica; 2022: Ahead of Print.
DOI: 10.25060/residpediatr-2022.v12n2-286

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INTRODUCTION

Cerebral palsy (CP) is caused by a brain injury in the prenatal, perinatal or postnatal period, and it has a potential effect on a child's general development, affecting their ability to explore, communicate, learn and acquire independence. Due to its chronic nature, this comorbidity has social implications that affect both CP patients and their families, especially their caregivers. The psychological and physical health of caregivers, a group consisting mainly of mothers, is strongly influenced by the CP-child's behavior and by the care requirements[1-3].

This is because, in mild forms, CP patients present with mild spasticity and contracture in one arm and one leg, affecting one side of the body, which interferes with the fluidity of movement and fine manual dexterity, and they may lack sensorial attention on the ipsilateral side of the body and in the corresponding visual field, in addition to the possibility of having an epilepsy trigger. Individuals with more severe manifestations may present involvement of the four limbs associated with spasticity and dyskinesia, as well as scoliosis and substantial contractures, thus requiring a wheelchair for mobility. In addition, they may have severe learning difficulties, cortical visual impairment, and be prone to chest infections[4].

Another important factor is the common presence of sleep disorders in the population with CP. The most common sleep problems are sleep-wake transition disorders, excessive daytime sleepiness and awakening disorders[5].

This chronic disease can have a direct impact on the patient's sleep, but also, indirectly, on the sleep of family members who provide night care. Caring for a family member with a chronic illness is not just a day job, but it can require a significant amount of work during the night, resulting in interruption and chronic partial sleep deprivation. In addition, there is discussion about an association between chronic sleep loss and the subsequent development or worsening of depressive symptoms. Furthermore, much of the scientific literature and research on caregiver populations focus on caregivers of adult patients, with less emphasis on caregivers of pediatric populations[6,7].

Meltzer e Moore (2008)[8], through a systematic review, presented four potential causes for sleep disruption in parents of children/adolescents with chronic illnesses. The first of these is the frequent need to provide care related to illness or nocturnal episodes of pain. The second corresponds to the need for monitoring the child or adolescent by the parents at night. The third refers to false alarms from monitors, in particular, in children/adolescents who depend on this technology, while the fourth cause corresponds to the stress of caring for young people with chronic illnesses. The authors also evidenced the presence of a relationship between the child's sleep, the parents' sleep and their daytime functioning.

Major physiological systems are influenced by sleep, and sleep disorders can contribute to or exacerbate medical or psychiatric disorders. There is evidence that sleep must have sufficient duration and continuity to ensure consistent levels of wakefulness, attention, cognition and effective neurobehavior, as well as to avoid predisposition to comorbidities, including diabetes, obesity and hypertension. The most reliable changes are lapses in sustained attention and disinhibition of the compensatory response, psychomotor and cognitive retardation, working memory deficits, slow eyelid closure, and reduced physiological sleep latency[9,10].

The American Academy of Sleep Medicine, taking only sleep duration into account, recommends that adults get seven to eight hours of sleep for optimal performance and good health. They further stress that meeting the individual need for sleep duration, timing, regularity and quality requires volitional behaviors, partially dictated by genetic and physiological factors, but that a large proportion of inter-individual sleep variability is likely explained by psychological, behavioral, social, cultural and environmental factors and that sleep disorders, often undiagnosed and/or untreated, contribute to this variability[11].

Sleep quality can be assessed using the Pittsburgh Sleep Quality Index (PSQI), which Brazilian version was validated by Bertolazi et al in 2010. The questionnaire consists of 19 items grouped into seven components, with scores ranging from zero to three (where zero means no difficulty and three means severe difficulty). The components are: C1 subjective sleep quality; C2 sleep latency; C3 sleep duration; C4 habitual sleep efficiency; C5 sleep changes; C6 use of sleep medication; C7 daytime sleep dysfunction. To final scores are added to a total score that can range from zero to 21 points. A total score of less than five indicates good sleep quality, between five and ten indicates poor sleep quality, and greater than ten indicates sleep disorder[12].

Bearing this in mind and considering the evident importance of the study of chronic sleep deprivation, the objective of this study was to evaluate the sleep quality of the main caregiver of the child or adolescent with CP.

METHODS

After approval by the Ethics in Research with Human Beings Committee, we ran a prospective cross-sectional descriptive study involving primary caregivers of children or adolescents with a confirmed diagnosis of CP. We assessed data on the sleep quality of the main caregiver, totaling a sample of 55 participants. Primary caregivers under 18 years of age were excluded from the survey.

The data were tabulated in an Excel® spreadsheet and analyzed using the StatSoft Statistica software, version 10, to identify the frequency of gender and caregiver's education, family income, paid activity, items present in the PSQI and to perform a descriptive statistics of caregiver age, score obtained on the PSQI, time to sleep (in minutes) and total sleep duration in hours.

When the guardian attended the consultation, accompanying the child or adolescent with CP, he/she was invited to participate in the study and answer a form with general data (APPENDIX 1) and the Pittsburgh Sleep Quality Index (ANNEX 1), after signing the Free and Informed Consent Form. The General Data Sheet was created by the research authors and was filled in by the person in charge with the following information about the main caregiver: identification data and socioeconomic information (educational level, occupation and monthly family income). The primary caregiver's sleep quality was assessed by the Pittsburgh Sleep Quality Index.

RESULTS

We had 55 primary caregivers of children or adolescents with CP included in the analysis, four (7.27%) were male and 51 (92.72%) were female. Of the caregivers, 43 (78.18%) were not paid to work and 12 (21.81%) were. The median age was 41 years, ranging from 23 to 68. The median total hours of sleep was seven hours, ranging from two to ten hours, and the median time to sleep was 30 minutes, going from three minutes to 120 minutes. The total score of the PSQI had a median of seven points, with variations between one and 16 points (table 1 e 2).

DISCUSSION

In this study, 51 (92.72%) participants were female. This expressive number agrees with other studies that also showed a higher prevalence of women assuming the role of main caregivers[2,13,14].

Most caregivers did not perform paid work (78.18%). This result can be attributed to the overload of care provided to children and adolescents with CP, requiring that a large part of the caregivers' time be dedicated to them, not having enough free time to assume the responsibilities of a paid full--time or part-time job[15].

Approximately 80% of the participants in the sample had a family income of up to three minimum wages. This may be related to the absence of monetary contribution from the caregiver due to the absence of paid work. In addition, 89.09% of the participants had education below high school, with 49.09% having elementary education or being illiterate.

Low socioeconomic status, whether by income, education or occupation, is related to poor sleep quality[16]. Therefore, further studies are needed to correlate the socioeconomic status of this population with sleep quality.

Most primary caregivers considered they had a good quality of sleep. This perception was assessed by the items "Subjective sleep quality" (50.90%) and "Sleep classification during the past month" (52.72%) of the PSQI. However, the analysis of other variables in the PSQI leads to a questioning about the real quality of sleep of these caregivers. This is because, in the analysis of sleep duration, only 21 caregivers slept the appropriate amount of hours (seven hours or more) for an adult, and nine slept an amount far below what is necessary for the effective performance of daily functions of an adult (slept less five hours a night). In addition, 85.44% of caregivers have a sleep latency of 16 minutes or more. That is, only 14.54% of the sample slept the ideal time (sleep latency time of less than 15 minutes, defined by the American Academy of Sleep Medicine). Corroborating this information, 40% said it took

Table 1. Characteristics of caregivers of children or adolescents diagnosed with cerebral palsy.

Variable	n	Percentage
Schooling		
Illiterate	1	1.81%
Studied 1st to 4th year of elementary school	15	27.27%
Studied 5th to 8th year of elementary school	11	20.00%
High School	22	40.00%
College	5	9.09%
Graduate School	1	1.81%
Family income[a]		
No income	-	
Up to 1 minimum wage (up to 880.00)	10	18.18%
From 1 to 3 minimum wages (from 880.00 to 2,640.00)	34	61.81%
From 3 to 6 minimum wages (2.640,00 to 5.280,00)	8	14.54%
From 6 to 9 minimum wages (5,280.00 to 7,920.00)	1	1.81%
From 9 to 12 minimum wages (from 7,920.00 to 10,560.00)	2	3.63%
More than 12 minimum wages (10,560.00)	-	-

Note: As a basis for income stratification, we considered the minimum wage in force in 2016, approved by Decree 8.618/2015. n, Number of individuals.-, Absence of individuals in the question.

Table 2. Pittsburgh Sleep Quality Index (PSQI)a, applied to caregivers of children or adolescents diagnosed with cerebral palsy.

Variable	n	%	n	%	n	%	n	%
	Very good		**Good**		**Bad**		**Very bad**	
Subjective sleep quality	5	9.09%	28	50.90%	16	29.09%	6	10.90%
Sleep classification during the past month	4	7.27%	29	52.72%	17	30.90%	5	9.09%
	<15 minutes		**From 16 to 30 minutes**		**From 31 to 60 minutes**		**More than 60 minutes**	
Sleep latency	8	14.54%	14	25.45%	17	30.90%	16	29.09%
	More than 7 hours		**From 6 to 7 hours**		**From 5 to 6 hours**		**Less than 5 hours**	
Sleep duration	21	38. 18%	19	34.54%	6	10.90%	9	16.36%
	More than 85%		**From 75-84%**		**From 65-74%**		**Less than 65%**	
Habitual sleep efficiency	37	67.27%	8	14.54%	3	5.45%	7	12.72%
None	**None**		**Little**		**Moderate**		**Much**	
Daytime sleepiness	15	27.27%	16	29.09%	20	36.36%	4	7.27%
Indisposition or lack of excitement for daytime activities in the past month	17	30.90%	12	21.81%	17	30.90%	9	16.36%
	None		**Less than once a week**		**1 to 2 times a week**		**3 or more times/week**	
Sleep disorders	1	1.81%	30	54.54%	23	41.81%	1	1.81%
Use of sleep medication	51	92.72%	-	-	1	1.81%	3	5.45%
Took more than 30 minutes to catch sleep in the past month	15	27.27%	5	9.09%	13	23.63%	22	40%
Woke up in the middle of the night or very Early in the morning in the past month	15	27.27%	3	5.45%	12	21.81%	25	45.45%
Woke to go the bathroom in the past month	29	52.72%	3	5.45%	6	10.90%	17	30.90%
Had difficulty breathing in the last month	46	83.63%	3	5.45%	3	5.45%	3	5.45%
Cough or snore very loud in the past month	42	76.36%	1	1.81%	5	9.09%	7	12.72%
Feel very cold in the past month	41	74.54%	5	9.09%	4	7.27%	5	9.09%
Feel very hot in the past month	33	60%	3	5.45%	7	12.72%	12	21.81%
Have bad dreams or nightmares in the past month	38	69.09%	5	9.09%	8	14.54%	4	7.27%
Feel pains in the past month	26	47.27%	3	5.45%	10	18.18%	16	29.09%
Trouble sleeping in the past month	27	49.09%	2	3.36%	9	16.36%	17	30.90%
In the past month took some medication to sleep, prescribed by a doctor, someone else or on your own	52	94.54%	-	-	-	-	3	5.45%
Had problems to keep awake with driving, during meals or Other social activity	34	61.81%	4	7.27%	12	21.81%	5	9.09%

Note. Data referring to the Pittsburgh Sleep Quality Index (PSQI), obtained through the application of a form to the main person responsible accompanying a child with cerebral palsy. n, Number of individuals.%, Percentage corresponding to the preceding "n". -, Absence of individuals in the question.

more than 30 minutes to fall asleep, three or more times a week. Another data that contradicts the results of good subjective sleep quality is the variable "Daytime sleepiness". To obtain a good quality of sleep, there should be no daytime sleepiness, a result presented by only 27.27% of the present sample. Furthermore, only one participant claimed to have no sleep disturbance during the week, and the majority (45.45%) woke up at night or very early in the morning three times or more a week. On the other hand, the analysis of "Habitual sleep efficiency", which evaluates the relationship between the number of hours slept and the number of hours spent in bed, being ideally greater than 85% (67.27% of the sample), which is consistent with good sleep quality subjectively assessed by most caregivers[11,12,17,18].

Approximately half of the sample showed indisposition or lack of enthusiasm for daily activities (47.26%, considering moderate and high responses). This data may be related to the development of mood disorders in caregivers of patients with CP, corroborating previous studies that claim that there is a relationship between poor sleep quality and the development of these comorbidities. In addition, low socioeconomic status, together with poor sleep quality, interfere with the mental health of these caregivers and may predispose them to depression[4,16].

The hypothesis of the present study is the presence of poor sleep quality in the main caregivers of children or adolescents with CP, using the PSQI for the analysis. The results presented allow us to identify changes in the sleep quality of the present sample, which challenges the perception of most participants regarding the presence of a good quality of sleep. Therefore, there is an indication of evaluation of these participants with polysomnography, in order to complement the analysis of sleep quality and generate more hypotheses. Other studies are also needed to demonstrate whether there is a relationship between the gross motor skills of children or adolescents with CP and the quality of sleep of their primary caregiver.

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Appendix 1. General data sheet.

Evaluation date: / /

DATA OF THE RESPONSIBLE

Name: _____

Address: _____

Neighborhood: _____ City: _____ State: ____

Telephone: (__) _____ (__) _____

Email: _____

Gender ( ) F ( ) M Date of birth __/__/____ Age: _____

CHILD OR ADOLESCENT DATA

Name: _____

Gender ( ) F ( ) M Date of birth __/__/____ Age: _____

Attends school: ( ) YES ( ) NO Which shift: ( ) morning ( ) afternoon ( ) full time

School name: _____

Does he/she do any kind of therapy?

( ) Physiotherapy How many times a week? _____

( ) Hydrotherapy How many times a week? _____

( ) Equine therapy How many times a week? _____

( ) Occupational therapy How many times a week? _____

( ) Speech Therapy How many times a week? _____

( ) Psychology How many times a week? _____

( ) Music Therapy How many times a week? _____

FAMILY SOCIOECONOMIC INFORMATION

1. What is the educational level of the main caregiver of the child or adolescent?

( ) From 1st to 4th grade of Elementary School (former primary)

( ) From the 5th to the 8th grade of Elementary School (former gymnasium)

( ) High School (former 2nd grade)

( ) Higher education

( ) Specialization

( ) Did not study

( ) I don't know

2. Adding your income to the income of the other people who live with you.

( ) No income

( ) Up to 1 minimum wage (up to BRL 880.00)

( ) From 1 to 3 minimum wages (from BRL 880.00 to BRL 2,640.00)

( ) From 3 to 6 minimum wages (from BRL 2,640.00 to BRL 5,280.00)

( ) From 6 to 9 minimum wages (from BRL 5,280.00 to BRL 7,920.00)

( ) From 9 to 12 minimum wages (from BRL 7,920.00 to BRL 10,560.00)

( ) More than 12 minimum wages (more than BRL 10,560.00)

3. Do you work?

( ) Yes. What is the job? _____

( ) No

4. Who are the people who live in your house? (Inform the degree of kinship)

_____

_____

ABOUT THE HEALTH OF CHILDREN OR ADOLESCENTS

5. Does he/she have epilepsy?

( ) No

( ) yes

If answer 5 was positive. Answer questions 6 and 7. If no, skip to question 8.

6. epilepsy medication ? (Which one(s)?

_____

_____

7. When did the last seizure episode occur?

_____

_____

8. Does he/she have any other health problems?

( ) No

( ) Yes. Which one?

_____

How long?

_____

9. you have any medications that your child takes regularly? Which are they? How long?

_____
_____

10. sleep medication ?

_____
_____

11. Is he/she undergoing any medical treatment?

( ) No

( ) Yes. Which one?

_____

How long?

_____

12. recent surgery ?

( ) No

( ) Yes. Which one?

_____

13. Has he/she recently been hospitalized for a respiratory problem?

( ) No

( ) Yes. What problem?

_____

When?

_____

14. Does he/she have any breathing problems?

( ) No

( ) Yes. Which one?

_____

How long?

_____

Are you in treatment?

_____

What is the treatment?

_____

15. Is he/ she tracheostomized ?

( ) No

( ) Yes. How long?

_____

16. Does he/she use a tube to feed?

( ) No

( ) Yes. How long?

_____

ABOUT CHILD OR ADOLESCENT SLEEP

17. What time does he/she wake up during the week? _____
18. What time does he/she sleep during the week? _____
19. What time does he/she wake up on the weekend? _____
20. What time does he/she sleep on the weekend? _____
21. Does he/she sleep during the day?

( ) No

( ) Yes. How much time? _____

22. During the night do you usually change his/her position while he/she sleeps?

( ) No

( ) Yes.

23. If the last question was yes, how often do you change his/her positioning during the night?

( ) 1 time

( ) 2 times

( ) 3 times or more

24. Does he/she share a room at bedtime?

( ) No

( ) Yes. With how many people? _____ Who are? _____

25. Does he/she share a bed at bedtime?

( ) No

( ) Yes. With how many people? _____ Who are? _____

Annex 1. Pittsburgh sleep quality index.

Pittsburgh Sleep Quality Index (IQSP)

Instructions:

1. The following questions refer to your sleep habits during the past month.
2. Your answers should demonstrate, as accurately as possible, what happened on most days and nights of this month alone.
3. Please answer all questions.

1) During the past month, what time did you usually go to bed?
BED TIME .....:.....

2) During the past month, how long (in minutes) did it usually take you to fall asleep, most of the time?
HOW MANY MINUTES DOES IT TAKE TO GET SLEEP .....

3) During the past month, what time did you wake up in the morning most of the time?
WAKE UP TIME: .....

4) During the past month, how many hours of sleep per night did you get? (may be different from the number of hours you stayed in bed)
HOURS OF SLEEP PER NIGHT:..... ....

For each of the questions below, mark the best answer. Please answer all questions.

5) During the past month, how often have you had trouble sleeping because of:
a. Take more than 30 minutes to fall asleep ( )not at all ( )once or twice a week ( )less than once a week ( )three or more times a week or more

b. Waking up in the middle of the night or very early in the morning ( )not at all ( )once or twice a week ( )less than once a week ( )three or more times a week or more

c. Getting up to go to the bathroom ( ) not once ( ) once or twice a week ( ) less than once a week ( ) three or more times a week or more

d) Having trouble breathing
( ) not once
( ) once or twice a week ( ) less than once a week ( ) three or more times a week or more

e) Coughing or snoring very loudly ( ) not once ( ) once or twice a week ( ))less than once a week ( )three or more times a week or more

f) Feeling very cold ( )not at all ( )once or twice a week ( )less than once a week ( )three or more times a week or more

g) Feeling very hot ( ) not once ( ) once or twice a week ( ) less than once a week ( ) three or more times a week or more

h) Having bad dreams or nightmares ( ) not once ( ) once or twice a week ( )less than once a week ( )three or more times a week or more

i) Feel pain( )not once ( )once or twice a week ( )less than once a week ( ) three or more times a week or more

j) other reason (please describe):

_____

k) How many times have you had trouble sleeping for this reason during the past month?
( ) not once
( ) once or twice a week ( ) less than once a week ( ) three or more times a week or more

6) **Over the past month, how would you rate the overall quality of your sleep?**
( ) very good
( ) good ( ) bad ( ) very bad

7) **During the past month, have you taken sleeping pills, prescribed by your doctor, or recommended by someone else (pharmacist, friend, family member) or even on your own?**
( ) not once ( ) once or twice a week ( ) less than once a week ( ) three or more times a week or more Which(is)?

_____
_____
_____

8) **During the past month, if you have had difficulty staying awake while driving, eating, or participating in any other social activities , how often has this happened?**
( ) not once
( ) once or twice a week ( ) less than once a week ( ) three or more times a week

or more

9) **During the past month, have you felt unwell or lack of enthusiasm to carry out your daily activities?**
( ) not once
( ) once or twice a week ( ) less than once a week ( ) three or more times a week or more

Interviewee comments (if any):

_____

component score

1: ____; two: ____; 3: ____; 4: ____; 5: ____; 6: ____; 7: ____