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Evaluation of an Ecologically Valid Group Intervention to Address Sleep Health in Families of Children With Allergic Diseases

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Abstract

Sleep issues in children with allergic diseases may be a result of illness related factors (e.g., itching, wheezing) and/or poor sleep habits due to disrupted routines and parental permissiveness. However, the ability of parents to attend a multi-session sleep intervention may be limited. Thus we examined the validity of a one-time sleep health group intervention for parents of children with allergic diseases. Ninety-three parents of children who were admitted to a two-week intensive day hospital treatment program completed measures of child sleep habits (Children's Report of Sleep Patterns), parent sleep habits (Sleep Hygiene Inventory), parent sleep quality (Pittsburgh Sleep Quality Index), and parental insomnia symptoms (Insomnia Severity Index) before the group intervention and one-month after program discharge; 54 parents attended the sleep health group. Sleep habits and sleep quality improved for both parents and children at the one-month follow-up. However, improvements were seen regardless of group attendance. Potential reasons for the lack of difference between those who did and did not participate in group are presented, and implications of this study for pediatric psychologist in practice are discussed.

Keywords

sleep; asthma; eczema; group intervention; parent; child

Sleep disruptions in children with allergic diseases (e.g., atopic dermatitis, asthma) and their parents have been consistently reported (Camfferman, Kennedy, Gold, Martin, & Lushington, 2010; Koinis-Mitchell, Craig, Esteban, & Klein, 2012). While illness related factors (e.g., itching, wheezing) may play an important role in sleep disturbances, it is also possible that poor sleep habits (e.g., inconsistent sleep schedule, caffeine use, electronics prior to bedtime) develop as a result of necessity, accommodations, and/or parental permissiveness around sleep that are commonly seen in the context of chronic illness (Pinquart, 2013; Shorer et al., 2011). Although interventions to improve bedtime problems, night wakings, and insomnia in healthy typically developing children are well established (Meltzer & Mindell, 2014; Mindell et al., 2006), there have been no studies of the effectiveness of these treatments in children with chronic illnesses, a population with unique characteristics that may impact sleep (e.g., illness related nighttime symptoms and medical

needs) (Lewandowski, Ward, & Palermo, 2011; Meltzer & Mindell, 2014; Meltzer & Moore, 2008). Further, parents of chronically ill children spend a substantial amount of time in health-care related tasks that contribute to significant caregiving burden and time constraints (**Cousino & Hazen, 2013; **McCann, Bull, & Winzenburg, 2012). As a result, many families may find it difficult to attend a multi-session treatment focused on sleep. A single-session intervention implemented in a group format, or integrated into other treatments (e.g., cognitive therapy for coping/adherence), may be preferable for time-strapped families. Thus the purpose of this study was to examine an ecologically-valid single session group intervention to improve the sleep habits, sleep quantity, and sleep quality of children with allergic diseases and their parents.

Due to severe itching, up to 83% of children with atopic dermatitis have been shown to have poor sleep quality and shortened sleep duration (Camfferman et al., 2010; Hon et al., 2005). Similarly, up to 66% of children with asthma also have sleep disturbances (Dean et al., 2010; Desager, Nelen, Weyler, & De Backer, 2005; Koinis-Mitchell et al., 2012; Strunk, Sternberg, Bacharier, & Szefer, 2002) and shortened sleep duration (Jensen et al., 2012; Sadeh, Horowitz, Wolach-Benodis, & Wolach, 1998; Stores, Ellis, Wiggs, Crawford, & Thomson, 1998). In many cases when children do not sleep, neither do their parents who are required to monitor their child's illness overnight (Moore, David, Murray, Child, & Arkwright, 2006; Reid & Lewis-Jones, 1995). However, to our knowledge, no studies have examined possible interventions to improve sleep in children with allergic diseases and their parents (Lewandowski et al., 2011; Meltzer & Mindell, 2014; Meltzer & Moore, 2008).

The basic rules of healthy sleep habits involve a consistent sleep schedule, a calm and simple bedtime routine, an environment conducive to sleep (cool, dark, comfortable, and technology free), and limited caffeine use after lunch. However, daily routines can be disrupted due to childhood illness, which in turn can also disrupt sleep (e.g., Fiese, Winter, Sliwinski, & Anbar, 2007). In addition, the literature has shown that parents may make special accommodations or become more protective when their child has a chronic illness (Pinquart, 2013; Shorer et al., 2011). While this is understandable, changes to routines and parental inconsistencies likely have a significant impact on the sleep habits of all family members. These same characteristics may also make parents reluctant to implement behavioral sleep recommendations out of concern for their child's health (e.g., increased scratching or wheezing exacerbations during extinction protocols). The role of healthy sleep habits on quantity and quality of sleep in children with chronic illnesses and their parents has also received little attention in the literature.

A small number of studies have examined group interventions for children with developmental disorders, showing benefits in terms of increased knowledge about sleep and child sleep outcomes. For example, one study that included a single 90-minute group session for young children with Down syndrome reported an improvement in maternal knowledge about sleep and child sleep behaviors (Stores & Stores, 2004). Another study examined a single 45-minute education and prevention session for children with ADHD, reporting improvements in child sleep problems 2 and 5 months post-treatment (Sciberras, Fulton, Efron, Oberklaid, & Hiscock, 2011). However, these studies included relatively small samples, and few measures of parent sleep.

Similarly, only a few studies have looked at sleep interventions for caregivers of adult patients, with all showing sleep improvements (Akkerman & Ostwald, 2004; Carter, 2006; McCurry, Logsdon, Vitiello, & Teri, 1998). However, these programs involved anywhere from two to nine sessions. Given the significant time required in parenting a child with chronic illness (**Cousino & Hazen, 2013; **McCann, Bull, & Wisenberg, 2012), multi-session interventions may not be feasible for many parents.

At [masked], families come for a two-week intensive day hospital program that provides a multi-disciplinary approach for the treatment of allergic diseases. As part of the program, parents participate in daily psychosocial groups that cover a variety of topics. One of these parent groups focuses on sleep health for children and their parents (details provided in the methods section). However, this one-time intervention could easily and realistically be implemented in nearly any hospital or health care setting. Thus the purpose of the current study was to evaluate the impact of this ecologically-valid intervention on the sleep health of children with chronic illnesses and their parents.

Methods

Study Overview

The study was approved by [masked]'s Institutional Review Board. Eligible families were approached and invited to participate. Those who agreed were consented and completed a series of questionnaires prior to the group intervention. This study utilized a single-blind intervention. As we were unable to consent all families prior to the group intervention, it was possible that some group participants were not in the study. To avoid bias in how the intervention was delivered, the group facilitator [masked] was not informed about which families were participating in the research study. One month after discharge from the medical center participants completed the same set of questionnaires online.

Participants

Families of children participating in a two-week intensive multi-disciplinary treatment program for children with allergic disease were invited to participate in the study. Eligibility criteria included 1) being the primary caregiver of the child in the day hospital program and 2) English fluency (as the intervention group was only conducted in English). During the study period there were 163 participants in the treatment program. Of those who were approached (n=131), 93% consented to be in the study and completed a series of questionnaires prior to the group intervention. There were no demographic differences between participants in the treatment program who were consented and participants who were not consented. One month after discharge 89 participants (73% of those consented) completed the second set of questionnaires online. There were no differences in demographic variables, health, or sleep between participants who completed and did not complete the second set of questionnaires.

The final sample included 77 mothers and 12 fathers and 83% of parents were White. See Table 1 for complete demographic information. All caregivers in the multidisciplinary treatment program are expected to attend the daily groups, however due to unavoidable

conflicts (e.g., a consult appointment, food allergy testing requiring parental supervision) 36 caregivers did not attend the group intervention and thus served as a natural control group. There were no demographic differences between caregivers who attended the group intervention and those who did not (Table 1).

Group Intervention

The one-hour group intervention provided sleep health education to parents/caregivers covers five primary areas. First, there is an overview of normal sleep architecture, the two-process model of sleep, and developmental sleep needs. This information is provided in order to help frame the importance of healthy sleep habits and understand the common sleep disruptors experienced by these families (e.g., children who “scratch in their sleep” every 60–90 minutes are likely having normal arousals where the itch sensation causes the scratching). Second, the consequences of deficient sleep are discussed to help frame the importance of making sleep a priority for every family member. Third, common sleep disorders and the impact of chronic illnesses on sleep are discussed. Fourth, parents are provided with basic behavioral strategies to improve sleep in children of all ages. Finally, healthy sleep habits are reviewed. Written information on these topics is provided to parents/caregivers.

Measures

Pittsburgh Sleep Quality Index (PSQI)—The PSQI is a 19-item self-report measure that evaluates adult sleep quality (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). The PSQI includes seven subscale scores (sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, sleep medications, and daytime dysfunction) as well as a global score ranging from no sleep difficulty to severe difficulties. A total score of five or higher is considered clinically significant sleep disruption and poor sleep quality, and a change of 3 or greater is considered treatment responsive (Buysse et al., 2011). The PSQI is well-validated and has demonstrated good reliability (Buysse et al., 1989; Mollaveva et al., 2015).

Insomnia Severity Index (ISI)—The ISI is a seven-item self-report measure that examines the severity of insomnia in terms of sleep onset, sleep maintenance, and early morning awakenings (Bastien, Vallieres, & Morin, 2001). It also provides information regarding an individual’s satisfaction with the current sleep pattern, interference with daily functioning, noticeable impairment due to sleep disruptions, and worries/distress caused by sleep problems. The ISI has demonstrated adequate reliability and validity (Bastien et al., 2001). A total score on the ISI of 15 or greater is considered clinically significant for moderate to severe insomnia, and a change of greater than 7 is considered clinically responsive (Morin, Belleville, Belanger, & Ivers, 2011).

Sleep Hygiene Index (SHI)—The SHI is a 13-item questionnaire developed to assess sleep habits in adults (Mastin, Bryson, & Corwyn, 2006). Items focus on commonly recommended areas of healthy sleep habits including consistent sleep schedules, napping, exercise, caffeine use, etc. Items are scored on a 5-point Likert scale from Always to Never,

with higher scores indicating poorer sleep hygiene. The SHI has been shown to be reliable and valid in community-recruited adults (Mastin et al., 2006).

Children's Report of Sleep Patterns (CRSP) – Parent Proxy Version—The CRSP is a 60-item questionnaire with three modules: Sleep Patterns, Sleep Hygiene Indices, and Sleep Disturbances Scales, and includes a parent proxy version where the parents report on the child's sleep (Meltzer et al., 2013). The Sleep Patterns module assesses bedtimes, wake times, sleep schedule regularity, night wakings, and sleep quality. For this study, the Sleep Hygiene Indices included were Caffeine Use, Activities in the Hour before Bed, Electronics Use Prior to Bedtime, and Sleep Location, and the Sleep Disturbances Scales included were Bedtime Fears/Worries and Insomnia. The Sleep Patterns module provides descriptive data, while higher scores on the Sleep Hygiene Indices and Sleep Disturbances Scales suggest poorer sleep behaviors/more sleep disturbances. The CRSP has been shown to be reliable and valid in both children (Meltzer et al., 2013) and adolescents (Meltzer et al., 2014).

Data Analytic Approach

Means and frequencies were used to provide demographic information. One-way analysis of variance (ANOVA) and chi-square analysis was used to ensure that post-treatment differences in outcomes were not due to baseline differences between participants who did and did not complete the intervention. Mixed-model ANOVA allowed us to examine changes over time (pre-post group intervention), as well as between groups (parents who did and did not participate in the interventions) for the outcome measures of parental sleep, parental insomnia, sleep hygiene, and child sleep patterns. Chi-Square and Likelihood Ratio were used to examine differences in participants whose sleep quality and insomnia symptoms improved based on the clinical cutoff scores post-treatment. To control for multiple comparisons a more conservative p-value of .001 was used to indicate a significant difference for all analyses.

Results

Preliminary Analyses

No significant differences on any demographic variable or outcome measure were found at baseline between those who participated in the sleep group and those who did not.

Parent Sleep

Mixed model analyses of variance (ANOVA) was used to examine treatment effects on measures of parent sleep quality, parent insomnia, and parent sleep hygiene. Means and standard deviations for outcome variables at pre- and post-treatment, by group, are presented in Table 2. Results revealed a significant effect for time for PSQI Total Score ($F(1,84) = 29.92, p < .001$), but did not reveal a significant interaction between time and group. In other words, parents reported improvements in sleep quality one month after discharge from the multidisciplinary treatment program, regardless of their participation in the sleep group. No significant effects for either time or group were found for parental insomnia (ISI Total Score) or parent sleep hygiene (SHI total score).

One month after discharge, 37% of parents (n=17) who participated in the group and 49% of parents (n=19) who did not participate in the group met criteria for treatment responsiveness in terms of sleep quality (PSQI). For insomnia, 17% of parents (n=9) who participated in the group and 6% of parents (n=2) who did not participate in the group met criteria for treatment responsiveness in terms of insomnia (ISI).

Child Sleep Problems

Mixed model analyses of variance (ANOVA) was used to examine treatment effects on child sleep problems, as measured by the CRSP. Results revealed a significant time effect for the Activities in the Hour Before Bed Index ($F(1, 86) = 70.64, p < .001$), the Sleep Location Index ($F(1, 86) = 12.45, p < .001$), the Use of Electronics at Sleep Onset Index ($F(1, 86) = 19.27, p < .001$), and the Insomnia Scale ($F(1, 82) = 15.20, p < .001$). No effect for treatment group was found. These results suggest that one month after discharge from the multidisciplinary treatment program children engaged in more activities in the hour before bed, but also were more likely to sleep in their own bed, use less electronics at sleep onset, and had fewer symptoms of insomnia.

Discussion

Because of the significant need for interventions to improve the sleep health of children with chronic illnesses and their parents this study examined an ecologically-valid, one-time group intervention aimed at improving sleep habits and sleep quality for both children and parents in a multi-disciplinary treatment program for allergic diseases. One of the strengths of this study was the focus on both parent and child sleep, both in the intervention and the measured outcomes. That said, while our results found an improvement in most areas of sleep measured, no statistically significant differences were found between those families who participated in the group and those who did not, for either child or parent sleep outcomes. As this was not the expected outcome, we consider some potential reasons for our findings.

One potential explanation is that the severity of the child's illness resulted in such significant sleep disruption prior to program admission, once the child's health improved through intensive medical treatments, their sleep also improved. While we do not have the corresponding medical data to support this supposition, our clinical experience suggests that improved health at discharge resulted in improved sleep for study participants, regardless of group participation. Patients who attend this tertiary care program come from all over the United States, and almost all have failed previous medical (and often behavioral) interventions to manage their illness. After participating in the two-week multi-disciplinary program almost all children are discharged with significantly improved health. For example, most parents of children with atopic dermatitis will anecdotally state that "this is the first time in my child's life that his/her skin has been clear and he/she is sleeping so much more peacefully!" Thus, it is possible that improvements in child sleep were a direct result of the improvements in the child's health, which also resulted in improved parental sleep. Future research should directly examine the potential for mediating relationships between illness severity, child sleep, and parental sleep disturbance.

Another potential explanation for our results is that the milieu environment includes down time where parents can interact in a communal space. Thus it is possible that parents who did not attend the group learned information about sleep health from parents who did attend the group. In addition, families may have discussed sleep issues with medical and psychosocial clinicians outside of group, which may have contributed to the improvements post-discharge and the lack of differences between families who did and did not attend group.

Finally, sleep disturbance is a presenting complaint for almost every child and parent who present to our program. Anecdotally, most families have tried multiple interventions to improve their child's sleep, but find the standard recommendations given by pediatricians (e.g., "cry it out" for young children, remove electronics from the bedroom for older children) are not feasible because if their child becomes upset or agitated at bedtime this can result in illness exacerbation (e.g., increased itching). Further, many parents feel compelled to co-sleep with their child to monitor their illness (e.g., prevent itching to prevent bloody sheets in the morning, be available to provide asthma treatment if needed). Thus, many families may not report their true sleep habits to pediatricians and other health providers for fear of being told they need to change their sleep-related behaviors. However, after discharge when their child's health has improved, it is possible that parents who did not attend our group finally felt comfortable seeking out information and/or implementing healthy sleep habits.

There are a number of limitations with regard to measurement and design that must be acknowledged. First, the majority of parents were White, which limits the generalizability of results. Second, the intervention was conducted in a tertiary care center for children with severe allergic disease and results therefore cannot be generalized to other illness groups, or to those with less severe allergic disease. In addition, it is possible that the content presented in our group intervention may have been overly broad. Trying to address normal sleep, the consequences of deficient sleep, healthy sleep habits, sleep disorders, and basic behavioral sleep interventions in a single one-hour session may have prevented us from seeing significant changes in sleep outcomes. Finally, sleep disturbances were assessed via parent-report only. Future research should examine the effectiveness of sleep interventions using objective measures such as actigraphy for both parents and children.

Implications for Practice

Despite these limitations and the lack of significant changes that resulted from group participation, this study highlights the impact of severe atopic dermatitis and asthma on both child parent and sleep. In addition, it is important for psychologists to work with medical teams to provide behavioral sleep interventions for both children and parents when possible, but also to highlight the importance of optimal medical management of these diseases in order to improve the sleep of both parents and children. Thus there is a need for the implementation of structured screening, assessment, and treatment of sleep disturbance not only in children with chronic illnesses, but also in their parents. Significant sleep disruptions, as those identified in this study, can have a considerable impact on child health outcomes, parent quality of life, and family functioning. Additional research is clearly

needed to develop and evaluate brief interventions that will improve the sleep of both children with chronic illnesses and their parents.

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Table 1

Demographic Variables by Treatment Group Presented at Mean (SD) or Percent (n)

	Group Intervention (n=53)	Control Group (n=36)	Test Statistic
Parent Age	37.81 (7.90)	37.92 (7.76)	F (1,88) = 0.004
Parent Years of Education	15.92 (2.18)	15.56 (1.52)	F (1,88) = 0.77
Parent Gender (% Female)	88.7% (47)	83.3% (30)	LR (1) = 0.52
Parent Race			LR (3) = 9.38
White	79.2% (42)	88.9% (32)	
Black	11.3% (6)	0% (0)	
Asian	1.9% (1)	8.3% (3)	
Other	7.5% (4)	2.8% (1)	
Child Gender (% Female)	64.2% (34)	52.8% (19)	X ² (1) = 1.15
Child Race (% White)	73.6% (39)	77.8% (28)	LR (3) = 5.06
Child Ethnicity (% Hispanic)	11.3% (6)	2.8% (1)	LR (1) = 2.46
Child Age	6.96 (5.27)	7.47 (5.09)	F (1,87) = 0.21
Child Diagnosis			X ² (2) = 2.06
Atopic Dermatitis	30.8% (16)	17.6% (6)	
Asthma	21.2% (11)	29.4% (10)	
Atopic Dermatitis + Asthma	48.1% (25)	52.9% (18)	

Table 2

Means (Standard Deviations) or Percent (n) for Outcome Variables at Baseline and Post-Treatment

	<u>Participated in Sleep Group</u>		<u>Treatment as Usual Control Group</u>	
	<u>Baseline</u>	<u>Post-Treatment</u>	<u>Baseline</u>	<u>Post-Treatment</u>
PSQI Total Score **	9.60 (4.26)	7.83 (4.45)	9.07 (3.40)	6.73 (3.11)
PSQI >5 (%/n)	82.4 (42)	64.2 (34)	88.6 (31)	52.8 (19)
ISI Total Score	12.54 (7.17)	11.65 (5.89)	10.82 (5.13)	11.17 (5.46)
ISI 15 (%/n)	42.3 (22)	28.3 (15)	17.6 (6)	27.8 (10)
SHI Total Score	46.89 (6.69)	48.55 (7.73)	46.86 (6.00)	48.95 (5.17)
CRSP Caffeine Index	4.63 (1.78)	4.50 (1.74)	4.63 (1.68)	4.69 (1.67)
CRSP ACT Index **	13.72 (3.09)	17.47 (3.20)	13.77 (3.90)	17.96 (2.96)
CRSP Sleep Location Index **	9.44 (3.66)	8.53 (3.20)	10.31 (3.74)	9.25 (2.68)
CRSP Elect Index **	5.93 (2.43)	4.85 (1.95)	5.86 (2.74)	5.21 (2.11)
CRSP Bedtime Fears/Worries Scale	3.83 (1.78)	3.33 (1.64)	3.89 (1.95)	3.78 (1.42)
CRSP Insomnia Scale **	15.55 (3.92)	13.02 (2.44)	13.61 (4.49)	12.72 (2.51)

Note. PSQI = Pittsburgh Sleep Quality Index. ISI = Insomnia Severity Index. SHI = Sleep Hygiene Index. CRSP = Children's Report of Sleep Problems. ACT = Activities in the hours before bed. Elect = Use of electronics at sleep onset.

** significant effect for time, $p < .001$.