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Posture and Sleep in Children with Cerebral Palsy: A Case Study

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ABSTRACT

Aims

To explore the views of children on using a sleep system, the role of their parents and therapists in its use, and the quality of sleep achieved as a result.

Background

Night-time postural support is often recommended for children with bilateral cerebral palsy. The views of the children who use them, their parents and therapists have not been explored.

Design

A multiple case study.

Participants

Seven children aged between 18 months and 9 years with bilateral cerebral palsy in GMFCS Levels III–V, due to be prescribed a sleep system, their parents and therapists were included in the study.

Results

Children as young as 3 years old were able to express their views using a Talking Mat. Sleep difficulties were found in 6 out of 7 children. Quality of sleep in 2 improved with the use of a sleep system. Six children were thought to experience regular pain or discomfort, 2 reported greater comfort when sleeping in their sleep system. Some of the therapists who were prescribing sleep systems seemed to lack knowledge and experience of postural management.

Conclusions

Sleep systems may enable some children to sleep more comfortably and even young children are able to express their views about them if given the appropriate tools. Sleep difficulties are prevalent in this population and families need timely access to sleep services to facilitate change in poor sleep behaviours. Postural management may need to be seen as a specialist area and therapists working in postural management should be able to evidence their competency.

Introduction

Prevention of pain and deformity remain priorities in treatment for the most severely affected children with cerebral palsy (CP). Twenty-four hour postural management is a conservative, non-invasive approach commonly adopted by therapists to try to achieve these aims although there is, as yet, limited evidence of its effectiveness.

Night-time postural support is recommended on evidence provided by an expert group (Gericke 2006) however there is little research evidence to date of its role in the prevention of deformity. Experience from clinical practice and some evidence from available literature (Pountney et al 2009) suggests that families abandon sleep systems more frequently than other pieces of postural management equipment. Poor sleep and inability to adapt to a change in sleeping position is thought to be a cause of abandonment (Hankinson and Morton 2002; Pountney et al 2009). It is also suggested that children with severe difficulties may experience pain while using sleep systems, resulting in parents abandoning the equipment (Gough 2009).

The experiences of children using sleep systems and their parents would inform the causes of non-adoption or abandonment of sleep systems, but this has yet to be explored. Children with little or no verbal communication, who may also have cognitive impairments, are rarely consulted on therapy interventions. The techniques required to consult with young children are not well-tested or described.

It is expected that therapists should have the knowledge, skills and experience to be able to competently assess a child for the requirement for postural management at night (DH 2004). Despite guidance from national bodies and specific interest groups, therapists' provision of sleep systems continues to vary across the country. The clinical reasoning, knowledge, skills and experience of therapists who are prescribing sleep systems has not been investigated.

The aims of the study were to explore the views of children and their parents on using a sleep system, the role of the therapist in the child's and family's experience of using a sleep system, and the effects of using a sleep system on quality of sleep.

Methods

The practical approach to answering the research question was to use case study which is described by Robson (2002) as involving: *'… an empirical investigation of a particular contemporary phenomenon in its real life context …'* This was a multiple case study design with each case consisting of a child, the child's parents or main carers and the child's therapist (physiotherapist or occupational therapist). The method used within each case was semi-structured interviews for the parents and structured interviews, using Talking Mats where necessary, for the children.

Children were included if: they had bilateral CP classified in levels III, IV or V on the Gross Motor Function Classification System (Palisano 1997); had just been prescribed a sleep system by their local therapist; and were between the ages of 18 months and 9 years.

The study was approved by the University of Brighton's Faculty Research Ethics and Governance Committee, and the Devon and Torbay Research Ethics Committee. The Peninsula Primary Care Research Management and Governance Unit administered requests for research governance approval and this was gained in 9 trusts in the South-West of England.

The study was presented to therapists in their local settings. They were introduced to the Chailey Sleep Questionnaire version 4[1] (Khan and Underhill 2006) which when completed with parents not only provides a sleep history but also highlights potential risks from sleep apnoea, reflux and epilepsy.

Therapists were asked to select parents and children on their caseloads who met the inclusion criteria and to explain the study to them. They were asked to contact the researcher if they were interested in taking part. Interested parents were sent information sheets for the child, themselves and the treating therapist. Consent forms for the parents and therapist were also included. Therapists were asked to use the Chailey Sleep Questionnaire prior to prescription of the sleep system and were encouraged to discuss the results with the child's paediatrician if concerns were raised and before final decisions about sleep system prescription were taken.

Consent for the children was a process rather than a single event and was requested on an ongoing basis. The research team checked with the child throughout the interview process that they were willing to continue, by taking notice of their facial expression, vocalisation, eye-pointing and body movement.

Data collection

Interviews

Therapists were interviewed only once prior to interviews with the parents and child. Knowledge obtained from the therapist concerning the child's particular circumstances and family situation was used to inform the subsequent interviews with the parents and child.

The interviews with parents were semi-structured but with the opportunity for parents to talk about their experiences freely if they wished. The first interview was just after prescription of the sleep system but before the equipment was in place. The second interview with the parents was conducted between 4 and 6 months after the child received the sleep system.

All children aged 3 and over were interviewed by the researcher and an experienced speech and language therapist using the Talking Mat method (Murphy 1998). This consists of a velcro mat and picture symbols. A question was posed and placed in the centre of the board, at the top. Symbols representing what the child may like to say were then offered which the child could place, either

[1] The published version of the Chailey Sleep Questionnaire is available from Chailey Heritage Clinical Services.

physically or by indicating with their eyes, under a "yes" or "no" or in other instances a "like", "don't like" column. Likely vocabulary was established in a pilot study in which a number of children with CP with good verbal skills talked about their own sleep preparations and night awakenings in a pass-the-parcel type game. Photographic records were made of the mats after each question had been answered. Children under the age of 3 were not interviewed.

Sleep diaries

Parents were asked to keep a diary of their child's sleep for 10 consecutive nights prior to each interview. The diary recorded how long it took for the child to get to sleep, the number of hours asleep and the number of awakenings during the night. A record of whether the child fell asleep in their own bed and whether they needed the presence of a parent to enable them to fall asleep was also made.

Data analysis

The Framework method, developed by the National Centre for Social Research, was used to analyse the interview responses from the therapists and parents. Thematic content analysis, in which common themes are identified, was considered appropriate for analysing the children's responses (Green and Thorogood 2004).

Results

Participants

The details of the children in the study are presented below in Table 1.

Results from the sleep diaries

Only 3 of the 7 sets of parents returned the diaries. The sleep diaries were able to provide valuable information on the length of time taken to settle to sleep, the number of awakenings and length of time asleep, both prior to commencement of sleep system use and following it. Where no sleep diaries were available, details were taken from the interviews with parents and children.

Data analysis

The Framework method clearly described by Ritchie and Spencer (1994), involves a process of familiarisation and the formation of thematic frameworks for each case. With further abstraction and synthesis five key dimensions were identified which distilled the range of views and experiences across the cases.

Child number	Age on entry to study	Diagnosis	GMFCS Level	Child Interviewed	Type of sleep system	Prior preferred sleeping position	Sleeping position in sleep system	Outcome at conclusion of data collection period
1	6yrs 0mths	CP Spastic diplegia	III	Yes	Chailey Lying Support	Supine	Supine	Child sleeping well in SS
2	3yrs 4mths	CP Spastic quadriplegia	IV	Yes	Leckey Sleepform	Supine or side lying	Supine	Child sleeping well in SS
3	2yrs 2mths	CP or possibly West Syndrome	V	No	Leckey Sleepform	Cuddled up to parent	Supine	Child not using SS
4	2yrs 3mths	CP Spastic quadriplegia	IV	No	Symmetrisleep	Right side lying	Right side lying and supine	Child not using SS
5	3yrs 6mths	CP Spastic quadriplegia	IV	Yes	Jenx Dreama	Supine	Supine	SS not fully set up
6	4yrs 5mths	CP Spastic diplegia	III	Yes	Chailey Lying Support	Side lying	Supine	Child unhappy but parents persevering
7	3yrs 11mths	CP, microcephaly	V	No	Chailey Lying Support	Foetal position	Supine	Child sleeping well in SS
8	3yrs 8 mths	CP, microcephaly	V	No	N/A	N/A	N/A	Child excluded due to identification of risks

Table 1: Details of the children participating in the study SS = sleep system

Key dimensions

Case number	Self-reported? i.e. in interview	Pain?	Pain at night before using a SS?	Cause of pain	Pain at night with a SS?
1	Yes	Yes	Needs to have leg gaiters taken off after a few hours	Muscle stretching	Continues to have leg gaiters within SS and needs them removed after a few hours
2	Yes	Yes	Yes	Muscle spasm described by carers as "cramps"	Much reduced, wakes much less
3	Not interviewed	No?	N/A	N/A	N/A
4	Not interviewed	Yes	Yes	Inability to change position ?Asymmetrical / unsupported positions	Woke less so presumably more comfortable but only tolerated for 2 weeks
5	Yes	Yes	Yes, significant	Spasticity?	Yes SS not completely set up at end of data collection period
6	Yes	Discomfort mentioned by parents but not by child	Many sleep difficulties. Pain probably not a significant factor	N/A	N/A
7	Not interviewed	Yes	Yes, very significant	Immobility and adoption of extreme postures	Very significantly reduced

Table 2: Child's pain SS = sleep system

1. Child's pain

Of the 7 children, 6 were thought to have pain, or at least discomfort, either during the day or which caused them to wake at night. Of the 4 children interviewed, 2 reported pain at night and were able to identify the site of the pain. Both of these children were only 3 years old at the first interview and said specifically that the pain was in their legs.

Discomfort at night as a result of being in awkward positions was reported by 3 out of the 7 families. Prior to receiving the sleep system child 7 slept in a tightly curled-up foetal position and was described as being so stiff in the mornings that she screamed whilst being dressed.

"She had awful problems sleeping, her arm got trapped underneath her. She was so stiff in the night it was difficult to stretch out her legs to turn her over. Dressing was uncomfortable and took a long time; she used to scream the house down." (Mother of child 7)

2. Child's ability to adapt and parents' readiness to persevere

Of the 4 children interviewed: 2 said that they liked their sleep systems and were comfortable in them at night; 1 said she definitely did not like hers; and 1 was ambiguous although he continued to sleep well in it (Table 3).

Two children demonstrated significantly improved sleep. One was reported by the child's nursery also to have increased concentration. Another parent reported improved quality of life for the whole family as a result of the child sleeping well (Table 4).

At the close of the data collection period, parents of 2 of the 7 children were persevering in encouraging their child to adapt to sleeping in their sleep systems. One of these was still awaiting correct set-up of the sleep system 7 months after it was delivered although she was sleeping in it. Her parents were expressing extreme frustration by the wait.

"It feels like it's been quite a long haul really. …(the physio) did come a few times to try and sort it out but I think she can be unsure of what we need to do and what we need to change so then the rep will have to step in. And I'm just not that very good at waiting. I'm just impatient." (Mother of child 5)

The remaining 2 children were not using their sleep systems. One was experiencing severe fits, was wakeful at night and could not settle alone. The second child initially slept better in the sleep system but became distressed after 2 weeks. In both cases the parents of these children thought their child's sleeping position had been improved in the sleep system.

Case number	Likes SS?	Comfy in SS?	If not, why not?	Comfy in the morning when wake up in SS	Continues to sleep in SS?
1	Undecided. Prefers weekends when he is out of his SS	Undecided	"I don't know"	"Urrr no" Prefers "just in my bed"	Yes
2	Yes	Yes	N/A	No pain	Yes
3	Child too young to be interviewed				No
4	Child too young to be interviewed				No
5	Yes	Yes	N/A	Fine	Still awaiting correct set-up
6	No	No But later said yes	Can't turn over and wants to turn over Likes to lie on side not on her back	Wakes up out of SS	Still trying
7	Child thought by local team to be unable to give her views				Yes

Table 3: Child's view of sleeping in sleep system SS = sleep system

Case number	Parents' anticipated difficulties	Parents view of child's experience	Use of sleep system (SS)	Parents attended formal PM training?	Parents' comments
1	Parents thought child would miss being able to get out of bed at night	Quite happy to go in SS	5 nights a week, weekends out Supine not prone as anticipated	Yes	Having a SS from an early age would prevent bad habits forming
2	Told by PT SS may not work for their child	Relaxed in it when demonstrated and screamed "blue murder" when taken away	Used in daytime for nap but also from first night Used every night	No	Had to persevere for 3 weeks of "screaming habdabs". Child sleeps much better Better concentration reported by nursery
3	Discomfort from having a major fit in the SS Won't go to sleep without being cuddled	Woken by fits. Needed to be cuddled back to sleep	Tried for 4 weeks	No	Thought position was good until he moved with a fit Sleep problems just too severe
4	Uncertain if child would tolerate it	Used for 2 weeks and child slept through 2/3 times which was unusual Then child not happy to be restricted because she'd learnt to roll	Used for 2 weeks successfully then child resistant	No	Liked the position it held child in especially top leg in side lying Would have been better when child was younger before she could move
5	Hopeful child will be more comfortable and with a better posture	Takes time to get used to change but has moved from cot to bed	Still not set up correctly	No	Frustrated with time taken to get right. PT doesn't have the knowledge to set it up & has to wait for rep
6	Parents thought child would miss being able to get out of bed at night	Child very unhappy and distressed Doesn't like not being able to turn over	Is always put into SS but comes out either before going to sleep, early evening or at best at 12.00/1.00	Yes	Parents are determined to continue.
7	Desperate for anything that might improve child's sleep	Settled very quickly Not so stiff at night or in morning	Slept through the night from first night	Yes	"SS has improved everybody's QOL, everyone is sleeping better"

Table 4: Parents' views of the sleep system SS = sleep system

3. Knowledge and experience of therapist

Six therapists (5 physiotherapists and 1 occupational therapist) were interviewed with one therapist having 2 children in the study.

Case number	Knowledge and experience of therapist	Experience of different SSs
1	Worked in community paediatrics for 15 years Experienced with complex cases Involved in the local postural management group Conducts parent and carer training Applied criteria for care pathway in reasoning why a SS Able to quote and use evidence base for PM Uses an X-ray protocol	Has prescribed many SSs and uses different types
2	Worked as a paediatric physio for 20 years but "very, very part-time" Does not have many complex cases	Has prescribed one SS previously
3	Ditto (same therapist as above)	ditto
4	OT – works with physio Has access to specialist in PM Takes detailed sleep history Considers sensory issues in relation to poor sleep	As a team has provided several but usually use Symmetrisleep
5	Worked for 3 years then career break then 8 years part-time	Has prescribed one other SS
6	Newly qualified physio. Has worked in paediatrics for 7 months Has had in-house training in PM and a one-day course Has access to colleagues experienced in PM	Has inherited children with a range of SSs
7	Worked in community paediatrics for 18 years Experienced with complex cases Manages the service Involved in the local postural management group Applied criteria for care pathway in reasoning why a SS Able to quote and use evidence base for PM Uses an X-ray protocol	Has prescribed many SSs and uses different types

Table 5: Knowledge and experience of therapist SS = sleep system; PM = postural management

From the therapists' perspective, the desired outcomes for the provision of a sleep system were:

1. to improve posture, reduce asymmetry and/or hip migration - mentioned by the 5 physiotherapists;

2. to improve sleeping - mentioned by 5 out of 7 therapists.

Of the 3 children who continued using their sleep systems, 2 had Chailey Lying Supports and one used a Leckey Sleepform. The sleep systems prescribed are given below.

Type of Sleep system	Number of therapists
Chailey Lying Support	3
Leckey Sleepform	2
Symmetrisleep	1
Jenx Dreama	1

4. Process of introduction to a sleep system

Of the 7 families in the study, 3 had previously attended formal postural management training. This was a set programme, led by therapists, in a group setting. The remaining 4 participant families had been given varying amounts of information on an ad-hoc basis as the new equipment was being introduced.

5. Sleep difficulties

Six out of the 7 children in this study had sleep difficulties. One parent reported:

"You just walk around like constant zombies. Me and my husband are both on anti-depressants. You sit down and you think 'Oh God', I could just sit here and close my eyes now and we've got headaches all the time." (Mother of child 3)

Another parent reported that prior to using the sleep system her child might wake 10 or 11 times a night.

Case number	No. of awakenings before SS	No. of awakenings with SS	Average no. of hours asleep before SS	Average no. of hours asleep with SS
1	Only 1 in 10 nights	0	11.hrs 5mins	12 hrs 25 mins
2	2 -4 times a night	1 a night	?	? but reported as much more
3	Child waking 6 -8 times a night but unable to use SS			
4	2/3 times a night	0 for 3 nights then would not tolerate SS	?	?
5	0 – 2 times a night	1 a night	11 hrs 2 mins	11 hrs
6	2 -3 times a night with night terrors	Wakes several times in evening and then taken out of SS	?	?
7	10 -11 times a night	0 -1 times a night	?	?

Table 7: Sleep patterns of participants with and without a sleep system

? = data not available; SS = sleep system

The parents' suggestions for the causes of night waking are presented in Table 8.

Cause of waking	Number of children
Cramp, pain, discomfort	4
Needing to be turned	1
Fits	1
Behavioural / habitual	2
Night terrors	1
Having had a nap during the day	2

Table 8: Causes of night waking.

Four out of the 7 children had not learned to fall asleep alone at commencement of the study. Two of these 4 children learned to fall asleep alone when they had their sleep systems.

None of the parents had received helpful advice or support for their child's sleep difficulties. A community nurse with a special interest in sleep had said one family's circumstances were too complex and a paediatrician suggested another parent had a glass of wine and some of her child's Melatonin when it was her husband's turn to stay up with the child at night.

Discussion

Seeking the voice of the child

An aim of the study was to gain the views of children about their new sleep system and to use methods to enable children with little or no verbal communication to be included. Interviewing children as young as 3 is novel and not reflected in the literature, yet in this study 3-year-olds were able to make their views known. Three out of 4 of these children, albeit in a limited way, were clear whether they did or didn't like their sleep system and if not, why not. Therapists will be more confident in encouraging parents to persevere with using a sleep system if the child reports that he or she is comfortable and, if not, with finding alternative solutions.

The child in pain

Pain arose as a central issue in this study in relation to posture and deformity and difficulties with sleep and was specifically mentioned by 2 of the youngest children interviewed.

The causes of pain in children with CP include spasticity and immobility (McKearnon et al 2004). Pain in muscles and joints associated with spasticity was evident in some of the children in this study. A 3-year-old in category GMFCS Level V who frequently complained of pain and was a likely candidate for early hip displacement, had significantly increased muscle tone particularly around her hips and knees. Two other children in this study exhibited pain caused by immobility and the adoption of stereotypical postures as reported by Hodgkinson et al (2001). These children appear to have been more comfortable when supported in a sleep system.

Sleep difficulties

None of the parents interviewed in this study had access to structured services to help them improve their child's poor sleep. This confirms the consensus in the literature that families of children with disabilities struggle with poor sleep and that help is frequently not available. This situation is acknowledged in the National Service Framework for Children, Young people and Maternity Services (DH 2004) and re-iterated in the Aiming High for Disabled Children programme (DFES 2007). In the

latter document it is suggested that programmes to help families manage their child's sleep pattern should be available from an early age to prevent parents experiencing the consequences of chronic sleep deprivation.

Competency of therapists

The findings of this study raise the question of whether generalist paediatric therapists are likely to have the required level of knowledge and experience to identify appropriate children and to recommend appropriate sleep systems for them. Postural management may need to be seen as a specialist area and competency levels used to guide and measure the gaining of experience and expertise.

Integrated care pathways may help therapists negotiate the complexities of providing postural management equipment. Therapists, in an earlier study, reported that using a postural management care pathway was useful as a signpost and made their practice proactive rather than reactive (Humphreys and Pountney 2006).

Specialists may be required to lead postural management services, identify the training needs of the families and staff and to provide support for individual patients and their therapist.

Limitations of the study

The number of participants recruited into the study was fewer than anticipated. This was because the majority of children being prescribed sleep systems in the region at the time, did not have a diagnosis of CP and therefore did not meet the inclusion criteria. A further limitation was the poor return of the sleep diaries. It may suggest that keeping a sleep diary is an onerous task for parents who already have an increased burden of care.

Generalisability and transferability

The number of participants in this study is small and their circumstances are unique but concepts arising from the findings of the study may be helpful to therapists considering the use of sleep systems.

Conclusions and clinical implications

In conclusion, when children are given the appropriate tools they can give their views about sleeping in a sleep system and these need to be taken into account when decisions are made.

Parents in this study were generally motivated to encourage their child to become accustomed to using the sleep system but parents need to have information as to why this recommendation is being made if they are to opt for, and continue to persevere with, using a sleep system. Some parents received ad hoc instructions about each piece of postural management equipment as it was acquired but without the wider context of how children with CP change as they grow. Formal training that includes the likely progression of musculoskeletal difficulties and the role that postural management may play in maintaining comfort is important.

Therapists in this study had a wide range of experience with some less competent in making postural management decisions for complex children. Therapy service managers may like to consider the possibility of appointing a specialist clinician to lead postural management services and to put in place training and competency measures to ensure that all therapists involved in postural management services have the necessary knowledge and experience.

The findings from this study suggest that for some children sleep systems enable better sleep. These children were waking frequently during the night because they had discomfort or pain which was relieved when held in a supported more symmetrical position in a sleep system. This would tend to refute the claim that children with the most severe difficulties are more, not less, uncomfortable in a sleep system (Gough 2009).

An exploratory study, a precursor to a randomised controlled trial, to assess the benefits of night-time postural management on quality of sleep, pain and posture is currently underway and the results will be crucial to therapists' future recommendations for this complex group of children and their parents.

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