



## Pathological Sleep Disorders Among Caregivers of Children With Cerebral Palsy

### KEYWORDS

Cerebral palsy, caregivers, sleep disorders

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**ABSTRACT** *Background : Current literature highlights the high stress levels experienced by mothers caring for children with CP; however sleep disorders (SD) and its associated factors suffered by such mothers have not been well documented.*

*Objective : To provide relevant evidence and consequential guide on the management of patients and caregivers suffering sleep disorders.*

*Study design : By way of a cross sectional questionnaire designed to calculate correlation of child vis-à-vis carer factors causing SD, participated by 99 respondents.*

*Results : 73% of our caregivers had pathological SD, with significant correlation ( $p= 0.039$ ) seen in the working population. Factors that were previously perceived to cause SD eg. co-sleeping, child with epilepsy, severe disability and use of night orthoses demonstrates no significance.*

*Conclusion : Screening for SD among caregivers should be an integral part of the management of patients with CP. Common misconceptions on causes of SD may be identified and capable of being treated.*

### INTRODUCTION

Disabled children require adaptation from all individuals who come in direct contact with them including parents, siblings, grandparents, other relatives and even friends. The particular adaptation in this research relates to sleep deprivation or disorders (SD) which the caregiver may be prone to suffer when caring for a child diagnosed to have cerebral palsy (CP). The SD suffered may be of diverse levels depending on the disability suffered by the child as well as the attachment of the child caregiver to the said child<sup>1</sup>.

SD among CP children is a recognised concern and extensive research has been done to govern the elements contributing to SD<sup>2,3,4</sup>. Factors commonly associated with SD among children with CP include muscle spasms, pain, drugs that cause day time drowsiness, nocturnal seizures, visual impairment affecting melatonin secretion, behavioural problems, poor sleep hygiene and use of night splints<sup>2,3,4,6</sup>. These circumstances may result in an intensified nocturnal monitoring of the child which sequentially disrupts their caregiver's sleep.

The family is a primary unit in the rehabilitation process and the main caregiver, predominantly the mother, forms a vital link between healthcare professionals and the child<sup>10,12</sup>. An effective "good health care model" for patients with CP, cannot be complete without due concern being directed towards the wellbeing of the caregiver.

Stress among mothers of children with CP has been explored by various studies with the majority emphasizing the need for psychosocial support<sup>1,2,5,9,10,11,12</sup>. SD has been considered as one of the components generating stress and depression particularly among these mothers<sup>1,5</sup>.

Sleep arrangements and habits differ according to socio-economic environments and different cultural backgrounds. Co-sleeping with children is common practice among Asian parents, and reported to significantly increase SD among parents but not the afflicted children<sup>2,9</sup>. Night-time parental attention results in a vicious cycle of severe sleep disruption/deprivation escalating the risk of depres-

sion and stress among caregivers<sup>1,5</sup>.

The primary aim of this study is to determine the prevalence and severity of pathological SD amongst primary caregivers. Secondly, recognising the specific domains of child factors that predisposes their carer's to sleep disorders and finally, distinguishing carer domains, principally carer's vocation, work habits and sleeping arrangements that give rise to SD.

### MATERIALS / METHODS

#### Participants

Ninety nine caregivers were enrolled into the study conducted in the Rehabilitation Medicine Outpatient Clinic situated in Hospital Sultan Ismail, Johor, Malaysia. This clinic treats referrals from the entire State of Johor, with patients from both urban and rural areas made up of diverse ethnic groups consisting predominantly Malays plus Chinese and Indians. Sample size calculation was based on previous Asian studies with similar design with number of participants ranging from 50 to 110<sup>2,9,10,11,12</sup>.

Those included in the study were primary caregivers of children who have been diagnosed with CP by a paediatrician. Primary caregiver here refers to any person who devotes the most number of hours in any one day, including night and day, tending to the CP child. Caregivers formerly or currently being treated for sleep disorders and who have been diagnosed to have depression or any other psychiatric disorders were excluded from this study. Likewise, caregivers on prescribed or un-prescribed medication which is capable of altering normal sleep patterns for the period preceding 6 months were excluded.

#### Assessments

Written informed consent was acquired from all primary caregivers as a prerequisite to answering the Pittsburgh Sleep Quality Index (PSQI) questionnaire. A demographic survey on the participant's age, relationship with patient, ethnicity, employment status, whether working night shifts and sleeping arrangements (bed sharing with child) was recorded. Pertinent medical data consisting of child's disabil-

ity level, type of CP, presence of seizures, medication type and use of orthosis was sourced from the patient's medical records.

Pittsburgh Sleep Quality Index (PSQI) is a questionnaire assessing the sleep disturbances and sleep quality of adults over the preceding one month. The PSQI has been validated in healthy controls and consists seven component scores which include subjective sleep quality, sleep duration, sleep latency, sleep efficiency, sleep disorders, use of medication that can alter sleep or to initiate sleep and daytime dysfunction. The component scores range from 0 (no difficulty) to 3 (severe difficulty). A score of 5 or more will represent the existence of pathological sleep disorder. The PSQI is reported to be able to detect sleep disturbances with a sensitivity of 0.90 and specificity of 0.877. Written permission was obtained from the author Buysse et al. 1989 for the use of the original version of PSQI (English) and a validated Malay version (PSQI-M) which was used as an alternative when necessary. Scores were computed based on the formula given in the University of Pittsburgh Sleep Medicine Institute website.

Gross Motor Classification System (GMFCS) is a classification used to indicate the severity of movement disability explicitly in children with CP and has demonstrated good reliability and validity<sup>9</sup>.

Ethical approval was obtained from the Ministry of Health Malaysia and the Medical Ethics Research Committee. This study is registered with the National Medical Research Registry Malaysia; reference: ID NMRR-15-667-25814.

#### Statistical analysis

All data retrieved was coded and analysed using SPSS (Version 21). Study population data was analysed by frequencies and cross tabulations. Variables like CP type, GMFCS level, bed-sharing, seizures, use of night orthoses, use of sedative medication in child and caregiver pursuing a career were analysed using Chi-square test. A *p*-value of less than 0.05 was considered to be statistically significant.

#### RESULTS

The study had ninety nine (n=99) data sets that were available for analysis. The caregivers mainly were the child's mother (n=83) followed by the father (n=9), grandmother (n=5) and sister (n=2) respectively. The ethnicity of the study population mirrored the Malaysian national average makeup at 62 % Malays, 24 % Chinese, 12 % Indians and 1% others. The majority were homemakers (n=66) and the other 33 participated in paid employment outside the home. Among the 33 who were in employment, only 6 performed night shifts. Co-sleeping with the child was common among Malaysian caregivers; practised by 76.8% (Table 1).

Characteristics of the children with CP demonstrated 57.6% in the age group 3 - 8 years; 30.3 % in the age group were between 9-13 years; and the remaining 12.1 % in the age group of 14-18 years. CP type among the study children were 45 spastic quadriplegic, 28 spastic diplegic, 7 hemiplegic and 18 others (dyskinetic/ataxic/mixed). Based on the GMFCS classification, 57.1% of the children were classified as having moderate to severe disability (GMFCS V and IV). Seizures were present in 26 of the children, 39 of them were using orthoses throughout the night and 83 of them were on medication that causes sedation eg. antiepileptics or muscle relaxants.

Table 2 shows the prevalence of pathological SD among caregivers (71.7%) with a mean score of 7.29 (standard deviation = 4.525). Significant correlation was seen between SD and caregivers having a career (paid employment outside the home) with *P* value of 0.039. No significant association was seen with other child or carer domains (Table 3).

#### Discussion

Sleep patterns among caregivers of children with CP, regardless of the level of disability was found to be severely altered. Majority of the caregivers suffered from pathological sleep disorders (71.7%) and this potentially deleterious condition needs crucial awareness followed by management.

An interesting outcome of this study is that it has debunked previous theories that SD is exclusive and restricted to only caregivers of children afflicted with severe disability (GMFCS IV or V). The study shows that SD has wider affliction potential. Universal screening of cares of CP children independent of GMFCS level is therefore recommended.

The survey identified mothers as the main caregivers (n=83). This study being not limited exclusively to mothers alone revealed that fathers and grandmothers made up the second predominant category of caregivers. Engaging various members of the family unit and dispersing the burden of care is advisable when tending to patients with chronic disease. Mothers who primarily shoulder the sole responsibility of care showed a predisposition to anxiety, higher levels of stress and even depression<sup>10</sup>.

Infants and children unaffiliated by CP were excluded from this study in order to eliminate other factors that contribute to sleep deprivation in mothers who are caregivers of infants and children without CP. Incidentally there were no adult CP patients recruited therefore, conclusions on incidence of SD among caregivers of this population were not made. The distribution of patients with various GMFCS levels and CP types is analogous with other Malaysian studies<sup>2,10</sup>. This variable allows us to establish our point that CP type and GMFCS levels are not components for consideration when predicting SD in caregivers.

The significant association of pathological SD among working caregivers (*P*= 0.039) indicates that participating in paid employment outside the home is a predisposing factor. Paradoxically, Wayte et al. does not concur with this finding, citing social isolation as a causative element to sleep problems<sup>5</sup>. It has been reported that generally caregivers who pursue employment outside the home suffer some form of SD and this condition is further escalated among those who work shifts<sup>13</sup>. Given the small number of caregivers working night shift (n=6) who participated in the survey, we are unable to establish whether this category poses an elevated risk of SD. The high demands of attending to a CP child after work could be postulated as the propagating factor for SD in working caregivers.

Based on this study, 76.7 % of the deponents practised co-sleeping with their CP child. This is not uncommon among Asian parents and similar results can be seen in other studies<sup>2,9</sup>. Co-sleeping arrangements prompted by the need for vigilant monitoring of the child is commonplace in cases of children with concomitant nocturnal epilepsy or sleep apnoea or severe dependency requiring frequent turning.

In the final analysis however, bed-sharing did not demonstrate an association with SD in the caregiver. Such a find-

ing contradicts the position taken by Atmawidjaja et al and Adiga et al who cite bed-sharing as a significant component to impaired sleep in Asian caregivers<sup>2,9</sup>. One explanation to this variance could be that the participants of the survey on being reassured of being in close proximity with their CP child throughout the night encouraged reassurance thus creating better sleep environment. Such an explanation is reinforced by the survey data which show that in cases of CP children with epilepsy or using night orthosis or under treatment of sedative medication, caregivers were not inflicted by SD.

Family focused interventions to assist caregivers with adapting to the high burden of care of a disabled child needs to start even at the first encounter. Establishing good parent-clinician rapport ensures effective communication especially in addressing sensitive and intimate issues pertaining to the carer's psychosocial well being. Undiagnosed sleep deprivation of a parent may escalate to chronic insomnia and other detrimental conditions that has important implications to the CP child. Therefore, it is of paramount importance to advocate medical, educational and social services to all caregivers involved in the care of children with CP.

**CONCLUSION**

There is a high incidence of SD amongst Malaysian caregivers of children with CP and there is a correlation with such incidence with those caregivers who are employed outside the home. There was no cogent evidence to show that Malaysian caregivers who are not in active employment are afflicted by SD. Co-sleeping arrangements involving the caregiver and the CP child cannot be held to be the sole reason for the occurrence of SD amongst caregivers. Screening parents for SD is recommended in all CP children regardless of GMFCS level.

**TABLE 1**

Caregiver Domain		Cerebral Palsy Child Domain	
Characteristics		n = 99 (%)	
Ethnicity			
Malay		62 (62.6)	
Chinese		24 (24.2)	
Indian		12 (12.1)	
Other		1 (1.0)	
Bed sharing			
Yes		76 (76.8)	
Characteristics	n = 99 (%)	Characteristics	n = 99 (%)
Age mean (SD)	39.10 (8.45)	Age (years)	
		3 - 8	57 (57.6)
		9 - 13	30 (30.3)
		14 - 18	12 (12.1)
Relationship		Type of CP	
		Mother	28 (28.3)
		Father	45 (45.5)
		Grandmother	7 (7.1)
		Sister	18 (18.2)
Occupation		GMFCS level	
		I	8 (8.2)
		II	19 (19.4)
		III	15 (15.3)
		IV	21 (21.4)
		V	35 (35.7)

Works shift		Seizures	26 (26.5)
Yes	6 (6.61)	Night orthoses	39 (39.4)
No	93 (93.9)	Sedative drugs	83 (83.8)

CP = Cerebral palsy, SD= Standard deviation, GMFCS = Gross motor functional classification system

**TABLE 2**

SD in Caregivers According to PSQI	
Score range	Value
Mean	7.29
Standard deviation	4.525
Cut off	≥ 5
Normal (n)	28
Pathological n (%)	71 (71.1%)

PSQI = Pittsburgh sleep quality index, SD = standard deviation

**TABLE 3**

**Association of Sleep Disturbances in Caregivers with Other Factors**

	CP type	GMFCS	Seizures	Bedshare	Orthoses	Medication	Career
	P-value	P-value	P-value	P-value	P-value	P-value	P-value
PSQI	0.277 <sup>a</sup>	0.137 <sup>a</sup>	1.000 <sup>a</sup>	0.790 <sup>a</sup>	0.494 <sup>a</sup>	0.392 <sup>a</sup>	0.039 <sup>a</sup>

PSQI=Pittsburgh sleep quality index, a= Pearson Chi-Square test, P value < 0.05 consider as significant association

**REFERENCES :**

- Mobarak R, Khan N.Z., Munir S., Zaman S.S., McConachie H. Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *Journal of Pediatric Psychology*. 2000;25(6):427-433.
- Atmawidjaja RW, Wong SW, Yang WW, Ong LC . Sleep disturbances in Malaysian children with cerebral palsy. *Dev Med Child Neurol*. 2014 Jul;56(7):681-5.
- Romeo DM, Brogna C, Quintiliani M, Baranello G, Pagliano E, Casalino T, Sacco A, Ricci D, Mallardi M, Musto E, Sivo S, Cota F, Battaglia D, Bruni O, Mercuri E. Sleep disorders in children with cerebral palsy: neurodevelopmental and behavioral correlates. *Sleep Med*. 2014 Feb;15(2):213-8.
- Angriman M., Caravale B., Ferri R., Bruni O. Sleep in Children with Neurodevelopmental Disabilities. Review article. *Neuropediatrics* 2015;46: 199-210.
- Wayte S, McCaughey E, Holley S, Annaz D, Hill CM. Sleep problems in children with cerebral palsy and their relationship with maternal sleep and depression. *Acta Paediatr*. 2012 Jun;101(6):618-23.
- Simard-Tremblay E, Constantin E, Gruber R, Brouillette RT, Shevell M. Sleep in children with cerebral palsy: a review. *J Child Neurol*. 2011 Oct;26(10):1303-10.
- Buysse DJ, Reynolds CF, III, Monk TH, Berman SR, Kupfer DJ. The Pittsburgh sleep quality index: A new instrument for psychiatric practice and research. *Psyc Res*. 1989;28:193-213.
- Palisano R, Rosenbaum P, Russel D, Wood E, Galup B. Development and Reliability of system to classify gross motor function in children with cerebral palsy. *Developmental Medicine & Child Neurology* 1997;39 (4).
- Adiga et al. Sleep disorders in children with cerebral palsy and its correlation with sleep disturbance in primary caregivers and other associated factors. *Ann Indian Acad. Neurol*. 2014 Oct- Dec; 17(4) : 417-476.
- Ong L.C., Afifah I, Sofiah, Lye M.S. Parenting stress among mothers of Malaysian children with cerebral palsy: predictors of child and parent-related stress. *Annals of Tropical Paediatrics*. 1998;18:301-307.
- Norizan A., Shamsuddin K. Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *Journal of Intellectual Disability Research*. 2010 Nov;54: 992-1003.
- Ong L.C., Chandran V., Peng R. Stress experienced by mothers of Malaysian children with mental retardation. *J.Pediatr Child Health* 1999; 35: 358-362.
- Drake C.L., Roehrs T., Richardson G., Walsh J.K., Roth T. Shift work sleep disorder: prevalence and consequences beyond that of symptomatic day workers. *SLEEP* 2004;27(8):1453-62.