


An exploratory study: The effects of sleep systems on sleep quality, pain and carer goals for non-ambulant children and young people with cerebral palsy

Journal of Rehabilitation and Assistive Technologies Engineering
Volume 9: 1–9
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DOI: 10.1177/20556683211070729
journals.sagepub.com/home/jrt


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Abstract

Introduction: Sleep systems are supports used in lying, forming part of 24 h posture management programmes, for children and adults with severe motor disorders. Improved posture reduces likelihood of secondary complications such as pain and poor sleep quality, thus improving quality of life. The study aims are to investigate the effect of sleep systems on sleep quality and quantity, pain for young people with Cerebral Palsy and outcomes for carers.

Methods: Baseline data were gathered for 1 month prior to sleep system provision. Comparative data with the sleep system in place, were gathered for 5 months. The sample comprised four children with Cerebral Palsy, GMFCS level V, average age of 11.5, who did not have a sleep system. Data on sleep quality and quantity was gathered using the Chailey Sleep Questionnaire and sleep diaries and pain levels using the Paediatric Pain Profile. GAS Light verbal outcome measure was used to measure carer goals.

Results: Descriptive statistics and paired sample t-tests were used, demonstrating pain levels remained static, improvements in sleep quality and quantity were found and carer goals achieved.

Conclusion: A small sample size and subjective data collection methods were used; further research is required to obtain more conclusive results.

Keywords

posture analysis, assistive technology, self-care, rehabilitation, rehabilitation devices, neurorehabilitation

Date received: 8 January 2020; accepted: 16 December 2021

Introduction

Sleep systems are used as part of a 24 h posture management program, with the aim of maintaining posture, reducing the likelihood of secondary complications such as pain and improving sleep quality.^{1,2} Sleep systems are prescribed postural support systems which contain components, held in place using a base or sheet.³ In 2012 the National Institute for Health and Care Excellence (NICE) recognised the need for a 24 h postural care programme to protect the body shape and manage spasticity.^{1,4,5} States that children

with Cerebral Palsy (CP) who have gross motor functional classification system score of V–IV should start postural

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management programmes in lying as soon as 6 months after birth to reduce the likelihood of hip migration.

There is little evidence at present to support the effectiveness of sleep systems as an intervention, with studies found to be small and mostly of low quality.⁶ Sleep system studies to date have focussed predominantly on pain or comfort,^{7,8,10-12} management of posture deformity^{5,7,9-11,13} and sleep quality.^{7-9,12,14,17} Research has shown that chronic poor posture and loss of mobility are strongly associated with secondary complications such as: restricted breathing, pressure ulcers, distortion of body shape, pain and discomfort.^{2,7,15} Children with CP commonly experience poor posture and resulting secondary complications including pain and sleep disturbance at night, the likelihood of which increases with age and higher GMFCS levels.^{7,16} There have been fewer studies investigating quality of life^{8,10,11} and outcomes for carers.^{7,8} Following a systematic review⁶ recommendations were made for further research to establish benefits, including pain, posture and sleep quality and the impact on users and carers.

Underhill and Poutney (2012)¹² investigated the effect of sleep systems on sleep wake patterns and pain for children with CP. The authors found the use of sleep systems did not affect either outcome. However, variability in the sleep systems used, may have affected the reliability of these findings. Also, the limited measurement period of eight nights, may not have allowed for fluctuations in pain.¹⁷ Used polysomnography to research if sleep systems affected sleep quality and respiratory function, for children with CP. However, data was not taken over multiple nights, which does not take into account variability in sleep patterns.¹⁸ Found that for reliable collection for data for sleep patterns and actigraphy, that one to two nights of data were not sufficient. The findings indicated that one full week of recordings should be taken to achieve five nights of data, which would be sufficient to draw conclusions. To reduce variability and improve reliability of data, research is required which has homogeneity of participants and model of sleep system, with data taken over a time frame which will capture any variability in participant presentation.

Previous research has shown pain interferes with sleep quality and quantity.^{19,20} Investigated pain in children with CP, reported 52% of the children reported pain at all severity levels. This may be caused by increased muscle tone and spasticity in muscles and joints caused by postural deformity.⁸ The outcome of poor sleep quality caused by chronic pain, for children with CP, results in lower school achievements, participation reduced in everyday situations, behavioural problems^{20,21} and have a lower quality of life than those without pain.^{8,22} Reported that the children in the study appeared more comfortable when supported in a sleep system. Participants had reduced pain, improved sleep quality and had developed the ability to fall asleep alone without a carer.

The Paediatric Pain Profile (PPP) has been shown to be a valid and reliable tool^{25,26} in collecting comparative data for pain levels in children with CP, with sensitivity of 1.00 and specificity of 0.91 reported.^{26,27} By collecting data relating to pain levels using the PPP, we can establish if sleep systems affect levels of pain and investigate if this correlates with an increase in sleep quality and quantity.

Research has shown the impact of poor posture on quality of sleep.¹⁶ Chronic sleep disruption can have an impact on cognitive functioning, mood and fatigue (Reynolds et al., 2010).⁸ Reported improved sleep quality following provision of a sleep system. Polysomnography is the current gold standard for measuring sleep quality and quantity. As polysomnography is laboratory-based and is not always practical, actigraphy has been used in studies as it enables the measurements to be taken within the participant's home environment and is more cost efficient.^{5,28-30} Found actigraphy is a useful tool in estimating sleep quantity and wakefulness, with limitations on specificity. Previous studies have used sleep charts and the Chailey Sleep Questionnaire and sleep diaries^{12,31} to gather data on sleep quality and quantity.

Polysomnography was discounted as a measurements tool for this study, as it would not have been feasible, due to the 6 months proposed time frame for the research. The authors preferred method of measurement was actigraphy combined with sleep diaries, due to its reliability and ability to be used in the home environment. Limited funding did not allow for use of actigraphy within this study. The Chailey Sleep Questionnaire and sleep diaries were used, as these had been used in previous research.³² Found high correlation between self-monitored daily sleep diaries and retrospective questionnaires. Indicating both can complement each other in recording sleep quantity. However, as these are both subjective, this may impact on the reliability of the data.

Humphrey (2011)²³ found that the introduction of sleep systems as part of a child's postural management reduces the carer burden.²⁴ Discussed parental stress in caring for children with developmental delay was the biggest factor in poor sleep quality. The Goal Attainment Scale (GAS)³³ has been widely used in clinical practise to measure client and carer goals with respect to an intervention.³⁴ Found between 77 and 88% of therapist ratings for infants with motor delays, met the criteria for content validity. This technique is suitable for interventions which require and individually prescribed intervention and rehabilitation plan. GAS can enable the carer to choose their own goals in relation to the prescription of the sleep system and whether the sleep system enables them to achieve these goals.

There is limited research as to the effectiveness of sleep systems as an intervention, in relation to pain, sleep quantity and quantity and the impact on quality of life for carers. The aim of this study is to investigate the effects of sleep systems on pain and sleep quality and quantity and whether carer goals for the outcome of the sleep system were met.



Figure 1. Flow chart describing intervention delivery approach.

Method and materials

Design

This was an exploratory study, in the child's home environment, investigating the differences in pain levels, sleep quantity and quality and carer goals, with and without a Symmetrisleep sleep system overnight, for children with CP. [Figure 1](#) describes the delivery approach for the study. Participants did not have sleep system prior to the study. Participants were not randomised, with the aim of collecting baseline data which would not be affected by prior use of a

sleep system. The study collected data at monthly intervals over a period of 6 months. Sleep diaries were sent to participants 1 month prior to the initial assessment, for daily completion by carers. Baseline data using the Chailey Sleep Questionnaire, Neutral Zero joint range assessment³⁵ and PPP were collected at the initial assessment by the researching therapists. Sleep diaries were collected and GAS light verbal goals were agreed with carers. Following handover of the sleep system by the researching therapist, data were collected retrospectively at monthly intervals by the researching therapist, for a total of 5 months, with the

sleep system in use during this time. Carers completed the sleep diaries every night, which were collected at monthly intervals by the researching therapist. Ethical approval was given by the Medical Research Council and by HRCH Trust research governance. All participants were offered to keep their sleep system following the study.

Materials

All participants were prescribed Symmetrisleep sleep systems, to reduce variability. The Symmetrisleep system was chosen by the research team, as it had been used in previous research studies^{7,8,12} and has a wide range of supports that would meet a range of clinical needs. The system is able to be transported and used on any type of mattress. Many families within the recruitment area visit family abroad for extended periods of time, so the ability for the system to travel was important for continued use. To reduce likelihood of bias, the study did not receive funding from the manufacturers or suppliers of Symmetrisleep. The study and systems were funded by the Hounslow and Richmond Community Healthcare 'Dragons Den' fund. Representatives from Symmetrisleep were present at the initial assessment as part of the prescription. Symmetrisleep representatives were not present at any subsequent follow up assessments to gather data or analysis of the data.

The research participants sleep systems were assessed, prescribed and reviewed by the researchers at Hounslow and Richmond Community Healthcare Trust (HRCH) Hounslow Wheelchair Service. Education, guidance in pictorial formats and support was given to the families and carers throughout.⁷ Reported the importance of support and education for families, particularly in the early stages in promoting the success of the intervention.

Participants

Children were included in the study if they had a diagnosis of CP, non-ambulant, Gross Motor Function Classification System levels IV–V³⁴ and were aged between 2–18 years. Children were recruited from the Hounslow borough area by the Physiotherapy, Occupational Therapy and Wheelchair Service teams within HRCH.

Children with sleep systems already in place were excluded. Children under the age of two were excluded, as they may not have established sleep patterns. Children over the age of 18 were excluded, as they may move onto adult services with differing care teams and routines, which may affect the reliability of the study.

The research aims and design were explained face to face and in an information sheet provided by the Hounslow Wheelchair Service. Translations of written information, including easy read and interpreters were offered to all participants and their carers. Written informed consent was given by all participants' legal guardians.

Sample size

Previous studies had calculated a sample size of $n = 20$ ¹² is required to detect change in sleep quality and pain in children with CP. Due to the limitations in funding for the study and geographical area, four children were recruited to the study between the ages of 6 and 16 years of age, mean age of 11.5.

Assessment process

Procedure

The baseline initial assessment was conducted prior to the sleep system being in use, to collect comparable data for sleep quality and quantity, pain and carer goals, without a sleep system. A full posture assessment was completed at the baseline initial assessment, using the neutral-zero method,³⁵ as part of the sleep system prescription process. Following handover of the sleep system, the researching therapist collected data at monthly reviews for a total period of 5 months. Carers completed the sleep diaries on a daily basis, with sleep diaries being collected monthly. In collecting monthly data, therapists were able to give further training of required and make changes to the equipment prescription which may improve the outcomes of the sleep system and acceptance by the participant and carers.

Sleep quality and quantity

The Chailey Sleep Questionnaire and sleep diaries were used to collect data for sleep-wake patterns as a measure of sleep quantity. The Chailey Sleep Questionnaire Sleep Profile, which records carer observations in changes in the sleep behaviour of participants, was used as a measure of sleep quality. The Chailey Sleep Questionnaire includes a Clinical Profile and Sleep Profile. The Clinical profile records medical data, potential risks and clinical information highlighting issues which may affect sleep quality. The sleep profile records sleep quantity and sleep quality information. The sleep diaries recorded times for going to bed and getting up in the morning, night time waking frequency, duration and reason as to waking and nap times during the day.

The Chailey Sleep Diaries completed by the participant's carers for 4 weeks prior to the baseline initial assessment. These were collected at the baseline initial assessment by the researching therapist. Sleep diaries were then completed by the carers for 5 months following handover of the sleep system and collected at monthly reviews by the researching therapist.

Data was analysed from the baseline initial assessment to the data collected from the 5 months review at the completion of the study. This established if there had been any changes to sleep quality and quantity following the

introduction of the sleep system, compared to the baseline data without the sleep system.

Paediatric pain profile

Pain levels were assessed using the Paediatric Pain Profile (PPP).²⁶ The PPP rates pain on a scale from 'not at all' to 'a great deal'. Each rating has a numerical score and can be grouped into levels correlating with the total numerical score. Mild pain is rated from 10–19, moderate is rated 20–29, severe 30–39 and very severe 40–60. The PPP data were completed by the researching therapist at baseline and then at monthly reviews for a total period of 5 months. These comprised of face-to-face domiciliary visits, with the researching therapist, the participant and their carers present. Overall scores set at baseline were compared to the overall scores at the 5 months review at the completion of the study.

Goal attainment scale Light verbal

GAS Light verbal³⁶ was used to collect participant, carer and therapist goals for the sleep system. GAS is a validated outcome measure used to record the extent to which the individuals' goals have been achieved.³³ The goals are scored in a way that allows analysis. GAS Light verbal was used as this simplified version made it more accessible to the participants and their carers.

GAS Light Verbal goals for the sleep system, were set at the baseline initial assessment by the carers. Following handover of the sleep system, Goals were reviewed with carers at face-to-face domiciliary visits with the researching therapist, at monthly intervals, for a total period of 5 months. Data were analysed comparing baseline goal scores to 5 months goal scores at the completion of the study.

Data analysis

Descriptive statistics were used to quantify and describe the characteristics of the sleep quantity and quality and PPP data from the study, as this was most suitable for providing information regarding the variables in the data set.³⁷ Measures of central tendency were used to describe the participants characteristics and measures of dispersion to describe the extent of variability.³⁸ For GAS light verbal data, in order to investigate difference in GAS goal scores from baseline to completion of the study, a paired sample t-test was used. All data as found to be normally distributed prior to conducting t-tests, statistical significance was set at a $p < 0.05$.

Results

Four children with CP, living at home with their parents, participated in this study. Table 1 shows the details of

participants in the study. The mean age was 11.5, with a standard deviation of 2.93, ranging from 6 to 16. All were non ambulant and had a GMFCS classification of V.

Two participants had 1 month gap in data collection due to illness or being unable to attend. One participant had a period of prolonged ill health, which resulted in two out of five reviews with the sleep system in place, being unable to be completed. The participants did not attend respite or any holidays during the research and had the same carers fitting the sleep system and reporting the data, throughout.

Sleep quality and quantity

Of the four participants, two fully completed the sleep diaries, with all four participants completing the Chailey Sleep Questionnaire and Sleep Profile.

For three of the four children positive changes in sleep quantity were reported, with a decreased number of night time waking. Mean number of night time waking at baseline was three, with a standard deviation of 1.87. At completion this reduced to a mean number of night time waking of 1.25, with a standard deviation of 2.2.

Sleep quality was also reported by carers subjectively using the Chailey Sleep Questionnaire using the Sleep Profile. Table 2 shows changes reported by carers regarding night time behaviour with the sleep system in place. The results show that for two participants that they became less restless and required less turning by their carer. This improved quality of sleep correlates with their having reduced number of night time waking and improved sleep quantity (Figure 2).

Pain

The Paediatric Pain Profile (PPP) scores are displayed in Figure 3. For all the children there were no changes in scores following use of the sleep system. The mean score for participants at baseline was 8.75, standard deviation of 5.7, with no change in pain with the sleep systems issued.

Goal attainment scale Light verbal goals

GAS Light verbal was used to record carer, client and therapist goals for the intervention at baseline. The carers scored the goals set at monthly reviews with the researching therapist. The scoring system for GAS Light verbal was used to record the outcome of the goals set consists of six verbal ratings, worse, no change, partially met, as expected, a little more and a lot more. The numerical conversion for GAS light verbal describes worse = -2, no change = -1, partially met = -1, as expected = 0, a little more = +1, a lot more = +2. Table 3 shows the objectives set and scores given by carers. Carers reported improvement at completion

Table 1. Characteristics of participants.

Child number	Diagnosis	Age on entry	Gender	GMFCS level	Preferred lying position	Prescribed lying position	Improvement in sleep quantity	Pain maintained or reduced	GAS objectives met
1	CP	11	F	V	Side	Side	Y	Y	Y
2	CP	6	M	V	Side	Side	No change	Y	Y
3	CP	13	M	V	Supine	Supine	Y	Y	Y
4	CP	16	F	V	Side/Supine	Side/Supine	No change	Y	Y

Table 2. Chailey Sleep Questionnaire sleep quality with the Sleep System in place.

Changes observed following sleep system study completion	Participants							
	1		2		3		4	
	Baseline	Study completion	Baseline	Study completion	Baseline	Study completion	Baseline	Study completion
Use of sleep system (nights per week)	0	7	0	4	0	7	0	7
Screaming, distressed during night	Never	Never	Never	Never	Never	Never	Never	Never
Sweating during night	Never	Never	Usually	Never	Never	Never	Never	Never
Restless and moves a lot during the night	Usually	Never	Sometimes	Never	Sometimes	Usually	Usually	Usually
Someone to change position during the night	Usually	Never	Usually	Never	Usually	Usually	Never	Never
Moved to someone else's bed during night	Usually	Rarely	Never	Never	Rarely	Never	Never	Never

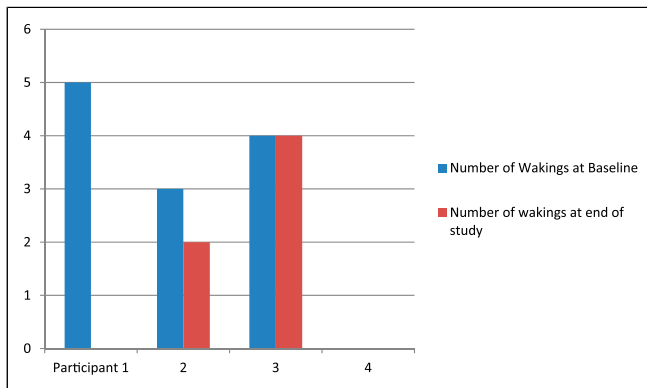


Figure 2. Chailey Sleep Diaries reported frequency of waking during the night.

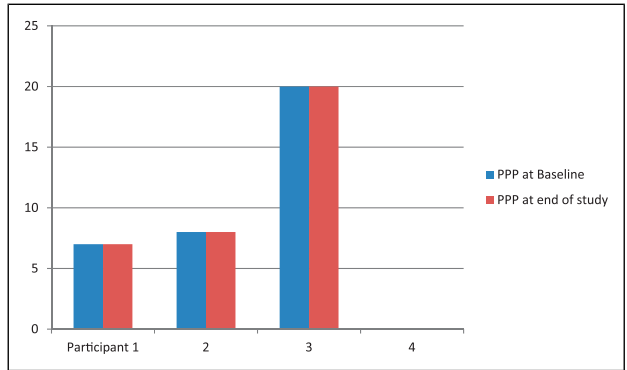


Figure 3. Paediatric Pain Profile Scores for each participant at baseline with no sleep system and at the end of the study following use of the system.

six out of seven goals set at baseline, scoring a little more and a lot more.

Carers were able to choose any goal in relation to the use of the sleep system by their child and were not limited in the number of goals that could be set. Goals set by carers were set around the themes of improved posture and comfort for their child.

Paired sample T tests was conducted to analyse GAS light verbal scores, having had two experimental conditions, with the same subjects, over a period of 5 months.³⁹ A paired samples t-test was conducted to evaluate the impact of the sleep system intervention on GAS scores. There was a statistically significant increase in GAS scores from baseline

Table 3. GAS Light verbal goals at baseline and completion of study.

Participant	Gas Objective	Set by	Baseline	Completion of study	GAS Numerical Conversion Score
1	Improve comfort and help her to relax	Carer	None 0	A little more	+1
	Maintain symmetry and alignment. Maintain head position and prevent arching of back and neck. Prevent scissoring of lower legs	Therapist	None 0	A lot more	+2
2	Posture – prevent legs from rolling out	Carer	None 0	A lot more	+2
	Maintain comfort	Therapist	None 0	As expected	0
3	Improve comfort	Carer	None 0	A lot more	+2
—	Promote and support good posture	Therapist	None 0	A little better	+1
4	Good posture to prevent hip operation	Carer	None 0	A little more	+1

($M = 0$, $SD = 0$) to completion ($M = 1.29$, $SD = 3.43$), $t(6) = 4.5$, $p.0041$ (two tailed).

Discussion

The results show that sleep quantity improved with the sleep system for the majority of participants or remained the same as baseline. Sleep quality was shown to have remained same as baseline or to have improved with the sleep system intervention. Pain remained unchanged from baseline to the completion of the study, for all participants. GAS light verbal goals were shown to have improved following completion of the study, with statistically significant results.

The subjective data collected from the Chailey Sleep Questionnaires gave insight into the reported waking in the sleep diaries. Participant three night time waking reduced from 3–4 times a night to 2–3 times a night mid study. It then increased to 3–4 times a night by the conclusion of the study. During the study participant three was fitted for a new orthopaedic spinal brace and advised by his physiotherapist to wear this during the night. This may have impacted on his comfort during sleep and increased night time waking. Participant 1's carers reported reduction in waking from every 1–2 h to waking after a full night's sleep of 8–10 h in the sleep diaries due to improved comfort. Participant 2's carers reported that prior to using the sleep system he would wake up to three times a night for up to 2 h in duration, as he was hot and uncomfortable. With the sleep system in place, he woke up 1–2 times a night, for a duration of 20 min.

The Paediatric Pain Profile scores remained constant for all participants from prior to the study to during the study whilst using the sleep systems. There was variability within the group as to the reporting of levels of pain, with participant four reporting having no pain and participant 3 scoring 20, primarily due to seizure activity when asleep.

Using the GAS Light verbal outcome measure, carers reported an improvement from baseline in the majority of goals. The goals set were centred around improvement of posture and comfort. Participant 1's carers reported that their child's goals had been met as their extensor spasms had

reduced at night, resulting in improved comfort. Since the sleep system had been in place, participant 1 was now able to sit comfortably when having a bath, dressing and brushing her hair. Resulting in requiring assistance of only one carer, instead of two. Participant 1 was now ready to get up in the mornings and get into the chair, where previously she used to struggle.

The study had a small sample size, with potential for bias as participants were not randomised and researchers were not blind to the intervention and results analysis. There are, therefore, limitations to the validity of the results and for use within clinical practice. The limitations in for the study had an impact on the number of participants that could be recruited and the accuracy of the measurements that could be taken. GAS Light verbal proved to be a useful tool for collecting data for carer goals and the Chailey Sleep Questionnaire complemented this data to give a picture of the impact on the sleep system for both the participant and carers.

Conclusion

Previous authors have recommended that sleep systems are prescribed as part of a 24 h posture management program for children with CP from an early age. Assessment of sleep quality, sleep quality, pain and carer goals should be considered as part of the prescription process. Due to the small sample size of this study and limitations in measurements taken, further studies are required to ascertain what changes to sleep quantity, quality and pain can be expected with sleep systems as an intervention and what impact they have on carer burden and carer goals. To improve the validity of results, we would recommend further studies with a larger cohort, over a sufficient period of time as to take into account and variability in presentation and use of accurate data collection such as actigraphy.

Acknowledgements

We would like to thank Dr Donna Cowan in her assistance and guidance in this research and giving permission for the Chailey Sleep Questionnaire and Diaries to be used.

Author contributions

NW and SB researched the literature and designed the study. SB obtained funding via the HRCH Trust Dragons Den initiative. NW and SB were involved in patient recruitment, clinical assessment and gathering data. NW analysed the data and wrote the first draft of the article. Both authors reviewed and edited the article and approved the final version of the article.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Hounslow and Richmond Community Healthcare (HRCH) Trust. A sleep system representative from Helping Hand was involved in the initial assessment of the sleep system, in collating quotes for purchasing following receipt of the prescription from the researching Therapists.

Guarantor

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