Providing the Best Sleep Bedroom Environment for Children with Cerebral Palsy

by

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Abstract

Sleep is an active process, essential for physical, emotional and cognitive development of children. Between 23-46% of children with cerebral palsy (CP) have sleep problems. Often sleep problems go undiagnosed and undertreated in spite of the serious impact of sleep deficiency on children's health and development. Interventions, if they are offered, are most often pharmacological. However medication side effects are a significant concern and the evidence-base is lacking. There is a need for effective non-pharmacological intervention to address sleep problems.

Objectives: 1) To determine if providing parents with sleep education and problem solving strategies, in the form of a manual, increases parental knowledge. 2) To determine if increases in knowledge then translate to parents taking actions to address features in the bedroom that negatively affect sleep.

Methods: This pilot study used a single-case series design. Recruitment of child/parent participants was through community partners. Baseline and 6 week follow-up data collection included the Parental Sleep Environment Knowledge Questionnaire (PSEKQ), Parental Interactive Bedtime Behavior Scale, Child Sleep Habit Questionnaire, Parent Knowledge of Healthy Sleep and objective sleep actigraphy. Parents received the Children's Best Bedroom for Sleep (CBBES) manual (including basic sleep science information, a self-assessment tool, and environmental modification recommendations) as the intervention post-baseline. Descriptive statistics were used for analysis.

Results: There were 6 parent/child participants. As expected, minimal change was demonstrated in parents sleep behavioural measures. Scores on the Parent Sleep Environment Knowledge Questionnaire (PSEKQ) improved slightly (66.66% at baseline to 78.33% at follow-up). Also, the post-intervention results using the bedroom environment assessment checklist provided in the CBBES manual demonstrated improved parent ability to assess their child's bedroom and act to correct problems.

Conclusion: Results support that providing parents with a sleep environment psycho-education manual to build knowledge and skills for addressing environmental components of their child's sleep problems. This research is innovative and will benefit not only children with cerebral palsy and their parents but may also apply to children with other health conditions.

Preface

This Thesis is original work by Risha Dutt. The research project, of which thesis is a part, received research ethics approval from the University of Alberta Human Research Ethics Board, Project name "Providing the best sleep environments for children with cerebral palsy , No. MS2_Pro00045478, 24 March 2014. Chapter 2 of this thesis has been published as Dutt, R., Roduta-Roberts, M., Brown CA. (2015) Sleep and Children with Cerebral Palsy: A Review of Current Evidence and Environmental Non-Pharmacological Interventions. Children 2015, 2(1), 78-88; doi: 10.3390/children2010078 http://www.mdpi.com/2227-9067/2/1/78/html".

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Chapter 1: Introduction

Studies show that over the last 20 years sleep duration in children has declined (Magee, 2012) and the incidence of diagnosed sleep disorders is increasing. The prevalence of sleep problems is estimated to be 20% to 42% across childhood (Bharti et al., 2013). Sleep is one of the most important factors to consider in any disorder, since it promotes healthy neurophysiologic functioning, learning and memory (Heraghty et al., 2008; Wayte et al., 2012). Combinations of various factors, which include genetic, biological, environmental, and behavioral, influence and regulate sleep (Magee, 2012). Insufficient, inefficient sleep in children not only predisposes children to mood, behavioral and cognitive impairments but also predicts emotional problems, poorer school performance and health problems (Jan et al., 2008; Magee, 2012) which in turn further predispose them to sleep difficulties. These effects are more pronounced in children with underlying neurodevelopmental disabilities (Jan et al., 2008)

1.1 Rationale of the study

Cerebral palsy is one of the most common conditions associated with childhood disability (Wayte et al., 2012). Cerebral palsy is defined as a group of non-progressive disorders of movement and posture. Children with cerebral palsy are at higher risk for sleep problems because of their presented disability (Wayte et al., 2012). These children have sleep disorders, which significantly affect their development and performance, and have been reported to have a significant effect on the child's caregivers and family (Magee, 2012; Simard et al., 2011). Particularly in mothers, depression and other health issues have been noticed (Wayte et al., 2012). All these factors can lead to parental anxiety and nighttime monitoring of the child (Wayte et al., 2012) and makes this a concerning issue.

Sleep disturbance is very common in children with cerebral palsy (Chambers, 2002). Approximately 23% to 46% of children with cerebral palsy suffer from sleep problems (Chambers, 2002; Newman et al., 2006). Researchers (Wayte et al., 2012) reported in one study, of 173 children

aged 6-11 years with cerebral palsy in Ireland, sleep problem in 23% of children with cerebral palsy compared to 5% of typically developing children. Another Swedish study, including 216 children with cerebral palsy aged 1-16 years, reported sleep problems in 50.5% of participating children (Wayte et al., 2012).

The various sleep problems faced by children with cerebral palsy are: difficulty in initiating and maintaining sleep, sleep wake transition, sleep breathing disorders, sleep bruxism, excessive day time sleeping, nightmares and sleep talking (Chambers, 2002; Newman et al., 2006). A study conducted by Elsayed (2013) of 100 children with cerebral palsy, divided into preschool and school groups, showed high incidence of sleep problems in both groups. In the preschool group 46.2% suffered from early insomnia and 50% had sleep bruxism. In the school group, 50% suffered from sleep disordered breathing, 50% had nightmares, 12.5% experienced sleep talking and 62.5% had excessive day time sleeping. High incidence (50 %+) of awakening after sleep onset has also been reported in several studies of children with cerebral palsy (Elsayed et al., 2013; Pruitt & Tsai 2009).

Pruitt & Tsai (2009) concluded that sleep not only affects the overall development of the child, but also affects the child's entire family. One study found that 39.8% of children with cerebral palsy required parental attention on at least one occasion every night (Wayte et al., 2012). In another study 74% of parents felt that because of their child-sleeping problem, their own daytime functioning get affected (Wayte et al., 2012).

It is very important to consider the sleep problems in children with cerebral palsy because sufficient nighttime sleep is important for healthy development (Magee, 2012). Sleep loss is known to result in increased irritability, depression, poor affect modulation, and aggressiveness. Jan et al (2008) emphasize that there is a lack of clinical and research emphasis on sleep issues in children with cerebral palsy, and this needs to be considered.

There is a need for effective and efficient interventions. Additionally, more information about evidence-based non-pharmacological sleep interventions for children with cerebral palsy is needed, to help guide initial steps in the development and evaluation of future interventions.

1.2 Objective of the study

This study addresses the need parents have to access and apply evidence-based environmental sleep interventions (ESI) for their child with cerebral palsy. Society currently values work, it does not value rest, and environments are built accordingly. Visual standards and privileging of productivity have resulted in the artificial electronic lighting of spaces such that the body's ability to produce the hormones required for sleep is severely compromised. The popular media and many well-meaning but poorly informed healthcare providers promote pharmacological and behavioral interventions for the consequences of sleep deprivation. This type of medicalization ignores the significant role the built environment plays in precipitating and maintaining sleep deprivation. There is high quality research evidence demonstrating the role of environment in sleep. However, education about this, and about how to apply this evidence to practical environmental modifications that will improve sleep, is sorely lacking. The study objective addresses this research to action gap.

1.3 Research Question

The research question for the study is:

"Will providing sleep education and problem solving strategies to parents of young children with CP in the form of a psycho-educational manual (**Children's Best Bedroom Environment for Sleep -CBBES**) result in the primary outcomes of:

i) Increased parental sleep environment knowledge, ii) 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?

Chapter 2: Literature review[1]

2.1 Cerebral palsy and sleep problems

Cerebral palsy is one of the most common disorders in children and occurs at a rate of 2 to 2.5 per 1000 live births (Jan, 2006). "Cerebral" refers to the cerebrum and "palsy" means disorder in movements. Therefore, in cerebral palsy, movement abnormalities result from cerebral damage and, consequently, childhood musculoskeletal problems are common (Chambers, 2002). Although presentation of cerebral palsy is quite varied a recent US study reported that approximately 48% of children having some form of mobility problem (Christensen et al, 2014). Cerebral palsy 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 (Chambers, 2002). In turn, persisting body reflexes interfere with development of gross and fine motor movement. An additional feature of cerebral palsy is the high incidence of physiological problems such as gastro-esophageal reflux disorder (GERD). Chambers (Chambers, 2002) reports that upwards of 80%–90% of children with severe cerebral palsy will also have chronic gastrointestinal issues of which gastro-esophageal reflux is the most common condition. Apart from musculoskeletal and physiological problems, other conditions associated with cerebral palsy include epilepsy, visual impairment, respiratory problems (Wayte et al., 2012), drooling and uncoordinated swallowing (Chambers, 2002). All of these problems can impact a child's sleep and will be discussed in greater depth in later sections. For a fully detailed review of the types of cerebral palsy and the range of severity readers are referred to the comprehensive work of Bax and Gillberg (2010)

[1] This chapter is largely the material from the author's (RD) publication " Dutt, R., Roduta- Roberts, M., Brown CA. (2015) Sleep and Children with Cerebral Palsy: A Review of Current Evidence and Environmental Non-Pharmacological Interventions. Children 2015, 2(1), 78-88; doi: 10.3390/children2010078 http://www.mdpi.com/2227-9067/2/1/78/html". Inclusion of this material was done in consultation with the author's supervisor (CB).

Sleep disturbance is reported to be very common in children with cerebral palsy and 23% to 46% of children with cerebral palsy suffer from sleep problems (Chambers, 2002; Newman et al., 2006). This is significantly higher than that reported for typically developing children (20%–30%) (Tikotzky & Sadeh, 2001). Sleep problems experienced by children with 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(Chambers, 2002; Newman et al., 2006). In Elsayed's study (2013) (Elsayed et al., 2013), involving 100 children with cerebral palsy divided into preschool and school-age group, both groups showed a high incidence of sleep problems. In the preschool group 46.2% experienced early insomnia and 50% demonstrated sleep bruxism (teeth grinding). In the school-age group 50% experienced sleep disordered breathing, 50% had nightmares, 12.5% regularly talked in their sleep, and 62.5% had excessive daytime sleeping. A high incidence of awakening after sleep onset (50%) in children with cerebral palsy was also found in a study by Pruitt and Tsai (2013).

As mentioned previously sleep not only affects the overall development of the child, but also affects the well-being of the entire family. As Wayte et al. (2013) reports, nearly 40% of children with cerebral palsy required parental attention on at least one occasion every night. In the same study 74% of parents reported that because of their child's SD, their own daytime functioning was impaired.

2.1.1 Etiology of sleep problems

As previously mentioned, children with cerebral palsy are at high risk for sleep problems because of the numerous negative consequences of the condition (for example pain, spasticity, epilepsy and seizures). Epilepsy, for example, is a co-occurring condition in approximately 41% of children with cerebral palsy (Christensen et al., 2014), and is associated with disturbed sleep. Children on antiepileptic drugs can also suffer from excessive daytime sleepiness (Newman et al., 2006). Some children with cerebral palsy are also vulnerable to respiratory problems such as upper airway obstruction, which in turn can lead to repeated arousal from sleep (Wayte et al., 2012).

Glossoptosis (abnormal downward or back placement of the tongue) and recurrent aspiration pneumonia related to gastro-esophageal reflux are also features of cerebral palsy in children with high level involvement and this can also induce sleep related breathing disturbance (Newman et al., 2006).

Newman's review (2006) of sleep and cerebral palsy also reported that disorders of initiation and maintenance of sleep were strongly associated the presence of visual impairment because abnormal light perception affects the regulation of sleep-related hormones such as melatonin and adenosine. Lastly, the review noted the significance of environmental factors (such as light, temperature, sound, and bedding) as contributors to the increased prevalence of sleep problems in children with cerebral palsy.

While there are many factors related to cerebral palsy that can interfere with sleep, pain is one factor that is common in children with cerebral palsy and is known to be underreported and undertreated in pediatric populations. For these reasons the remainder of this section will focus on the relationship between pain and sleep in children with cerebral palsy.

2.1.2 Sleep and pain

Pain is known to interfere with sleep and there is evidence that the relationship may be bi-directional such that sleep deprivation increases the severity of pain experience and increased pain interferes with sleep (Schuh-Hofer et al., 2013). The risk of pain is highly prevalent in children with cerebral palsy and warrants particular attention in discussing sleep problems. Factors such as skin breakdown and pressure ulcers (Wayte et al., 2012), spasticity, abnormal muscle tone, involuntary movements, and abnormal postures in children with cerebral palsy, can decrease their ability to change body position during nighttime and increases their experience of pain. In combination, these factors act as predisposing influences for sleep problems (Newman et al., 2006). Ramstad, et al (2011) surveyed 153 participants with cerebral palsy aged 8 to 18 years and their

parents. They found that 65% of the children reported moderate pain. Interestingly, parental reports of pain and perceived impact of pain on sleep were even higher than the children's reports.

Research specific to pain and cerebral palsy is limited but what does exist seems to indicate that the two are closely related such that they may indeed have a bi-directional relationship. As a recent editorial in *Developmental Medicine and Child Neurology* about under-addressed issues for managing cerebral palsy points out "…pain is the most frequent problem and it is surprising how little attention it receives" (Baxter, 2013). Baxter cites the systematic review by Novak et al (2012) to support his position. The review appraised 82 research papers and concluded, among other things, that high level evidence existed demonstrating that three in four children with cerebral palsy experienced pain. Coupled with the high incidence of sleep disorder in children with cerebral palsy Novak et al. concluded that there is an "under-researched link between chronic pain, sleep and behavioural problems" and that this relationship "warrants urgent attention" (Novak et al.,2012). Pruitt and Tsai (2009) also reviewed the cerebral palsy literature and concluded that possible major causes of pain include musculoskeletal pain (such as hip dislocation or scoliosis), neuromuscular pain (such as muscle spasm), and gastrointestinal pain (such as gastro-esophageal reflux and constipation). They identified additional, less common, and potentially overlooked causes of pain including dental problems (such as abscesses), ophthalmologic problems (such as corneal abrasions), and urologic problems (such as bladder spasm).

The results of a study involving 123 children with cerebral palsy (divided into three groups; those having no pain, those with treated pain, and those with untreated pain) indicated that children who had pain also had significantly more sleep problems overall, more night awaking, parasomnia, sleep disordered breathing and shorter sleep duration. Breau et al (2011) Findings were similar in a study of 20 youths with cerebral palsy between the ages of 6 and 17 years, where the results indicated that pain interfered with participants' self-care and with sleep (Engel et al., 2005).

Sleep disturbance in children with persistent pain may also be associated with underlying disease-related mechanisms (such as muscle spasm, or contractures), and treatment regimens (such

as analgesics and antiepileptic sleep-disrupting medication). Emerging research seems to indicate that insufficient sleep contributes to increased pain sensitivity and dysregulation of the hypothalamic pituitary adrenal axis (HTPA). Evidence is accumulating that supports the existence of a bi-directional relationship between pain and sleep such that problems in one increase the risk of problems with the other (Goodin et al., 2012; Valrie et al., 2013).

2.2 Physiology of sleep and Effect of Environmental Factors

Researchers determined that medical residents in the United Kingdom receive no more than 5 hours of sleep-related education (Jin et al., 2013). As such, their knowledge base can be limited. They concluded that it is therefore unsurprising that parents of children with cerebral palsy most often receive only pharmacological intervention despite the existence of evidence identifying side-effects and the limited evidence-base regarding long-term tolerability and efficiency of most pharmacological sleep interventions used in pediatric populations (Jin et al., 2013). The need for non-pharmacological interventions (such as cognitive behavioural, activity-based, environmental and sleep hygiene interventions) is evident. There is a small but growing volume of literature exploring how environmental features in the home affect sleep. For example, types of bedding material, window coverings, artificial blue spectrum bright-light exposure at night (from televisions, computers and other electronic devices for example), nighttime household noises, and bedroom temperatures, all have a demonstrated physiological base for consideration in interventions to promote sleep. In keeping with the objective of this paper to present evidence-based knowledge that can be integrated into all healthcare providers' interventions and recommendations, regardless of their professional background, and, because of the clear influence environmental features exert on sleep physiology, the remainder of this chapter will focus more on environmental modifications and their particular relevance for children's sleep. This is not intended to imply that other interventions (as listed above) are less effective. However, pragmatic, effective, sleep-promoting changes to the bedroom environment that should form the foundation to support any other sleep intervention can often be overlooked. This review will now focus on providing a

general review of the evidence-base of the physiological relationship between sleep and light, sound, temperature and allergens.

Sleep is generated by the activity of specific brain structures (such as the superchiasmic nucleus and hypothalamus), neurochemicals and neural networks (Moszczynski & Murray, 2012). There are four stages to a sleep cycle that repeat throughout the night in a pattern of Stages 1 through 3, categorized as "non-rapid eye movement" NREM, leading to Stage 4, categorized as "rapid eye movement" (REM). Each cycle of all 4 stages is of approximately 90-min duration (Heraghty et al., 2008). Stage 1 is light sleep, where eye movement and muscle activity slows. In Stage 2, eye movement stops and neural activity become slower; with an occasional burst of oscillatory brain activity, generated in the thalamus, called sleep spindles. In Stage 3 (called "deep sleep") extremely slow brain waves (called "delta waves") begin to appear and it is usually difficult to wake the sleeper. Stage 4 sleep consists of REM sleep and is characterized by high levels of neuronal activity. This stage is most commonly associated with dreaming (Heraghty et al., 2008).

There are two main processes that affect the sleep-wake cycle. Firstly, the primary sleep-inducing neurotransmitter adenosine accumulates during the day leading to activation of the areas of the hypothalamus creating a homeostatic drive for sleep (Evers, 2010). Secondly, the suprachiasmatic nucleus in the hypothalamus (which is considered to be the control centre of autonomic functions such as thermoregulation), receives direct blue spectrum light input from the retina via the retinohypothalamic tract and this mechanism coordinates circadian rhythm (Moszczynski & Murray, 2012). Circadian rhythm is largely regulated by the light/dark cycle and, to a lesser degree, temperature (Heraghty et al., 2008).

2.2.1 Effect of light

Light directly impacts human physiology and behavior through its alerting effects on circadian rhythm (Chellappa et al., 2013).The hormone melatonin is regulated in the hypothalamus and plays a central role in synchronization of circadian rhythm and especially the sleep/wake cycle.

Bright blue spectrum light inhibits melatonin secretion during the day, and lower light levels (dusk) increase melatonin secretion in the evening and night (Van et al., 2011). Excess exposure to artificial blue spectrum light, usually through electric room lighting and electronic devices, will alter the timing, duration and amount of melatonin synthesis (Gooley et al., 2011). Exposure to blue spectrum light of as little as 50 lux has been shown to inhibit melatonin secretion (Wood et al., 2013) and researchers consistently recommend that the bedroom should be as dark as possible to promote sleep onset and maintenance. The increasingly prevalent practices of providing a television in children's bedrooms, allowing the use of electronic mobile devices at night, and using electronic devices for bedtime story telling and games are therefore of concern. These electronic screens emit varying degrees of blue spectrum light and can lead to disrupted melatonin production which, in turn, greatly delays sleep onset (Garrison et al., 2011).

A comprehensive review of infants' sleep physiology concluded that infants who are exposed to constant illumination in the nursery face more problems with circadian rhythm as compared to those who are exposed to dim light (Heraghty et al., 2008). It has been suggested that the pattern of light/dark exposure has an even greater influence on a child's circadian rhythm than does a fixed sleep schedule (Appleman et al., 2013). Therefore both daytime blue spectrum light exposure and also controlling evening blue spectrum light exposure can be manipulated to promote sleep onset and maintenance. Careful consideration of frequency and timing of blue spectrum light is particularly important for children with cerebral palsy who may not have the same opportunities and abilities to participate in outdoor e activities required to receive sufficient daytime blue spectrum light exposure.

2.2.2 Effect of temperature

Ambient temperature has an important influence on sleep because thermoregulation affects circadian rhythm and other sleep governing mechanisms (Okamoto et al., 2012). Normally, a slight drop in core temperature occurs when the homeostatic drive to sleep is high and so the likelihood of sleep initiation increases. High ambient temperatures interfere with the body's ability to achieve

a drop in core temperature and so slightly cooler bedroom temperatures are recommended. Core body temperature continues to decreases slightly through the night, and particularly during REM stage sleep when skin temperature in the peripheral extremities is at its lowest. The amount of time spent in REM stage sleep increases over the night and most REM sleep occurs in the 2–3 h prior to wakening. Children with cerebral palsy and motor impairments may require the bedroom ambient temperature to be increased during this period because the thermoregulatory responses of shivering and body movements are suppressed during REM stage sleep (Okamoto et al., 2012). A recommended ambient temperature for sleeping is between 18–22 degrees Celsius (Okamoto et al., 2012). A programmable thermostat set for lower temperatures at bedtime and then increased temperature two hours before wakening can help create an optimum sleep environment for these fluctuating needs.

2.2.3 Effect of sound

Environmental noise is one of the risk factors that influences sleep/wake behavior and sleep quality (Van et al., 2013). Environmental noise is defined as unwanted or harmful sound in the home environment that can be caused by human activity (for example running machinery, conversation, and also outdoor activities such as that produced by vehicles). Sound has an influence on the central nervous system and on various autonomic functions, such that stress hormones are released. For example, the stress hormone cortisol is produced as a response to alerting night time noises, and leads to autonomic reactions such as increased heart rate, blood pressure, respiratory rate and muscle tension (Van et al., 2013). Increased production of cortisol is also of significance because in well-rested individuals cortisol levels drop over the nighttime. This means that elevated cortisol levels on wakening indicate a cause for concern. The effect of noise on sleep includes; a delay in sleep onset, inability to move into the deeper stages of sleep, more frequent awakenings

(and thereby interrupted sleep cycles), increased restlessness and body movements, and an overall shortening of total sleep time. To-date there is a paucity of research directly related to children with cerebral palsy and noise. However, lessons from other studies can be extrapolated and the review by Jan et al (2006) concluded that slight modifications in the bedroom, the use of ear plugs, or the use of "white noise" machines (which produce a mixture of all frequencies and can mask discrete alerting sounds) may be of benefit.

2.2.4 Effect of bedding

There is little evidence-based research regarding the impact of the sleeping surface and bedding on the sleep quality of children with neurodevelopmental disability (Jan et al., 2006). However, choice of mattress, pillow, sheets and blankets may be important for some children for both comfort and for allergen reduction. Children with decreased motor control, or inability to independently reposition themselves, can benefit from environmental modifications (such as the use of programmable thermostats) to create sleep conducive atmospheres. Certain types of bedding are more likely to trigger wheezing, and particularly wheezing caused by house dust mites (HDM) related airway obstruction (Ponsonby et al., 2004). Synthetic quilts, pillows, and electric blankets are very commonly in use these days, and these have been associated with frequent breathing problems during sleep in children. Some research suggests this is because higher counts of HDMs and allergens occur in synthetic quilts and pillows as compared with feather duvets and pillows that have tight cotton ticking that reduces the ability of HDM and particles to be released near the child's airway (Ponsonby et al., 2004). All forms of bedding, including mattresses, pillows, duvets, bedding and under-bedding can be significant HDM and allergen reservoirs (Ponsonby et al., 2004). Allergen barrier under bedding and pillow covers, frequent washing of bedding, putting pillows and duvets through the dryer, and frequent vacuuming of mattresses can help reduce the risk exposure.

Children with neurodevelopmental disability and sensory processing problems (such as tactile defensiveness) also may have a specific preference for either light or heavy blankets (Dawson et

al., 2000; Jan et al., 2006). Children who has sensory processing (or sensory interpretation) problem can, for example, find a light blanket painful or very distressing to have in contact with their skin. In these situations they try to avoid the blanket; hence the term, "tactile defensiveness". Use of sleep products such as supracor® sheets (http://www.supracor.com/company/), which are made of a flexible, breathable, honeycomb-like, absorbent material, may help minimize the need to change pajamas and bedding which, in turn, may result in less sleep disruption for both the child and caregivers.

2.3 Evidence based Non pharmacological intervention

Non-pharmacological sleep interventions (NPSI) are important in addressing sleep problems and are recommended as adjunctive or alternatives to long-term use of sleep medication (Brown et al., 2013; De Neit et al., 2009; Heussler et al., 2013). Such sleep interventions 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 the reader is referred to a recent critical review of NPSI for youth with chronic health conditions which found that the methodological quality of the few existing studies of NPSIs for this population was low (Brown et al., 2013). However for certain interventions (specifically bright light therapy, activity, massage and behavioural interventions) the reported outcomes of studies in the review were consistently positive and with no adverse effects. The authors concluded these interventions were promising and warranted more rigorously designed and contextually relevant study.

2.4 Conclusion from literature review

Research demonstrates that sleep deficiency is a common consequence with significant negative impact for children with cerebral palsy. Not only are sleep deprived children at risk of

developing or exacerbating other physical and emotional health problems but so are other members of the family, who themselves become sleep deprived consequent to caregiving roles and additional family pressures. Knowledge of basic sleep physiology, and how to apply this knowledge to make non-pharmacological, sleep environment recommendations to parents, will be of benefit to healthcare providers from all disciplines. There is a clear gap in the application of the existing light, temperature, sound and bedding evidence-base. Studies of parent and healthcare professional knowledge translation of NPSIs (particularly those focusing on environmental modifications) are warranted.

Chapter 3: Research Methods

As discussed in Chapter 2, the incidence of sleep problems in children with cerebral palsy (CP) is quite high (Chambers, 2002) Further, the review of the methodological quality of non-pharmacological sleep interventions (NPSI) for children with chronic health conditions has shown that there is a growing body of evidence that supports the importance of providing parents with knowledge and tools with which to help their children who have sleep problems. Therefore, the focus of this study was knowledge translation for parents of children with cerebral palsy and providing them with an evidence based intervention tool to understand and modify the effect of the environmental on sleep. This chapter discusses the research methodology used, why it was chosen, and how it was implemented in the study.

3.1 Study Design

Studies may be classified either as descriptive or analytical. Descriptive studies are defined as "observational studies and they describe general characteristics related to place, person and time (Kooistra et al., 2009, p.21)." These include cross sectional studies, case reports, and case series analyses. Analytic studies are used to test hypotheses about the differences between treatments and outcomes, and include such designs as randomized controlled trials (RCT) (Kooistra et al., 2009).

The research design applicable to this study was a single case series design. This was a descriptive study that followed patients with similar diagnoses (Kooistra et al., 2009). In this study, a within-case analysis was performed, as each child/parent served as his/her own control, and pre- and post-intervention data were compared. Despite randomised control trial (RCT) having a level 1 in the hierarchy of evidence, the reasons for using a single case series design for the study rather than RCT were "technical and ethical" (Kooistra et al., 2009, p. 21). RCT is not an appropriate design with which to address all clinical questions (Kooistra et al., 2009). For example, in this study, it would be technically very difficult to have the same number and characteristics of children

with CP in the control and experimental groups; moreover, it is a very vulnerable group and it would be unethical to include a control group that received no intervention.

The strength of this design is that it concentrates on one research site, has high external validity, can accommodate a wide range of patients, is inexpensive, fits well with small-scale research studies, and takes little time to conduct (Kooistra et al., 20069). Further, the case study approach can be used to identify positive outcome, and test theories (Denscombe and Martyn, 2007). Common point's observed during case series analyses can be useful to identify important implications for decisions regarding treatment (Ritchie, 2001). The limitations of this type of design are that it lacks a control group, may have incomplete data, and is susceptible to biases (Kooistra et al., 2009).

Despite these limitations, a case series design was suitable for this study because it served to test and report a novel therapeutic strategy (Kooistra et al., 2009). Another advantage of the design is that the results are closer to those obtained in daily clinical practice, which makes them more relevant than those obtained with RCT (Kooistra et al., 2009).

3.2 Theoretical Framework

It appears clear from the literature review in Chapter 2 that providing knowledge translation can help provide parents with knowledge and tools to modify their practice so that their children sleep better. Among children with CP who have restricted mobility and other cognitive issues, such as problem solving and decision-making skills, the parents are responsible for helping them develop appropriate sleep habits. This was the primary reason for the intervention of providing evidence-based practice information, in the form of a sleep environment education manual (Children's Best Bedroom Environment for Sleep—CBBES), to parents as opposed to an intervention targeting children.

To identify the steps required to conduct a knowledge translation activity suitable for the study, the researcher conducted a literature review to search for knowledge translation theories and framework. The review revealed that there are two primary theories or models for knowledge translation activities, the classical theory, and the planned action theory (Graham & Logan, 2004). Classical theory is also referred to as a passive model, as it describes a "naturalistic process of change." Diffusion of innovation is one example of the classical theory (Graham & Logan, 2004; Rogers, 2003) which focuses on spreading a new idea from source to adopter. Planned action theory provides a "set of logically interrelated concepts" by which planned change will occur, and although it works with individuals, its goal is to alter societal practices, for example, the Ottawa Model of Research Use (OMRU) (Graham & Logan, 2004).

The framework that directed this study was the "knowledge to action cycle" (KTA) (Graham et al., 2006). These authors defined this cycle as one that consists of the activities needed for knowledge application, the steps of which can lead to the implementation or application of knowledge. This study employed the following steps of the KTA cycle: 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 (Claude et al., 2012;Graham et al., 2006).

The study began with the literature review discussed in Chapter 2 to help identify the issue, that of sleep problems among children with CP. Information about the prevalence of sleep problems in this population, the importance of sleep, how sleep problems affect children and their families, evidence-based NPSI, and the effects of environmental factors on sleep was also gathered. The literature search supported the need for non-pharmacological interventions to deal with sleep problems in children with CP, as explained in section 2.12. The next step was to identify the knowledge in the context of the problem identified, and the study focused on providing evidence-based knowledge about the effects of components of the bedroom environment. There were two

main reasons to use these environmental components: (1) parents control the bedroom environment and so will be able to adopt the knowledge provided in the study, and the bedroom environment is influenced strongly by parents' beliefs and knowledge about sleep, and (2) sections 2.7, 2.8, 2.9 and 2.10 explained that environmental components, such as light, temperature, bedding, and sound have a clear evidence base of beneficial effects on a child's sleep.

The next step was to collect all evidence-based information about environmental factors and prepare it in the form of a psycho-educational manual (the CBBES manual) that also provided an evidence-based bedroom assessment tool and actions/suggestions, as explained in section 3.8. The researcher identified the target population, as well as any barriers to translating the knowledge for that population. The barriers identified by the researcher included identifying the need of the parents of children with cerebral palsy so that proper information can be provided to them, as children with cerebral palsy are a very vulnerable population and there is a lack of research in the area of sleep. The barriers identified by the researcher also include, the high demand of care parents have for their children with CP, and determining the easiest action parents can use to make their child's bedroom sleep friendly. Also, as mentioned above, children with cerebral palsy are a vulnerable population, their time is really important, thus the use of any tedious and complicated tasks in the study were avoided.

With the assistance of community partners participants were recruited. Thereafter, the data were collected and analyzed, and the outcomes are discussed in detail in Chapter 4- Results.

Supplemental feedback and data

Over the course of the primary study, there were several unplanned opportunities to gather additional feedback from other stakeholders. These included online data collection from participants (parents and healthcare providers) in several educational workshops about sleep and

children with CP held by the researcher while in India, parents from University of Alberta affiliated daycares, and a group of parents of children with CP on Facebook (Canada and US membership). Because this was supplemental feedback that was not a component of the original project, it is reported and discussed separately in Appendix J.

3.3 Sampling

The sampling method used in this study was convenience sampling, a form of non-probability sampling. This form of sampling was used because it is difficult to contact the targeted population through conventional sampling methods, such as RCT, as explained in section 3.1. This study sought a diverse sample, because little sleep research has been conducted about children with CP and their families. Therefore, this study was a pilot designed to obtain proof of the principle and to refine the study protocol.

The recruitment of parents of children with CP was performed with the help of the following community partners: "Get Ready for Inclusion Today (GRIT) Edmonton, and the Cerebral Palsy Association of Alberta (CPAA). These groups were chosen because (1) many of the children with CP in Edmonton are users of the services at these centers, and (2) they took an interest and agreed to become partners in the study.

3.4 Recruitment Methods

GRIT and CPAA acted as gatekeepers in the recruitment process, and identified 18 potential participants from GRIT and 20 participants from CPAA who fit the inclusion criteria for the study (section 3.6). A package containing an introductory letter (Appendix A) and an informed consent

form (Appendix B) was prepared by the researcher, and mailed to all potential participants by the community partners. They also informed parents about the study via their monthly newsletters. Participants who agreed to volunteer for the study returned their consent forms to the researcher via mail, fax, or email. An initial contact was set up via email, in which the researcher asked each participant whether it would be acceptable to discuss the details of the study during a phone conversation. If so, a phone call was scheduled to answer their questions about the study and to set up a time for the first home visit. The parent who was the children's primary night time caretaker was involved in the study, in order to avoid potential bias and achieve a clear evaluation of the designated parents personal sleep knowledge and any changes in their knowledge over time.

Because of the low recruitment rate in the initial process, another invitation was sent to all participants via the community partners' electronic newsletters. They asked interested volunteers to contact the researcher directly via the email address provided in the information flyer (Appendix H).

3.5 Sample Size

Because of the exploratory nature of the pilot study, within-subjects analyses were performed. This was used because of the diversity in the features associated with children with CP. The study planned to recruit a minimum of 10 children through the community partners.

3.5.1 Inclusion criteria.

The inclusion criteria for this study were: (1) parent and child, or parent alone, where the child was from 2 to 10 years and had CP as their primary diagnosis, as reported by a neurologist, and (2) where the child also had a sleep problem as reported by the parent. Parents of children of the

appropriate age were the focus of the study, as they were the potential adopters of the knowledge, even if the child did not take part in the study.

3.5.2 Exclusion criteria.

There were no exclusion criteria for this study, as each child served as his/her own control. Exclusion criteria only pertained to children during the consent/assent process (Appendix C). If, for example, they declined to wear an actigraph during the pre- or post-data collection period, the child was excluded from the study and only the parent participated.

3.6 Development of the intervention tool- the *Children's Best Bedroom for Sleep* (CBBES) manual (Appendix I)

The CBBES is a psycho-educational manual and was the intervention tool used in the study. The CBBES served the combined purpose of empowering parents of children with CP experiencing sleep problems with both the scientific evidence and practical application of that evidence in the context of their own child and situation The CBBES manual was designed to serve in knowledge translation, and compiled evidence-based information about components of the child's bedroom environment. This tool was developed in-house, under the supervision of the researcher's supervisor. Amelia Rajala, an MScOT student at the University of Alberta, worked on the manuscript of the CBBES psycho-education manual with content provided by the researcher. The researcher's supervisor edited the final version of the manual.

The information was compiled in two sections, "What you should know about the sleep," and "What you can do." The first section explains basic sleep physiology, the sleep cycle, and key bedroom environmental factors, such as bedding, temperature, sound and light. The information in these sections discusses why these components are important, and how they affect the child's sleep physiology. The key feature of this section is that after each component, there is a sample case

study, which helps readers understand how that particular component can lead to sleep issues in the child.

The second section describes what parents can do to make their child's bedroom environment more conducive to sleep. The section contains a checklist of each environmental component, which can be used by the parents to assess their child's bedroom environment. The researcher used the same checklist to assess the child's bedroom, as discussed in section 3.7 below. Further, a list of evidence-based recommendations is included for each component that helps make a child's bedroom environment conducive to sleep. At the end of the CBBES manual, there is a list of additional resources for parents that they can read to obtain more information about sleep issues and effects of environment.

To establish its validity, three faculty members at the University of Alberta with knowledge of pediatrics piloted the intervention tool before it was used in the main study. The feedback and comments provided by them were then included in the manual. The manual was written in lay language with a reading level of grade 8.

3.7 Study protocol: Children Who Participated in Sleep Actigraphy

Data collection included three phases: Pre-intervention data collection, follow-up, and post-intervention data collection. Four home visits were made during the data collection process.
The researcher scheduled the first home visit during a phone call with each participating parent. The researcher explained the study during the first home visit, and included the purpose of all of the visits. Using an in-house background information form, information was collected about the participant and his/her child, including their dates of birth, level of education, place and time of their child's sleep, bedtime routine, and sleeping habits (Appendix E). Further, participants were asked to describe their child's sleep habits in a series of open-ended questions, including:

"Can you describe your child's activity before going to bed?"

"Can you tell me what changes in your child's bedroom once s/he falls asleep?"

The parent/s' responses were recorded by the researcher. The data collection tools and process of data collection were explained to the participants. The surveys used to collect the data included a Parental Interactive Bedtime Behavior Scale (Morrell & Cortina-Borja, 2002); a Child's Sleep Habits Questionnaire (Owens et al., 2000); Parental Sleep Environment Knowledge Questionnaire (Appendix D); Parental Knowledge of Healthy Sleep in Children Questionnaire (Jones et al., 2011); an actigraph, and a Parental Sleep Diary.

Parents were told how to keep a sleep diary, the process of actigraphy was explained, and a sample sleep actigraph report was shown to them. Participants were asked to fill out the surveys (described in section 3.8), the data collection measures, and the sleep education questionnaire to the best of their knowledge and ability.

Instructions provided to participants included:

"Fill [out the form] according to your perceptions about your child's sleep."

A consent/assent process for the actigraph procedure was conducted with each child after permission was granted by his/her parent. As not all of the children were able to communicate verbally, a decision was made based on their facial expressions, such as smiling, crying, etc. The meaning of the facial expressions was confirmed by the parent/s.

With consent from the parent, the researcher performed an assessment of the child's bedroom following the assessment checklist points included in the CBBES education manual. The parent was asked to set up the child's bedroom in the way it would be when the child went to bed at night. As part of the bedroom assessment, light levels were measured with an app lux meter (https://play.google.com/store/apps/details?id=com.notquitethem.android.luxmeter&hl=en) and sound level by a decibel meter app (https://play.google.com/store/apps/details?id=kr.sira.sound&hl). The sleep actigraph and sleep diary were provided to the participants, and they were given instructions on how to fill out the sleep

diary. Sleep actigraph protection tips (Appendix L) were provided as well. At the end of the first home visit, the researcher scheduled a time for the second visit.

Follow-up took place during the second home visit, one week after pre-intervention data collection. During the follow-up, the researcher gave the participants the intervention tool, the CBBES educational manual (Appendix I). 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 questions or confusion, 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 information provided was noted in each participant's coded files.

Post-intervention data collection was identical to baseline data collection. After six weeks of follow-up, all of the participants were asked to fill out the data surveys and sleep education questionnaires. The seven nights of sleep actigraphy and the parent/s reported sleep diary was explained to the participants again. Instructions provided to them included:

"Place the actigraph in the same place where you put it the last time."

The researcher performed a second bedroom assessment following the checklist on the back of the CBBES manual, and light and sound level measurements were measured again in the child's bedroom. In addition, the assessment pages where the parent/s noted the changes they made in their child's bedroom and the effective date were removed from the CBBES manual as part of the data collection to determine if they had taken any action after reading the CBBES manual; new, empty

pages were provided to them. At the end of the visit, a time was scheduled for the final home visit to collect the actigraphs and sleep diaries.

3.8 Data collection measures

This section explains the data collection tools used in the study.

3.8.1 Parental Interactive Bedtime Behavior Scale (PIBBS) (Morrell & Cortina-Borja, 2002).

The PIBBS is a self-reported parental questionnaire that consists of 22 items that the parents rate on a 0 to 4-point scale. The goal of the questionnaire is to have parents rate the behaviors they employ to settle the child to sleep. The 17-item scale has internal consistency (Cronbach's alpha = 0.70) and reported convergent validity (Morrell & Cortina-Borja, 2002). The researcher used this scale because it captured the parent/s' behavior. Pre- and post-data were compared to identify any changes in the parent/s' behavior after receiving the intervention education manual.

3.8.2 Child's Sleep Habits Questionnaire (Owens et al., 2000)

The child's sleep habits questionnaire is also a self-reported parental questionnaire. The scale consists of 45 items related to the key domains of sleep that constitute major sleep complaints in that particular age group. This is presented on a 3-point scale, in which parents are asked to rate the problem as "usually," "sometimes," and "rarely." Parents were asked to recall the sleep behavior of their child during the past week. The Cronbach's alpha of the scale is approximately 0.70 (Owens et al., 2000).

3.8.3 Parent Knowledge of Healthy Sleep Habits in Children (Jones et al., 2013).

This is also a self-reported questionnaire. The items in the pre-intervention include background information (8 items), sleep habits (12 items), sleep health beliefs (4 items), and healthy sleep knowledge (10 items). In the sleep habits section, parents document the child's usual sleep habits, such as bedtime and wake up time, and estimate the amount of sleep their child needs. In the sleep beliefs section, parents respond on a 3-point scale (agree, neither agree nor disagree, disagree). The sleep knowledge section consists of 10 questions in which parents respond either true, false or do not know. The post-intervention survey consisted of only the sleep beliefs and knowledge sections. Permission to use this scale was obtained from the author (Owens) prior to the study.

3.8.4 Parental Sleep Environment Knowledge Questionnaire (PSEKQ: Appendix D).

The PSEKQ was developed in-house by an MSc OT student under the supervision of the researcher's supervisor, and was edited further by the researcher and her supervisor. The validity of the tool was established through a pilot test with other professors from the university. Feedback provided by them was used before the questionnaire was employed in the main study. The PSEKQ contains 10 statements of fact with 3 possible explanations for each fact. The facts in the questionnaire included evidence-based information from the background literature search, which made it reliable for use in the study. The multiple choice questions (MCQ) followed the recommended format of having simple vocabulary, having a stem, and having intermingled correct key and incorrect plausible responses (Considine et al., 2005). For example:

STEM: Children who sleep on their back and have beds with synthetic bedding are more likely to have problems breathing. This is because:

a. Synthetic bedding is more likely to collect allergens from the environment (**incorrect plausible response**),

b. b. More body heat will be trapped and sweating interferes with breathing. (**Incorrect plausible response**)

c. In this position the bedding is closer to the child's nose and mouth when they breathe **(Correct key)**

The questionnaire includes 10 evidence-based facts that are presented in lay language and covered in the content of the CBBES psycho-education manual. Three possible reasons are associated with every fact, and the parents have to select the reason that explains why the fact is true; the facts focus on the child's bedroom environmental components, such as light, temperature, bedding, and sound. The literature search in Chapter 2 supported the decision to choose these four factors in the questionnaire.

PSEKQ is intended as a KT tool in itself, as it collects data about whether parents already know the science behind a common recommendation (e.g. decreasing light exposure in the bedroom) when they started the study or if they learnt the reason behind each correct fact though using the CBBES manual. The assumption was that if people know the reason (the 'why') underlying a fact they could better generalize the information to their own context and take appropriate action. The purpose of this questionnaire was to assess whether the manual helped parent learn why the bedroom environment is important for their child's sleep. Pre- and post-intervention scores were compared to check whether there was any change in knowledge that could be attributed to the manual. Although changes of knowledge could not be interpreted as directly resulting in changes in parents' behaviour, when knowledge change occurred in tandem with changes in the bedroom environment this was accepted as indirect evidence of the CBBES manual's effectiveness.

3.8.5 Actigraph and parent-recorded sleep diary (Appendix F and G).

The actigraph is a sleep monitoring device that contains an accelerometer. The actigraph used in the study was a WGT3X-BT monitor (Actisleep) from Actilife (http://www.actigraphcorp.com/products/wgt3x-bt-monitor/). The monitor contains a 3-axis accelerometer and a light sensor. The monitor used in the study was implemented for 60 epochs of

data collection, which means that a movement longer than 60 seconds was reported by the actigraph (http://www.actigraphcorp.com/support/activity-monitors/gt3xplus/).
The data generated from actigraph includes, sleep latency (min), total sleep time (min), total time in bed (min), sleep efficiency (%), wake after sleep (min), number of awakening, average of awakenings (min).

Parents were instructed to put the actigraph on the child's non-dominant wrist. Actigraphy was selected for this study because it is a recommended, widely used and simple method of data collection (Wiggs, Montgomery, & Stores, 2005). Wiggs reports that sleep actigraphs are sensitive devices; the actigraphs tested in Wiggs et al's study had sensitivity of 0.97 with polysomnography, which means motion sensed by actigraph is 97% times correct when compared with polysomnography. When measured minute by minute, it had a specificity of 0.44 (Wiggs et al., 2005).

A pen and paper parent-recorded sleep diary was used concurrently to record parent reported time of going to bed and waking up. Version A (Appendix F) of the sleep diary, which was used in the initial phase of the study, was changed to the in-house version B (Appendix G) for all follow-up phases because parents reported that Version A was difficult to complete for seven days, and there was no space for comments which led parents to provide incomplete responses. Based on this feedback given by participants the new version had four columns and parents wrote down the start date of data collection, the time their child went to bed, when s/he woke up and any additional comments, such as crying, midnight awakenings, etc. The parent's responses were completed when the diary was switched to Version B.

3.9 Data Management

The data collected included participant-reported surveys, actigraphy reports, sleep diaries, and lists of changes parents made to their child's bedrooms. Each participant's identity was coded, and there were no pictures or videos made of participants' bedroom environments.

3.10 Data Coding and Storage

Data were stored in a locked file drawer in a lab in Corbett Hall that has key access only. Each participant file from the actigraph group was coded as AB 1 to AB 6. Information gathered during all home visits, surveys completed by participants, and actigraphy reports are stored in these files and can be accessed only by the researcher and her supervisor. Actigraphy reports were generated only by the researcher's supervisor and are kept in her office.

3.11 Data analysis

Data were analysed with descriptive statistics. The percentage of correct responses on the pretest was compared to that on the post-test. The researcher used the mode to identify which fact in the sleep education questionnaire received the maximum number of correct responses in the post-test compared to the pretest. The mode was used to establish the effect of a change in knowledge about the each particular fact.

The 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.

Chapter 4: Findings

In this study, data was collected using self-reported measurement tools and sleep actigraphy, as explained in section 3.8. This chapter presents the findings as detailed below.

4.1: Participants' involvement

A total of 38 potential participants were identified by the community partners GRIT (20) and CPAA (18) met the inclusion criteria for the study. Introduction letters were mailed to each by GRIT and CPAA. Three potential participants emailed consent forms to the researcher, and two potential participants mailed consent forms to the research lab address in this first phase of recruitment. The researcher received no response from 30 of the addressees, and three recruitment packages were returned to the researcher as wrong addresses. Because of the low response, the researcher initiated another recruitment process, resulting in one additional participant Five participants completed the eight-week study, and one participant dropped out after seven weeks and did not complete the post intervention data collection.

4.2 Participant demographics

The six participants who agreed to be the part of the study were all female parents ranging in age from 29 to 44, with a mean age of 36.6 (Table 1). Their children with cerebral palsy included five males and one female, ranging in age from 4 to 12, with a mean age of 7.1 (Table 1). All the participants were residents of Edmonton or St. Albert in Alberta, Canada. The participants had varied educational backgrounds (Table 1); three participants indicated that they were undergraduates, one completed some high school, and one some graduate school. Four participants

were homemakers, one worked from home and one worked outside the home. Five of the children involved in the study had at least one sibling, and one participant had no siblings.

4.3 Sleep habits

The sleep habits of the participants' children were gathered using the background information form (Appendix E) and sleep characteristics information gathered from Sleep Habits of the Children (Owens et al., 2000). Table 2 shows the results from the Sleep Habits of the Children (Owens et al., 2011). The results suggested a few positive points and a few negative points about the children's sleep habits. Positive points include that 83.33% of participants said that their children have a regular bedtime and wake up time for seven days, with a regular bedtime routine; that all the participants said that there was no TV in their child's bedroom; and that they do not have any form of caffeine in their diet. Only 33.33% of the participants said that watching TV was part of the bedtime routine, and 66.66% of the participants said reading stories was a part of their bedtime routine. Further, 66.67% said that there was an adult in the room while the child fell asleep only once a week or less.

There was some negative sleep behaviors as well reported by parents; 83.33% of the participants said that they had at least one type of electronic device in their child's bedroom, and 66.67% said their child's bedtime was later than 9 pm. Additional information about the sleep habits of the children were also elicited from parents in the form of open-ended questions; the researcher noted parental responses. Participant 1 described her child's sleep habits as the following: child sleeps in his own bedroom, child stretches before going to bed, sometimes watches TV, there is no change in the bedroom environment between when the child goes to bed and he fell asleep, child does not take any naps, child sleeps alone with a closed door, and is on baclofen medication for morning and evening.

Participant 2 described her child's sleep habits as: child sleeps on a regular twin bed and shares bed with his twin brother, child sleeps with door closed, reads stories with books, listens to music, bedroom environment remains almost same while going to bed and once the child fell asleep, except for music turns off automatically and they have twilight celling lights that turn off automatically.

Participant 3 described her child's habits as: child sleeps alone in her own room, with door partially open, take naps in daytimes, wakes up couple of hours at night, the hallway light is on always, child is on melatonin since May 2014, they have a small sound making machine which turns off automatically after an hour, sometimes they put heavy pillows on child legs as a calming activity, on weekdays parents try to wake the child in daytime and try to avoid taking naps.

Participant 4 mentioned that the door of the child's bedroom is open when he falls asleep, also, the child wants somebody with him at time of sleep, and they turn on the night lamp in the child's room which emits blue light.

Participant 5 described that her child sleeps in own bedroom, and sleeps initially 20 minutes with parent, child is on G-tube feed, watches movie before going to bed, they play lullaby music in child's room, sleeps on his back, child plays with his iPad 45 minutes before going to bed, and music shuts off automatically once child falls asleep.

Participant 6 described that her child sleeps with mother, with door partially open, child is on vitamin D supplements, child eats after supper and before going to bed, reads books in bed for approximately 15 minutes, and child always wakes up after half an hour once he falls asleep.

The next section (4.4) explains the results from the measurement tools.

4.4 Findings

In this section, the findings generated from the measurement tools are described.

4.4.1 Parental Interactive Bedtime Behavior Scale (PIBBS) (Morrell & Cortina-Borja, 2002)

This is a self-reported questionnaire to gather information regarding the parents' behavior during the child's bedtime using a five-point Likert-type scale (1 - never, 2 - rarely, 3 - sometimes, 4 - often and 5 - very often). The PIBBS contains 22 items. Six participants completed the pre-test, and five completed the post-test. Table 3 shows the raw scores of the parents' report in pre- and post-test data collection.

We analyzed this scale on the basis of a percentage of the most-often and least-often behavior followed by parents (Table 4). Fifty percent (50%) of parents reported in the pre-test that talking softly to a child, singing a lullaby, and using a music tape or musical toy were their most-used bedtime behaviors. The three behaviors reported by parents in the pre-test as being used least were walks in pram or stroller (0%), standing near cot without picking infant up (16.67%), and settling infants on sofa with parent (16.67%). The follow up data collection shows a slight change in the bedtime behaviors and their percentages; the top three behaviors were use of music tape or musical toy (66.66%), talking softly to child (66.66%), and reading a story (50%). Walks in pram or stroller (33.33%), standing near cot without picking infant up (33.33%) and carrying child around house in arms (16.67%) were the least-reported bedtime behaviors according to the follow up data collection.

The baseline data analysis also suggested that parents did not perform the following bedtime behaviors: 66.67% of the parents said they never settle the child in the parents' bed, and 50% of the parents never leave their child to cry. The follow up data analysis suggested that, based on what can be determined from this small sample, there was not much change in the bedtime behavior of the parents apart from the increase in the use of musical tapes and toys and reading a story.

4.4.2 Child's Sleep Habits Questionnaire (Owens et al., 2000).

The Child Sleep Habit Questionnaire is a self-reported questionnaire containing 45 items about a child's sleep habits and possible difficulties with sleep in the previous week. If something happened five or more times in a week, parents were asked to answer "usually" (scored as 1); if something occurred 2-4 times in a week, parents answered "sometimes" (scored as 2); if something rarely or never occurred, they answered "rarely" (scored as 3). A total of six participants completed the pre-test and five participants completed the post-test.

Owens et al. (2000) eliminated some of the original 45 CSHQ items, considering them as redundant or ambiguous, and analysed only 35 items (Owens et al., 2000). The researcher used the original CSHQ questionnaire; however, in the analysis, only the 35 items recommended by Owen's et al (2000) were sorted into the eight subscales and analyzed. The CSHQ scale is divided into eight subscales: bedtime resistance (six items); sleep onset delay (1 item); sleep duration (3 items); sleep anxiety (3 items); night waking (3 items); parasomnias (7 items); sleep disordered breathing (3 items); and daytime sleepiness (8 items). Table 5 represents the raw score of the 35 items on the CSHQ scale sorted by subscale. The questionnaire items marked with an asterisk were reverse-scored, consistent with Owen's guidelines. Questionnaire items that were reverse scored included struggles at bedtime, afraid of sleep alone, child sleeps too little, child needs parent in the room to fall asleep, child has trouble sleeping away from the home, child awakes once during night, child awakes more than once during night, child wets the bed at night, child is restless and moves a lot, and child wakes up in a negative mood.

Table 5 presents the mean of each subscale and subscale questionnaire items for baseline and follow-up. A lower score indicates more positive behaviors. **Baseline** analysis showed that the mean value of participants for bedtime resistance ranged from 1.66 to2.33, with a mean of 1.91; as there was just one item in the sleep onset delay it ranged from 1-3 with a mean of 1.833. The mean value for sleep duration ranged from 1.33 to 2.33 with a mean of 2.05. Night waking's mean ranged from 1.66 to 2.66 with a mean of 2.27. Parasomnias had a mean range from 1.28 to 2.42 with a mean of 2.30. Sleep disordered breathing ranged from 1.33 to 3.0, and one participant indicted N/A instead of marking a frequency, so this had a mean of 2.16. The daytime sleepiness subscale ranged from 1.75 to 2.37 with a mean of 1.95.

Follow up data collection suggested that there was not much change in the scores of subscale items. Bedtime resistance had a mean range of 1.5 to 2.0 with a mean of 1.69; sleep onset delay ranged from 1-3 with a mean of 2.0; sleep duration ranged from 1.0 to 2.33 with a mean of 1.59; sleep anxiety ranged from 1.33 to 2.66 with a mean of 2.19; night waking ranged from 2.33 to 3.0 with a mean of 2.46; parasomnias ranged from 1.85 to 2.57 with a mean of 2.13; sleep disordered breathing ranged from 2.0 to 3.0 with mean of 2.6; and daytime sleepiness ranged from 1.75 to 2.37 with a mean of 2.02.

To look more closely for any changes in behavior, the mean value of each item was calculated and presented in table 5. The researcher numbered this table according to their sequence in the CSHQ scale, and the pre-test mean value of each habit was compared to the post-test mean value.

Table 6 shows some changes in the parents' habits in the post-test, although the change is negligible. There is a change in the mean values, especially in that the mean value of child sleeps the right amount changes from 2.33 to 1.6, which indicates a positive change. Also, there is a decrease in the mean score of positive habits, such as child goes to bed at the same time at night, child falls asleep alone in own bed, and child sleeps about the same amount each day, which suggests a change in sleep habits. The table shows the change in the negative behaviors as well; there is a decrease in the mean value of scores of such behaviors as child resists going to bed at bedtime, moves to other bed in night, is alarmed by scary dreams, others wake child, and child sleeps while riding in a car.

4.4.3 Parent Knowledge of Healthy Sleep Habits in Children (PKHSH) (Jones et al., 2013)

PKHSH results in the pre-test were divided under four sections, and in the post-test under two sections. The first section in the pretest is about the background information of each participant, which is explained in section 4.2 and Table 7. The second section is about the sleep habits of the

participant's child, the third section was about sleep heath beliefs and fourth section contained healthy sleep questions. The post-test contains two sections: sleep health beliefs and healthy sleep questions. Table 7 gives a comparative over view of the findings across participants. These are also detailed below.

Section 2: Sleep Habits

Participant 1 responded that 12 hours of sleep was the average amount a child of her child's age needed; 12-14 hours of sleep were required by her child; the child had regular sleep and wake up times for during the week and weekends; her child took no naps; there was no adult in the child's room; the child's bedtime was 7.30-8.30pm on both weekdays and weekends; and the child's wake up time was 7.30-9.30 am both on weekdays and weekends.

Participant 2 responded that 10-12 hours of sleep was the average amount a child of her child's age needed; her child needed 10-12 hours of sleep; her child had a regular wake up and bedtime for both weekdays and weekends; her child did not take any naps; there was never any adult in the child's bedroom at night; the child followed the same bedtime of 7.30-8.00 pm on both weekdays and weekends; and the child had a wake time of 6.30-7.30 am.

Participant 3 responded that an average of 10 hours of sleep is needed by her child's age group; her child needed 8-10 hours of sleep; her child followed a regular bedtime and wake up time on both weekdays and weekends; her child took naps for 1-2 hours each day; there was an adult in child's bedroom about once a week during the night; bedtime was usually 8.00 pm for both weekdays and weekends; and wake up time was usually between 7.30 am on weekdays and in between 7.30 and 9am on weekends.

Participant 4 responded that an average of 10 hours of sleep is needed by her child's age group; her child needed 8 hour of sleep; followed a regular bedtime and wake time on both weekdays and weekends; did not take any naps; a few nights a week there was an adult in child's bedroom during the night; the child usually went to sleep in between 10.30 and 11.30 pm on both

weekdays and weekends; and woke up in between 6.00 and 7.30 am on weekdays and 7.30 and 9.00 am on weekends.

Participant 5 responded that an average of 10-11 hours of sleep is needed by her child's age group; her child needed 11 hours of sleep; followed a regular bedtime and wake up time on both weekdays and weekends; did not take any naps; every night there was an adult in child's bedroom during the night; the child's usual bedtime was 7.45 pm for both weekdays and weekends;, and the child had a wake up time of 4.00-4.20 am on both weekdays and weekends

Participant 6 responded that an average of 10-12 hours of average sleep is needed by her child's age group; her child needed 11 hours of sleep; followed a regular bedtime on both weekdays and weekends (usually 6.00 pm); child did not take any naps; almost every night there was an adult in child's bedroom; and child did not follow a regular wake up time (between 4.00- 6.00 am for both weekdays and weekends).

Section 3: Sleep beliefs

Table 7 presents an analysis of parents' sleep beliefs performed on the basis of agree responses by parents in four questionnaire items; results shows that 50.83% (n=3) of participants agreed to the following statements: their child gets enough sleep; their child has healthy sleep habits; they plan to change their child sleep habits; and they would like to talk to their child's doctor about his/her sleep problems. However, post-test results suggest that now only 48% of parents agreed to these sleep health belief statements.

Section 4: Sleep knowledge questionnaire

Table 7 represents the results generated for the sleep knowledge questionnaire. There was no change in the percentage of agree responses by one participant; two participants agreed by 75% in

the pre-test but only 50% in the post-test; one participant did not agree to any sleep health belief facts in the pre-test but agreed by 25% in the post-test; and one participant agreed with the sleep beliefs by 80% in the pre-test but agreed by 90% in the post-test.

The analysis of the sleep knowledge questions was done on the basis of percentage of correct responses. In the pre-test, 83.33% of participants made correct responses and, in the post-test, 84% of the participants got the correct response. Only two participants showed an increase by 10% from pre-test to post-test; the percentage of correct responses remained same for remaining three participants.

4.4.4 Parental Sleep Environment Knowledge Questionnaire (PSEKQ: Appendix D)

The Parental Sleep Environment Knowledge Questionnaire was developed in-house and contains evidence-based sleep environment facts on temperature, light, bedding and sound. Parents were asked to select one of three possible explanations for why each of the 10 fact was true. This questionnaire contains four facts on light, two facts on bedding, two facts on sound, and two facts on temperature. All six participants completed the pre- and post-test for this questionnaire.

Analysis of this questionnaire was performed on the basis of percentage of correct responses; Table 7 shows the results from pre- and post-test analysis. Specific details by participants are as follows. Participant 1 made 80% of correct responses in the post-test in comparison to 70% in the pre-test; participant 2 scored 70% correct responses as compared to 50% in the pre-test; participant 3 made all correct responses in the follow up as compared to 80% in the pre-test; the 4th participant's correct response rate was 80% as compared to 60% in the pre-test; the 5th participant was the only participant who showed a decrease in correct responses from 80% to 70% in post-test; and participant 6 marked 70% correct responses as compared to the 60% in the pre-test. When the mean was calculated, 66.66% of participants marked the correct reasons for each facts in the pre-test and 78.33% in the post-test.

There were several trends identified across all participants' responses. For fact 1 and fact 5, only four participants were able to identify the correct reasoning in both pre- and post-tests.

None of the participants was able to select the correct explanation for fact 2, "children who sleep on their back and have beds with synthetic bedding are more likely to have problems breathing "at post-test and after reading the manual only 50% of the participants were able to select the correct explanation.

All the participants were able to select the correct explanation for facts 3, 6 and 9 correctly in both pre- and post-tests. Facts 4, 7, 8 and 10 showed a change in knowledge from 80-100%, 80-100%, 40-80%, and 60-100% respectively from pre- to post-test.

4.4.5 Actigraph and parent-recorded sleep diary (Appendix F & G)

A sleep actigraph 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. Table 9 shows the actigraph positions and results of all participants and the means of all outcomes. Six participants completed the pre-test and only five participants completed the post-test. Actigraphy participation was done by participant 4 in the pre-test but, due to the technical problems with the monitor a sleep report could not be generated. A sleep diary was used by parents in conjunction with the sleep actigraph and parents recorded the bedtime and awakening times that were entered into the actigraphy software analysis program to generate the sleep reports. Some parents reported they did not place the sleep actigraph on the child until they were asleep. Four of the participants placed the actigraph on the wrist position, while one participant placed it on the ankle and one placed it on the wrist for two days and then on ankle for five days in the pre-test. In the follow up data collection, four participants placed the actigraph on the wrist and one placed it on the ankle.

Table 9 shows the results generated from actigraphy in the six participants' children; the scores are calculated as a mean of seven nights of data collection. There is a continuing mean calculation for the pre- and post-tests as well.

The sleep latency report came out to be zero minutes in the pre-test for three participants, as they placed the actigraph after the child fell asleep; in the post-test only one child's report indicated zero latency. At follow-up parents were more diligent to place the actigraph on the child at the time they went to bed latency increased on average to 6.97 minutes in the post-test as compared to 1.71 minutes in the pre-test.

The sleep efficiency (ratio of total sleep time to total time spent in bed), shown in tables 7 and 9 calculated percentage ranges from 65.53% to 93.47% in the pre-test with a mean value of 85.91%. Follow up efficiency percentage ranged from 61.55% to 93.27% with a mean value of 78.47%. The decrease in sleep efficiency percentage may be due to several parents correctly placing the actigraph only in the follow up data collection period and/or that they also maintained one position for placement of the actigraph during follow-up. This will be discussed in depth in section 5.1.

Total time in bed calculated in minutes spent in bed ranged from 597.97 minutes to 685.71 minutes with a mean of 650.83 minutes in the pre-test. The follow up range was from 535.71

minutes to 722.86 minutes with a mean value of 642.57 minutes. There is not much change in the minute value of total time spent in bed in pre- and post-tests.

Total sleep time in baseline ranged from 455.0 minutes to 609.71 minutes with a mean of 559.22 minutes. The follow up range was from 337 minutes to 641.5 minutes with a mean of 508.01 minutes. Wake after sleep onset ranged from 41.75 to 227 minutes with a mean of 89.86 in the pre-test and ranged from 48.5 to 212 minutes with a mean of 127.59 minutes in the post-test.

Number of awakenings ranged from 13.43 to 28.43 with a mean value of 17.93 in the pre-test and ranged from 14.29 to 37 in the post-test with a mean value of 23.44. Average awakenings calculated in minutes ranged from 2.86 to 8.12 with a mean of 4.63 in the pre-test and 3.79 to 11.5 with a mean value of 6.02 in the post-test.

4.4.6 CBBES manual assessment checklist findings (Bedroom Environment Assessment Checklist)

The CBBES manual is the intervention tool used in the study, and it contained the bedroom environment assessment checklist (BEAC) (developed in-house for this study) and recommendations for a healthy sleep environment.

The researcher used the BEAC to assess the bedroom environment at baseline and at follow-up. Parents used the same BEAC checklist to assess their child's bedroom during the intervention period after they had access to the CBBES manual. Bedroom assessment was done for six participants in the baseline data collection and for five participants in the follow up data collection. Only five parent participants completed the checklist and recommendations suggested in the manual. However, one participant was not able to find the hardcopy of the manual at the time of the follow up home visit, but she remembered the recommendations that she followed from the manual. The bedroom environment assessment checklist performed by participant was not provided by participant 6, however rest of the information was used for analysis except for BEAC results performed by participant.

Table 10 presents the findings generated from the bedroom environment assessment in the CBBES manual. It includes the number of problems identified by the researcher at baseline and follow data collection; problems identified by parents using the same checklist; and recommendations suggested in the manual that were followed by parents. Table 10 also contains information on how many recommendations parents followed under each of the categories of temperature, light, sound and bedding.

The researcher's assessment of child participant 1 baseline bedroom assessment identified the following problems: sound level was 35 decibel; there were conversations in the house that occurred close to the bedroom while child was sleeping; temperature was 25 degrees Celsius; and the child's bed had polyester bedding. In the post-test, problems identified was sound at 38 decibels. Problems identified by parent participant 1 were that sound was 52 decibels (parent reported that music was on during sleep), conversations in the house that occurred close to the bedroom while the child was sleeping, and synthetic bedding.

The researcher's assessment of child participant 2 baseline bedroom assessment identified the following problems: sound level was 33-56 decibels; synthetic bedding was used; child shared a bedroom; child's roommate listened to music while falling asleep; and music turned off automatically after certain time. Follow up bedroom assessment generated the following results: sound level was at a 43-56 decibel level and the child shares a bedroom. Problems identified by parents were that child shared a bedroom and used synthetic bedding.

The researcher's assessment of child participant 3 baseline bedroom assessment identified the following problems: the light level was 40 lux; lights got through existing curtains; child liked to sleep with door open; light got through the space between the door and floor; decibel level was 43; conversations in the house occurred close to the child's bedroom when child was falling asleep; appliances made noise near child's bedroom when child fell asleep; and synthetic carpet was in the room. The follow up assessment results were that decibel level was 40 and synthetic bedding was used. Problems identified by parent were light getting through existing curtains; child liked to sleep

with the door open; light got through the space between door and the floor; child used electronic devices within one hour of bedtime; and synthetic bedding was used.

The researcher's assessment of child participant 4 baseline bedroom assessment identified the following problem: lux level was 32; light got through the existing curtains; child liked to sleep with the door open; child watched TV within one hour of bedtime; child slept with a night lamp which emits blue light; there was a printer in the child's bedroom; the sound level was 53 decibels; the child shared a bedroom; and the roommate snores. The follow up assessment resulted in the following: light got through the existing curtains and the sound level was 31 decibels. Problems identified by parents were that child liked to sleep with the door open; light got through the space between door and the floor; child slept with a night lamp that emits a blue light; child used electronic devices within one hour of bedtime; and there were conversations in the house near the child's bedroom when the child fell asleep.

Participant 5 only participated in the baseline data collection; she did not perform the checklist, and the researcher was not able to obtain data on post-testing as the participant dropped out of the study at that point. Problems identified by the researcher in the baseline were: child watched electronic devices within one hour of bedtime; there was a CD player in the child's room; the sound level was 41 decibels, and the bedroom is near a park.

The researcher's assessment of child participant 6 baseline bedroom assessment identified the following problems: bright light coming into the child's window; light coming through existing curtains; sound level was 40 decibels; child lived near a busy street; child shared a room and roommate went to bed later than the child; and TV made noise close to the bedroom while the child was sleeping. In the follow up, the sound level was 42 decibel, and the child's roommate slept later than the child. The parent was not able to find the CBBES manual assessment checklist at the time of the follow up home visit, so no information is available.

Problems identified by the researcher in the baseline range from 4 to 8 with a mean value of 6, and during the follow up problems identified by the researcher range from 1 to 3 with a mean of 2. Problems identified by parents range from 2 to 5 with a mean value of 3.5.

Recommendations followed by participants range from 2 to 12 with a mean value of 5.4. The most frequently followed recommendations were for light, which range from 2 to 5 with a mean value of 2.6. Suggestions followed by parents for bedding was next, with a range from 0 to 5 and a mean value of 2. Recommendations followed for sound range from 0 to 3 with a mean value of 1, and temperature suggestions were the least followed with a range from 0 to 2 and a mean value of 0.8.

Parents were able to identify most of the problems in their child's bedroom environment using the assessment checklist, and they followed the recommendations to solve those problems. The change in knowledge using the CBBES checklist and recommendations will be further discussed in the section 4.4.

4.5 Findings summary

As explained in section 3.2, the study is based on the theoretical framework of knowledge-to-action cycle and the last step of the cycle was evaluating the outcomes. The outcome from the study would be, if study results can answer the research questions stated in section 1.4.

As the number of participants in the study was very low, it is very difficult to generate any conclusions from the findings. However, there are certain noticeable changes that show promising effects about the knowledge translations.

The results generated from the PIBBS, the CSHQ, and the Parent Knowledge of Healthy Sleep did not show a marked difference in the scores of post-test from pre-test. However there were a few changes that support the findings from the parent sleep environment knowledge questionnaire, actigraphy, and CBBES manual. The Parent Sleep Environment Knowledge Questionnaire results in table 7 indicates the change in knowledge; the percentage of parents' reasoning for why the fact is true either increased in three facts or remained the same. The data in Table 7 show that knowledge translation occurred as evidenced by the change in correct responses from 66.66% at baseline to 78.33% at follow up. Table 10 also displays that knowledge translation contributed to action because of participating in the study. This was inferred on the basis of the total number of recommendations suggested in the manual (29) and the number implemented by participants. The rate of recommendation implementation ranged from 6.89% to 41.97% with a mean percentage of 18.62%. The CBBES manual suggested the importance of white noise, and recommended the importance of music for sleep, and the PIBBS table 4 shows that the percentage of use of a musical toy or music was increased from 50% in the pre-test to 66.67 % in the post-test. The subscale item "child sleeps right" in the CSHQ changed from 2.33 to 1.6, which most likely suggest the inference that parents followed the suggestions of CBBES manual.

The increase in the percentage correct responses in the Parent Sleep Environment Knowledge Questionnaire and recommendations followed by parents from the CBBES manual from pre- to post-test indicates change in the knowledge, and decrease in the sleep negative features in a child bedroom environment. This is further supported by the lower numbers of problems identified in childrens bedroom environment by researcher at follow up data collection.

As expected there were few changes in the score of PIBBS, CSHQ, and Parent Knowledge of Healthy Sleep Knowledge Questionnaire, but the study aim was not to make any changes in the sleep behavior area. However, there are some points that suggest some promising effects. In the

CSHQ subscale item, the mean for "awakes once during night" was 2.0, which is the "sometimes" score in the pre-test, and 2.8 during the post-test, which is the "rarely" score. The results from the actigraph suggest that the average number of awakenings was 17.93 in the pre-test and 23.44 in the post-test. This suggests that there may be a discrepancy between parents' perception for their child's sleep patterns and the actual sleep patterns of the child. Further discussion on the results and their future implications will be discussed in the next chapter.

Chapter 5: Discussion

The results of this study generated some key findings. This chapter begins with a discussion of the inferences derived from those findings, and describes the degree to which participants appear to have translated their knowledge into action. The chapter addresses the implications and significance of the study, and makes recommendations for future work as well.

There were too few participants to generate any strong conclusions about the efficacy of the Children's Best Bedroom Environment for Sleep manual (Intervention tool). However, the results were promising, and addressed the study's research questions, which were designed to determine whether providing parents of children with CP with a sleep environment education manual and problem solving strategies would: 1) increase parental knowledge; 2) decrease negative features of sleep in the child's bedtime environment measurably, and 3) improve children's sleep efficiency between baseline and follow-up.

5.1 Inferences from the findings

The results generated from the Parent Sleep Environment Knowledge Questionnaire (PSEKQ) (Appendix D) measurement tool appeared to indicate that there were changes in parents' knowledge. The decrease in the number of sleep environment problems identified from baseline to follow up after using the Bedroom Environment Assessment (BEAC) Checklist in the CBBES manual, and the number of recommendations to improve the sleep environment that the participants implemented suggested that they did translate their knowledge into action.

The results from the PSEKQ showed that parental knowledge about the components of the bedroom environment, including bedding, temperature, light, and sound, increased from 66.66%

at baseline to 78.33% correct identification of explanations for each fact at follow up. Table 7 contains the results of percentage of correct responses in PSEKQ and it shows that 83.33% of the participants scored a higher number of correct responses on follow up than at baseline; only one participant had a lower score on follow up. However, this may be a result of participant dropping out of the study on the follow up assessment day. This participant might not have read the manual, or been interested in filling out the PSEKQ, or might not have read the questions or options properly.

To assess the negative sleep features in the child's bedroom, both the parents and the researcher used the BEAC (Bedroom Environment Assessment Checklist) provided in the CBBES manual. The decrease in the number of problems recorded on the BEAC suggested that parents were more knowledgeable about the components of the bedroom environment after having the opportunity to read the CBBES manual. Section 4.4.6 in Chapter 4 elaborated on the sleep environment problems both the researcher and the parents independently identified while using the same checklist during baseline and follow up data collection. The decrease in the number of problems the researcher identified in the children's bedroom environments between pre and post-test indicates that the manual likely resulted in a parents taking action to improve the sleep environment such that there was a measurable decrease in negative sleep features in the bedroom environments. This supports the study assumptions that providing parents with information in the form of the CBBES education manual would increase their knowledge about healthy bedroom sleep environments and cause them to take action to decrease those negative factors.

The sleep actigraph reports did not support the third research question related to a measurable increase in the child's sleep efficiency; however, numerous factors potentially contributed to this outcome. Fidelity with the intervention was very problematic with this sample. First, during the pretest, parents placed the actigraph on *after* the child fell asleep, which resulted in a sleep latency of 0 minutes for 50% of the participants. During follow up data collection, parents reported that they placed the actigraph properly, and the latency was 0 minutes for only 20% of the participants. Actigraph battery issues resulted in no data during the pretest for one of the participants, which affected the mean value of the sleep parameters from baseline to follow up, as discussed in detail

in section 6.2. Not all of the children accepted the actigraph well, as some parents reported finding the actigraph lying on the bed in the morning and some parents changed location of the actigraph on the child's limbs such that test conditions varied across nights (for example placing the actigraph on the dominant wrist one night and then the ankle the next night). Parent's decision to choose the child comfort over the researcher's instruction affected the actigraphy results.

Another possible reason for poor sleep actigraph response could be sensory issues in children with cerebral palsy. For example 90% of children with CP are reported to have sensory dysfunction and the main sensory impairment is tactile (Pavao et al., 2015).

The position of the actigraph may have been another reason that the findings did not support the hypothesis. The researcher found that changes the participants made in the position of the actigraph altered the actigraph reports, although the data were too few to draw any firm conclusions, as only one participant changed the position from the wrist to ankle during baseline, and then again to the wrist during follow up data collection. The drastic increase in the number of awakenings of participant 6 when the position was changed from the ankle to the wrist shows the possible effect of actigraph position on results.

The scores on the Parental Interactive Bedtime Behavior Scale (PIBBS) (Morrell & Cortina-Borja, 2002) and Child Sleep Habit Questionnaire (CSHQ) (Owens et al., 2000) used to measure the children's sleep behaviors showed few changes between baseline and post-test.

The PIBBS and CSHQ were designed to capture a diverse range of parents' behaviors around their child's sleep and bedtime during baseline data collection and track changes in behavior over time at follow up. There were no significant changes in the pre and post-test scores for the PIBBS and CSHQ. This was not unexpected as the intervention provided no behavioural information and recommended changes. The goal of the study was not intended to change parents' bedtime behavior. The lack of change in the PIBBS and CSHQ scores seem to support that parents were not exposed to any other type of sleep intervention that would contaminate the study findings. This allows us to be more confident that the changes in the sleep environment, parental knowledge and

objective sleep data if there had been any, were a result of the CBBES intervention and not something else.

5.2 Knowledge to action

The theoretical framework for the study was the Knowledge to Action (KTA) Cycle. The KTA theory views research as a dynamic process of decisions and action used to translate knowledge into practice (Campbell, 2010). Campbell (2010) described the KTA cycle 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 (Campbell, 2010).

The KTA 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 a form accessible (the CBBES education manual) for the intended user- parents of children with CP.; the researcher also identified the problem and target population. The child's bedroom environment was the practice environment in which the acquired research knowledge was applied. Parents were the potential adopters of the knowledge and played an important role testing the intervention intended to facilitate practical application of the sleep evidence-base. In the following section the study outcomes are described in relation to the stages of the KTA cycle.

The CBBES manual (step 1: synthesis of evidence based knowledge) was designed to bridge the gap between existing research based knowledge and action. The baseline data gathered from the PSEKQ and the BEAC showed both gaps and existing strengths in parents' knowledge and actions related to the sleep environment. Knowing these gaps and strengths helps identify what knowledge areas are most important to target. Knowledge strengths and then key gaps are discussed in depth below.

The parents' existing strengths included awareness of the role of temperature. The PSEKQ fact "Using timers on fan and heaters and using programmable thermostats can change room temperature to help a child sleeping better. This is because:" had 80% correct responses in pretest and 100% correct responses in post-test. This was also supported by the BEAC results. There were no changes between the BEAC results gathered at baseline and those at follow up, suggesting that parents knew that temperature plays an important role in influencing good sleep. The house temperature for all of the participants ranged between 18-25^{0}C, and parents were able to adjust the bedroom temperature with fans, windows, and blankets. The baseline data suggested that knowledge was already present among the potential adopters (parents) in this setting and the same results obtained at follow up indicated that there was no gap between knowledge and action. The results from the PSEKQ and the BEAC did demonstrate a few gaps between baseline knowledge and the post intervention actions taken to address those gaps. The PSEKQ results indicated that the parents were already aware that sound levels higher than 30 decibels are not conducive to good sleep; however, the BEAC results showed that this knowledge was not translated into action. The researcher recorded sound levels higher than 30 decibels in the bedrooms of all of the children during baseline data collection, and at follow up, the sound level was still higher than 30 decibels for 83.33% of the participants.

It is possible that parents were unable to understand what 30 decibels actually sounds like, and might have needed more detailed guidelines to help them apply their knowledge, such as using a smart phone application to measure decibel levels or offering parents sound comparisons (e.g., 30 decibels is equivalent to whispering) in the CBBES manual and on the BEAC form. The baseline data suggested that the knowledge was present, but the follow up data indicated a gap in the knowledge and ability to apply that knowledge on the part of the potential adopters. However, the researcher cannot draw any firm conclusions about this gap, as it may have been caused by several factors. For example, if baseline data were collected in the evening, but follow up data were not collected at the same time due to the participants' schedules, differences between the researcher's assessment and the parents could occur.

The PSEKQ also indicated that parents already knew that melatonin plays a major role in the sleep cycle, and that light affects melatonin production. However, the researcher's lux meter scores in the BEAC were higher than 30 for two of the participants, and so it appeared that this knowledge was not translated into action. The post-test analysis indicated that the lux level was less than 30 for all of the participants, suggesting that parents implemented the CBBES suggestions to cover the windows, and to use towels to block the light that entered the room through gaps under the door. The change in the lux level scores from baseline to follow up suggested that the adopters took action to fill the gap in their knowledge. Further, the number of CBBES manual recommendations for reducing light exposure followed by parents seems to indicate they were able to apply their new knowledge in this area.

The KTA cycle is designed to implement evidence-based knowledge and then to evaluate how that knowledge is adopted (Campbell, 2010). The six-week period between providing the CBBES manual and follow up was the time allowed for the adopters (parents) to implement their new knowledge, and the comparison between baseline and follow up data was used to evaluate the degree and type of sleep environment knowledge adopted.

The summary of inferences discussed in section 5.1 and generated from the Bedroom Environment Assessment Checklist scores demonstrates that there was a decrease in the number of problems identified by the researcher in the BEAC between baseline and follow up (Table 10), and supports the conclusion that parents applied their new knowledge by acting on a number of recommendations in the CBBES manual (Table 10). These outcomes suggest that the KTA cycle (Graham et al., 2006) was a useful framework to guide implementing sleep environment interventions and promoting parental knowledge. This conclusion is also supported by the change in PSEKQ scores from baseline to follow up.

Although there were too few data to make strong conclusions about the effectiveness of the KTA cycle for this study, as defined in section 3.2, the activities used in this study for the implementation of knowledge showed promising effects related to all of the research questions except for improved sleep efficiency.

5.3 Implications of the study

This was a pilot study designed to test the efficacy of an intervention manual with the goals of increasing parental knowledge, decreasing negative sleep features in the child's sleep environment, and increasing child sleep efficiency. A literature search indicated that sleep problems are very prevalent among children with CP (Wayte et al., 2012) and that ongoing sleep medication is usually contraindicated. Thus, there is a need for evidence-based, non-pharmacological sleep interventions. The literature review also supported the fact that the environment has significant effects on sleep.

Campbell (2010) stated that knowledge must be relevant, appropriate, applicable, and reasonable for those whom the knowledge affects. Thus, this study was designed to increase parents' knowledge and problem solving skills by providing the intervention in the form of the CBBES psycho-education manual.

The CBBES manual incorporated the four key points Campbell described, which addressed non-pharmacological sleep intervention that focused on basic sleep physiology. This was relevant, appropriate, and applicable for parents, the potential adopters, whose children had sleep problems. The CBBES manual was designed to be accessible and relevant for these parents, to help them understand the importance of sleep and how it is affected by environmental factors. The manual appears to have generated active self-management by the participants, as the intervention provided them with tools to assess the problematic factors in their children's bedroom environment with the BEAC, and empowered them with a list of recommendations to overcome those problematic factors.

The parents of children with long-term illnesses are those primarily responsible for their care, as most of the treatment takes place in the home (Nightingale et al., 2015). In these circumstances, healthcare professionals must play the role of teachers. However, in their review article,

Nightingale et al. (2015) reported that healthcare professionals struggle when they lack standardised ways of assessing parents' needs, for example, if English is not their first language (Nightingale et al., 2015). There is little research on effective methods to teach parents (Nightingale et al., 2015, p.8), and 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 literature search did identify self-report questionnaires that could perhaps be used by parents to infer information about healthy sleep or sleep-related bedtime behaviors. However, the researcher found no questionnaires designed to gather information about parents' understanding of the reason why bedroom environmental components have an effect on healthy sleep. Therefore, the PSEKQ was developed and piloted prior to the study to assess the "why" aspect of knowledge. The PSEKQ is unique in that it is a KT tool in itself. Most assessments only ask participants to select the correct answer. While these tools might be a measure of existing knowledge, because people can guess or simply recall what they have heard but failed to understand, they do not necessarily accurately reflect knowledge. The PSEKQ on the other hand, gives parents a statement of fact, and then tests if they understand the scientific rationale for the fact. The premise for this design was that parents would benefit, at a minimum, from receiving the statements of fact, even if they were unaware of the underlying rationale. As such the PSEKQ acted as a basic KT tool for parents participating in the study. A further important feature of this study was that it enhanced participants problem solving skills and learning by providing them first with necessary information, then with the BEAC to assess problems in their child's bedroom, and finally, recommendations to follow to manage the problems identified.

The evidence-based intervention tool (CBBES manual), helps participants learn, and helps healthcare professionals asses (through the PSEKQ) if parents understand the "why" underlying recommendations. This feature is important, because if parents are unsure about the rationale for tasks required for their child's management, they may not perform those tasks or recognise the changes required for their implementation (Nightingale et al., 2015). This knowledge translation

approach, which helped participants learn why something was true, can increase their acceptance of important knowledge and its use for other KTA activities.

The literature search of bedroom sleep environment assessment tools revealed none. This study developed the BEAC, which assists parents in identifying the negative sleep features in their child's environment in an organized and easy manner. The tool assessed the sound, temperature, bedding, and light in the child's bedroom, and suggested ways in which parents could measure the intensities of light and sound.

There are barriers for parents of children with long time illness which hinder parents learning. High time demand for child care, dual role of child care and jobs, fatigue, competitive care giving needs (such as gastric-tube feeding), and reading ability are possible barriers. The CBBES manual targets these barriers; it is written in layperson language, easily accessed as a hard copy printout, and takes a limited amount of time to read being as brief as possible and including only key information. The checklist for assessment and recommendations makes them easy to understand and apply. Additionally there are case studies after every environmental component which can help parents to relate the information to themselves and their child.

Finally, a potential lack of teaching skills, time, and resources on the part of healthcare professionals are barriers in identifying and addressing parent's information needs (Nightingale et al., 2015). This study is important because it focused on parents' needs, and the KTA approach, which provides healthcare professionals with a tool to assess whether parents' have learned the reasons for the knowledge provided.

5.3.1 Aligning the study with occupational therapy (OT) theory

The challenge for an OT is to address the barriers that hinder an individual's ability to engage in an occupation. The environment is one element that affects the performance of an occupation directly. An OT's task is to consider the fit between the individual, his/her occupation and the environment. In their review article, Wong and Fisher (2015) described three models in which there is a clear environmental focus: the Canadian Model of Occupational Performance and Engagement (CMOP-E); the Model of Human Occupation (MOHO), and the Person-Environment-Occupation-Performance Model (PEOP).

The CMOP-E is the model that illustrates best the relevance of this study to OT. The focus of intervention in the CMOP-E is the person-environment-occupation fit, which leads to engagement in the performance of an occupation (Townsend & Polatajko, 2013). CMOP-E adopts a client-centered approach, in which clients are active participants and whole persons who are affected by, and adapt to, their environments. Because the literature review in section 2.1 shows clearly that sleep problems not only affect the child, but the entire family, the intervention in this study focused on educating parents in order to decrease the sleep negative features in their child's bedroom environments and increase the child's sleep efficiency. Further, the CMOP-E focuses on occupational engagement to fulfill the individual's need to engage in a meaningful occupation (Clarke, 2003). In this study, these components can be identified as the person (parents of children with CP), environment (child's bedroom environment), and occupation (sleep quality). Occupational performance is the step taken by the parents to fulfill the task, as the performance demands their active participation. Wong and Fisher (2015) stated that occupational performance is an active means of engagement—the dynamic interaction between person, occupation, and environment. This can be illustrated in the context of this study: the parents (Person) assessed their children's bedroom environments using the BEAC, implemented the recommendations to solve their problem (Occupation), and made changes to their child's bedroom environment (Environment) that resulted in a decrease in the sleep negative features in that environment (Occupational Performance: Townsend & Polatajko, 2013, p. 23).

The features of CMOP-E that make it a useful framework with which to understand the relevance of this study are its core concepts of enablement and environment. Enablement is a form of helping that promotes client empowerment (Wong & Fisher, 2015), and in this study, the intervention tool gave parents the sleep knowledge, and the bedroom environment assessment tool, both of which empowered them to identify and correct the problematic elements in their children's bedrooms.

The CMOP-E considers environment broadly and attempts to provide resources for client-centered practice (Townsend & Polatajko, 2013). The CMOP-E shows that each individual is embedded within an environment, and lives within a unique context that affords occupational possibilities (Townsend & Polatajko, 2013, p.23). The CMOP-E defines environment as that which lies outside of individuals, but that affects their actions within the environment, including cultural, physical, and social environments (Townsend & Polatajko, 2013; Wong & Fisher, 2015). This study addressed a physical environment, the child's bedroom, in which components such as bedding, temperature, sound, and light play important roles in sleep physiology. The BEAC complied with the feature of COMP-E that indicates that each individual lives within a unique environmental context, as this assessment checklist gives parents a broader ability to identify the sleep negative features in their child's bedroom environment. For example, in the section on light, the BEAC provides parents with various options that allow them to solve the problem according to their particular environment, for example, by identifying whether light enters their child's bedroom through curtains or gaps between the door and floor.

Townsend & Polatajko (2013), in their book, *Enabling Occupation II: Advancing an Occupational Therapy Vision for Health, Well-being, and Justice through Occupation***,** stated that "Occupational therapy's vision is to promote social justice by enabling people to participate as valued member[s] of society despite diverse or limited occupational performance, this is an enabling rather than a treatment type of therapy" (Townsend & Polatajko, 2013 p. 3). In this study, the parents were enabled by being provided with both scientific information and a pragmatic recommendation checklist that they could follow and practice to decrease the features in their child's bedroom that had negative effects on sleep. This enhanced control and decision-making promotes parents' active

involvement in health self-management, their ability to make sound health decisions, and to take informed actions within the context of their own lives, as opposed to having a course of action prescribed by a healthcare provider.

OTs play an important role in enabling clients' to engage in occupations, and an OT performs this task by identifying the gaps between the desired and actual occupational participation (Wong & Fisher, 2015). The therapeutic approach emphasized by the CMOP-E includes remediation, compensation, and teaching strategies (Wong & Fisher, 2015). This study provides parents with a self-guided learning strategy. They are able to read and learn about sleep physiology, assess their child's bedroom environment using the BEAC, and make the bedroom more conducive to sleep by implementing the relevant recommendations. This study is important, as it empowered parents and provided a foundation that allows the OT to focus on simple sleep physiology. The study also provided information about the effects on sleep of simple changes in the environment. In addition, the PSEKQ also provides OTs with a tool to measure whether or not participants learned the reasons that a particular factor affects sleep patterns.

Therefore, this study was important from an OT point of view, as most non-pharmacological interventions available for sleep problems focus on sleep behaviors and hygiene practices. As discussed above, environment is one of the areas relevant to OT practice, and this study provided OTs with assessment, intervention, and KTA tools relevant to improvements in the sleep environments of children with CP.

5.4 Significance of the findings

This study provides a base for researchers and OTs alike by identifying one method of translating knowledge about the importance of a healthy sleep environment, ways in which to assess parents' uptake of that environment, and a technique to empower parents to follow recommendations to decrease the negative sleep features in the bedroom environment. The purpose of the study was to test whether or not providing parents of children with CP with an education manual about the sleep environment would increase their knowledge of these environments, and the results show promise towards that goal.

Children with chronic and long-term illnesses require treatment at home, which is their parents' responsibility (Nightingale et al., 2015). Thus, this study empowers these parents with an evidence-based intervention tool, as well as a tool with which to assess the problem in the child bedroom environment.

This study was a preliminary step in building an effective suite of non-pharmacological interventions that will benefit parents by fulfilling their information needs, families by providing healthy sleep environments, and healthcare providers by providing a non-pharmacological intervention and client sleep knowledge assessment tool. The results presented here demonstrate a need for more rigorous research in the future designed to facilitate better assessment fidelity, in order to test further the CBBES intervention and assessment tools developed in the study.

5.5 Recommendations for future research

Future research should focus on obtaining larger sample sizes and should use quantitative methods. Ultimately a randomized, controlled trial to establish the efficacy of the CBBES manual is required. An RCT would help reduce bias (such as confounding bias), increase the reliability of the results generated, and allow researchers to use more rigorous statistical analyses to increase the reliability of the PSEKQ as an assessment tool, and the CBBES manual as an intervention tool. These RCTs should include control groups of children who exhibit normal development.

Qualitative research would be used for future research to explore parents feelings about the acceptability and usefulness of the manual with different age group, diagnosis, and in different cultural environment. Further, qualitative studies can be used to explore the relationship sleep and between values and beliefs related to individual children's bedroom environment component. Children as well as parents should be involved in developing these studies so as to be more inclusive and participatory.

This study targeted children between the ages of two and ten. Additional research to test this KTA strategy should include older children. Ultimately, to build resources for other children with different conditions, such as autism and other neurodevelopmental disorders, the CBBES manual should be revised and tested with these groups. Finally, a series of studies with different groups or one study with multiple diagnoses and one generic CBBES manual will help us gain a broader understanding of how to translate knowledge to facilitate parents to take action on the separate environmental components of sleep.

Additional data was collected on the CBBES manual outside of this study because of several unplanned opportunities that arose. These findings hold some relevance to this study and recommendations from supplemental data collected from India and Facebook groups, is discussed in Appendix J.

5.6 Conclusions

The findings showed some potential positive effects of the CBBES intervention. The slight increase in the PSEKQ scores from baseline to follow up suggested that parental knowledge increased. The study also demonstrated effects that were consistent with most of the research questions. However, due to the small sample size, it is very difficult to draw any strong conclusions or comment on the efficacy of the CBBES manual. The study is important as it aim to decrease the sleep negative feature in children with cerebral palsy bedroom environment. However, the study is novice in the field of sleep and occupational therapy.

Chapter 6: Challenges of, and reflections on, the study

The study findings showed some promising effects of the CBBES manual, and although it is not possible to draw strong conclusions from the results, this study paves the way for future research in the field of sleep and the environment. This chapter explains the limitations of the study, ethical considerations, and challenges during the recruitment and assent process. In addition, this chapter describes the changes made to the manual after additional feedback. The chapter ends with a brief summary of the study. Appendix K offers the researcher's reflections on what the researcher learned from the study, and how it helped the researcher understand what it means to be an effective researcher.

6.1 Limitations

There were some limitations in the study that future work can address. The Child Sleep Habit Questionnaire (CSHQ) (Owens et al., 2000) tool used in the study was a first-generation version with 48 items. However, after data collection the researcher became aware that there was a revised 35 item version. Consequently only the 35 items retained in the revised version were analysed. It is possible that parents experienced some unnecessary assessment fatigue and/or that this introduced a confounder into the study, and future work should use the latest version for both data collection and analysis.

The recruitment process was not very successful, possibly because of the lack of involvement of social networking sites in the initial recruitment strategy. Initially, the evidence base reviewed to plan the recruitment strategy lead the researcher to focus on community partner involvement and there was no plan to use such sites in recruitment. A variety of factors may have limited how successful recruiting through community partners was so a second recruitment was carried out through social media. This too proved of limited value. We can only speculate at this point as to

why this occurred. The sample size was too small to draw any strong conclusions (n=6), and one participant withdrew. Thus, replications with larger sample populations are needed.

As explained in section 3.8, the study collected data using different measurement tools. In section three of the Parent Knowledge of Healthy Sleep in Children (Owens & Jones, 2011), parents had to indicate whether they agreed or disagreed with the fact that their child had an appropriate sleep habit. Possibly due to research bias in the study, the majority of the participants responded in the post-test that they agreed with the fact that their child did not sleep properly.

The researcher used a published sleep diary but did not pilot test the sleep diary used in the initial phase with parents prior to the study. Parents found the diary difficult and as a result, another sleep diary was constructed based on the parents' feedback and was used from participant 5's pretest data collection onwards.

The CBBES manual was reviewed by pediatric researchers prior to use, however, it was not piloted with parents and we received little feedback from the parent participants at the end of the study. Feedback on the CBBES was received from Sue McCabe, senior Occupational Therapist, Australia at the mid-point of the study and this will be included in the final, post study, version of the manual.

6.2 Ethical challenges

Ethical issues in studies of children are complex, because they are unable to take responsibility for their own decisions, and therefore, must rely on a third party (Attard-Montalto, 2002).

The book, *Ethical Issues in Community-Based Research with Children and Youth* (Leadbeater, 2006) stated various ethical issues that a researcher will face. First, accountability—in this study, the researcher considered accountability before the research commenced, as all of the parents' questions related to the study and data collection measures were explained in the first

home visit. Second, protection of the child's best interests—the study involved children with CP, and due to their disability, they have greater sleep problems, which makes them a vulnerable population. Although the primary goal of the study was to provide parents with knowledge, its ultimate goal was to enhance the child's sleep efficiency, and decrease the negative sleep features in the child's bedroom environment. Third, informing the child—the assent process in the study was challenging, and is explained further in section 6.1.3. Fifth, equity and non-discrimination—these were maintained throughout the recruitment and data collection process, as each of the participants was given the same information and intervention tool. Sixth, respect of children and their views—because the population in the study was children with CP who could not communicate verbally, parents made the decisions; although the child was involved in the study only during the actigraph data collection, an assent process was performed. Finally, ownership of data was addressed by mailing a copy of the pre and post-test actigraph reports to each participant (Leadbeater, 2006).

6.2.1 Challenges during recruitment

Over enthusiasm about a research project can sometimes lead to ethical issues of participants potentially feeling pressured to participate. In this study, enthusiasm on the part of one of the community partners during the recruitment process could have violated the principle of the participants' autonomy, because it would have possibly taken advantage of the relationship between the collaborator and the participant in the process of obtaining consent.

6.2.2 Challenges during the assent process

Assent (Appendix B) is the term used frequently with respect to consent from minors, who are not permitted legally to enter into an agreement. Assent is a moral requirement to attain the closest estimate of consent within the child's capacity to understand (Helseth, 2004). The purpose of assent is to achieve the child's maximum involvement in the research. The difference between assent and consent is that assent is not a legal process, but refers simply to the child's affirmation of participation (Lambert & Glacken, 2011). Thus, it is a process in which the child freely expresses a preference to participate in research (Helseth, 2004). Some of the questions that described the design of the assent letter that was used in this study were as follows: Why does the researcher want to talk with the participant? Why is the participant being asked to take part in this study? What is the role of the participant? What does the sleep monitor (actigraph) look like? What are the good and bad things about this study? And, What if they (participants) have any questions?

When working with children with disabilities, the assent process requires additional time and patience, especially when children had to use augmentative communication devices (Phelan & Kinsella, 2013). These authors described that it was helpful to read the assent form with the child, or when feasible, to have the child read and answer the questions, after which the researcher reads their answers back to them.

The research participants in this study were parents of children with CP and the children themselves, who have cognitive impairments that affect their ability to comprehend and make decisions. Having an assent form for such population is necessary but require creativity for the process; the challenge was to explain the assent process to this population. Because they had limited ability to comprehend and make decisions, the researcher tried to make it comprehensible for the children. The actigraph was shown to the children and they were allowed to feel it. Thereafter, the researcher strapped the actigraph on the child's wrist to see if s/he accepted it. The decision was made based on the children's facial expressions, the meaning of which was confirmed by the parents.

6.2.3 The challenge of sleep actigraph and placement

The researcher used actigraphy in this study, as the literature suggests that this is the method is evidence-based, used most widely and accepted most easily (Wiggs et al., 2005). However, the researcher found that actigraphy might not be an efficient method for children who have CP, as they did not accept it well, despite their introduction to it prior to data collection. Strategies to increase adherence to actigraphy need to be tested.

6.3 Feedback and changes made in the CBBES manual

The CBBES study manual, the intervention tool used in this study, showed promising results in creating a bridge between knowledge and action. However, at present, no strong conclusions can be drawn regarding its efficacy.

Based on the results of the study, as well as expert feedback, seven items in the manual were added and/or clarified that were absent or ambiguous before:

- In the Parent Sleep Environment Knowledge Questionnaire, there were no correct responses in the pretest, and only 50% correct responses in the post-test to factual question number 2, "Children who sleep on their backs and have beds with synthetic bedding are more likely to have problems breathing. This is because:" The correct answer should be "In this position the bedding is closer to the child's nose and mouth when they breathe" The reason for this outcome might be that the information provided in the bedding section of the manual was ambiguous and/or insufficient, this requires further study and revision.
- The information provided on the science of sleep and the sleep cycle section, as well as that in the section on light, emphasized that children require exposure to natural daylight. The information was not directly stated in the light section of CBBES manual. The information on importance of daylight exposure for child was added to this section.
- Information on body positioning at the time of sleep, the effects of positioning and temperature, and information about bedding, mattresses, and bed frames also were added to the manual.

Based on feedback from Australian occupational therapist Susan McCabe, the following points were added to the Bedroom Environment Assessment Checklist, and the recommendation section in the CBBES manual:

- Squeaking sounds made by the child's bed and information about mattresses.
- The term "black out blinds" was introduced in the section on lighting changes.
- Using Velcro straps for the blinds to block the light that came in at night was suggested, as the straps also helped parents allow sunlight in the bedroom during the day.
- Resources for bedding were missing before, and were added to the edited version of the manual.

6.4 Brief summary of the study

This pilot study examined if providing the CBBES education manual to parents of children with CP was an effective KTA intervention to increase sleep environment knowledge, decrease negative sleep features in the environment, and increase the children's sleep efficiency. The KTA cycle (Graham et al., 2006) provided the theoretical framework of the study, as the study's goal was to translate knowledge to action.

The tools used to measure the parents sleep habits were the PIBBS, CSHQ, and PKHSHQ. The PSEKQ was used to determine whether the parents understood "why" an environmental factor was important for sleep, and also whether the CBBES manual was successful in providing the information to parents. The sleep actigraph was used to measure the sleep parameters of the children. The recruitment process was conducted with the help of community partners, but the study obtained a low recruitment rate and only five participants completed the study. Data analysis was performed using descriptive analyses and pre and post-test data were compared so that each child generated results. The results gathered from the measurement tools showed some positive trends with respect to the research question pertaining to the efficacy of the CBBES manual, and showed slight changes in the parent's knowledge (66.66% to 78.33% between baseline and follow up). However, the sample size was too small to generate any strong conclusions.

Although the study had several limitations, and did not provide strong conclusions, it did offer some pioneering information in the area of non-pharmacological interventions for sleep problems. The study introduced the BEAC, CBBES intervention tool, and PSEKQ, and recommends that future studies maintain a focus on environmental interventions for sleep problems.

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Appendices

Appendix A: Letter of Information

Providing the best sleep environment for children with cerebral palsy
Parent information letter and invitation to participate in the study

Dear parents,

This letter is to invite you to participate in a study to learn if simple changes to your child's bedroom environment will lead to a better night's sleep. The Cerebral Palsy Association in Alberta is partnering with us in this study and they placed the mailing label on the envelop to protect your confidentiality.

My name is Risha Dutt, and I am doing this study for my Masters of Science in Rehabilitation Medicine at the University of Alberta. I am an occupational therapist by background and worked for several years with children who have cerebral palsy. Dr. Cary Brown, Associate professor,

Department of Occupational

Therapy, University of Alberta, is my supervisor, and I am doing this study under her guidance. I would like to invite you to participate in the study that is described below. This letter will also tell you how the study can benefit you, your child and other children with cerebral palsy.

Why are we doing a study about sleep?

Sleep is important for children's function, learning and development. Unfortunately, because of pain and other factors, sleep problems are very common in children with cerebral palsy. Research tells us that many healthcare providers and parents currently know little about the effect of poor sleep on children. Also, very few parents and healthcare providers are aware of how much influence the environment (for example light, temperature, bedding) has on a child's sleep. Our study is to help find effective ways to get parents the information they need. When you have the right information you can then help your child have better sleep. When your child sleeps better, he or she will be more healthy, active and able to learn.

Purpose:

We are going to provide all parents who take part in the study with a sleep manual called "***The Children's Best Bedroom Environment for Sleep: Parents' Manual"*** (or ***"the CBBES***" for short). This study will test if the CBBES manual is useful to help you and other parents understand how the environment can affect children's sleep. The CBBES will also explain how to check that your child's bedroom environment promotes good sleep. At the end of the CBBES there will be information about simple, research tested, and ways to change the environment and improve sleep.

What are we asking you to do?

Your involvement

- Once you have agreed to participate in the study we will set up a time with you when the researcher can visit you at home.
- When the researcher comes to your home she will:
    - Ask you to fill out three different surveys about your sleep knowledge and what typically happens at your child's bedtime,
    - Assess your child's sleep environment,
    - Demonstrate the use and care of the sleep recording monitor we will ask children to wear so we can see if their sleep improves during the study. The monitor looks like a wristwatch and causes no pain or discomfort. We will ask you to put the monitor on your child's arm every night for 5 nights before they go to sleep. For these 5 nights you will also need to record the bedtime and getting up time of your child in a sleep diary. With this information we can do an analysis of your child's sleep. After five (5) days the researcher will return to pick up the sleep monitor and sleep diary, give you the CBBES manual and explain how to use the manual.
- After reading that CBBES manual you can make as many or as few of the research based suggestions for changing your child's sleep environment as you like. We will give you a record sheet to write down the changes you make.
- Three (3) weeks after you get the manual, we will contact you to set up a time for the researcher to come back to your home. At that visit she will give you surveys similar to the ones you did at the start of the study. She will also reassess your child's bedroom. The researcher will also give you the sleep monitor for your child to wear for five more nights, a new copy of the sleep logbook, and a pre-paid, addressed, envelope to return the sleep monitor and sleep diary to us.
- Each of the three visits will be no longer than one hour.
- At the end of the study we will send you a copy of your child's sleep analysis and an invitation to a presentation for the public that explains more about children's sleep.

The event will be public and no one will be identified as having participated in the study. You are welcome to bring friends and other family members as well to this event.

Your child's involvement

- We will ask your child to wear a sleep monitor (about the size of a wristwatch) for 5 nights at the beginning of the study and then again three (3) weeks later for five (5) nights. The sleep monitor is quiet, not painful and causes no discomfort. Even if your child chooses not to participate in wearing the sleep monitor you are still able to participate in the other parts of the study.

Benefits and risk:

We anticipate there are no risks associated with this research for you or your child. If for any reason, the study becomes distressing to you or your child you can stop your involvement right away. As a direct benefit of the study, you will learn more about sleep and about how to change the bedroom environment to help your child sleep better. Additionally, you will receive a copy of the CBBES manual to keep and copies of your child's sleep analysis based on the data collected by the sleep monitor. This study will also benefit other parents and children as we develop and test sleep resources that meet their needs.

Confidentiality and security:

Your identity and results will only be known to the researchers and not shared with any organizations. Data collected are kept confidential in a locked file cabinet and in the researcher's password protected computers. You are free to withdraw from the study anytime

and we will not contact you again. We will not be able to return your data if you withdraw but it will only be reported in a manner so that no one will know who you and your child are.

Contact information:

If you need any further information on study procedure please contact Risha Dutt at 780-492-9545 or email her at rdutt@ualberta.ca.

Alternatively, you can contact her supervisor Dr Cary Brown at (780) 492-9545.

If you need any information about the researcher and governance of the study, you can contact

Dr. Tammy Hopper, Associate Dean, Graduate Studies and Research, Faculty of Rehabilitation

Medicine, University of Alberta, telephone number: 780-492-0836, tammy.hopper@ualberta.ca

How to volunteer: After reading this letter, if you agree to participate in the study please complete and sign the enclosed consent letter and send it to Risha Dutt by fax (780-492-4628), as a PDF attachment to an email (rdutt@ualberta.ca), or by post in the enclosed, stamped, self- addressed, envelope.

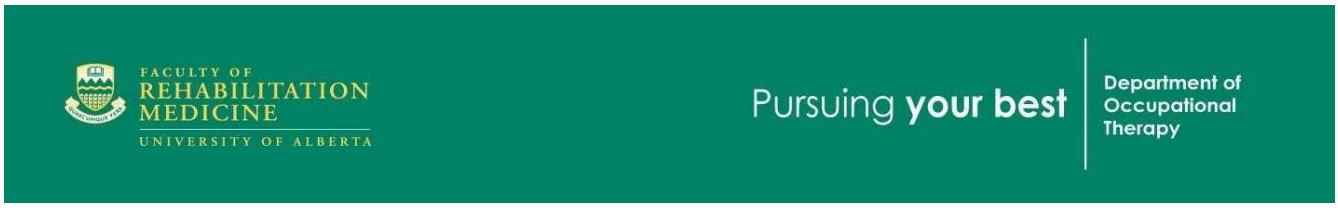
Thank you

– Your participation matters and we appreciate your time and interest.

Sincerely

Risha Dutt, BOT, MSc Rehabilitation Medicine student
2-64 Corbett Hall, University of Alberta
Edmonton, Alberta
T6G 2G4

Appendix B: Letter of Consent



Letter of Consent

Title of study

Providing the best sleep environment for children with cerebral palsy

Dr Cary A Brown, FHEA, PhD, Associate Professor, Department of Occupational Therapy, Faculty of Rehabilitation Medicine**,** University of Alberta, 2-64 Corbett Edmonton, Alberta, Canada, T6G 2G4.

Risha Dutt, MSc Rehabilitation Medicine student, Faculty of Rehabilitation Medicine, University of Alberta, 1-45 Corbett Edmonton, Alberta, Canada, T6G 2G4.

Research participant to complete	**Yes**	**No**
I understand and agree to participate in the "*Providing the best sleep environment for children with cerebral palsy*" study.		
I had the opportunity to have the study explained to me verbally.		
I understand that participating is voluntary and that I, or my child, can choose to leave the study at any time.		
I understand that participating will not affect my child's healthcare in any way.		
I understand that the sleep monitor device used will not harm my child in any way.		
I understand that I must tell the researchers if my child's health changes in any way from now to when the study period is complete		

I understand that no information identifying my child or myself will be released or printed without my consent.		
I understand the benefits and risk of this study		
I understand that the researchers will also seek your child's assent to be involved in one part of the study as outlined in the letter. The researcher will explain this process to you on the phone or when you meet. I understand my child does not need to take part in the study although I chose to participate.		

I have read and understood the above information. All of my questions have been answered and I understand that I can ask more questions at any time by contacting the researcher Risha Dutt by email at: rdutt@ualberta.ca Phone: (780) 492-9545)

_____ _____

(Print name of parent participating in study)

_____ _____

(Signature of parent participating in study) (Date)

_____ _____

(Signature of witness) (Date)

_____ _____

(Signature of researcher) (Date)

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Please send the completed, signed consent letter to Risha Dutt by fax (780-492-4628), as a PDF attachment by email (rdutt@ualberta.ca), or by post in the stamped, self-addressed, envelope enclosed in this pack.

When we receive your consent form, we will phone you to explain more about the study and set up a time to meet.

Appendix C: Letter of Assent

Assent Form

Determination of capacity to consent/assent guide

Risha Dutt will use the process outlined below to determine assent for incapable children. Consent for these children will be sought from their parents/guardian. An information letter will be provided to their parents about the study and a separate consent form will be requested of parents for their participation in the parent specific part of the study. The parent-specific part of the study can proceed independently of the child.

The assent guide will be used to give study information and to seek verbal assent/dissent from children who are incapable of giving written assent.

Risha Dutt (RD) has a working experience as an occupational therapist in pediatric practice in India.

Process

- RD will review the information letter and study details in conversation with both the child and parent.
- Through this conversation, RD will determine the child's capacity. Questions to help assess capacity may include:
    - What is this study is about? o Who can be a part of this study? o What will you do in the study? o What if you start and decide you do not want to do it

anymore? o Will I use your name when I write a report? o Do you have to do this?

- Will taking part hurt you in any way?
- Who can tell you more if you have questions?

Title of the research study:

Providing the best sleep environments for children with cerebral palsy.

Investigators:

Risha Dutt, MSc Rehabilitation Medicine student, Faculty of Rehabilitation Medicine, University of Alberta, 1-45 Corbett Edmonton, Alberta, Canada, T6G 2G4.

Dr Cary A Brown, FHEA, PhD, Associate Professor, Department of Occupational Therapy, Faculty of Rehabilitation Medicine**,** University of Alberta, 2-64 Corbett Edmonton, Alberta, Canada, T6G 2G4. **Why do I want to talk with you?**

My name is Risha Dutt. I am a researcher at University of Alberta and this is an invitation for you to participate in my study.

Why are you being asked to take part in this study?

This study is a part of a research project in which we are giving information to your parents about the role of environmental factors (such as temperature, light, sound and bedding) on their child sleep. Risha is the working on this project working under the guidance of Dr. Cary Brown.

What is your role?

We will ask you to wear a sleep monitor on your wrist, for five nights at the beginning of the study and then again for five nights after three weeks.

How does sleep monitor look like?

The sleep monitor is about the size of a wristwatch, is quiet, not painful and will not cause any discomfort to you.

What are the good things about this study?

We expect that this study will help you in sleeping better. We will be giving some practical tips about sleep and environmental factors to your parents.

What are the bad things about this study?

We do not think there are any bad things associated with this study. You can stop wearing the sleep monitor whenever you want.

Do you have to be in the study?

You do not have to be in the study. If you do not want to be in the study, you just have to tell us. It is up to you.

What if you have any questions?

You can ask any questions that you want. If you have a question later that you did not think of now, you can call us or have your parents call (780-492-0836)

Please check your answer:

☐ Yes, I want to take part in the study

☐ No, I don't want to take part in the study

_____

Print name of Child

_____ _____ _____

Signature of Child Age Date

_____ _____ _____

Person obtaining Assent Signature Date

I have discussed this research study with _____ using simple language, which is understandable and appropriate for the participant. I believe that I have fully informed him/her of the nature of the study and its possible risks and benefits. I believe the participant understood this explanation and assent to participate in this study.

_____ _____

Signature of Person Obtaining Assent Date

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 4922615.

Appendix D: Parent Sleep Environment Knowledge Questionnaire (PSEKQ)

SLEEP ENVIRONMENT QUESTIONNAIRE (SEQ) **Pre or Post Manual Date** _____

Participant code: _____

This questionnaire will help us learn what parents know about sleep. Each of the following statements is true and based on research. Your answers before and after you receive the CBBES manual will help us learn if the manual is a useful source of information for parent. (Correct responses are shaded in yellow).

There are a number of research-based actions parents can take to improve a child's sleep setting. This questionnaire will tell us if parents have enough information about why these actions work or if we need to provide more details. Instructions: Please circle the number of the answer that you think best explains the reason for each of the following facts.

1. **Fact:** With exposure to natural light during the day children sleep better at night. This is because:

   a. Daylight motivates children to be active in daytime and not watch TV.

   b. Daylight stimulates children's production of the hormone melatonin.

   c. Daylight decreases the physical need to sleep or nap in the daytime**.**

2. Fact: Children who sleep on their back and have beds with synthetic bedding are more likely to have problems breathing. This is because:

a. Synthetic bedding is more likely to collect allergens from the environment.

b. More body heat will be trapped and sweating interferes with breathing.

c. In this position the bedding is closer to the child's nose and mouth when they breathe.

3**. Fact**: 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:

a. Decreases a child's sensitivity to sound that would wake him/her up.

b. Increases a child's ability to filter out light that would wake him/her up.

c. Increases a child's ability to enter and move through all stages of sleep.

4. Fact: Using timers on fan and heaters and using programmable thermostats can change room temperature to help a child sleeping better. This is because:

1. Room temperature can be adjusted according to the outside temperature and season.

2. Room temperature needs to be cool to go to sleep and then warmer to wake up.

3. Room temperature can allow children to wear fewer constricting layers of night clothes.

5. **Fact**: 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:

a. White and blue light decrease melatonin production and delay falling asleep.

b. Red light is softer, with no glare, so children are not frightened if they wake up.

c. White and blue light imitate daytime and the child may then want to get up.

6. **Fact**: 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:

a. Noise in the bedroom and rest of the house lead to nightmares that break the sleep cycle.

b. Each stage of sleep is for different physical, emotional and cognitive functions in the body.

c. Children have not yet learned how to move from one sleep stage to another the way adults do.

7. Fact: 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 distractive noises that increase heart-rate.

8. Fact: 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:

a. Bright electronic light stimulates children to be more active so they do not realize it is bedtime.

b. Bright electronic light causes eye strain that prevents children from sleeping comfortably.

c. Bright electronic light keeps the body from producing the melatonin hormone needed for sleep.

9. Fact: For the best sleep children's bedrooms should be slightly cooler at night than during the day. This is because:

1. Children produce sleep hormones when their core body temperature is slightly cooler.

2. Children are less tempted to get out of bed and play when the room is cooler.

3. Children sleep better when they are wearing warm flannel pajamas in a cool room.

10. Fact: 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:

a. Loosely woven fabrics are more likely to harbor dust mites and other allergens that interfere with breathing.

b. It is easier for bacteria and germs that can cause infections to grow on stretchy bed sheets and blankets.

c. Frequent washing removes dyes and other manufacturing chemicals that prevent deep sleep.

Appendix E: Background Information Form

Participant code

Date

Background information form

Child Information	Parent Information
➢ Name: ➢ Date of birth ➢ Place of sleep ➢ Time of sleep On weekdays On weekends ➢ Sleeps with ➢ While sleeping the door is open or closed?	➢ Name: ➢ Date of birth ➢ Highest Level of Education 1-High school 2-Undergraduate 3-Graduate ➢ Employment

Describe the bedtime routine of your child

Appendix F: Sleep Log Version 1

Sleep Diary

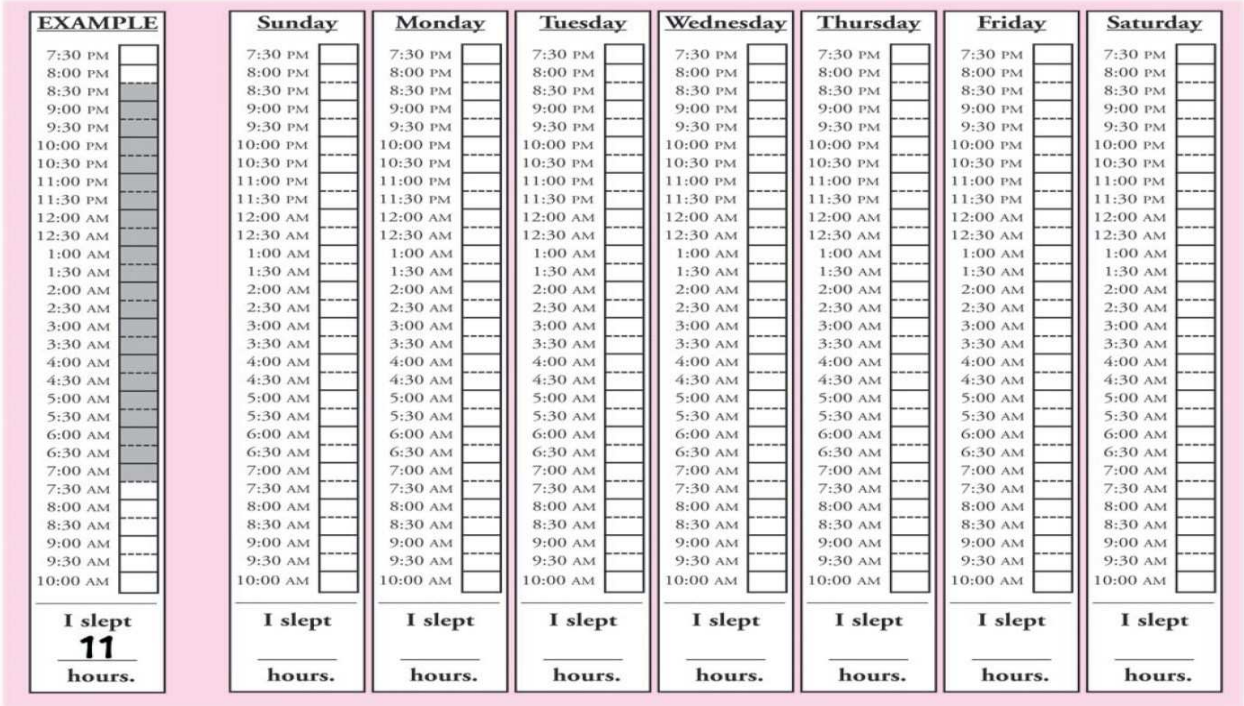
The sleep diary is used to record your child sleep and waking time. It is to be filled by you, the parents.

Height of your child: Weight of your child:

Gender of your child: Dominant arm of your child:

Arm in which your child wearing actigraph: Date of Data Collection:

Color in the boxes from the time you fell asleep last night until the time you woke up this morning. Count the number of boxes you colored in to figure out how many hours you slept. Write the number of hours you slept below each day.



Appendix G: Sleep Log Version 2

The sleep diary is used to record your child sleep and waking time. It is to be filled by you, the parents.

Height of your child: Weight of your child:

Gender of your child: Dominant arm of your child:

Arm on which your child is wearing actigraph: Start date of data collection:

How much sleep did your child get last night?

Fill in the boxes from the time your child fell asleep last night until the time your child woke up this morning.

	1: Last Night Your Child Went To Bed At:	**2: This Morning Your Child Woke Up At:**	**Comments:**
Example: Day 1 Date June 12 2013_	8.30 PM	7.30 AM	
Day 1 Of Data Collection Date_____			
Day 2 Of Data Collection Date_____			
Day 3 Of Data Collection Date_____			
Day 4 Of Data Collection Date_____			
Day 5Of Data Collection Date_____			
Day 6 Of Data Collection Date_____			
Day 7 Of Data Collection Date_____			

Appendix H: Flyer

Does your child have cerebral palsy and difficulty falling asleep?

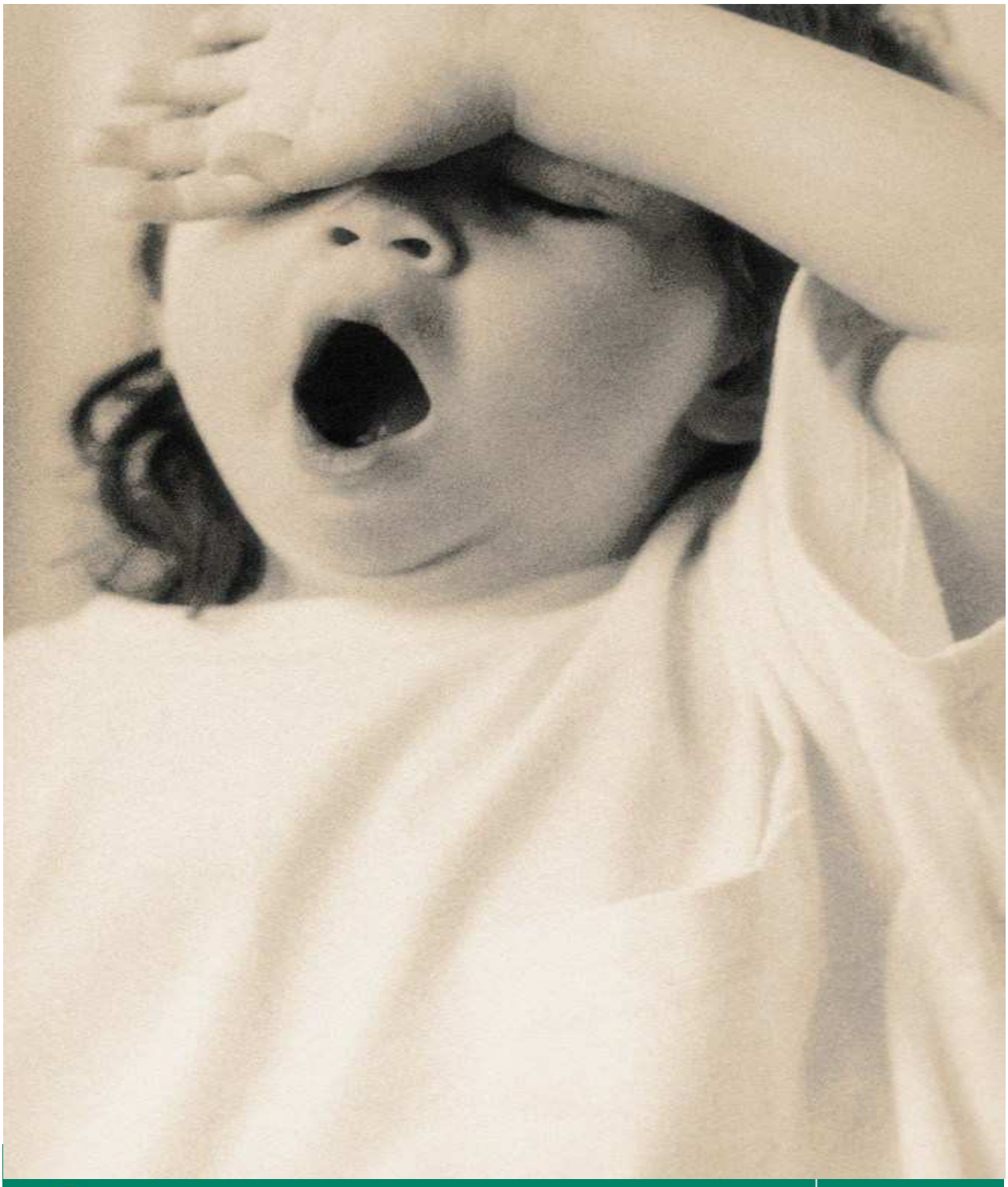
Then this might be of interest to you.

We would like to let you know about an upcoming **research project** "Providing the Best Sleep Environment for Children with Cerebral Palsy". Dr Cary Brown and Risha Dutt from Department of Occupational Therapy, University of Alberta, will soon be recruiting parents of children between the ages of 2-10 years old who have cerebral palsy for a research study.

The study is to test the usefulness of the *Children's Best Bedroom Environment for Sleep (CBBES) Manual for Parents*. The manual is intended to help parents learn about the effect of environmental factors on sleep and how to change their child's bedroom environment to promote better sleep.

Invitation packages to participate in the study will soon be mailed out to parents of children with cerebral palsy. Please watch your mailbox for this. If you would like more information, please contact Risha Dutt (rdutt@ualberta.ca)

Appendix I: CBBES Manual



FACULTY OF REHABILITATION MEDICINE
UNIVERSITY OF ALBERTA

Pursuing **your best**

Department of Occupational Therapy

Dear Parents:
Welcome to the **Children's Best Bedroom Environment for Sleep (CBBES)** manual. If you are concerned about your child's sleep- you are not alone. Every day we hear more and more about how much sleep matters for children. But it can be quite a challenge to find out how sleep works and what you can do to help your child get a quality sleep. That's what the **CBBES manual** is all about- helping you understand sleep so you can make good decisions based on the best research available.

The **CBBES manual** was developed by researchers in the Department of Occupational Therapy, Faculty of Rehabilitation Medicine at the University of Alberta. We designed it for busy parents like you, who are concerned about their child's ability to get the best quality of sleep possible.

The amount of information available can be overwhelming, and it is difficult to know what is reliable and based on facts, not fads. We understand that this makes it difficult for you and other parents to find the information that will help guide you in making your decisions. Our role as researchers is to make information, based on the best scientific evidence possible, available so you can make informed choices about your child's sleep

This manual has two goals:

1. To help you understand the science of children's sleep, and
2. To provide you with research-tested ways to change your child's bedroom environment so he or she gets the best sleep possible.

How to use the CBBES manual
It is best to start at the beginning and read through the whole CBBES manual. That way you will understand the sleep science supporting the recommendations in this manual. Once you understand the sleep science you will be able to select recommendations that best fit your child and family. Not all of the recommendations will work for every child so don't feel discouraged if you need to be creative- after all, being creative is what parents do best!

This workbook has used the best scientific evidence available regarding the sleep environment. Key references are included on page 24. For more information about behavioral interventions and other aspects of sleep you can visit as the SleepRight website at http://www/Sleepright.ulberta.ca.

Prepared by:
Cary Brown, PhD Professor, Amelia K. Rajala, MScOT student, and Risha Dutt, BOT, MSc Rehab Med student, Department of Occupational Therapy, University of Alberta. May 2014. We would like to acknowledge the significant contribution of all the parents and healthcare providers who gave us feedback and, particularly, the input of Sue McCabe, B.App.Sc (OT), M.Sc. (OT), Perth, Western Australia.

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Part 1

Sleep Science Basics

Introduction

To better understand '**what'** you can do to help your child sleep, you need to first understand '**how**' sleep works and '**why**' children might be having problems. All of the following information is from recent research. The numbers at the end of a sentence tell you what specific scientific publication the information in the **CBBES manual** is based on. A list of all these references is on page 24.

Children's sleep problems

As many as three of every ten young children experience sleep problems [1, 2].

- Sleep problems can include: not getting enough sleep, poor sleep quality, restlessness and frequent waking up during the night. Some children resist going to bed. Some children have other health conditions that interfere with their sleep. Examples of these would be asthma, pain, and sensory problems such as being hypersensitive to certain textures or sounds. Sometimes medications can interfere with sleep [2].

If your child has a health condition you should discuss sleep with a healthcare provider. The **CBBES manual** is only intended to help you understand the environmental factors that can interfere with sleep and is not intended to substitute for healthcare provider assessment and treatment.

Do sleep problem last?

It may be encouraging to know that many of these sleep challenges are temporary. Often they get better over time, as your child ages and matures. However, for children with chronic health conditions, like cerebral palsy, poor sleep can remain an ongoing problem.

Fortunately, scientific research has shown that there are many practical steps parents can take to help improve their child's sleep.

The **CBBES manual** focuses on the important role of the bedroom environment in helping children sleep. The manual also shows you how to assess the bedroom environment and offers a number of research tested ways to improve the environment to help your child sleep.

This workbook will tell you about the four key bedroom environment factors that influence children's sleep:

- light
- temperature
- sound
- bedding

The second half of the **CBBES manual** will explain how to assess and improve your child's bedroom environment to help them sleep.

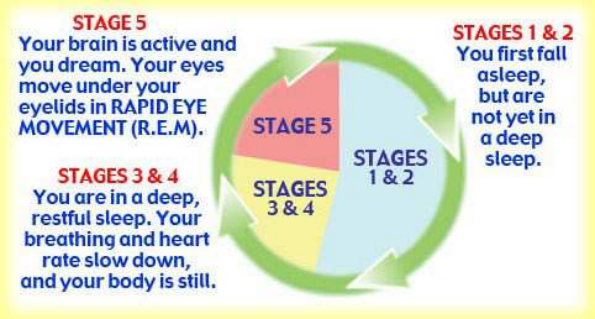
Why is sleep important?

When children and adults don't sleep their mood is often affected. Sleep deprived children have difficulty thinking, concentrating, staying alert and do daily activities. Not having enough sleep interferes with a child being able to learn, play, manage daily activities and make friends. Not having enough sleep also affects children's ability to heal, digest food and produce body chemicals and hormones that are important to physical function, emotions, thinking activities, and overall health[3]. Hyperactivity and irritability can sometimes be signs of insufficient sleep.

Language development and success at school can all be affected if a child suffers from sleep problems. Also, children with sleep deficiency are at higher risk of developing health problems (such as obesity, diabetes and depression) later on in life.

In summary, sleep deficiency in childhood can interfere with health throughout a person's whole life.

There are many factors that are important for quality sleep. Sleep science can help us to understand the importance of the environment.



The Science of Sleep

Sleep occurs in cycles throughout the whole time sleep period. Each cycle lasts about 90 minutes. Each cycle also consists of four stages[4]: This means a night's sleep is composed of a series of 90 minutes cycles. It is normal for your child to return to light Stage 1 sleep each cycle so you should not be overly concerned about light sleep at times during the night.

- Stage 1- light sleep
- Stage 2- moderately deep sleep
- Stage 3- very deep sleep
- Stage 4- REM (Rapid Eye Movement) sleep.

Stages 1 through 3 do not involve REM. During these stages your child's body carries out functions that are important to healing, digestion and hormone production.

Stage 4 (REM sleep) is also referred to as 'dream sleep' because this is when dreams are remembered. REM sleep is very important for memory, learning, concentration and emotions. Children often have more REM sleep then adults.
It is possible for a child to achieve only Stage 1 and 2 sleep because of factors (such as light or noise) in the environment that prevent them moving into deep Stage 3 sleep and REM. Each stage of the sleep cycle occurs in order and it is not possible to skip stages 1 and 2 to go directly to deep sleep and into REM sleep.

Sleep requirements [4]**:**

- **Infants** < 6 months: up to 16 hours of sleep a day
- **6 months** 12 hours plus two naps.
- **Preschoolers** 12 hours plus one nap

How **Light** Affects Sleep

Sleep is controlled by two body mechanisms:

1. **Sleep-wake homeostasis**: This is also called 'Sleep Drive". Basically, sleep drive means that the need for sleep increases the longer an individual has been awake.
2. **The circadian rhythm**: This is also known as our "body clock". The circadian rhythm cycle in the body regulates feelings of sleepiness and wakefulness.
   The cycle of light we are exposed to between day and night organizes the circadian rhythm and provides it with information[6]. Light and dark are the most important influence on the circadian rhythm cycle. Circadian rhythm organizes the timing of sleep, and influences change in our body temperature, thirst and appetite.

The hypothalamus (see picture) is an area of the brain that controls circadian rhythm [4]. The amount of blue spectrum light perceived by the eyes determines whether your child's brain is signaled to produce chemicals and hormones to keep him awake or help him fall asleep and stay asleep. We will explain more detail about blue spectrum light on page 7.

Basically, the greater the amount of blue spectrum light at night – the more alert your child will be. The less blue spectrum light before bed and at night - the easier it is for your child to fall asleep. Blue spectrum light is most concentrated in natural daylight, electronic devices and artificial lighting.

Body temperature also cycles with the circadian rhythm. It is highest during the day to keep your child alert. At night core body temperature needs to drop slightly to help your child sleep. This temperature cycle appears to affect REM sleep. The amount of time spent in REM sleep is longest when body temperature is at its lowest [6].

The hypothalamus contains an area called the pineal gland. The pineal gland is important in circadian rhythm because as it gets darker this is the area that controls production of the hormone melatonin [6].

Melatonin is an important hormone because it facilitates sleep. The following section on **Light** (page 7) will give you more detail about melatonin [4].

The circadian rhythm also regulates the secretion of the stress hormone cortisol. Cortisol also follows a daily cycle. It peaks in the morning and is lowest between 12-4am [6].

In summary: Circadian rhythm is influenced by light and temperature. We need bright light to stay alert and dark, cool environments to sleep better. Sound and bedding are two more important influences on sleep. All four environmental influences will be discussed in detail in the next section.

Important points:

- Sleep is important for developing emotional, cognitive and social skills.
- Reduced sleep in children is associated with behavioral problems.
- Your child needs all 4 stages of sleep.
- The circadian rhythm is important for the regulation of sleep-wake cycle.
- A hormone (melatonin) promotes sleep in response to darkness.
- The stress hormone cortisol is low during sleep.

Light is perhaps the most important environmental influences on your child's sleep. Specifically, **light at the blue end of the light spectrum** (see picture) is a key influence on circadian rhythm. Children need lots of blue spectrum light in the daytime and as little blue spectrum light as possible in the 2 hours before bed.

Blue spectrum light is produced by:

- Natural sunlight
- Televisions
- Electronic games, tablets, computers and lap tops
- Artificial light from lightbulbs and florescent tubes

Blue spectrum light sends a message to the hypothalamus (see page 6) in the brain to stop producing melatonin. That's a good thing in the daytime when we need to be awake, but at night your child needs to produce melatonin to go to sleep and stay asleep. [7,8,9]

Light is measured in **lux**. Research shows that blue spectrum light of more than **30-40 lux can prevent your child from producing melatonin**. Also, once melatonin production is slowed down by blue spectrum light it can take 60-90 minutes in the dark for it to become active again. Laptops and electronic tables produce high amounts of lux and are held close to the eyes- that's why they should not be used close to bedtime. [10]

The amount of blue spectrum light in a child's bedroom can add up depending on the number of light sources. For example sitting in a bright room,

texting on a smart phone, while the television is on, can add up to a high amount of light exposure.

Average lux levels

- Sunny day at noon 5,000-10,000
- Average office 400-500 lux
- Living room in the evening 300-400 lux
- Laptop 25-80 lux
- Smart phone 10-45 lux

Note: Lux emission from electronic devices is quite varied depending on the brand.

What does this mean for your child?

Bright blue spectrum light exposure within the 90-120 minutes before bed can suppress melatonin production and so interfere with sleep. Also, sources of light during the night can interfere with melatonin production and deep sleep. For example if there is light coming through the curtains, under the door from the hallway and from a night light, the light level may exceed 30 lux and interfere with your child's sleep.

Light and electronics are an important part of our lives. We use these devices for entertainment and for learning so we can't, and don't want to, just turn everything off. The good news is there are ways to reduce the amount of blue spectrum light exposure your child receives in their bedroom environment. See page 19 for practical, research tested options to find ones that are right for your child and family.

Key points:

- Blue spectrum light suppresses production of melatonin need for sleep.
- Blue spectrum light sources include electronic devices, lap tops, tablets, smart phones and televisions.
- Blue spectrum light exposure above 30-40 lux can suppress melatonin production by 90-120 minutes.
- **You can measure lux** with a smartphone light meter app (see the Resource section for more information).

How **Temperature** Affects Sleep

Temperature is an important influence on your child's circadian rhythm. High or low temperatures in the bedroom environment can disrupt sleep for everyone. This is an even greater problem for children who cannot easily move around in bed. The ideal temperature for sleep is recommended to be between **20-22 degrees Celsius**. [20]

Why is temperature important?

Each person's circadian rhythm causes his or her core body temperature to vary over each day's 24 hour period. Your child's core body temperature will usually be highest around 3pm in the mid-afternoon and lowest around 4 am in the morning. [6,3]

- For sleep to occur your child's core body temperature needs to drop slightly. This drop of a few degrees helps your child fall asleep.
- Without this drop in core temperature it is also difficult for your child to stay asleep.
- Core body temperature decreases until about 3am and then starts to increase gradually which helps the body prepare to wake up.
- Blood flow to the skin is also affected and changes over the sleep period.

The temperature in the bedroom combines with the temperature created by trapped body heat when your child is under the covers. If the combined temperature is greater than 22 degrees Celsius or cooler than 18 degrees Celsius it can interfere with your child's ability to sleep. Most people can find the right balance by adjusting bedding and/or room temperature. For example, if your child is very fond of warm flannelette sheets and pajamas the bedroom temperature might need to be decreased slightly more.

During the REM stage of sleep we are not as able to shiver or move around – this means we are less able to regulate our own body temperature. 15 Children usually have longer periods of REM sleep later in the night. This means that they need to be cool to go to sleep but by around 3 or 4 am they need to have a warmer temperature or more bedding to stay comfortable and asleep. The best solution is using timers on fans and heaters and programmable thermostats.

During the REM stage of sleep we are not as able to shiver or move around – this means we are less able to regulate our own body temperature. [15] Children usually have longer periods of REM sleep later in the night. This means that they need to be cool to go to sleep but by around 3 or 4 am they need to have a warmer temperature or more bedding to stay comfortable and asleep. The best solution is using timers on fans and heaters and programmable thermostats.

Important considerations:

- Exercise and **vigorous play** close to bedtime raise your child's core temperature and that makes it difficult for them to sleep.
- It can take up to two hours for elevated core body temperature to drop.
- Showers and baths before bed can raise core temperature and then, when the core temperature drops, the child becomes sleepy. For more about this see "passive Body warming" on page 23.
- **Sleeping position** can also raise core temperature- when a child lies on his or her side there is less contact with the mattress and less warm air gets trapped between the bedding and body. [13] This means that side lying is often a cooler position. However, for medical reasons, some children need to sleep on their back

(for example, children with high muscle tone, contracture, and muscle tightness). For these children adjustable bedding that allows for core temperature fluctuation is important.

- **Bedding that is in layers** and easily pulled up or thrown off can also help with regulating core body temperature as it changes during the sleep period.

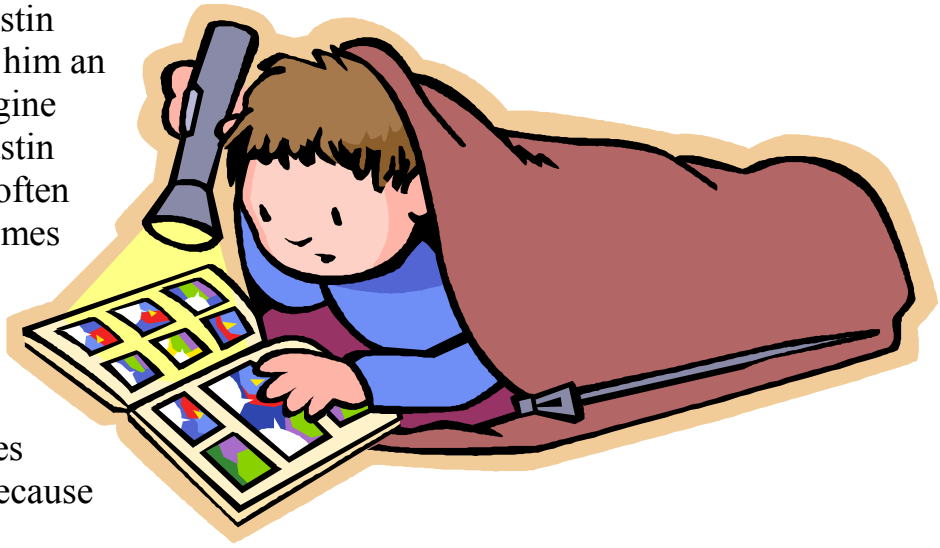
An example of how light can interfere with sleep: "Dustin can't sleep"

Dustin is a 3 year-old boy. He lives with his parents and cat in a home just outside of Edmonton. Dustin loves trains, he enjoys playing with trains, watching train movies and making train noises. He also loves playing with his electronic tablet. His mother lets him play with it for 2 hours before he goes to bed while she and his father are tidying up after dinner. After Dustin gets ready for bed his Dad reads him an interactive Thomas the Tank Engine story on his electronic tablet. Dustin has difficulty falling asleep and often gets up out of bed a number of times once his parents turn the light out. When he is having difficulty sleeping sometimes his parents let him sit with them while they watch TV. Dustin goes to preschool in the afternoons, because he often needs to sleep in late, sometimes until 11am.

In this example Dustin is getting too much blue spectrum light during the evening. Blue spectrum light coming from his electronic tablet and the television suppress his body's ability to produce the melatonin he needs to fall asleep and stay asleep.

There are a number of environmental changes Dustin's parents can make to help decrease his exposure to blue spectrum light before bed and
Once he is in bed for the night.

See page 23 for a list of **research tested suggestions** to reduce blue spectrum light exposure at night.



How **Sound** Affects Sleep

An example of how bedtime activity can interfere with sleep: "Isabel is very busy".

Isabel is 3 and ½ years old. She has lots of energy and is very active! Her parents try to keep her as busy as possible. She goes to preschool in the morning and takes a nap in the afternoon. Her regular bedtime is 7pm but on the evenings she has skating lessons and gymnastics club Isabel does not get home until at least 630 and so seldom gets to bed by 7pm.

Her mother says she tries to keep her active in the evenings because that way Isabel will be tired out and fall asleep more quickly. However, Isabel has a hard timing getting to sleep after a very busy evening, and she gets upset and cries. Isabel's mother says that often she seems to pick a fight with her parents and her older sister at bedtime. Isabel's mother also keeps the bedroom warm (about 25 degrees Celsius) because Isabel kicks off her covers at night and her mother is worried she will get cold.

Isabel's **core body temperature** becomes raised when she has vigorous activity (like gymnastics) before bedtime. A raised core body temperature takes about two hours to drop enough so that Isabel can sleep more easily. Also, because **the bedroom is kept above the recommended** temperature of between 22 degrees Celsius, she is less able to stay asleep. Being unable to stay asleep means she is unlikely to get the **REM sleep** she needs for emotional development and learning. Instead she ends up unrested, cranky, and easily upset.

Page 22 has **research tested recommendations** to help create a good temperature for sleep in the bedroom environment.

Sound in the bedroom

A quiet environment is also important for quality sleep. Certain types of sounds and sound over a certain level of loudness can cause physical reactions in your child's body that will interfere with him or her going to sleep and staying asleep.

Sound is measured in decibels (also written as dB). Sounds that are between 30 and 40 decibels can cause your child to wake up. Sounds that are 60 decibels or greater can cause a stress response in your child's body and his heart rate will increase, breathing becomes more rapid and stress hormones are released. All of this interferes with sleep.

Ideally noise levels in the bedroom should not be above 30 decibels (see the box for more information about decibels). Noises that are sudden and infrequent (like a door opening and closing, or a burst of laughter on the television) are the most alerting. If the noise is constant and with a stead, unchanging sound (like an air conditioner or a fan) it will be less alerting. That is why running a fan at night is often a good strategy to block out other infrequent noises.

Noise affects sleep and often causes awakenings.

- Noises outside the bedroom and outside the home are also a problem.[17,18]
- Noise disturbances at night have also been shown to affect mood and level of fatigue during the day.

During sleep we are especially sensitive to noise:

- Noise can disturb sleep even when it does not wake your child up. This is because noise influences the body's essential functions including release of hormones (like the stress hormone cortisol), and changes in heart rate, blood pressure, breathing rate and muscle tone.[18]

Environmental noise will impair sleep and prevent your child from going through all four stages of the sleep cycle (see page 5). For example your child may stay lightly asleep for the whole night but loud traffic noise will prevent him from Stage 3 (Deep sleep) and Stage 4 (REM sleep). Your child will be cranky and feel unrested in the morning when that happens. Other sources of noise that commonly interfere with a child's sleep include sharing a room with someone on a different bedtime schedule or who snores; being able to hear the TV from other areas of the house; conversations near the bedroom; and the noise from household appliances like dishwashers.

In summary- the negative effects of noise on sleep include:

- increased time to fall asleep
- interruptions in the sleep cycles,
- increased restlessness and broken sleep,
- increased heart rate and alerting, and
- Decreased total sleep time.

Decibel levels of common noises [16]

140 dB= airplane taking off, firearms
110 dB= car horn, rock concert, baby crying
90 dB = subway, passing motorcycle, truck
80–90 dB = blow-dryer, kitchen blender, food processor
70 dB = busy traffic, vacuum cleaner, alarm clock
60 dB = typical conversation, dishwasher, clothes dryer
50 dB = moderate rainfall, refrigerator
40 dB = quiet room, quiet residential area
30 dB = whisper, quiet library

Research shows that a constant background hum (also known as 'white noise') can help to block out other sounds that interfere with your child's sleep. Sources of white noise include fans, special white noise machines and smart phone apps (for example - http://www.simplynoise.com/appstore/) or on the internet (for example - http://mynoise.net/NoiseMachines/whiteNoiseGenerator.php)

An example of how sound can interfere with sleep: "Aiden is tired in the morning".

Aiden is a 4 year-old who lives in an apartment with his mother Paula and his 28 month-old sister Ava.

Aiden and his sister share a bedroom across from the living room. Paula works during the day, and the children go to daycare. When Paula gets home she gets the children's dinner ready and lets them watch TV while they are eating. Then she gets them ready for bed. Ava and Aidan go to bed at the same time and Paula leaves the TV in their room on to help them fall asleep. Sometimes when she comes in to turn it off around 10 pm Aiden is still awake. She often finds him sitting quietly looking out of the window which looks down onto **a busy street with lots of traffic noise** and bright electric lights.

Paula likes to make her own dinner and prepare the lunches for the next day when her children are in bed. She then talks to friends on the phone and watches TV in the living room.

Aiden often seems tired in the mornings. His preschool teacher expressed concern that he is easily distracted and irritable and sometimes falls asleep at school.

Aiden is exposed to a great deal of noise at night.

Paula's occupational therapist friend suggested she **test the decibel level** in Aiden's room at night with a smart phone app (for example https://itunes.apple.com/ca/app/decibel-10th/id448155923?mt=8).

Paula was surprised to learn there were more than 60 decibels of sound created by her work in the kitchen, the TV, and the street noises. Sixty decibels is likely to increase Aiden's heart rate and stress response in his body. When this happens he is not able to move out of light sleep and into the Stage 3 deep sleep and the REM sleep stage he needs to be rested and ready to learn and play during the day (see page 5 to review the reason he need REM sleep).

Page 20 has **research tested suggestions** to help reduce disruptive noise in the bedroom.

How **Bedding and other Fabrics** Affect Sleep

The fact that **fabric** can be an environmental factor that interferes with sleep seem less obvious to most people. This means bedding and other soft furnishings (like toys and carpets) are often over looked as a something that might affect getting a good night's sleep.

Many of the **synthetic materials** that are often used in pillows, quilts, mattresses and other fabrics in the bed and soft toys can collect **dust, dust mites, and other allergens.** An allergen is a tiny, sometime almost impossible to see, bit of material that can cause an allergic reaction and problems breathing. For example dust floating in the air or pollen from flowers can be allergens for some people.

It is more difficult to remove dust and allergens from many synthetic fabrics than it is to remove them from natural fabrics.

Common man-made or synthetic fabrics in the bedroom include:

- polyester fleece blankets and pajamas
- stuffed toys
- shag pile rugs
- foam mattresses or pillows.

Tightly woven fabrics are a much better barrier to dust mites and allergens than loosely woven or stretchy fabrics. For example cotton sheets with a **high thread count** are tightly woven and don't keep as much dust and allergens close to your child's face. You can also purchase dust mite barrier mattress and pillow covers that go between the mattress and pillow and the bedding.

Research tells us that:
If children sleep on their back they may be more susceptible to the allergic effects of synthetic

bedding.[19] This is likely because the bedding is closer to their nose and mouth. However, **some children must sleep on their backs for medical reasons** – for these children frequently washing bedding and antiallergenic fabrics are important.

Synthetic bedding contains **8 times the allergens** and other fungi (for example dust mites) compared to feather bedding with tightly woven cotton covers. Tightly woven fabrics are needed to keep the feathers inside and so they also prevent dust and other allergens from coming through the fabric.

Of course some children are allergic to feathers so then parents would not use feather duvets and pillows – rather they should make sure all other bedding fabric is as tightly woven as possible. [19]

Most department stores sell dust mite barrier mattress and pillow covers because it is a common problem.

Pets in the bed can also affect sleep:

- Pets can make it difficult for your child to sleep in a comfortable position.
- They may also shed fur and dander that interfere with breathing.

Children who usually snore or breathe through their mouth may have a sleep disorder that should be checked by a doctor. There are many effective treatments to help your child breath easily at night.

If you believe that your child may benefit from changes in bedding see page 21 for research-tested suggestions.

Comfortable bedding that can be easily removed or pulled up is important as well. And if your child is unable to move easily in bed he or she can have a significant amount of **pain**. If your child has bed mobility problems, is unable to adjust his own bedding, and/or gets very hot and sweaty during sleep a your occupational therapist can give you suggestions about special bedding materials that will help reduce the problem.

An example of changing the environment to help a child with cerebral palsy have a better sleep: "Lydia gets her own bedroom".

Lydia is a 4 year-old girl with cerebral palsy. She lives in a one storey house with her mother, her father, and her 10-year old sister Stephanie. Lydia shares bunk beds with Stephanie. Stephanie sleeps on the top bunk and Lydia sleeps on the bottom. There is lots of light (from a nearby streetlamp) that reaches the room through the window. Stephanie usually goes to bed about two hours after Lydia.

Lydia often has a hard time falling asleep and staying asleep. Lydia's parents say that she normally wakes up several times throughout the night. They have also noticed that Stephanie snores and that Lydia often complains of a stuffy nose.

Lydia often needs two naps during the day. Lydia's occupational therapist is concerned as Lydia often seems to not have enough energy to fully participate in her weekly therapy sessions. Lydia gets easily frustrated and often has to leave therapy early. Lydia's occupational therapist suggests that the family look at Lydia's sleep routine and her sleep environment.

The **light from the streetlamp** may be preventing Lydia from falling asleep. The occupational therapist explains how bright blue spectrum light inhibits production of the melatonin that Lydia needs to fall asleep and stay asleep (page 7). Lydia also has many **disruptions** at night because of Stephanie's routine to go to bed. Because Lydia is not able to stay asleep she spends less time in **REM sleep**. She needs REM sleep to be motivated, to control her emotions and to function during the day. As a child with cerebral palsy, lack of sleep may also cause Lydia to experience more pain. **Pain** will also make it harder for her to sleep.

Lydia's parents decide to change the sleeping arrangements. They decide that they will give up having a guest bedroom so that Lydia and Stephanie will each have their own bedroom. This means that Lydia will no longer be interrupted when Stephanie goes to bed.

Lydia's parents put in very good curtains in her new bedroom to block out outside light. Lydia is nervous about being alone so her parents install a special night-light that has a bulb that filters out **blue spectrum light** (page 23 for more information). The family also decides to change their polyester comforters to a brand with more tightly woven covers, run all the comforters and pillows through the dryer every two weeks, and make sure the family cat does not stay in Lydia's bed all night (see page 13 for the reasons why).

Stephanie downloaded a sound monitor app to her smart phone and found out that, because Lydia's new room is close to the living-room, the noise level when Lydia is trying to sleep can be **over 30 decibels** (see page 11). Lydia's parents also checked the temperature in her new bedroom- they were surprised to find out that it is often **over 25 degrees** Celsius. The therapist explains that temperature greater than 22 degrees or lower than 18 degrees Celsius may interfere with sleep (page 8). Lydia's parents decide to run a fan in Lydia's room to block out background noise and help cool the air. They also give

her layers of bedding that **she can easily** remove, so that she is warm enough but does not overheat.

Soon after making these modifications the family notice changes in Lydia's mood, her motivation to participate in therapy and to play with her siblings. They also notice a decrease in the amount of pain that Lydia seems to be experiencing. Lydia has an easier time falling asleep and does not wake up and call out during the night as often. Everyone seems much happier (except of course the cat, who now sleeps on a chair in the living-room instead of with his best friend- Lydia)!

Part 2

Creating a sleep-friendly bedroom environment

The Bedroom Checklist

Now that you know the science explaining the influence the environment has on sleep you are better able to make changes in your child's bedroom that best match your own situation.

Start by going through this list of questions to identify potential problem areas in your child's bedroom. Check the boxes 'yes' or 'no'. Once you identify where the problems are you can go to pages 19-22 to find a list of research tested options for making changes to improve your child's sleep.

A. Questions about Light:	Yes	No
1. Is the light intensity of the bedroom once your child is in bed for the night greater than 30 lux? (See the Resource section on page 22 for information of how to assess lux).		
2. Is there bright light from outside coming into the bedroom through your child's window? (For example from street lights or a patio light).		
3. Are there any windows without curtains?		
4. Does light get through existing curtains?		
5. Does your child like to sleep with the door open?		
6. If your child sleeps with the door closed, is there light that gets through the space between the door and the floor?		
7. Does your child sleep with a nightlight or lamp? If so, does this emit blue or white spectrum light?		
8. Are any electronic devices (such as a TV, laptop, or electronic tablet) left on in the bedroom once your child is in bed for the night?		
9. Does your child use any of these electronic devices within one hour of bedtime or once he or she is in bed for the night?		

Did you answer "Yes" to any of these questions? If so, see the suggestions on page 19 in **Lighting changes.**

B. Questions about Noise:	Yes	No
1. Is the noise level in your child's bedroom at night higher than 30 decibels? (See the Resource section on page 22 for suggested smart phone apps to test decibel levels).		
2. Do you live on a busy street or in a neighborhood where there is lots of noise outside? (For example noise from cars and traffic).		
3. Does your child share a bedroom?		
4. Does your child's roommate snore?		
5. Does your child's roommate go to bed later than your child?		
6. Are there conversations or sounds in the house that occur close to the bedroom while your child is sleeping?		
7. Is there a TV, radio or other appliance (washing machine, dishwasher, blender etc.) that makes noise close to the bedroom while your child is sleeping?		
8. Does your child listen to music or watch TV while trying to fall asleep?		
9. If your child watches TV or listens to the radio when he or she is in bed, are these devices left on all night or until someone turns them off manually?		
10. Does your child bed frame make a squeaky noise?		
11. Do your child's sheets make a noise when he moves in bed? (This is common with plastic undersheets for example).		

Did you answer "Yes" to any of the questions? If so, see the suggestions on page 20 in **Noise-**

C. Questions about temperature		
	Yes	**No**
1. Is the temperature of the bedroom when your child is sleeping between 18 to 22 degrees Celsius?		
2. Is the temperature in the bedroom adjustable? (For example a separate control/thermostat to adjust heat in the room, or a window you can open).		
3. Can your child easily adjust layers of bedding depending on feeling too hot or cold?		
4. Is your child's nightwear made of different fabric depending on the season? (For example light cotton in the summer and flannelette in the winter).		
5. Does your child participate in only calming activities 1 hour before bed? (For example- reading a book is calming, playing video games is not calming).		

Did you answer "No" to any of the questions?

If so, see the suggestions on page 23 in **temperature-related changes.**

Jot down any comments about these temperature items in this space or on the back of the page.

D. Questions about Bedding (sheets, blankets & other fabrics):		
	Yes	**No**
1. Is there carpet in the bedroom?		
2. Is the bedding synthetic?		
3. Are the sheets changed less than once a week?		
4. Are the pillows, blankets, duvet and any soft toys on the bed washed less than once a month?		
5. Does your child suffer from asthma or allergies?		
6. Does your child complain or appear to experience a recurrent stuffy nose?		
7. Does your child sleep with a pet on the bed?		
8. Are sheets and pillow cases directly on top of the mattress and pillow?		
9. Is the mattress more than a year old?		

Did you answer "Yes" to any of the questions?

If so, see the suggestions on page 21 in **bedding-related changes.**

Jot down any comments about bedding in this space or on the back of the page.

Part 3
Creating a Sleep-Friendly Bedroom

In Part 1 of the CBEES manual you learned about the science of sleep. Then in Part 2 you checked your child's bedroom to see where there might be some problems. This section will now help you pick changes you can make to the bedroom to improve your child's sleep.
Please check off all of the changes you think would be realistic to try. Then, for any changes you actually make, put in the date. Remember- **it takes time to see results** from most changes so it is best to give all changes atleast 2-3 weeks trial before you decide if they are useful.
If you have comments about the changes you made please write them in the box at the end of the section.

A. Lighting changes	This is something I could try	I tried this on- (insert date):	I did this for (fill in number of days)
1. Purchase dark curtains/black out blinds that filter out all light			
2. Place cardboard sheets over the window at night that can be easily removed to let in daylight in the morning.			
3. Make sure the bedroom door is closed at night or light from the hallway is blocked out by a curtain over the door.			
4. Turn of all the lights in surrounding rooms/hallways or minimize the light coming from them - Test the lux level using a simple app (see Resources on page 23)			
5. Cover the crack under the door to the hallway with a towel.			
6. See if your child would be willing to wear an eye mask to block out light.			
7. Use a motion activated night light (this will only come on when your child is awake and moving). (see page 23)			

Comments about the changes you tried ? (pleae write in here and on the back of this page)

B. Noise related changes	This is something I could try	I tried this on- (insert date):	I did this for (fill in number of days)
1. Try soft classical or non-classical music with a tempo of 60-80 beats per minute for 20-45 min. See Resource section on page 23 for information about how to check the appropriateness of your music online).			
2. Put any music, taped books or television on a timer so it shuts off after 15 minutes.			
3. Try playing white noise for your child. White noise machines can be purchased at most major electronic retailers. A fan can also be used to block out noise.			
4. Try having your child sleep with earplugs.			
5. Try to have anyone sharing your child's room go to bed as close to the same time as possible to avoid disruptions.			
6. Minimize the use of dishwashers and other household appliances while your child is sleeping.			
7. Keep TV on low or use headphones when you are watching it so no sound reaches the bedroom.			

C. Bedding related changes	This is something I could try	I tried this on- (insert date):	I did this for (fill in number of days)
Change sheets weekly.			
Run pillows, blankets and stuffed toys in the dryer weekly on medium heat.			
Wash pillows and other duvets/bedspreads and soft toys monthly.			
Use natural fabric bedding with high thread count sheet (300 and greater).			
Vacuum weekly.			
Replace synthetic bedding with natural fabrics.			
Remove pets from the bed OR at change the bedding the pet sleeps on every two days.			
Use dust mite barrier mattress and pillow covers underneath the bottom sheet and the pillow case.			
Consider purchasing a new mattress at least every two years.			
D. Temperature related changes	This is something I could try	I tried this on- (insert date):	I did this for (fill in number of days)
1. Keep your child's bedroom less that 22 degrees Celsius until approximately 2 to 3am and then gradually warm the room up to a comfortable temperature for getting out of bed. A fan and a heater on timers can help with this if you do not have a programmable thermostat.			
2. Layer the bedding so children can adjust the amount themselves or you can do it without waking the child at night.			
3. Avoid physical activities and sports at least 90 minutes before bed.			

RESOURCES

General Resources for children's sleep:

- Canadian Sleep Society Brochures: www.canadiansleepsociety.ca/publisher/articleview/fmArticleID/341
- SleepRight website for children with chronic health condition http://www/SleepRight.ualberta.ca
- Sleep for Kids: www.sleepforkids.org
- Your child's sleep: www.kidshealth.org/parents/general/
- Sleep for toddlers and preschool children: www.bbc.co.uk/parenting/your_kids/toddlers_sleeping2.shtml
- Sleep- Child and Family Webguide: http://www.cfw.tufts.edu/?/category/young-children/17/topic/sleep/79/
- Sleep behaviour – the Encyclopedia of Early Childhood Development http://www.child-encyclopedia.com/en-ca/child-sleeping-behaviour/how-important-is-it.html

Light:

- Visit www.justgetflux.com to download free f.lux software to filter out bright white and blue light in the evening on your computer or tablet.
- Blue light filtering goggles, electronic device filters, bulbs and nightlights- https://www.lowbluelights.com/
- Apps that measure amount of light intensity in Lux:
    - For android devices: https://play.google.com/store/apps/details?id=com.notquitethem.android.luxmeter
    - For Apple devices: https://itunes.apple.com/ca/app/luxmeter-pro/id408369821?mt=8

Sound:

- For helpful tool to determine the beats per minute of your child's music visit www.songbpm.com or www.bpmdatabase.com
- Examples of white noise apps and software http://mynoise.net/NoiseMachines/whiteNoiseGenerator.php
- Apps that measure decibel level (dB):
    - For android devices: https://play.google.com/store/apps/details?id=kr.sira.sound
    - For Apple devices: https://itunes.apple.com/ca/app/decibel-10th/id448155923?mt=8

Bedding:

- For information about allergens visit

http://www.worldallergy.org/professional/allergic_diseases_center/allergen_avoidance/ scroll to the end of the document for strategies to reduce dust mites and other allergens.

Temperature:

- For information about passive body warming (using baths, electric blankets or wheat sacks) see http://www/SleepRight.ualberta.ca

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Appendix J: Supplementary Data Collection

The researcher got the opportunity, to collect data from a group of students, practitioners and parents from India, Facebook and parents of typically developing children's. This was not the part of the study, but opportunity was utilised to get the additional feedback for Child Best Bedroom Environment Study (CBBES) manual. This group only took part in the online study, no bedroom assessment, and actigraphy was performed. Child was not the part of this component of study.

Participants from India

Invitations from two hospitals, one private clinic, and one special school in India to conduct workshops offered the opportunity to recruit another set of participants to the study. The volunteers from this group participated in an online version of the study. The participants who were interested in attending the workshop were asked to go to the pre-intervention fluids survey link and take part in the study. This was the only prerequisite for participation in the workshop. However, not everyone participated in the study prior to the workshop, so we sent a reminder email to each participant through the workshop organisers and the presenter.

Participants from Facebook

Cerebral palsy has an open access information group on Facebook, which is composed primarily of parents of children with cerebral palsy. A flyer that included information about the research was posted to this group. Parents who were interested in taking part in the study sent a message to the researcher to indicate their interest. Parents were asked where they lived, because if they lived outside of Edmonton, they qualified for the online component of the study. All of the information, and the pretest link were emailed to the email addresses the participants provided during their online correspondence with the researcher; completion of the pretest link included providing informed consent for the study.

Participants from university-affiliated daycare centers

Participants from this group involved parents of typically developing children. We added this section to the study because of the low rate of participation in the main study. The purpose of

studying this group was to test how effective the sleep education manual was for the knowledge translation activity. An email that included an information letter was sent to daycare supervisors to circulate among the parents of children in the same age group (2-10 years). Parents who were interested in the study emailed the researcher, and the pretest link was provided to each volunteer.

Data Collection Procedure for Online Study

The online study was divided into three groups, including participants from India, participants from Facebook, and participants from university-affiliated daycares. During the recruitment process, all of the participants received an email that solicited volunteers for the study. Interested participants emailed the researcher and a pretest fluids survey link was provided to these participants. However, for the participants in India only, completing the pretest link was a prerequisite to attending the workshop. After six weeks of follow-up, the post-test link was emailed to participants who completed the pretest.

Findings

A total of 33 participants from India, four participants from day care, and four participants from Facebook group, agreed to be a part of the study. They completed the online baseline survey. However, only 18 participants from India, three from Facebook group and one from day care completed the baseline survey. Data was analysed using the descriptive statistics. Table 11 contains the results from online study. The mean of correct responses for participants from India was 45.75% (N=33) in baseline data collection for Parent sleep Environment Knowledge Questionnaire, and in the follow up responses from the same group the mean was 88.88% (N=18) of the participants got the correct responses for PSEKQ. In India, researcher performed the series of workshop, and completing pretest survey was pre requisite to avoid adding any prior information before reading the manual. However, only 24 participants fulfill the requirements, data was analysed again for those participants who completed the survey before attending the workshop. Participants mean percentage of correct responses was 47.50% (N=24) in baseline and 88.88 % (N=18) in follow up.

The Facebook group got the mean percentage of 55% (N=4) in baseline data collection and 56.66 %(N=3) in follow up data collection. The mean of correct response percentage for group from day care in baseline data collection was 67.50% (N=4), and in follow up 90% (N=1).

Although, the percentage of correct responses for PSEKQ has increased from pre to post test, but due to low participation rate strong conclusions cannot be made. However, the positive trends of results show promising effects for CBBES education manual.

Discussion

The results shows a change on pre and post test scores, which suggest that there was a change in the knowledge. However, it is very difficult to make any conclusions for daycare and Facebook group as only four participants completed the pretest and three from Facebook and one from daycare completed the post test. The low participation rate from all three groups could be of several reasons such as, due to lack of paper based information not all of the participants showed their interest in the study, in India lack of computer accessibility in homes and the pretest link was not opening in the smart phones could be other reason, apart from that busy schedule of parents and healthcare providers could be one of the possible reasons.

However, the study conducted in India has 33 participant in the pretest and 18 in the post-test. The results generated showed the increase in the knowledge of participants. The result showed that in India, therapist, students and parents were not aware of the white noise concept, but the post test results show they gained the information on the use of white noise.

In the additional comment section, participants from India added that the temperature requirements were according to the weather condition in Canada and should have a section in the CBBES manual for rest of the world. They also added that few of the recommendations such as purchasing blackout blinds and change in the bedding were difficult to apply by the population in India as not all of the can afford that.

This additional data collection opportunity suggested that manual was effective, as there were slight changes in the pre and post-test. This study added and gained attention of therapist, and parents towards the importance of environment especially in India.

Appendix K: Reflection on Study

It was very difficult for me as a novice researcher to avoid therapist behavior and adopt the researcher's point of view while working on the study. I received wonderful guidance from my supervisor, who helped teach me the research approach in every area and stage of the study.

The study was unique in nature, and many points arose when I realized that I had to have a clear understanding of its importance. In the application to the Ethics Board, I learned how to apply for permission to undertake a study with children. As an international student with a different cultural background, I had to learn the interview skills required for the study, and my committee members were generous in helping me acquire those skills. I also learned that it was very important for me to have insights about the study before beginning data collection so that I could answer all of the parents' questions.

Although there were few data gathered in the study, there were many small links that I needed to connect and analyse. It was very important for me to understand and implement all steps of the knowledge to action cycle. The literature review, together with motivation from my supervisor, helped me to achieve an in-depth analysis of the data I gathered in the study.

This study not only increased parents' knowledge of important environmental components of healthy sleep, but mine as well. I remember I used to schedule my therapy sessions at or around 9 p.m., without realising that this would affect the child's sleep patterns. This study not only helped me to develop my perspective as a researcher, but as a therapist as well. There was one case study that encouraged me to conduct this study: I was dealing with a hyperactive child whose mother complained that she did not sleep properly. One small suggestion about monitoring her sleep patterns and establishing a sleep schedule helped the child so much that after only a week, she was better oriented during sessions.

Despite the problems with the study, my interactions with the parents and their comments on the CBBES manual motivated me and helped me determine one of my future goals, to disseminate more information about the effects of the environment on sleep. Although I understand that the participants have praised the CBBES manual, research requires proof, and only future studies of a

larger population can answer the question of whether CBBES manual is effective in improving sleep problems.

Appendix L: Actigraph Checklist

- Your child should wear Actigraph every night before going to bed.
- Actigraph preferably should be on non-dominant hand of child.
- Remove Actigraph every morning after your child is awake.
- Enter the time your child goes to bed and wakes up in the sleep log. Accurate entries will help with a more accurate assessment.
- Do not get the Actigraph wet.
- Actigraphs are sensitive, expensive and can be damaged. Please do not let your child and others in the home play with it.

Thank you for your participation
See you on ……

If you have any questions regarding Actigraph please email at rdutt@ualberta.ca

Table: 1 Outline of 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)
Male	0
Characteristics of the Children	Percentage
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)

Table 2: Baseline Sleep Habits of the Children (Owens & Jones, 2011)		
	Sleep Habits	_Proportion of children (% of yes responses) (N=6)
1	Regular bedtime 7 nights a week <7 nights a week	 83.33 (5) 16.67 (1)
2	Regular wake time 7 days a week <7days a week	 83.33 (5) 16.67 (1)
3	Late bedtime 9 Pm or earlier Later than 9 Pm	 33.33 (2) 66.67 (4)
4	Adult in the room when child falls asleep At least a few time a week Once a week or less	 33.33 (2) 66.67 (4)
5	Electronics in the bedroom None At least 1	 16.67 (1) 83.33 (5)
6	TV in the bedroom	0 (6)
7	Regular bedtime routine	83.33 (5)
8	Reading is a part of bedtime routine	66.66 (4)
9	Watching TV is part of bedtime routine	33.33 (2)
10	Drinks caffeine everyday	0 (6)

Table 3: Parental Interactive Bedtime Behavior Scale (Morrellet al., 2002)						
PIBBS Subscale Items 1: Never, 2, Rarely, 3: Sometimes, 4:Often, 5: very often	AB 1	AB 2	AB 3	AB 4	AB 5	AB 6
	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test
1. Stroke part of child or Pat	5 3	1 1	3 3	3 2	1 No data	1 1
2. Cuddling or rocking in arms	5 3	1 1	2 2	1 2	1 No data	5 1
3. Carrying around house in arms	2 1	1 1	1 1	1 1	1 No data	2 1
4. Walks in pram or stroller	1 1	1 1	1 2	1 1	1 No data	1 1
5. Car rides	4 1	1 1	2 2	1 1	1 No data	3 4
6. Music tape or musical toy	1 1	5 5	5 5	1 1	5 No data	1 1
7. Talking softly to child	4 4	3 1	4 4	3 3	2 No data	4 3
8. Singing a lullaby	3 2	1 1	4 4	3 2	1 No data	3 5
9. Reading a story to child	4 3	5 5	4 3	3 3	1 No data	5 5
10. Playing with child	2 2	1 1	2 2	3 2	1 No data	1 1
11. Offer a special toy/cloth	4 5	1 1	1 1	1 1	2 No data	5 5
12. Give a feed/drink	4 3	2 2	1 1	4 4	1 No data	5 5
13. Leave to cry	3 2	1 1	1 2	3 3	1 No data	1 1
14. Stand near cot without picking infant up	1 1	1 1	3 3	1 1	1 No data	1 1
15. Settle infant on sofa with parent	1 1	1 1	3 2	1 2	1 No data	1 1
16. Lie with chid next to their cot	2 1	1 1	3 2	1 3	1 No data	1 5
17. Settle in parents bed	2 3	1 1	1 1	1 1	1 No data	5 5
18. Others	5 1	1 1	1 1	1 1	5 No data	1 1

Table 4: Select Items from Parental Interactive Bedtime Behaviour Scale Data (PIBBS) (Morrell et al., 2002)	
Three most used 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%)
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%)

Table 5: Children Sleep Habit Questionnaire Data Table (Owens, et al 2000) Key: 1= Usually, 2= Sometimes, 3= Rarely							
Subscale item	AB 1	AB 2	AB 3	AB 4	AB 5	AB 6	Mean
1.Bedtime Resistance	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test
i. Child goes to bed at the same time at night	2 1	1 1	1 1	1 1	1 N/A	1 1	1.16 1.0
ii. Child falls asleep alone in own bed	1 1	1 1	1 1	2 1	3 N/A	3 1	1.83 1.16
iii. child fall asleep in parent's or sibling's bed	3 3	3 3	3 3	3 3	3 N/A	1 1	2.66 2.6
iv. Child resists going to bed at bedtime	2 2	3 3	3 2	2 2	3 N/A	2 1	2.5 2.6
v. struggles at bedtime*	2 2	1 3	1 1	2 2	1 N/A	2 1	1.5 2.0
vi. afraid of sleep alone*	1 1	1 1	1 1	3 2	3 N/A	2 N/A	1.83 1.83
Mean Bedtime Resistance score	**1.83 1.66**	**1.66 2.0**	**1.66 1.5**	**2.16 1.83**	**2.33 N/A**	**1.83 1.5**	**1.91 1.69**
2. Sleep onset delay	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test
i. falls asleep within 20 minutes after going to bed	2 2	1 1	2 2	3 2	1 N/A	2 3	1.833 2.0
3. Sleep Duration	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test
i. child sleeps too little*	2 2	2 1	2 2	3 2	3 N/A	3 3	2.5 2.0
ii. child sleeps the right amount	2 1	1 1	3 2	3 1	3 N/A	2 3	2.33 1.6
iii. child sleeps about the same amount each day	1 1	1 1	2 2	1 1	1 N/A	2 1	1.33 1.2
Mean of Sleep Duration scores	1.66 1.33	1.33 1.0	2.33 2.0	2.33 1.33	2.33 N/A	2.33 2.33	2..05 1.59
4. Sleep Anxiety	Pre test	Pre test	Pre test	Pre test	Pre test	Pre test	Pre test

		Post test	Post test	Post test	Post test	Post test	Post test	Post test
i.	**Child needs parent in the room to fall asleep***	1 1	1 1	1 1	3 1	3 1	3 3	2.0 1.4
ii.	**Child is afraid of sleeping in the dark**	3 3	3 3	3 3	2 2	3 1	3 3	2.83 2.8
iii.	**Child has trouble sleeping away from home***	3 1	3 3	3 3	1 1	1 1	2 2	2.16 2.0
Average of Sleep Anxiety scores		2.33 2.33	2.33 2.33	2.33 2.33	2.0 1.33	2.33 N/A	2.66 2.66	2.33 2.19
5.Night waking's		Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test
i.	**Moves to others bed in night**	3 2	3 3	3 3	3 3	3 N/A	3 3	3.0 2.8
ii.	**Awakes once during night***	2 3	2 3	2 2	3 3	1 N/A	2 3	2.0 2.8
iii.	**Awakes more than once during the night***	1 2	1 1	3 2	2 1	1 N/A	3 3	1.83 1.8
Mean of Night Waking's scores		2.0 2.33	2.0 2.33	2.66 2.33	2.66 2.33	1.66 N/A	2.66 3.0	2.27 2.46
6.Parasomnias		Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test
i.	**Wets the bed at night***	1 2	1 1	1 1	3 2	3 2	3 2	3 2
ii.	**Talks during sleep**	1 1	1 1	3 1	3 2	3 2	3 2	3 2
iii.	**Restless and moves a lot***	1 N/A	1 1	3 3	3 2	3 2	3 2	3 2
iv.	**Sleepwalks**	N/A 3	3 3	3 3	3 2	3 2	3 2	3 2
v.	**Grinds teeth during sleep**	NA 3	3 3	2 2	3 2	3 2	3 2	3 2
vi.	**Awakens screaming, sweating**	3 2	3 3	1 3	3 2	3 2	3 2	3 2
vii.	**Alarmed by scary dreams**	3 2	3 3	N/A N/A	3 2	3 2	3 2	3 2
Mean of parasomnias scores		**1.28 1.85**	**2.14 2.14**	**1.85 1.85**	**2.42 2.57**	**2.14 N/A**	**3 3**	**2.5 2.2**
7.Sleep disordered breathing		Pre test	Pre test	Pre test	Pre test	Pre test	Pre test	Pre test

		Post test	Post test	Post test	Post test	Post test	Post test	Post test
i.	**Snores loudly**	NO 3	3 3	3 3	3 3	3 N/A	2 2	2.33 2.8
ii.	**Stops breathing**	NO 3	3 3	2 3	3 N/A	3 N/A	1 2	2.0 2.2
iii.	**Snorts and gasps**	NO 3	3 3	3 3	3 3	3 N/A	1 2	2.16 2.8
Mean of sleep disordered breathing scores		**NO** **3.0**	**3.0** **3.0**	**2.66** **3.0**	**3.0** **2.0**	**3.0** **N/A**	**1.33** **2.0**	**2.16** **2.6**
8.Daytime sleepiness		Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test	Pre test Post test
i.	**Wakes by himself**	1 1	1 1	1 2	1 1	1 N/A	1 1	1.0 1.4
ii.	**Wakes up in negative mood***	2 2	1 1	1 1	1 1	3 N/A	1 3	1.5 1.6
iii.	**Others wakes child**	3 3	2 3	2 1	3 2	3 N/A	3 3	2.66 2.4
iv.	**Hard time getting out of bed**	3 3	3 3	3 2	3 3	3 N/A	1 2	2.66 2.6
v.	**Takes long time to be alert**	3 3	3 3	2 3	3 3	3 N/A	2 2	2.66 2.8
vi.	**Seems tired**	2 1	2 2	2 2	2 2	1 N/A	1 1	1.66 1.6
vii.	**Watching TV**	2 2	1 2	1 2	1 1	2 N/A	2 2	1.5 1.8
viii.	**Riding in car**	3 2	2 2	2 2	1 1	1 N/A	3 2	2.0 1.8
Mean of daytime sleepiness scores		**2.37** **2.12**	**1.87** **2.37**	**1.75** **1.87**	**1.87** **1.75**	**2.12** **N/A**	**1.75** **2.0**	**1.95** **2.02**
• *** Reverse scoring of this subscale item**								

Table 6:CSHQ comparison between pre and post mean scores (Owens et al, 2000) (scale 1= usually, 2=sometimes 3= rarely)				
Numbering in original CSHQ before grouping into categories		**Subscale Item from CSHQ questionnaire**	**Mean of pre test (Three point scale)**	**Mean of post test (Three point scale)**
1	**C 1**	Child goes to bed at the same time at night	1.16	1.0
2		Child falls asleep alone in own bed	1.83	1.16
4		Child fall asleep in parent's or sibling's bed	2.66	2.6
9		Child resists going to bed at bedtime	2.5	2.2
10		Struggles at bedtime*	1.5	2.0
12		Afraid of sleep alone*	1.83	1.0
3	**C 2**	falls asleep within 20 minutes after going to bed	1.83	2.0
13	**C 3**	Child sleep too little*	2.5	2.0
15		Child sleeps the right amount	2.33	1.6
16		Child sleeps about the same amount each day	1.33	1.2
7	**C 4**	Child needs parent in the room to fall asleep*	2.0	1.4
11		Child is afraid of sleeping in the dark	2.83	2.8
27		Child has trouble sleeping away from home*	2.16	2.0
21	**C 5**	Moves to others bed in night	3.0	2.8
31		Awakes once during night*	2.0	2.8
32		Awakes more than once during the night*	1.83	1.8
17	**C 6**	Wets the bed at night*	1.33	1.4
18		Talks during sleep	1.33	1.2
19		Restless and moves a lot*	1.66	1.8
20		Sleepwalks	2.5	3.0
23		Grinds teeth during sleep	2.33	2.8
29		Awakens screaming, sweating	2.5	2.6
30		Alarmed by scary dreams	2.5	2.2
24	**C 7**	Snores loudly	2.33	2.8
25		Stops breathing	2.0	2.2
26		Snorts and gasps	2.16	2.8
34	**C 8**	Wakes by himself	1.0	1.4
36		Wakes up in negative mood*	1.5	1.6
37		Others wakes child	2.66	2.4
38		Hard time getting out of bed	2.66	2.6
39		Takes long time to be alert	2.66	2.8
44		Seems tired	1.66	1.6

46		Watching TV	1.5	1.8
47		Riding in car	2.0	1.8
***Reverse scoring of subscale item, C1: Bedtime resistance, C2: Sleep onset delay, C3:Sleep duration, C4: sleep anxiety, C5: Night waking's, C6: Parasomnias, C7: Sleep disordered breathing, C8: Daytime sleepiness**				

Table 7: Summary of demographics and outcome measures							
Child Participant gender (Age)	AB 1 M(5)	AB 2 M(5)	AB 3 F(9)	AB 4 M(8)	AB 5 M(12)	AB 6 M(4)	
Parental Sleep Environment Knowledge Questionnaire (from total of 10 questions, % of correct responses) (Appendix D)							**Mean**
Pre test	70	50	80	60	80	60	66.66
Post test	80	70	100	80	70	70	78.33
Parent Sleep Knowledge of Healthy Sleep in Children Questionnaire (Owens, et al, 2013)							
Section 2: Parents Sleep Beliefs (In % of agree responses)							
Pre test	25	75	75	0	50	80	50.83
Post test	25	50	50	25	No data	90	48.0
Section 3: Sleep Knowledge Questions (from total of 10 questions/% of correct responses)							
Pre test	90	80	70	80	100	80	83.33
Post test	100	80	70	80	No data	90	84.0
2.3 Actigraph (Number of awakenings)							
Pre test	13.43	15.29	28.43	No data	19	13.5	17.93
Post test	17.5	14.29	37.0	17.29	No data	31.14	23.44

Table 8: Parent Sleep Environment Knowledge Questionnaire (Appendix D) Analysis done by the number of correct reasoning identified by participants for each fact.	**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	4	66.66	4	66.66
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	0	3	50
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 and move through all stages of sleep.	6	100	6	100
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.	4	66.66	5	83.33
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.	4	66.66	4	66.66
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.	6	100	6	100
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 distractive noises that increase heart-rate.	4	66.66	5	83.33
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	2	33.33	5	83.33

light keeps the body from producing the melatonin hormone needed for sleep.				
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.	6	100	6	100
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.	3	50	5	83.33

Table 9: Actigraph reports
***RA: Right Ankle, RW: Right wrist, LA: Left Ankle, LW: Left wrist**

Participants code	AB- 1	AB- 2	AB-3	AB- 4	AB-5	AB-6	Average of all mean values	Average of all mean values
(Actigraph position)	Pretest (RA) Post-test (RA)	Pretest (RW) Post-test (RW)	Pretest (RW) Post-test (RW)	Pretest (LW) Post-test (LW)	Pretest (LW) Post-test (N/A)	Pretest (LW/LA) Post-test (LW)	Pretest	Post test
Latency (min)	0 0	4.86 16.29	3.71 8.29	NO DATA 8.57	0 NO DATA	0 1.71	1.71	6.97
Efficiency (%) (total sleep time x 100/ total time in bed)	91.67 93.27	88.22 87.29	65.53 69.91	NO DATA 61.55	90.67 NO DATA	93.47 80.33	85.91	78.47
Total time in bed (min)	664.29 690	666.43 661.43	685.71 722.86	NO DATA 535.71	597.57 NO DATA	640 602.86	650.83	642.57
Total sleep time (min)	609.71 641.5	590 574.14	455 502.57	NO DATA 337	543.14 NO DATA	598.25 484.86	559.22	508.01
Wake after sleep (min)	54.57 48.5	71.57 71	227 212	NO DATA 190.14	54.43 NO DATA	41.75 116.29	89.86	127.59
# of awakenings	13.43 17.5	15.29 14.29	28.43 37	NO DATA 17.29	19 NO DATA	13.5 31.14	17.93	23.44
Average awakening(min)	4.06 2.77	5 6.11	8.12 5.95	NO DATA 11.5	2.86 NO DATA	3.09 3.79	4.63	6.02

Table 10: CBBES MANUAL FINDINGS (Appendix I)	AB 1	AB 2	AB 3	AB 4	AB 5	AB 6	Mean
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
Number of Problem identified by parents independently after reading the manual in bedroom environment via the assessment checklist in CBBES manual.	3	2	5	5	No DATA	No information	3.5
Number of recommendations implemented by parents in bedroom environment independently out of 29 suggested recommendations in the manual.	6/29 (20.68%)	3/29 (10.34%)	12/29 (41.37%)	11/29 (37.93%)		2/29 (6.89%)	5.4 (18.62%)
➢ **Temperature (Number of recommendations implemented/3 possible recommendations in this category)**	0	0	2	2		0	0.8
➢ **Sound (Number of recommendations implemented/7 possible recommendations in this category)**	1	1	3	0		0	1
➢ **Bedding (Number of recommendation**	0	2	3	5		0	2

s implemented/8 possible recommendations in this category)							
➢ **Light (Number of recommendations implemented/11 possible recommendations in this category)**	5	0	4	4		2	2.6
Problem identified by researcher at follow up in bedroom environment via the assessment checklist in CBBES manual (number of problems reported)	1	2	2	2		3	2

Table 11: Results from online section of study		
Day Care Group		
Participants	**Pre Test**	**Post Test**
Percentage of correct responses	67.50(N=4)	90 (N=1)
Facebook Group		
Percentage of correct responses	55 (N=4)	56.66(N=3)
Group from India		
Percentage of correct responses	45.75(N=33)	88.88(N=18)
Percentage of correct responses from participants who did not attend workshop before doing Pre test	47.50 (N=24)	88.88 (N=18)