International Journal of Arts Humanities and Social Sciences
Volume 2 Issue 2 ǁ February 2017.
www.ijahss.com

Providing children with cerebral palsy the best bedroom environment for sleep

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ABSTRACT*:Sleep is an active process, essential for children's development. Between 23-46% of children with cerebral palsy (CP) have sleep problems. Sleep problems go undiagnosed and undertreated and interventions are most often pharmacological. There is a compelling need for effective non-pharmacological intervention to address sleep problems. The goal of this single case-series study was to determine if providing parents with a sleep education and problem solving psychoeducational manual will increase both parents' knowledge and their application of strategies to reduce sleep negative features in the child's bedroom based on this knowledge. Method: Recruitment of child/parent participants was through community partners. Data were collected with standardized measures, tools developed in-house for this study, and children's sleep actigraphy at baseline, post-intervention and 6-week follow-up. The Children's Best Bedroom for Sleep (CBBES) psycho-educational manual, developed for this project, was the tested intervention. Findings: For the six child/parent pairs who participated, sleep environment knowledge improved slightly, as did parents' ability to assess their child's bedroom and act to correct problems. Actigraphy data was insufficient for analysis. Conclusions: Results suggest that the CBBES manual can be an effective tool to improve parent knowledge and application of this new knowledge to improve their child's sleep environment.*

KEYWORDS*:sleep, environmental modification, cerebral palsy, parent education, psychoeducational intervention*

I. INTRODUCTION

Sleep duration in children is declining [1] and currently the prevalence of childhood sleep problems is estimated to range from 20% to 42% [2]. This is significant because sleep is foundational to overall wellbeing and healthy neurophysiologic functioning, learning and memory[3].Sleep deficiency (SD) in children has negative consequences for emotional health (such as depression and anxiety), behavior (such as emotional regulation and self-control), cognition, memory and school achievement, and physical health (such as increased risk for obesity, diabetes and sensory processing impairments)[1,4].In children with neurodevelopmental disabilities SD is yet more difficult to assess and treat [4].

This study addresses the need for non-pharmacological sleep interventions (NPSI) for children with cerebral palsy [5]. Cerebral palsy, one of the most common disorders in children [4], is characterized by an absence or delay in motor development, abnormal muscle tone, contractures, muscle tightness, deformities, and persistence of primitive and other body reflexes [6]. Conditions associated with cerebral palsy include gastroesophageal reflux disorder, epilepsy, visual impairment, respiratory problems [5], drooling, and uncoordinated swallowing; [6] all can contribute to SD. Sleep problems have been reported occurring in between 23% to 46% of children with cerebral palsy [6,7] compared to 20-30% in typically developing children [8].

Sleep problems in cerebral palsy include: difficulty in initiating and maintaining sleep, sleep wake transition, sleep breathing disorders, sleep bruxism, excessive day time sleeping, nightmares and sleep talking [6,7]. Nighttime care needs also interfere with the sleep of a high percentage of children with cerebral palsy [5]. A 2006 review [7] reported that problems with sleep initiation and maintenance of sleep were often associated with visual impairment in children with cerebral palsy because their abnormal light perception affects regulation of sleep-related hormones such as melatonin and adenosine. This same review noted that features of the environment (such as light, temperature, sound, and bedding) are significant contributing factors to sleep problems in children with cerebral palsy.

Pain interferes with sleep and poor sleep contributes to heightened experience of pain. As such, pain and sleep have a bidirectional relationship [9-11]. Children with cerebral palsy often experience pain as a consequence of contractures, skin breakdown and pressure ulcers, [5] gastric reflux, constipation, spasticity, abnormal muscle

tone, involuntary movements and abnormal postures, and decreased ability to independently reposition at night[7, 12-14]. Pain, in turn, heightens risk of SD. Children with cerebral palsy who have pain experience significantly more sleep problems overall, more night awaking, parasomnia, sleep disordered breathing and shorter sleep duration [15,16]. Treatment regimens, such as analgesics and antiepileptic medication, can also contribute to sleep deficiency.

Sleep management guidelines for children stress that non-pharmacological sleep interventions (NPSI) are important adjuncts or alternatives to medication [17-19]. Such NPSI include; therapeutic use of activity to develop a sleep routine with a regular bedtime and calming sleep behaviors, environmental modification in the home (such as light, temperature, bedding and sound), and interventions designed to improve parental sleep knowledge and ability to problem-solve. Applied research is sparse and a recent critical review of NPSI for youth with chronic health conditions revealed the methodological quality of studies was low [17].

1.1 Study Aim

This study tested the provision of sleep environment education and problem solving strategies to parents of children with CP in the form of a psycho-educational manual (*Children's Best Bedroom Environment for Sleep-CBBES*) to achieve the following outcomes: i) Increased parental knowledge of the role the environment plays in children's sleep, ii) parental action to achieve a measurable decrease in features that negatively affect sleep in the child's sleep environment, and iii) a measurable improvement in children's sleep efficiency (ratio of total sleep time to the amount of time spent in bed) between baseline and follow-up.

II. Methods

This study was approved by the Health Research Ethics Board of the University of Alberta and where children were not able to consent, a structured assent process involving parent and child was followed. The study was a single case series design [20] using a within-case analysis where each child/parent served as his/her own control, and pre- and post-intervention data were compared. The study objectives to test an intervention providing parents with knowledge and tools to modify their child's sleep environment was theoretically underpinned by the "knowledge to action cycle" (KTAC) framework [21]. This study employed the following steps of the KTAC to develop the CBBES manual intervention and evaluate the outcome: identifying the problem; reviewing and selecting the knowledge in the context of the problem; adapting the knowledge or research to the local context; assessing barriers; selecting, tailoring, and implementing interventions to promote knowledge; monitoring the use of knowledge, and evaluating outcomes [21,22].

The literature review revealed that there was strong evidence supporting the physiological influence of environmental factors (light, temperature, sound and bedding) on sleep. In general, most parents can exercise a high degree of control over the bedroom environment and so focusing on developing a parent-applied environmental intervention was considered to be relevant and pragmatic. The high demand care places on parents of children with CP can be a significant barrier to parents' use of sleep interventions. Consequently, we focused on developing a pragmatic tool that prioritized facilitating parental action and feelings of mastery in creating a more sleep-friendly bedroom.

2.1 Sample and recruitment

Convenience sampling was used and, because little sleep research has been conducted involving children with CP and their families, we were most interested in diversity as opposed to homogeneity. The study was a pilot designed to demonstrate proof-of-principle and to refine the study protocol. Community partners who provided services to children with CP mailed and handed out a printed study invitation package to parents who then contacted the researchers if they were interested in participating. Follow-up recruitment was done by sending an email invitation and postings of local cerebral palsy Facebook groups. The inclusion criteria included: (1) parent (primary bedtime care provider) and child with parent reported sleep problem (aged 2 to 12 years with a primary diagnosis of cerebral palsy and on stable medication if any), or parent alone. There were no exclusion criteria related to severity of disease or functional capacity as each child served as his/her own control.

2.2 Study procedure

Baseline data collection was carried out in the participants' home and consisted of demographic information, standardized and non-standardized parent sleep knowledge questionnaires, training and provision of an actigraph sleep monitor, and a child's sleep diary recorded by the parent. The researcher also completed a bedroom environment assessment checklist (BEAC) at baseline. Following one week of baseline actigraphy and

sleep diary data collection the researcher returned to the home and provided the CBBES manual intervention. During this visit, each participant was told that s/he would receive three follow-up phone calls, during which information was solicited regarding the manual. The goal of these phone calls was to encourage participants to read and implement the recommendations in the CBBES education manual. Questions asked during these phone calls included: "How is everything with the manual?" "Do you have any questions or confusion about any of the sections?" If participants had any sleep-specific questions, they were informed that their questions would be answered at the end of the study. The researcher did this to avoid introducing any bias in the study that might result from providing additional verbal information only to certain parents. The researcher returned at 2 weeks post-intervention to provide the actigraph and sleep diary for seven nights of follow-up data collection. Parents either mailed the actigraph back or the researcher picked it up. At 8 weeks the researcher returned to the home and administered the parent knowledge assessments used at baseline, had the parent complete a BEAC, completed the BEAC themselves for comparative purposes, administered the parent satisfaction with the CBBES manual questionnaire, and provided the sleep actigraph and diary for the child to use for the final 7 day data collection period. At the end of the study parents received a copy of all three sleep reports generated with the actigraphy data and a phone call from the researcher to answer any questions.

2.3 Intervention

The Children's Best Bedroom for Sleep (CBBES) psycho-educational manual used in this study serves the combined purpose of empowering parents with both the scientific evidence and practical application of that evidence in the context of their own child and situation. The CBBES manual was developed in-house based on best available evidence in the areas of sleep science, knowledge translation specific to parents, and health literacy. The manual, written at a grade eight reading level, was piloted and revised based on feedback prior to use in the study. The first section explains basic sleep physiology, the sleep cycle, and four key bedroom environmental factors: bedding, temperature, sound and light. Illustrative case studies are provided for each of the four factors. The second section presents strategies for parents to create the optimal sleep friendly bedroom environment and contains the BEAC and a list of additional information sources and resources.

2.4 Assessment tools

2.4.1 The Bedroom Environment Assessment Checklist (BEAC)

The BEAC, based on best evidence retrieved from our literature review, was developed in-house and piloted before use in the study. It is divided into sections covering four environmental components (light, temperature, sound and bedding) and contains a total of 34 environmental elements related to these components. BEAC users respond Yes/No to specific questions about features of the child's bedroom. For example in section D: Questions about Bedding (sheets, blankets & other fabrics), questions include 1) *Is there carpet in the bedroom?* (Yes/No); 2) *Is the bedding synthetic?* (Yes/No). At the end of each section BEAC users are referred to strategies to address any question where they replied 'Yes'. (For example, "*Did you answer "Yes" to any of the questions? If so, see the suggestions on page 23 in bedding-related changes.*") The BEAC was designed so parents could easily assess their child's bedroom environment and receive pragmatic advice about methods to improve identified problem areas. The researcher also used the BEAC to assess the child's bedroom at baseline and analysed the parent-completed BEAC at the 2 week follow-up to determine what, if any, actions parents took to modify the environment consequent to receiving the CBBES manual intervention.

2.4.2 Child's Sleep Environment Knowledge Questionnaire (CSEKQ)

An extensive literature search revealed no existing tool to assess caregiver knowledge of healthy sleep environments for children. Consequently the CSEKQ was developed in-house for this study and piloted prior to use. The CSEKQ contains 10 lay language statements of fact with three possible explanations for each fact. The facts in the questionnaire included evidence-based sleep environment information and the multiple-choice questions were constructed following evidence-based guidelines for designing assessments [23]. All of the content assessed in the CSEKQ is covered in the CBBES manual. CSEKQ also serves as a knowledge translation tool in itself. The instructions explain that each question first presents a statement of fact so that, even if the parent does not know why the action described in the factual statement facilitates sleep, they will at a minimum have correct information about key environmental aspects of sleep hygiene. For example:

"*Fact 7: Living near a busy street with lots of traffic and noise can be a problem for your child when sleeping. Running a fan or white noise machine in the bedroom can help your child sleep. This is because:*

a. *Running a fan creates white noise that increases production of the hormone melatonin.*
b. *Running a fan creates white noise that increases core body temperature in children.*
c. *Running a fan creates white noise to mask alerting noises that increase heart-rate".*

If we had simply asked for a yes/no response to the question 'Does running a fan or white noise machine in the bedroom can help a child sleep?" we may have received correct answers from all parents. However, we would have no measure of whether parents actually understand why this is a strategy that promotes sleep. Our assumption, informed by the KTAC theory, was that if parents do not understand the basic underpinning scientific rationale, they will not be able to generalize and problem-solve in other situations. With the CSEKQ we were able to measure baseline and post-intervention knowledge. Although change in knowledge could not be assumed to directly result in changes to parents' behaviour, it is reasonable to assume that when evidence of increase knowledge is followed by actual changes in the bedroom environment, this is indirect evidence of the CBBES manual's influence on parent knowledge-to-action.

2.4.3 Actigraph and parent-recorded sleep diary

Actigraphy is a widely used, objective tool for collecting sleep parameters [24]. The WGT3X-BT monitor (Actisleep) from Actilife ™ was used to collect children's sleep latency (min), total sleep time (min), total time in bed (min), sleep efficiency (%), wake after sleep (min), number of awakening, and average of awakenings (min) at baseline and both follow-ups. Parents were instructed to put the actigraph on the child's non-dominant wrist. A pen and paper parent-recorded sleep diary was used concurrently to record parent-reported time of going to bed and waking up. Parents were provided with demonstration and written instruction sheets about use, placement and care of the actigraph.

2.4.4 Light and sound measurement

Once the parent had set the bedroom up as it would be when the child went to bed the researcher measured light levels with the Lux Meter app (https://play.google.com/store/apps/details?id=com.notquitethem.android.luxmeter&hl=en) and decibel levels with the Sound Meter app (https://play.google.com/store/apps/details?id=kr.sira.sound&hl). We used apps as opposed to more stringently calibrated devices as we needed tools that were accessible to parents.

2.4.5 Parental Interactive Bedtime Behavior Scale (PIBBS)

The PIBBS is a 17 item self-reported parental questionnaire with reported internal consistency (Cronbach's alpha = 0.70) [25]. Parents rate the behaviors they employ to settle the child to sleep on a 0 (never) to 4 (often) scale. We used the PIBBS to indirectly monitor if parents had made any behavioural changes that could result in a co-intervention contributing to changes in actigraphy measured sleep efficiency over the duration of the study. Changes to parent bedtime routine for the child is not an intended outcome of the CBBES intervention and, consequently, we anticipated no significant change in the PIBBS scores pre/post intervention.

2.5 Analysis

Data were analysed with descriptive statistics. The percentage of correct responses on the baseline CSEKQ was compared to that on the post-test. The researcher used the mode to identify which fact in the CSEKQ received the maximum number of correct responses in the post-test compared to baseline and to establish the effect of a change in knowledge about each of the 10 facts. Mean scores of sleep latency, sleep efficiency, total time in bed, total sleep time, number of awakenings, and average awakenings values gathered by actigraphy at baseline and post-test follow-up, were compared as indicators of changes in the children's sleep patterns.

III. Findings

A total of six parent and child participants began the study, five completed the eight-week study, and one participant dropped out after seven weeks and did not complete the post intervention data collection. All parent participants were mothers (age from 29 to 44 years) with varying educational backgrounds. Five males and one female child participated, ranging in age from 4 to 12 (Table 1).

Table 1. Parent/Child Participants

Characteristics of Parents	Percentage (N=6)
Education level	
More than high school	83.33 (5)
High school or less	16.66 (1)
Age	
25-35 years	50 (3)
36-45 years	50 (3)
Gender	
Female	100 (6)
Characteristics of the Children	Percentage (N=6)
Gender	
Male	83.33 (5)
Female	16.66 (1)
Age	
2-5 years	33.33 (2)
6-9 years	33.33 (2)
10-13 years	33.33 (2)
Other children living in the house	
None	16.66 (1)
At least 1	83.33 (5)

3.1 Bedroom Environment Assessment Checklist

The BEAC was used at baseline and 8-week follow-up. Parents used the same BEAC tool to assess their child's bedroom during the intervention period. Only five parents completed the BEAC as recommended in the CBBES manual (Table 2). At baseline the researcher's BEAC score identified a range of four to eight problems (mean= six). At 8-week follow-up researcher-identified problems had reduced and ranged from 1 to 3 (mean= 2). At eight weeks' parents identified a range of 2 to 5 problems (mean= 3.5) and all participants had implemented between 2 to 12 recommendations (mean = 5.4). Parents attributed their actions to recommendations based on information from the CBBES manual. The most frequently followed recommendations were for light, followed by bedding, sound and temperature interventions. Parents reported being able to identify most of the problems in their child's bedroom environment using the assessment checklist, and that they were able to follow the corresponding recommendations to resolve those problems without difficulty.

3.2 Children's Sleep Environment Knowledge Questionnaire

The mean percentage of correct responses at baseline was 66.7% and at follow-up 78.3% (Table 3). All participants selected the correct explanation at both baseline and post-test for Facts 3, 6 and 9. Notably, Fact 2 (*Children who sleep on their back and have beds with synthetic bedding are more likely to have problems breathing. This is because:…*), Fact 8 (*Exposure to electronic light from bright lamps, TVs, computers or other electronic devices within 2 hours of bedtime reduces children's ability to sleep. This is because…*), and Fact 10 (*The fabric of children's bedding should be tightly woven (not stretchy) and washed or run through the hot cycle of a dryer weekly. This is because :…*) showed the greatest change in knowledge pre/post-test shifting from 0, 40 and 80% correct at baseline to 50, 80 and 100% correct at follow-up respectively.

Table 2. Bedroom Environment Assessment Checklist (BEAC) (%)

Participant	AB 1	AB 2	AB 3	AB 4	AB 5	AB 6	Mean
i. Number of problems identified at baseline by researcher in bedroom environment via the assessment checklist in CBBES manual.	4	5	8	7	4	7	6
ii. Number of problems identified by parents independently after reading the manual in bedroom environment and using the BEAC.	3	2	5	5	*	*	3.5
iii. Problem identified by researcher at follow up in bedroom environment using the BEAC	1	2	2	2		3	2
iv. Number of recommendations implemented independently by parents in bedroom environment out of 29 suggested recommendations in the manual (% of possible out of 29).	6 (20.7)	3 (10.3)	12 (41.4)	11 (37.9)		2 (6.9)	5.4 (18.6)
• Temperature (Number of recommendations possible in this category= 3)	0	0	2	2		0	0.8
• Sound (Number of recommendations possible in this category= 7)	1	1	3	0		0	1
• Bedding (Number of recommendations possible in this category= 8)	0	2	3	5		0	2
• Light (Number of recommendations possible in this category=11)	5	0	4	4		2	2.6
Key: *=Data missing; CBBES= Children's Best Bedroom for Sleep manual; BEAC= Bedroom Environment Checklist							

3.3 Actigraph and parent-recorded sleep diary

Sleep actigraphy was used in the study to measure sleep latency, sleep efficiency, total time in bed, total sleep time, wake after sleep onset time, number of awakenings and average awakenings. However, numerous challenges with placement adherence, child tolerance of the monitor, and correct logging of bedtime/waking time in the sleep diary were encountered. For example, at follow-up some parents reported they did not place the sleep actigraph on the child until they were asleep. Therefore, sleep onset was not accurately recorded and other calculations based on this data (sleep efficiency, latency, duration) were therefore inaccurate. Some parents modified data collection in responses to perceptions about their child's comfort which then invalidated comparable data between nights. For example, one parent placed the actigraph on her child's non-dominant wrist for two days and then on the ankle for five days in the pre-test. Children with CP can have significant pain problems and, although we had constructed and tested 'soft straps', parents made choices based on their knowledge of their child at multiple points unknown to the researcher. Consequently, reliable actigraphy data were not achieved and will not be discussed further in this report.

3.4 Parental Interactive Bedtime Behavior Scale (PIBBS)

We used the PIBBS as a method to indirectly monitor if parents had changed any bedtime behaviours which could then contribute a possible co-intervention resulting in a change to actigraphy measured sleep efficiency over the duration of the study. Changes to parent bedtime routine for the child was not an intended outcome of the CBBES intervention and, as anticipated, no significant change in the PIBBS scores of this small sample occurred between baseline and post intervention follow-up (Table 4). The two consistently popular bedtime behaviours were talking softly to a child and using a music tape or musical toy.

Table 3. Child's Sleep Environment Knowledge Questionnaire (CSEKQ)

(% parents who selected the correct rationale for each presented fact)		
Statement of fact (* indicates correct response of the three possible answers)	Pre test % (n=6)	Post test % (n=6)
1. With exposure to natural light during the day children sleep better at night. This is because: *Daylight stimulates children's production of the hormone melatonin	66.7 (4)	66.7 (4)
2. Children who sleep on their back and have beds with synthetic bedding are more likely to have problems breathing. This is because: *In this position the bedding is closer to the child's nose and mouth when they breathe.	0	3
3. A light level of more than 30 to 40 lux in the bedroom at night can reduce and delay melatonin production. Reduced and delayed melatonin means that a child will have difficulty going to sleep and staying asleep. This is because melatonin: *Increases a child's ability to enter sleep and move through all stages of sleep.	100 (6)	100 (6)
4. Using timers on fan and heaters and using programmable thermostats can change room temperature to help a child sleeping better. This is because: *Room temperature needs to be cool to go to sleep and then warmer to wake up.	66.7 (4)	83.3 (5)
5. If you use a nightlight in a child's bedroom it should have a red bulb and not a white or blue bulb. This is because: *White and blue light decrease melatonin production and delay falling asleep.	66.7 (4)	66.7 (4)
6. Sleep occurs in stages from light to deep sleep to REM sleep. Sounds at level of 40 decibels and above can prevent children from achieving the deep sleep stage of the sleep cycle. Without first having a deep sleep stage a child cannot move into the REM sleep stage of the sleep cycle. A child needs to go through all 4 stages of the sleep cycle to be healthy. This is because: *Each stage of sleep is for different physical, emotional and cognitive functions in the body.	100 (6)	100 (6)
7. Living near a busy street with lots of traffic and noise can be a problem for your child when sleeping. Running a fan or white noise machine in the bedroom can help your child sleep. This is because: *Running a fan creates white noise to mask distracting noises that increase alertness and heart-rate.	66.7 (4)	83.3 (5)
8. Exposure to electronic light from bright lamps, TVs, computers or other electronic devices within 2 hours of bedtime reduces children's ability to sleep. This is because: *Bright electronic light keeps the body from producing the melatonin hormone needed for sleep.	33.3 (2)	83.3 (5)
9. For the best sleep children's bedrooms, should be slightly cooler at night than during the day. This is because: *Children produce sleep hormones when their core body temperature is slightly cooler.	100 (6)	100 (6)
10. The fabric of children's bedding should be tightly woven (not stretchy) and washed or run through the hot cycle of a dryer weekly. This is because: *Loosely woven fabrics are more likely to harbor dust mites and other allergens that interfere with breathing.	50 (3)	83.3 (5)

Table 4.Three most and least frequently selected routine bedtime activities based on Parental Interactive Bedtime Behavior Scale (PIBBS) data [25]

Three most practiced bedtime behaviors by parents	
Pre intervention	**Post intervention**
Music tape or musical toy (50%)	Music tape or musical toy (66.66%)
Talking softly to child (50%)	Talking softly to child (66.66%)
Singing a lullaby (50%)	Reading a story to child (50%)
Three least practiced bedtime behaviors by parents	
Pre intervention	**Post intervention**
Walks in pram or stroller (100%)	Walks in pram or stroller (66.67%)
Stand near cot without picking infant up (83.33%)	Stand near cot without picking infant up (66.67%)
Settle infant on sofa with parent (83.33%)	Carrying around house in arms (83.33%)

IV. Discussion

Children with CP have significant challenges to achieving sufficient sleep [26]. This study addressed parents' need for accessible and pragmatic evidence-based environmental NPSIs for their child with CP. Specifically the study tested if provision of sleep education and problem solving strategies to parents of young children with CP, in the form of the CBBES psychoeducational manual, would achieve the following outcomes: i) increased parental knowledge of the role the environment plays in sleep, ii) parental action to achieve a measurable decrease in features that negatively affect sleep in the child's sleep environment, and iii) a measurable improvement in children's sleep efficiency (ratio of total sleep time to the amount of time spent in bed) between baseline and follow-up. There were too few participants to generate clear conclusions about the efficacy of the CBBESmanual. However, the results were promising, and particularly those related to changes in parental sleep knowledge as measured by the CSEKQ, knowledge-to-action as measured by the BEAC, and the number of sleep promoting changes to the environment parents implemented and that they attributed to learning from the CBBES manual.

Unfortunately, multiple challenges with sleep actigraph resulted in insufficient reliable data to determine if there was a measurable change in sleep outcomes. Fidelity with monitoring was problematic and not all of the children accepted the actigraph well, some parents reported finding the actigraph lying on the bed in the morning, and some parents felt it necessary to change placement of the actigraph on the child's limbs. These inconsistencies meant that test conditions varied across nights (for example, placing the actigraph on the dominant wrist one night and then the ankle the next night). Additionally, we know that as many as 90% of children with CP have sensory dysfunction (mainly tactile) [27] and this may have been a confounding factor in fidelity. More pilot testing to determine acceptable straps and perhaps a trial period with no actual recording so the child could become accustomed to the actigraph would be beneficial in future studies.

There were no significant changes in the baseline and post-test scores for the PIBBS. This was interpreted as a proxy indicator that no behavioural co-intervention for sleep had been put in place during the study and increased the likelihood that the changes in the sleep environment and parental sleep environment knowledge were a result of the CBBES intervention.

4.1 Knowledge-to-action

The theoretical framework for the study was the Knowledge to Action Cycle (KTAC). The KTAC theory illustrates a dynamic process of decisions and action used to translate knowledge into practice [28]. Campbell[28] described the KTAC as consisting of these key steps: knowledge creation; application in a practice environment; potential adopters taking action, and using the evidence-based innovation to translate the evidence into practice. The KTAC framework helps the researcher understand everyone's role in the cycle. In this study the researcher played a key role in synthesizing existing research knowledge into an accessible form (the CBBES manual) for the intended users, parents of children with CP. The child's bedroom environment was

the practice environment in which the acquired evidence-based knowledge was applied. Parents were the potential adopters of the knowledge and played an important role in testing the intervention intended to facilitate practical application of the sleep evidence-base.

Congruent with the first step of the KTAC, the CBBES manual was designed to synthesize existing knowledge and create a new tool to bridge the gap between pediatric sleep environment research and action. The baseline data gathered from the CSEKQ and the BEAC showed both gaps and existing strengths in parents' knowledge and actions related to the sleep environment. Determining these gaps and strengths helps identify what knowledge areas are most important to target. The parents in this study demonstrated existing strengths in their baseline knowledge, as assessed by the BEAC, for certain sleep-positive features that they had already incorporated into their child's bedroom (for example correct temperature). Other knowledge, as assessed by the CSEKQ, also appeared to exist at baseline (for example the importance of reduced lux levels) but the BEAC assessment suggested that this knowledge was not always translated to action. This reinforces that providing information alone is insufficient and that practical suggestions for how to operationalize information are important features of intervention strategies for parents. Once parents learned how to actually measure light exposure and reviewed some practical suggestions about reducing nighttime light it appears they were then able to take steps bridging the knowledge-to-action gap.

The next steps of the KTAC are implementing evidence-based knowledge and evaluating how that knowledge is adopted [28]. The six-week period between intervention and follow-up allowed the adopters (parents) time to implement their new knowledge. Follow-up evaluation determined there was a decrease in the number of problems identified by the researcher using the BEAC and, thus, seems to support the conclusion that parents applied their new knowledge by acting on a number of recommendations in the CBBES manual. Although there were insufficient data to make strong conclusions about the effectiveness of the CBBES manual as a KTA tool it showed promising effects related to all of the research questions, except for improved sleep efficiency for which there was insufficient data. The findings suggest that the CBBES psycho-educational manual for parents warrants further study.

There were some limitations in the study that future work should address. The sample was small and recruitment proved more challenging than anticipated. Adherence to the sleep actigraphy protocol was inconsistent and strategies to improve this, at the level of both parent and child, need to be tested. The BEAC and the CSEKQ assessment tools were developed in-house and require further testing of validity and reliability. The CBBES manual showed promising results in creating a bridge between knowledge and action. However, further testing of its content and generalizability are required.

V. Conclusions

This pilot study suggests that a psychoeducational intervention, in the form of the CBBES manual, can achieve the goals of increased parental sleep environment knowledge and decreased sleep-negative features in the child's sleep environment. There was insufficient data to draw conclusions about the secondary goal of increased child sleep efficiency. Given that sleep problems in children with CP are prevalent, exerting a significant functional toll [5], and that ongoing sleep medication is usually contraindicated and can have significant side-effects, this pilot study of a psycho-educational NPSI was an important first step. The preliminary findings and lessons learned can serve as a foundation to refine both the CBBES resource and its testing.

Campbell [28] stated that knowledge must be relevant, appropriate, applicable, and reasonable for those whom the knowledge affects. The CBBES manual was designed to incorporate these four key features in an accessible and relevant manner that builds parents' self-efficacy for being active participants in managing their child's sleep through simple, pragmatic and achievable actions. There is little research on effective methods to teach parents [29]. The challenge is to consider parents' information needs, while at the same time providing them with knowledge in a format that will increase their probability of applying that information. The CBBES manual, and the BEAC contained in the manual, appear to have strong potential to help parents acquire knowledge and skills to better manage a child's sleep environment. Additionally, with more development and study the CSEKQ has potential for clinicians to both assess parent knowledge and, at the same time, perform a basic sleep knowledge translation function.

There are barriers for parents of children with chronic illness which hinder their learning. High time demand for child care, dual role of child care and employment, fatigue, and level of health literacy are possible barriers. The CBBES manual targets these barriers; it is written in lay-person language, easily accessed as a hard copy

printout, and, because it was designed to be as brief as possible and include only key information, it takes a limited amount of time to read. The checklist assessment and recommendation items are pragmatic, easy to understand and apply within one's own context. The case studies also serve to help parents see relevance of the material for their own child.

The results presented here are promising but also demonstrate the need for more rigorous research, designed to facilitate better assessment fidelity, in order to test further the CBBES intervention and companion assessment tools. The CBBES manual was revised at the completion of this study can be downloaded at http://cbotlabs.wix.com/cbbes-workbook .

Acknowledgement

The authors would like to acknowledge the support of the Canadian Centre for Disability Studies (http://disabilitystudies.ca/) in funding this study

REFERENCES

[1]. Paruthi, S.; Brooks, L.J.; D'Ambrosio, C.; et al. Recommended amount of sleep for pediatric populations: a consensus statement of the American Academy of Sleep Medicine. *J Clin Sleep Med*. 2016; 12(6):785–786.
[2]. Bharti, B.; Mehta, A.; Malhi, P. Sleep Problems in Children: A Guide for primary care physicians. *The Indian Journal of Pediatrics*, 2013, 80: 492.
[3]. Heraghty, J.; Hilliard, T.; Henderson, A.; Fleming, P. The physiology of sleep in infants. *Archives of Disease in Childhood*, 2008, 93: 982-985.
[4]. Jan, M. M. Cerebral palsy: Comprehensive review and update. *Annals of Saudi Medicin*e, 2006, 26(2): 123-132.
[5]. Wayte, S.; McCaughey, E.; Holley, S.; Annaz, D.; Hill, C. M. Sleep problems in children with cerebral palsy and their relationship with maternal sleep and depression. *Acta Paediatrica*, 2012, 101(6), 618-623. doi:10.1111/j.1651-2227.2012.02603.x
[6]. Chambers, H. G. Advances in cerebral palsy. *Current Opinion in Orthopaedics*, 2002, 13(6): 424-431. doi:10.1097/00001433-200212000-00007
[7]. Newman, C. J.; O'Regan, M.; Hensey, O. Sleep disorders in children with cerebral palsy. *Developmental Medicine and Child Neurology*, 2006, 48(7):564-568.
[8]. Tikotzky L.; Sadeh A. Sleep patterns and sleep disruptions in kindergarten children. *J Clin Child Psychol*. 2001, 30(4): 581-591.
[9]. Goodin B.R.; Smith M.T.; Quinn N.B.; King C.D.; McGuire H. Poor sleep quality and exaggerated salivary cortisol reactivity to the cold pressor task predict greater acute pain severity in a non-clinical sample. *L.Biol Psychol*. 2012, Sep; 91(1):36-41. doi: 10.1016/j.biopsycho.2012.02.020. Epub 2012 Mar 16.
[10]. Valrie, C. R.; Bromberg, M. H.; Palermo, T.; Schanberg, L. E. A systematic review of sleep in pediatric pain populations. *Journal of Developmental and Behavioral Pediatrics*, 2013, 34(2): 120-128. doi:10.1097/DBP.0b013e31827d5848
[11]. Schuh-Hofer, S.; Wodarski, R.; Pfau, D. B.; Caspani, O.; Magerl, W.; Kennedy, J. D et al. One night of total sleep deprivation promotes a state of generalized hyperalgesia: A surrogate pain model to study the relationship of insomnia and pain. *Pain*, 2013, 154(9): 1613-1621. doi:10.1016/j.pain.2013.04.046
[12]. Pruitt, D. W.; Tsai, T. Common medical comorbidities associated with cerebral palsy. *Physical Medicine and Rehabilitation Clinics of North America*, 2009, 20(3):453-467. doi:10.1016/j.pmr.2009.06.002
[13]. Baxter, P. Comorbidities of cerebral palsy need more emphasis - especially pain. *Developmental Medicine and Child Neurology*, 2013, 55(5): 396-396. doi:10.1111/dmcn.12137
[14]. Novak, I.; Hines, M.; Goldsmith, S.; Barclay, R. Clinical prognostic messages from a systematic review on cerebral palsy. *Pediatrics* 2012, 130: e1285–e1312
[15]. Breau, L. M.; Camfield, C. S. Pain disrupts sleep in children and youth with intellectual and developmental disabilities. *Research in Developmental Disabilities*, 2011, 32(6): 2829-2840. doi:10.1016/j.ridd.2011.05.023
[16]. Engel, J. M.; Petrina, T. J.; Dudgeon, B. J.; McKearnan, K. A. Cerebral palsy and chronic pain: A descriptive study of children and adolescents. *Physical and Occupational Therapy in Pediatrics*, 2005, 25(4): 73-84. doi:10.1300/J006v25n04_06
[17]. Brown, C. A.; Kuo, M.; Phillips, L.; Berry, R.; Tan, M. Non-pharmacological sleep interventions for youth with chronic health conditions: A critical review of the methodological quality of the evidence. *Disability and Rehabilitation*, 2013, 35(15): 1221-1255. doi:10.3109/09638288.2012.723788
[18]. De Niet, G. J.; Tiemens, B. G.; Kloos, M. W.; Hutschemaekers, G. J. M. Review of systematic reviews about the efficacy of non-pharmacological interventions to improve sleep quality in insomnia. *International Journal of Evidence-Based Healthcare*, 2009, 7(4): 233-242. doi:10.1111/j.1744-1609.2009.00142.x
[19]. Heussler, H.; Chan, P.; Price, A. M. H.; Waters, K.; Davey, M. J.; Hiscock, H. Pharmacological and non-pharmacological management of sleep disturbance in children: An Australian paediatric research network survey. *Sleep Medicine*, 2013, 14(2): 189-194. doi:10.1016/j.sleep.2012.09.0233131
[20]. Kooistra, B.; Bernadette, D.; Thomas, E.; Mohit, B. How to Design a Good Case Series. *The Journal of Bone and Joint Surgery*, 2009, 91(3): 21-26. doi:10.2106/JBJS.H.01573.
[21]. Graham, I. D.; Logan, J.; Harrison, M, B.; Straus, S, E.; Tetroe, J.; Caswell, W et al. Lost in Knowledge Translation: Time for a Map? *Journal of Continuing Education in the Health Professions*, 2006, 26 (1): 13-24
[22]. Claude, K.M.; Kwibuka L.; Michael H. Applying a Knowledge-to-Action Framework for primary prevention of Spina Bifida in tropical Africa. *Maternal and Child Nutrition*, 2012, 8 (2): 174-184. doi:10.1111/j.1740-8709.2010.00271.x.
[23]. Considine, J.; Mari, B.; Shane, T. Design, Format, Validity and reliability of multiple choice questions for use in nursing research and education. *Collegian*, 2005, 12 (1): 19-24. doi:10.1016/S1322-7696(08)60478-3.
[24]. Wiggs, L.; Montgomery, P.; Stores, G. Actigraphic and parent reports of sleep patterns and sleep disorders in children with subtypes of Attention-Deficit Hyperactivity Disorder. *Sleep*, 2005, 28 (11): 1437-1445.

[25]. Morrell, J.; Cortina-Borja, M. The developmental change in strategies parents employ to settle young children to sleep, and their relationship to infant sleeping problems, as assessed by a new questionnaire: The Parental Interactive Bedtime Behaviour Scale. *Infant and Child Development*, 2002, 11(1): 17-41.
[26]. Dutt, R.; Roduta-Roberts, M.; Brown, C.A. Sleep and children with Cerebral Palsy: A review of current evidence and environmental non-pharmacological interventions. *Children*. 2015; 2(1):78-88.
[27]. Pavao, S. L.; Silva, F. P. D. S.; Savelsbergh, G. J. P.; Rocha, N. A. C. F. Use of sensory information during postural control in children with cerebral palsy: Systematic review. *Journal of Motor Behavior*, 2015, 47 (4): 291-301.
[28]. Campbell, B. Applying knowledge to generate action: A community-based knowledge translation framework. *Journal of Continuing Education in the Health Professions*, 2010, 30 (1): 65-71. doi:10.1002/chp.20058.
[29]. Nightingale, R.; Simone, F.; Veronica, S. Review: Parents' learning needs and preferences when sharing management of their child's long-term/chronic condition: A systematic review. *Patient Education and Counseling*, 2015, 98(11): 1329-38. doi:10.1016/j.pec.2015.05.002.