

SLEEP DISTURBANCE AND FUNCTIONAL OUTCOMES IN CHILDREN WITH DOWN SYNDROME

Relationship between Sleep Disturbance and Functional Outcomes in Daily Life Habits of Children with Down Syndrome

Shervin S. Churchill, PhD, MPH^{1,2}; Gail M. Kieckhefer, PhD, ARNP²; Kristie F. Bjornson, PhD, PT^{3,4}; Jerald R. Herting, PhD⁵

¹Biobehavioral Nursing and Health Systems, School of Nursing, University of Washington, Seattle, WA; ²Family and Child Nursing, School of Nursing, University of Washington, Seattle, WA; ³Seattle Children's Research Institute, Seattle, WA; ⁴Pediatrics, University of Washington, Seattle, WA; ⁵Psychosocial & Community Health, School of Nursing, University of Washington, Seattle, WA

Objectives: The goal of this study was to describe sleep patterns and accomplishment of daily life habits in children with Down syndrome (DS) and to investigate the relationship between subjective indicators of sleep disturbance with functional outcomes in daily life.

Design: Cross-sectional study with an Internet sample

Setting: Online survey filled out at home

Participants: 110 parents of children with DS and 29 parents of children with typical development (TD), age 5 to 18 years.

Interventions: N/A.

Measurements and Results: Children's Sleep Habits Questionnaire was employed to collect information about sleep disturbances in 8 domains (subscales) and a total score. The Life Habits questionnaire (Life-H) sampled information about daily life habits in 11 domains. Multivariable regression modeling was used to assess the associations between sleep disturbances and the accomplishment of daily life habits. Sleep disordered breathing (SDB) was a significant explanatory factor in 10 of 11 daily life habits and the total Life-H score. Sleep anxiety and parasomnias significantly influenced the accomplishment of life habits in children with DS as compared to children with typical development. When evaluated in multivariable models in conjunction with the other 7 domains of sleep disturbances, SDB was the most dominant explanatory factor for accomplishment of life habits.

Conclusions: Sleep disturbances are negatively related to accomplishment of daily life functions. Prevention and treatment of sleep problems, particularly sleep disordered breathing, in children with Down syndrome may lead to enhanced accomplishment of daily life habits and activities.

Keywords: Down syndrome, sleep disturbance and sleep disordered breathing, accomplishment, life habits, and functional outcomes
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INTRODUCTION

Children with Down syndrome (DS) are at greater risk for obstructive sleep apnea (OSA) and other sleep disturbances than children with typical development (TD).¹ Polysomnographic studies report shorter REM duration and preponderance of stage 1 and 2 sleep, episodic oxygen desaturation, increased inspiratory resistance and stridor, increased awakenings, arousals, and body movements, and reduced high-frequency and increased low-frequency heart rate.^{2–8} Southall et al. first reported the widespread prevalence of OSA in children with DS⁴; with the prevalence of OSA in the pediatric DS population, ranging from 54% to over 90% in clinical populations,^{9–12} and from 24% to 31% in nonclinical community-living populations.^{5,13} One parent report study documented restlessness during sleep (58%), night-wakings (40%), and daytime tiredness (70%)¹⁴; another study reported loud snoring, cessation of breathing, or snorting and gasping during the night in 60% of the study sample.¹⁵ Rosen et al. underscored the need for continued monitoring for sleep disordered breathing (SDB) after surgical intervention, as 47% of parents reported witnessed apneas following adenotonsillectomy.¹⁶

While sleep problems have been reported extensively, no studies have examined the health and functional implication

of sleep disturbances in this population of children. No studies have systematically investigated the relationship of sleep with the accomplishment of usual day-to-day life habits in children with DS. The objective of this study was to measure and describe sleep characteristics and daily life habits in a group of children with DS and to examine the relationship of sleep disturbances and accomplishment of daily life habits.

A conceptual model adapted from the model of the health consequences of sleep loss by Lee et al. forms the theoretical framework for this study.¹⁷ The model posits that lack of adequate sleep, due to sleep deprivation and sleep disruption, leads to adverse health outcomes and daytime consequences such as impaired function, fatigue, impaired short-term memory and problem solving, and impaired social and family interactions. A child with disrupted sleep may be excessively tired during the day, leading to poor accomplishment of daily life habits and lower participation level in typical daily activities.

This study examines the relationship between sleep disturbance indicators and the accomplishment of day-to-day life habits. It is hypothesized that while children with DS generally have lower levels of accomplishment of daily life tasks and habits than their peers with TD, those who have sleep disturbances fare even worse on the accomplishment of life's daily habits and activities.

Key Questions

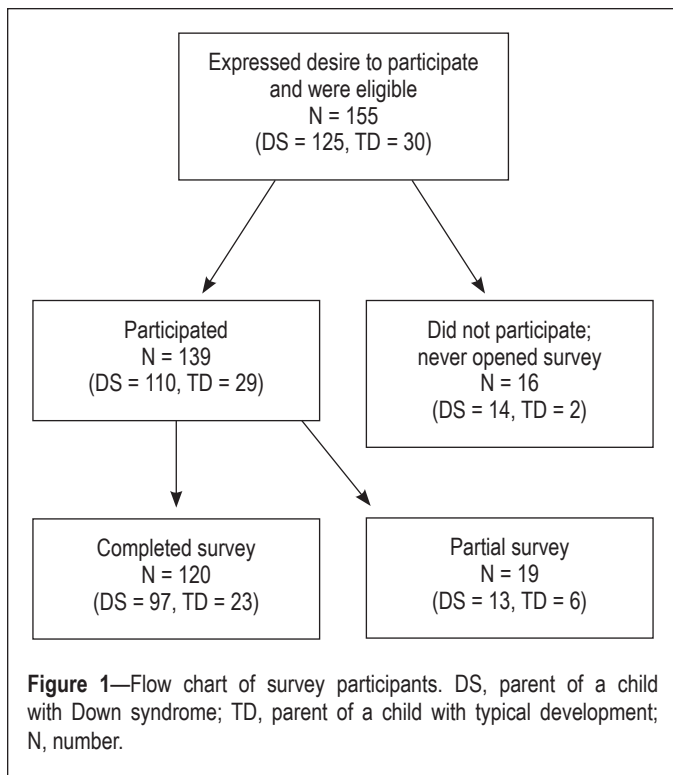
1. What are the descriptive characteristics of sleep in children with DS as compared to children with TD?
2. What are the levels of accomplishment of daily life habits and activities of children with DS as compared to children with TD?

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Address correspondence to: Shervin S. Churchill, PhD, MPH, Department of Family and Child Nursing, School of Nursing, University of Washington, Box 357262, Seattle, WA 98195-7262; Email: shervinc@uw.edu



3. What is the relationship between sleep characteristics and accomplishment of day-to-day life habits in children with DS?

METHODS

This study was approved by the Institutional Review Board at the University of Washington. A cross-sectional survey of parents of children with and without DS, ages 5 to 18 years, was conducted on the Internet. All participants received a consent form by email and provided electronic consent prior to completing the survey.

Participant Recruitment and Data Collection

The survey announcement was posted on an English language international listserv for a Down syndrome support group with a membership of approximately 700 members. The majority of listserv members were from the United States ([U.S.] 88%) and other English speaking countries—Canada, United Kingdom, Australia, and New Zealand (7%)—with the remaining 5% from countries in Europe, Asia, Middle East, and South America. The announcement was also posted on the U.S. National Down Syndrome Society’s “Directory of Current Studies,” and the greater Seattle area Down syndrome listserv and newsletter. Parents of children with DS were asked to forward the announcement to their friends and family who had children with TD. Each parent could participate only one time, reporting on only one of their children. Siblings were not allowed to be reported on by the other parent. An incentive of a \$10 or \$25 gift card (based on drawing), was offered to participants. Recruitment was carried out from June to November of 2012. Parents reported the DS or TD status of their child and the month and year of birth of the child. Child living at home with the responding parent, and English language ability

were required. Those with comorbidities were included in the study, as most children with DS and other special needs have one or more comorbid conditions present, some without the knowledge of parent.¹⁸ No recruitment quota was established; the expected number of participants was ≥ 100 parents, with a DS-to-TD ratio of 3:1.

Research Electronic Data Capture (REDCap), a secure web-based application for electronic data collection and management hosted at the University of Washington, was used for developing the Internet data collection tool and database.¹⁹

Among the 155 enrollees who received a private survey link, 139 (90%) participated. Figure 1 is a flow chart of participants, broken down by DS/TD status. Enrollees who had not opened the survey or had left it unfinished received up to 3 reminders. Lack of time, computer problems, and dislike for survey questions were reasons given by 8 enrollees who contacted the investigator and had incomplete or unopened surveys. Those with computer problems were offered the paper version of the survey by mail.

Measures

Demographic and Health Characteristics

Parents completed questions on height and weight of child, presence of siblings, frequency of exposure to tobacco smoke, and if the child had ever had any of the following: sleep study, diagnosis of sleep apnea, tonsillectomy, use of continuous positive airway pressure (CPAP) device, heart surgery, or diagnosis of gastrointestinal disease. Parent-reported height and weight were used to calculate body mass index (BMI) percentile using the Centers for Disease Control and Prevention’s (CDC) Children’s BMI Tool for Schools.²⁰ The same BMI standard was used for children with and without DS.

Sleep Characteristics

Sleep characteristics of children were determined using the well-established Children’s Sleep Habits Questionnaire (CSHQ),²¹ which has been used in numerous studies of children’s sleep, including studies of children with DS.^{14,15} The CSHQ is a 45-item questionnaire in which 33 items are grouped into 8 conceptual domains (subscales). The domains are: bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night wakings, parasomnias, SDB, and daytime sleepiness. The questions ask about the frequency of a particular sleep habit during a typical week. Each item in the subscales, for example “needs parent in the room to sleep,” is rated from 1 to 3, respectively, as “usually, 5–7 times a week,” “sometimes, 2–4 times a week,” or “rarely, 0–1 time a week.” Item scores are reversed if necessary, depending on the wording of the question, such that a higher score reflects more sleep disturbance. Subscales can range from 1–3 for a one-item domain (sleep onset delay) to 8–24 for an 8-item domain (daytime sleepiness). A total “sleep disturbance” score is calculated by the addition of all subscales (total CSHQ). Internal consistency (community sample Cronbach α [CA] 0.68; clinical sample CA 0.78), and test-retest reliability (Spearman rho range of 0.62–0.79), have been deemed acceptable for the CSHQ, which has been normed in typically developing healthy children and in clinical populations.²¹ The CSHQ includes weekday and weekend bedtime, wake time,

and duration of sleep. Details about questions comprising the subscales of the CSHQ can be found in the paper by Owens et al.²¹ The subscales of CSHQ within the present study were compared with previously published results in children with DS and TD to check for general consistency.

Accomplishment of Daily Life Habits

Daily life functional outcomes were assessed using the Life Habit questionnaire (Life-H), which is specifically designed for children with disabilities.²² The short version of this questionnaire consisting of 63 items was included in the Internet parent survey of the present study. These items form 12 domains of life habits: nutrition, fitness, personal care, communication, housing, mobility, responsibilities, interpersonal relationships, community life, education, employment, and recreation. The original domain names above are used by the authors of Life-H.²² Fauconnier and colleagues renamed several domains, making the names more closely reflective of their respective content. This manuscript uses 3 of Fauconnier's domain names.²³ The renamed domains are: "nutrition" to "mealtimes," "housing" to "home life," and "education" to "school." The employment domain, consisting of one item, was not used in the present analysis, as this domain was not applicable to most children in the study. For each item a score of 0 to 10 is possible. The item score is a composite of 2 aspects: (1) level of difficulty for the child: "no difficulty," "with difficulty," "accomplished by a proxy," and "not accomplished"; and (2) type of assistance needed to accomplish the task: "no assistance," "assistive device," "adaptation," and "additional human assistance," indicating human assistance in addition to what a typical child of the same age usually requires. The subscales and total scores are normed, weighted, and standardized, as per directions for the instrument, such that each subscale ranges from 0 to 10. A higher score indicates better accomplishment of daily life habits and activities. The psychometric qualities of Life-H have been assessed, with high intrarater reliability and intraclass correlation coefficient values ≥ 0.78 for 10 subscales and are acceptable for use in assessing children with disabilities by parent report.²² The Life-H has been used in a number of studies assessing the accomplishment of daily life habits and participation in life activities of children with disabilities,^{24,25} but it has not been used previously for assessing accomplishment of daily life habits and activities of children with DS. Details of items composing the subscales of the Life-H questionnaire are shown in the supplemental material.

Statistical Analysis

Stata software version 12.1 was used for statistical analysis.²⁶ Statistical tests were two-sided with significance level set at probability (P) < 0.05 . Descriptive demographic and health characteristics of the sample were summarized by listing means and standard deviation for continuous variables and frequencies for categorical variables. These characteristics were compared between groups with and without DS by t -tests for continuous variables, and χ^2 tests for categorical variables. Sleep characteristics derived from the CSHQ and daily life habits and activities derived from the Life-H questionnaire were summarized and compared between the 2 groups. Additionally, comparison was made by dividing all children into 2 age groups: (1) 5 to

12 years and (2) 13 to 18 years. This age grouping was based on previous studies of children with DS and children with TD using the CSHQ,^{14,21} and it reflects the notion that younger children's sleep is developmentally different than teenagers' sleep.

Regression analyses were performed to assess the relationship between sleep variables, explanatory variables, and accomplishment daily life habits and activities, the outcome variables. The goal of this assessment was to describe the trends and to test the hypothesis that sleep disturbances negatively affect the accomplishment of daily life habits. Each sleep domain variable was used independently in the models in order to assess the relationship of sleep disturbance scores without including sets of conceptually overlapping factors in the models. Three sets of ordinary least squares (OLS) regression models were run. First, models including all children with and without DS were tested to determine the association of sleep with daily life function in all children, while controlling for DS status, age, and gender. Secondly, OLS regression models were run within the DS group controlling for age and gender; and third, regression models within children with TD, controlling for age and gender. The secondary sets of models, within DS and within TD, were run to check for any interactions within these groups by age or gender. All models were tested for interaction between DS status and age, DS status and gender, and DS status and each of the independent sleep indicator variables in the model (bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night wakings, parasomnias, SDB, and daytime sleepiness, or total CSHQ score) and any interaction between age and gender. F tests were used to determine if the interaction terms significantly improved the models.

OLS regression models were run with all sleep disturbance variables, DS status, age, and gender, for Life-H outcome variables. The purpose of this analysis was to evaluate the role of SDB in conjunction with other sleep disturbance variables. Age was a continuous variable in all regression models. DS and gender were categorical variables. All outcome variables, Life-H scores, and explanatory variables, CSHQ scores, were continuous. R^2 for models was noted as an indicator of the fit of the model. Coefficients of regression and P values were reported in a regression summary table. Any interactions were noted within results. In this analysis, multiple models were tested, with 9 sleep disturbance explanatory variables and 12 Life-H outcome variables, including total scores. A Bonferroni-style correction for the P values was not adopted because this was an exploratory subjective study with theoretical backing.²⁷ Concordance of multiple models is considered confirmatory of the observed patterns.

RESULTS

Demographic, Health, and Family Characteristics

Participants were parents responding to questions about their child who lived with them at the time of the survey. A majority of respondents were from the United States, and were mothers. Table 1 summarizes the characteristics of the children. The samples of children with and without DS were balanced with respect to presence of younger and older siblings and exposure to cigarette smoke. One parent of a child with DS reported that their child had been diagnosed with autism. The scores from

that child were examined, and they did not appear to be outliers and were in the same range as other children with DS.

A majority of children with DS were male and the majority of the TD children were female. The gender imbalance and variation in age were taken into account in the statistical analyses. As expected, children with DS were more likely to be overweight, to have ever had a sleep study, ever been diagnosed with sleep apnea or gastrointestinal illness; and were more likely to have ever had tonsillectomy or heart surgery. Among children with DS, 15% had used a continuous positive air pressure device at some point, where none of the children with TD had ever used such device. Also, none of the children with typical development had ever had a sleep study, been diagnosed with sleep apnea, or had heart surgery.

Sleep Patterns

Table 2 summarizes parent-reported bedtime, wake time, and hours of sleep for weekdays and weekends by DS status. On average, children with DS had earlier wake times and bedtimes during the week and weekends, leading to significantly more hours of sleep during weeknights, largely due to significantly earlier bedtimes. There was no statistically significant difference in the amount of sleep time during weekends. The sleep disturbance variables derived from the CSHQ were summarized by DS status and age group in Table 3. Children with DS were reported to have significantly more night wakings, parasomnias, and symptoms of SDB. There were age variations in some of the indicators of sleep disturbance, but overall children with and without DS were reported to have similar bedtime resistance, sleep onset delay (> 20 min to fall asleep) and sleep anxiety. Figure S1 (supplemental material) shows a comparison between the CSHQ subscale scores attained by the present study and 2 previous studies.^{14,21}

Description Daily Life Habit Domains

Daily life habits, as characterized by the Life-H questionnaire, were compared between children with and without DS and by age group. All subscales and total score were significantly different between children with and without DS. As expected,

Table 1—Characteristics of the sample by Down syndrome status.

	DS (n = 110) mean (SD)	TD (n = 29) mean (SD)	P value t-test
Age in years	11.05 (4.25)	12.52 (3.90)	0.095
BMI percentile	72.54 (26.73)	59.16 (31.47)	0.023
	%	%	P value χ^2 test
Gender, Male	75.45	20.69	< 0.001
Age group			0.099
5 to 12 years	68.18	51.72	
13 to 18 years	31.82	48.28	
Relation of respondent to child			0.796
Mother	95.45	96.55	
Father	4.55	3.45	
Siblings			0.783
None	13.76	13.79	
Younger sibling(s) only	28.44	37.93	
Older sibling(s) only	35.78	31.03	
Younger and older siblings	22.02	17.24	
Country of residence USA	90%	100%	0.790
At risk or obese (BMI % \geq 85)	48.18	31.03	0.098
Obese (BMI % \geq 95)	28.18	6.9	0.017
Ever had a sleep study	48.18	0	< 0.001
Ever diagnosed with sleep apnea	34.55	0	< 0.001
Ever had tonsillectomy	55.45	6.9	< 0.001
Ever had heart surgery	22.73	0	0.005
Ever diagnosed with GI disease	21.82	3.45	0.022
Ever used CPAP	15.45	0	0.024
Using CPAP now	6.36	N/A	N/A
Exposure to cigarette smoke			0.205
Not at all	95.45	86.21	
Rarely: 1–2 times a month	2.73	10.34	
Occasionally: 1–2 times a week	0.91	3.45	
A few days a week: 3–4 times	0.91	0	
5–7 days a week	0	0	

DS, Down syndrome; TD, typical development; SD, standard deviation; BMI, body mass index; CPAP, continuous positive air pressure; GI, gastrointestinal.

Table 2—Weekday and weekend bedtime, wake time, and parent-reported hours of sleep, by Down syndrome status.

	Down syndrome		Typical development		P value
	mean (SD)	range	mean (SD)	range	
Weekday wake time	6:32 AM (42 m)	4:36–8:00 AM	6:46 AM (58 m)	5:00–10:00 AM	0.164
Weeknight bedtime	8:34 PM (47 m)	6:30–10:30 PM	9:25 PM (76 m)	7:45 PM–12:00 AM	< 0.001
Weekday hours of sleep	9 h 26 m (69 m)	6 h 30 m–12 h 0 m	8 h 49 m (95 m)	5 h 0 m–13 h 0 m	0.026
Weekend wake time	7:11 AM (63 m)	5:00–10:00 AM	8:32 AM (84 m)	6:30–11:00 AM	< 0.001
Weekend bedtime	9:10 PM (61 m)	7:00–12:00 AM	10:38 PM (88 m)	8:00 PM–1:00 AM	< 0.001
Weekend hours in bed	9 h 32 m (76 m)	6 h 0 m–12 h 0 m	9 h 40 m (83 m)	6 h 0 m–13 h 0 m	0.655

SD, standard deviation; h, hours; m, minutes.

Table 3—Means and standard deviations for CSHQ subscales, by DS status and age group; P values for difference between DS and TD within age group.

Sub-scales of CSHQ (range)	Ages 5 to 12 years			Ages 13 to 18 years			All ages, 5 to 18 years		
	DS (n = 68–75)	TD (n = 13–15)	P value	DS (n = 32–35)	TD (n = 12–14)	P value	DS (n = 100–110)	TD (n = 25–29)	P value
	mean (SD)	mean (SD)		mean (SD)	mean (SD)		mean (SD)	mean (SD)	
Bedtime resistance (6–18)	8.38 (2.28)	7.43 (2.41)	0.160	6.50 (1.14)	6.69 (0.85)	0.586	7.80 (2.17)	7.07 (1.84)	0.116
Sleep onset delay (1–3)	1.36 (0.63)	1.47 (0.64)	0.572	1.26 (0.51)	1.36 (0.63)	0.598	1.33 (0.60)	1.41 (0.63)	0.524
Sleep duration (3–9)	4.84 (1.77)	4.00 (1.53)	0.113	4.06 (1.39)	5.17 (1.75)	0.035	4.60 (1.70)	4.56 (1.71)	0.920
Sleep anxiety (4–12)	6.29 (1.77)	6.64 (2.17)	0.521	4.97 (1.19)	4.58 (1.16)	0.337	5.86 (1.71)	5.69 (2.04)	0.667
Night Wakings (3–9)	6.27 (1.17)	5.36 (0.63)	0.006	5.79 (1.19)	5.58 (0.67)	0.578	6.12 (1.19)	5.46 (0.65)	0.008
Parasomnias (7–21)	10.24 (2.03)	8.69 (1.65)	0.012	9.64 (1.65)	8.00(2.13)	0.010	10.04 (1.93)	8.36 (1.89)	< 0.001
SDB (3–9)	4.16 (1.64)	3.43 (1.16)	0.117	4.66 (1.56)	3.33 (0.89)	0.008	4.32 (1.63)	3.38 (1.02)	0.006
Daytime sleepiness (8–24)	13.00 (2.63)	13.00 (2.52)	1.00	13.22 (1.85)	11.58 (1.78)	0.012	13.07 (2.40)	12.32 (2.27)	0.160
Total CSHQ score (33–99)	52.41 (7.16)	47.64 (9.50)	0.034	49.06 (6.41)	46.17 (7.08)	0.200	51.35 (7.07)	46.96 (8.34)	0.007

DS, Down syndrome; TD, typical development; CSHQ, Children's Sleep Habits Questionnaire; n, number; SD, standard deviation; SDB, sleep disordered breathing.

Table 4—Comparison of Life-H scores between DS and TD groups.

Life-H subscales	Ages 5 to 12 years		Ages 13 to 18 years		All ages, 5 to 18 years	
	DS (n = 71/75) mean (SD)	TD (n = 13/15) mean (SD)	DS (n = 33/35) mean (SD)	TD (n = 12/14) mean (SD)	DS (n = 104/110) mean (SD)	TD (n = 25/29) mean (SD)
Nutrition	5.72 (2.56)	9.36 (1.32)	6.36 (1.86)	9.61 (1.06)	5.93 (2.37)	9.48 (1.18)
Fitness	7.00 (2.19)	10.00 (0.00)	7.71 (1.97)	9.46 (0.94)	7.23 (2.14)	9.75 (0.68)
Personal Care	4.74 (2.33)	9.35 (0.89)	6.43 (1.77)	9.70 (0.77)	5.30 (2.30)	9.52 (0.83)
Communication	4.75 (2.11)	9.65 (0.60)	5.90 (2.41)	9.60 (0.93)	5.13 (2.27)	9.63 (0.76)
Housing	7.90 (1.78)	9.93 (0.26)	8.30 (1.13)	9.70 (0.68)	8.03 (1.60)	9.82 (0.51)
Mobility	5.49 (2.17)	9.51 (1.02)	6.45 (2.09)	10.00 (0.00)	5.81 (2.18)	9.75 (0.76)
Responsibility	3.79 (2.39)	8.93 (1.93)	4.31 (2.41)	9.42 (1.32)	3.96 (2.40)	9.17 (1.65)
Interpersonal relations	8.03 (2.30)	9.76 (0.61)	7.91 (2.17)	9.43 (1.39)	7.99 (2.24)	9.60 (1.05)
Community life	4.73 (2.82)	10.00 (0.00)	4.68 (3.07)	9.00 (1.85)	4.71 (2.89)	9.50 (1.37)
Education	5.04 (2.00)	9.91 (0.32)	6.15 (1.99)	9.19 (1.73)	5.40 (2.06)	9.58 (1.21)
Recreation	5.39 (2.42)	9.91 (0.32)	6.35 (2.13)	9.44 (1.19)	5.71 (2.36)	9.68 (0.87)
Total Life-H score	5.71 (1.75)	9.67 (0.45)	6.26 (1.57)	9.45 (1.05)	6.44 (1.49)	9.47 (1.02)

Children with DS had significantly lower scores ($P < 0.01$) than children with TD in all domains and across all age groups. Life-H, Life Habit Questionnaire; DS, Down syndrome; TD, typical development; n, number; SD, standard deviation.

the scores for children with DS were generally normally distributed with a wider range and larger standard deviations, compared to the tighter range, smaller standard deviations, and skewed distribution of scores towards the higher end for children with TD. Table 4 contains a summary of Life-H scores and standard deviations.

Association between Sleep Disturbance and Accomplishment of Daily Life Habits

As expected, DS status was a highly significant explanatory factor in all domains of Life-H. Tables 5A and 5B summarize the results of these analyses. Below, results are described for each sleep disturbance subscale; a brief definition of the subscale is included. All but 3 of the associations between sleep indicators and Life-H outcomes (one positive and two zeros, Table 5A) were negatively associated with Life-H.

Bedtime resistance refers to a child's delaying or refusing to go to bed through various behaviors, resulting in a potentially shorter duration of sleep. Bedtime resistance was significantly associated with lower accomplishment scores in mealtimes,

fitness, personal care, relationships, community life, school, and total Life-H score. The Life-H domain most associated with this score was community life; for every point increase in the bedtime resistance score there was a 0.52-point decrease in community life score.

Sleep onset delay was defined as not falling asleep within 20 minutes of going to bed. This subscale was not significantly associated with any of the Life-H accomplishment scores in this study. There was a positive association between sleep onset delay and mobility; this relationship was not statistically significant. There were no differences in sleep onset delay by age, gender, or DS status.

Sleep duration is a measure of parents' perception of the adequacy of the length of sleep a child gets at night and if that amount of sleep is consistent from night to night. Sleep duration was significantly associated with accomplishment of mealtime habits, personal care, responsibilities, and community life for all children with and without DS. Sleep duration was significantly and negatively associated with community life in children with DS; for every point increase in sleep duration

Table 5A—Multivariable regression results: coefficients for life habit outcomes, DS, age, and gender; significance, and R²

Explanatory variable (score range)	Outcomes					
	Mealtimes	Fitness	Personal Care	Communication	Home life	Mobility
Bedtime resistance (6–18)	-0.30 ***	-0.38 ***	-0.30 ***	-0.12	-0.02	-0.09
DS presence	-2.75 ***	-1.96 ***	-3.37 ***	-4.13 ***	-1.64 ***	-3.67 ***
Age, years	0.05	0.02	0.16 ***	0.08	0.02	0.08 *
Gender, male	-0.60	-0.29	-0.39	-0.11	-0.11	0.01
R ²	0.37	0.32	0.53	0.45	0.18	0.40
Sleep Onset Delay (1–3)	-0.30	-0.32	-0.22	-0.39	-0.03	0.24
DS presence	-2.94 ***	-2.12 ***	-3.67 ***	-4.28 ***	-1.73 ***	-3.78 ***
Age, years	0.09 *	0.04	0.20 ***	0.09 **	0.02	0.10 **
Gender, male	-0.94 **	-0.72 *	-0.57	-0.19	-0.05	-0.06
R ²	0.33	0.23	0.48	0.45	0.19	0.41
Sleep duration (3–9)	-0.27 **	-0.15	-0.24 **	-0.16	-0.11	-0.04
DS presence	-2.71 ***	-1.92 ***	-3.45 ***	-4.08 ***	-1.60 ***	-3.92 ***
Age, years	0.09 **	0.04	0.21 ***	0.10 **	0.02	0.09 *
Gender, male	-1.13 **	-0.87 **	-0.85 **	-0.40	-0.18	-0.04
R ²	0.35	0.24	0.52	0.45	0.19	0.41
Sleep anxiety (4–12)	-0.19 *	-0.34 ***	-0.26 **	-0.09	-0.07	-0.19 *
DS presence	-2.88 ***	-2.06 ***	-3.48 ***	-4.17 ***	-1.64 ***	-3.69 ***
Age, years	0.05	-0.01	0.17 ***	0.08	0.01	0.07
Gender, male	-0.71	-0.45	-0.59	-0.13	-0.06	0.02
R ²	0.34	0.28/0.31	0.52	0.45	0.19	0.42
Night Wakings (3–9)	-0.22	-0.37 **	-0.15	-0.31 *	-0.08	-0.12
DS presence	-2.85 ***	-1.89 ***	-3.56 ***	-4.08 ***	-1.68 ***	-3.67 ***
Age, years	0.07	0.02	0.20 ***	0.09 *	0.02	0.08 *
Gender, male	-0.85 *	-0.67 *	-0.57	-0.22	-0.06	-0.11
R ²	0.33	0.26	0.49	0.46	0.19	0.40
Parasomnias (7–21)	-0.33 ***	-0.35 ***	-0.25 ***	-0.03	-0.05	-0.12
DS presence	-2.24 ***	-1.46 ***	-3.12 ***	-4.10 ***	-1.54 ***	-3.66 ***
Age, years	0.08 *	0.03	0.19 ***	0.09 *	0.02	0.09 *
Gender, male	-0.85 *	-0.58	-0.60	-0.20	-0.10	0.03
R ²	0.37	0.31	0.51	0.43	0.19	0.41
SDB (3–9)	-0.29 **	-0.29 ***	-0.28 **	-0.09	-0.40 ***	-0.26 **
DS presence	-2.73 ***	-1.93 ***	-3.35 ***	-4.18 ***	-1.38 ***	-3.55 ***
Age, years	0.09 *	0.04	0.20 ***	0.09 *	0.04	0.09 **
Gender, male	-0.71	-0.43	-0.50	-0.19	-0.09	0.14
R ²	0.35	0.27	0.51	0.46	0.34	0.42
Daytime sleepiness (8–24)	-0.10	-0.11	-0.03	-0.04	0.00	-0.09
DS presence	-2.82 ***	-1.99 ***	-3.44 ***	-4.04 ***	-1.68 ***	-3.57 ***
Age, years	0.08 *	0.04	0.20 ***	0.10 **	0.02	0.10 **
Gender, male	-0.89 *	-0.59	-0.74 *	-0.27	-0.13	-0.03
R ²	0.33	0.23	0.48	0.44	0.19	0.39
Total CSHQ (33–99)	-0.08 ***	-0.07 ***	-0.07 ***	-0.01	-0.03	0.00
DS presence	-2.52 ***	-1.76 ***	-3.23 ***	-4.14 ***	-1.51 ***	-3.75 ***
Age, years	0.08 *	0.03	0.19 ***	0.09 **	0.01	0.09 **
Gender, male	-0.84 *	-0.59	-0.67 *	-0.24	-0.12	-0.12
R ²	0.37	0.28	0.52	0.45	0.21	0.40

*** P ≤ 0.01; ** P > 0.01 and P ≤ 0.05; * P > 0.05 and P ≤ 0.10.

subscale (higher score is worse) there was a 0.35-point decrease in community life score.

Sleep anxiety is a measure of negative and fearful feelings at sleep time, at home or away from home, potentially leading to a lack of adequate sleep. Sleep anxiety was significantly related to fitness, personal care, relationships, community life, school, and the total Life-H score. Sleep anxiety was one of

2 explanatory sleep disturbance variables (the other was parasomnias) where there was a statistically significant difference between children with and without DS in influence of the measure on one or more of the Life-H accomplishment outcomes. For example, every point increase in the sleep anxiety score was associated with a 0.43-point decrease in the fitness score among children with DS. The corresponding regression

Table 5B—Multivariable regression results: coefficients for life habit outcomes, DS, age, and gender; significance and R²

Explanatory variable (score range)	Outcomes					
	Responsibilities	Relationships	Community Life	School	Recreation	Total Life-H
Bedtime resistance (6–18)	-0.12	-0.26 **	-0.52 ***	-0.30 ***	-0.15	-0.25 ***
DS presence	-4.92 ***	-1.34 **	-4.10 ***	-3.59 ***	-3.15 ***	-3.03 ***
Age, years	0.04	-0.09 *	-0.10	0.06	0.12 **	0.04
Gender, male	0.01	-0.22	-0.39	-0.30	-0.96	-0.38
R ²	0.45	0.15	0.41	0.49	0.41	0.51
Sleep Onset Delay (1–3)	-0.32	-0.14	-0.49	-0.31	-0.40	-0.16
DS presence	-5.10 ***	-1.45 **	-4.47 ***	-3.81 ***	-3.27 ***	-3.26 ***
Age, years	0.05	-0.06	-0.04	0.11 **	0.13 ***	0.07 *
Gender, male	-0.10	-0.52	-0.77	-0.55	-1.15 ***	-0.54 ***
R ²	0.46	0.12	0.35	0.45	0.42	0.48
Sleep duration (3–9)	-0.30 **	-0.19	-0.35 **	-0.18 *	-0.21 *	-0.19 **
DS presence	-5.34 ***	-1.44 **	-4.30 ***	-3.59 ***	-3.17 ***	-3.19 ***
Age, years	0.04	-0.06	-0.04	0.10 **	0.14 ***	0.07 *
Gender, male	-0.03	-0.55	-0.95	-0.75	-1.22 ***	-0.65 *
R ²	0.50	0.14	0.36	0.45	0.42	0.50
Sleep anxiety (4–12)	-0.18	-0.32 ***	-0.55 ***	-0.23 **	-0.10	-0.24 ***
DS presence	-4.98 ***	-1.41 ***	-4.21 ***	-3.72 ***	-3.21 ***	-3.11 ***
Age, years	0.03	-0.10 **	-0.10 *	0.07	0.11 **	0.04
Gender, male	0.04	-0.38	-0.69	-0.50	-0.99 **	-0.52
R ²	0.46	0.17	0.41	0.46	0.41	0.52
Night Wakings (3–9)	-0.44 **	-0.31 *	-0.53 **	-0.41 ***	-0.25	-0.28 **
DS presence	-4.80 ***	-1.25 **	-4.14 ***	-3.53 ***	-3.10 ***	-3.09 ***
Age, years	0.03	-0.07	-0.08	0.08 *	0.12 **	0.05
Gender, male	-0.13	-0.55	-0.09	-0.56	-1.16 ***	-0.50
R ²	0.48	0.14	0.37	0.48	0.42	0.49
Parasomnias (7–21)	-0.21 *	-0.30 ***	-0.24 *	-0.22 **	-0.16	-0.18 **
DS presence	-5.02 ***	-1.04 *	-3.88 **	-3.31 ***	-2.89 ***	-2.87 ***
Age, years	0.03	-0.07	-0.05	0.09 **	0.12 ***	0.06 *
Gender, male	0.16	-0.36	-0.71	-0.54	-1.07 **	-0.52
R ²	0.49	0.19	0.35	0.46	0.41	0.50
SDB (3–9)	-0.40 ***	-0.24 **	-0.38 **	-0.26 **	-0.36 ***	-0.28 ***
DS presence	-4.80 ***	-1.32 **	-4.25 ***	-3.61 ***	-3.01 ***	-3.07 ***
Age, years	0.05	-0.07 *	-0.06	0.09 **	0.13 ***	0.05
Gender, male	0.09	-0.23	-0.47	-0.39	-0.84 *	-0.33
R ²	0.51	0.16	0.40	0.47	0.44	0.53
Daytime sleepiness (8–24)	-0.17 *	-0.13	-0.21 *	-0.17 **	-0.07	-0.09
DS presence	-4.82 ***	-1.31 **	-4.12 ***	-3.52 ***	-3.11 ***	-3.04 ***
Age, years	0.06	-0.05	-0.02	0.12 ***	0.14 ***	0.08 **
Gender, male	0.01	-0.36	-0.69	-0.44	-1.08 **	-0.51
R ²	0.46	0.12	0.34	0.46	0.40	0.47
Total CSHQ (33–99)	-0.06 **	-0.06 **	-0.12 ***	-0.08 ***	-0.04	-0.05 **
DS presence	-4.74 ***	-1.19 **	-3.67 ***	-3.38 ***	-3.08 ***	-2.89 ***
Age, years	0.04	-0.07	-0.07	0.08 **	0.12 **	0.06
Gender, male	-0.12	-0.45	-0.85	-0.54	-0.12 **	-0.61 *
R ²	0.47	0.15	0.4	0.49	0.42	0.51

*** P ≤ 0.01; ** P > 0.01 and P ≤ 0.05; * P > 0.05 and P ≤ 0.10.

coefficient for children with TD was -0.04, meaning that while for all children there was a statistically significant decrease in fitness score, the slope of the regression line was significantly steeper for children with DS. This was determined by the significance of the interaction term for DS and sleep anxiety (DS [0 or 1] × sleep anxiety score) within the multivariable model (F test P value < 0.05). The addition of the interaction term

significantly increased the fit of the model (from R² = 0.28 to R² = 0.31).

Night wakings are a measure of the frequency of a child's wakings through the night and if the child moves to a sibling's or a parent's bed, disturbing the child's sleep (not to mention the sibling's or the parent's). Night wakings were significantly and negatively associated with fitness, responsibilities, community

Table 6—Coefficients and significance for life habit outcomes in multivariable regression models.

Explanatory variables	Models for Outcomes					
	Mealtimes	Fitness	Personal Care	Communication	Home life	Mobility
DS presence	-2.06**	-1.28**	-3.10**	-3.80**	-1.51**	-3.54**
Age, years	0.01	-0.05	0.15**	0.07	0.04	0.07
Gender, male	-0.53	-0.18	-0.35	-0.55	0.18	0.46
Bedtime resistance	-0.15	-0.22	-0.37**	0.21	0.04	0.24
Sleep onset delay	0.18	-0.27	0.01	-0.06	0.10	0.45
Sleep duration	-0.04	0.21*	-0.05	-0.10	0.00	0.07
Sleep anxiety	0.00	-0.07	0.04	-0.19	-0.06	-0.34*
Night wakings	-0.17	-0.28	0.05	-0.30	0.04	-0.15
Parasomnias	-0.14	-0.09	-0.08	0.06	0.14	0.04
SDB score	-0.26	-0.29**	-0.31**	-0.01	-0.55**	-0.18
Daytime sleepiness	-0.01	0.01	0.13	0.00	0.03	-0.07
R²	0.38	0.35	0.55	0.47	0.41	0.45

Explanatory variables	Models for Outcomes					
	Responsibilities	Relationships	Community Life	School	Recreation	Total Life-H
DS presence	-4.76**	-0.82	-3.90**	-3.08**	-2.66**	-2.75**
Age, years	0.02	-0.08	-0.14**	0.04	0.10*	0.02
Gender, male	0.33	-0.19	-0.44	-0.14	-0.72	-0.27
Bedtime resistance	0.19	-0.06	-0.19	-0.24	0.07	-0.07
Sleep onset delay	-0.14	0.01	-0.48	-0.35	-0.19	-0.07
Sleep duration	-0.09	-0.04	-0.06	0.06	0.04	0.00
Sleep anxiety	-0.16	-0.04	-0.35	0.05	-0.05	-0.11
Night wakings	-0.45**	-0.24	-0.39	-0.35*	-0.33	-0.21
Parasomnias	0.03	-0.15	0.24	0.01	0.00	0.03
SDB score	-0.33*	-0.14	-0.40*	-0.29*	-0.35**	-0.26**
Daytime sleepiness	-0.05	0.01	0.02	-0.04	0.01	0.00
R²	0.56	0.19	0.46	0.50	0.44	0.55

All explanatory sleep variables (CSHQ subscales) are in models, controlled for DS status, age, and gender **P ≤ 0.05; *P > 0.05 and P ≤ 0.10.

life, and school. For example, children with DS had a 0.48-point decrease (0.44 for all children) in responsibilities score for every point increase in night wakings score.

Parasomnias score consists of a measure of various unconscious and generally undesirable, behaviors during sleep such as sleep talking, bedwetting, and grinding teeth,²⁹ which compromise the quality of one’s sleep. Parents of children with DS reported more parasomnias than parents of children with TD. Parasomnias were associated in lower accomplishment scores in mealtimes, fitness, personal care, relationships, school, and the total Life-H score. In children with DS, every point increase in parasomnias score was associated with a 0.43-point decrease in the fitness score, where for children with TD the slope was in the opposite direction with a nonsignificant slope of +0.04. The interaction term for DS and parasomnias (DS [0 or 1] × parasomnias score) was significant in the multivariable model, indicating a significant difference between the coefficients of regression for children with and without DS. The addition of the interaction term significantly increased the R² from 0.31 to 0.33 (F test P value < 0.05). When measured in all children without considering the interaction described, the coefficient of regression was a statistically significant 0.35-point decrease in

the Life-H fitness score for every point increase in the CSHQ parasomnias score.

Sleep disordered breathing score measures the symptoms of SDB: snoring, temporary cessation of breathing, snorting, and gasping. SDB is the general term for conditions like obstructive sleep apnea that involve abnormal breathing patterns during sleep. The SDB score was a significant explanatory factor for 10 of 11 Life-H accomplishment scores in children with DS: fitness, personal care, home life, mobility, responsibilities, school, and recreation, in addition to being an explanatory factor for the total Life-H score. Most significantly SDB was associated with scores for accomplishment in home life and responsibilities, where for every point increase in the SDB score there was a decrease of 0.42 to 0.44 points on the Life-H accomplishment score for children with DS and 0.40 for all children.

Daytime sleepiness is the parent’s perception of how tired a child seems during the day. Daytime sleepiness was significantly associated with a single Life-H subscale in this study: accomplishment in school in all children. Children with DS had a 0.19-point decrease (0.17 for all children) in the Life-H school score for every point increase in the daytime sleepiness score.

Total CSHQ sleep disturbance score was significantly associated with accomplishment in mealtimes, fitness, personal care, responsibilities, relationships, community life, school, and the total Life-H score. The effect sizes ranged from a 0.06 to 0.12-point decrease in the accomplishment score for every point increase the total CSHQ score, a smaller point decrease than individual categories of sleep variables such as SDB and sleep anxiety; but the total CSHQ score has a large range of 33–99 points.

The Role of SDB Score among Other Sleep Disturbance Variables

Table 6 shows the results of a series of multivariable regression models, where the significance of the SDB score was tested against other sleep disturbance variables with all of the Life-H outcomes. The models were controlled for DS status, age, and gender. The SDB score demonstrates a consistent pattern of negative association with all Life-H outcomes, with the exception of the communication score in Life-H.

DISCUSSION

This is the first study to measure the association between sleep disturbances and the accomplishment of daily life activities in children with Down syndrome. Our findings show that sleep disturbances are negatively associated with the accomplishment of daily activities. Children with higher scores on sleep disturbance scales had lower scores for Life-H activity indicators. Specifically, increase in SDB score was significantly associated with lower scores in 10 of 11 Life-H domains. Sleep duration score was significantly higher for older (13–18 years) children with TD, indicating shorter sleep time in this group and longer sleep duration in the DS group; but daytime sleepiness score was significantly greater in children with DS in the same age range, potentially indicating more fragmented sleep due to SDB. Sleep disordered breathing was a significant explanatory factor in all domains of life habits in children with DS, with the exception of communication. The significance of SDB in the models presented in Table 6 is consistent with the association of SDB with other sleep problems,^{32,33} such as night wakings, length of sleep duration, parasomnias, and even sleep anxiety and bedtime resistance, where breathing difficulty could be thought of as an instigator for these additional disturbances which are behavioral rather than physiological (such as SDB).

This analysis shows that the presence of SDB in the models where other sleep variables are included generally overpowers the other sleep factors. The statistical significance of these models and the efficiency of the models are of marginal importance in this analysis; rather the consistent pattern of SDB is of significance. The number of explanatory factors in these models is 11 and reasonably intercorrelated, which makes the standard errors for explanatory variables large and thus makes it more difficult and more conservative to achieve statistical significance.

The presence of SDB and other sleep problems in this population is consistent with previous reports,^{14,15} pointing to the necessity of uncovering the implications of sleep disturbances on daily life activities in children with DS. Children without DS had similar sleep disturbances; however, in children with DS the effects are compounded by the underlying developmental delay. In all models, DS status was a strong statistically significant

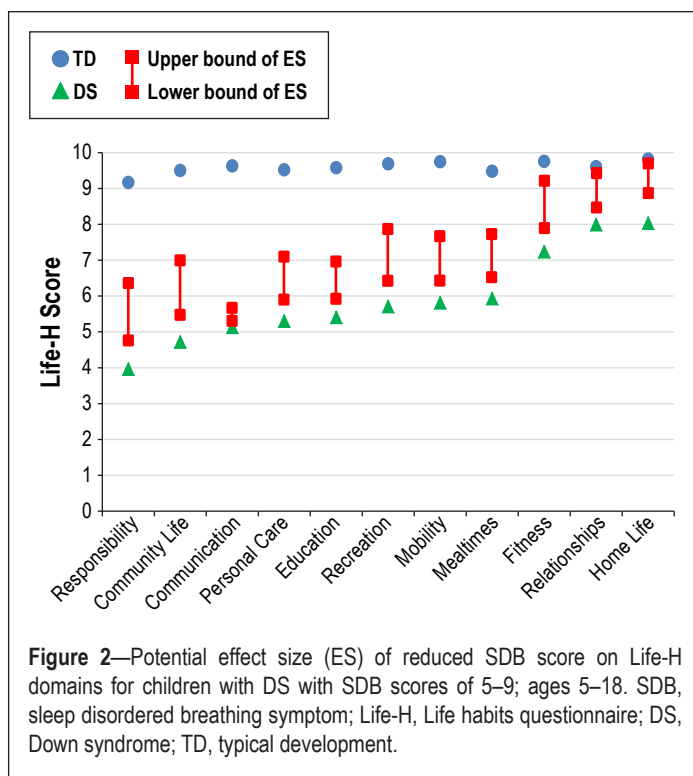


Figure 2—Potential effect size (ES) of reduced SDB score on Life-H domains for children with DS with SDB scores of 5–9; ages 5–18. SDB, sleep disordered breathing symptom; Life-H, Life habits questionnaire; DS, Down syndrome; TD, typical development.

factor in the Life-H scores. None of the sleep disturbance indicators was a significant explanatory factor in communication skills of children with DS. Communication difficulties in DS are generally extensive, complex, and related to oral motor and hearing skills.³⁴ Further studies are necessary for understanding the etiology of communication problems and any potential relation to sleep.

It is known, as demonstrated in these models, that children with Down syndrome generally function on a lower level than children with TD. However, the presence of Down syndrome, while a very important explanatory factor, may not be the only factor that determines functional and accomplishment outcomes in children with DS, according to these results. This may be a key clinical issue for youth with DS, as it is known that sleep disturbances in the general population of children are linked to decreased effective function in daily activities and mood impairments, behavior, and daily performance.^{35,36} If part of the deficiency in accomplishing daily activities in DS can be mitigated by improved sleep, it is critical to understand the potential relationship between sleep and daytime function within this population. Resolving sleep disturbances through clinical treatment may lead to enhanced daily function and improved quality of life for children and their families. Since adequate sleep is associated with better cognitive performance and learning, improvements in these domains might further support the child's active participation in developmentally appropriate accomplishment of day-to-day life habits.³⁵

The present study provides support for the hypothesis that sleep disturbances are important explanatory factors influencing several functional outcomes in children with Down syndrome. The magnitude of this influence could be significant, potentially translating into a 20%+ improvement in scores of several life habits based on observations in this study. Figure 2 shows the

estimated potential effect size in improvement in Life-H scores for children with the highest SDB scores. An improvement in Life-H scores due to decrease in SDB symptoms could potentially translate into a better life quality.

Factors not measured within this study may influence Life-H outcomes: a child's intellectual level, availability and intensity of educational interventions, family behaviors and environment, general health, and presence of thyroid disease, to name a few. Income and race information were not collected; it was outside the scope of the study to investigate the effects of these potentially confounding factors. Other known and unknown factors might also influence accomplishment of daily life habits and activities. The methodology in this study was subjective, relying on parent report; however, well-established and previously tested questionnaire tools were used to conduct the study. As with other parent report studies of sleep in children, if parents do not necessarily sleep in the same room as their child or are deep sleepers, the parents may not know about gasps, snoring, or other SDB symptoms and parasomnias in their child.

The imbalance in sample size for DS and TD limits interpretations about the TD group; nevertheless, this is the only study of its type to date that has related CSHQ to Life-H in children with typical development. The trends for the relationship of sleep disturbances with accomplishment of life habits are similar to children with DS, but statistical significance could not be achieved for observations within the TD group because of the small sample size of TD and the small effect sizes in the TD group. A larger sample size similar to the DS sample might have produced statistically significant levels of association between Life-H and sleep indicators for children with TD. For certain sleep indicators and age groups, the CSHQ scores for children with TD were similar to those of children with DS, potentially indicating increased sleep problems in TD populations as indicated by recent studies³⁰; or it is possible that parents of children with TD *and* sleep problems may have self-referred. Another limitation is that the DS sample consisted of mostly boys and the TD sample consisted of mostly girls; although gender was controlled for in regression analyses, the gender bias may explain some of the differences in Life-H. The questionnaires were originally developed for younger ages of children—CSHQ for children 4 to 12 years, and Life-H for children 5 to 13 years. The present study included children up to 18 years old. These questionnaires have, however, both been used previously in older populations of children with disabilities.^{14,31} Of note, one domain in the Life-H questionnaire, the "fitness" domain, includes questions about sleep. There is need for refinement of this Life-H domain for use within studies that investigate sleep.

This exploratory analysis aimed to find potential avenues for intervention to improve outcomes in children. The exploratory nature of this analysis justifies the development of over 100 models, considering all sleep disturbance subscales and Life-H outcomes. Total scores alone could have been tested in Life-H and CSHQ; however, total scores would have only shown general trends without specifically pinpointing problem areas. This analysis showed the significant influence of SDB in accomplishment of life habits in children with DS, showing a consistent pattern, even if not always statistically significant. SDB has been known as a major problem in Down syndrome since

the 1980s; this analysis shows that SDB could be implicated in poor accomplishment of daily life habits and activities in children with DS, over and above the contribution of the genetic condition itself.

CONCLUSIONS

Unlike many studies of sleep in children with DS, the Internet sample for this study did not represent a clinical population, but included parents from 21 US states and 6 other countries. The results may be generalizable to community-living children with DS. To date, this investigation has the largest sample for a parent-report study of sleep in children with DS. For the first time, this study has demonstrated that there is an association between sleep disturbances and functional outcomes in daily life among children with DS. Treating sleep problems in children with DS may lead to improved accomplishment of daily life habits and activities. There is a need for future objective studies to further understand the relationships between sleep and functional abilities. The data from this project suggest a need to test whether the treatment of SDB improves sleep and subsequently enhances accomplishment of daily life habits.

ABBREVIATIONS

CA, Cronbach alpha
CDC, Centers for Disease Control and Prevention
CPAP continuous positive airway pressure
CSHQ, Children's Sleep Habits questionnaire
DS, Down syndrome
ES, effect size
Life-H, Life Habit questionnaire
N, n, number
OLS, ordinary least squares
OSA, obstructive sleep apnea
REM, rapid eye movement
SDB, sleep disordered breathing
TD, typical development

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Life Habits Questionnaire Domains and Items (23)

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1. Mealtimes

Selecting appropriate food for snacks and meals, according to taste and particular needs (quantity, type of food, etc.)
 Taking part in meal preparation (including using certain kitchen appliances)
 Eating meals (including using dishes and utensils, standard table manners, etc.)
 Eating out at a restaurant (table service and fast food)

2. Fitness

Getting in and out of bed
 Sleeping (comfort, duration, soundness)
 Engaging in physical activities to maintain or improve physical health or fitness
 Engaging in quiet activities that are relaxing or require attention (listening to music or a story, memory games, etc.)

3. Personal Care

Attending to personal hygiene (washing, tooth brushing, hair combing, taking a bath or shower, etc.)
 Using the toilet at home (including flushing method or device)
 Using the toilet elsewhere than at home (including flushing method or device)
 Dressing and undressing the upper half of the body (including fastening buttons and zippers and choosing clothes)
 Dressing and undressing the lower half of body (including fastening buttons, zippers and laces and choosing clothes)
 Putting on, removing and maintaining assistive devices (orthotics, hearing aid, contact lenses, glasses, etc.)
 Taking part in personal health care (first aid, following treatment instructions, medications, etc.)
 Using services provided by a medical clinic, hospital, rehabilitation center, or community clinic

4. Communication

Communicating with an adult at home or in the community (expressing needs, having a conversation, etc.)
 Communicating with a young person at home or in the community (expressing needs, having a conversation, etc.)
 Communicating with a group of people at home or in the community (expressing ideas, having a conversation, etc.)
 Communicating in writing (writing words, sentences, a short text, etc.)
 Reading and understanding written information (words, books, pictographs, written instructions, signs, etc.)
 Using a telephone at home
 Using a computer
 Using a television, a video recorder, a sound system, an iPod, etc

5. Home life

Taking part in housekeeping tasks (light cleaning, making bed, tidying up)
 Taking part in maintaining the grounds (lawn care, snow removal, etc.)
 Entering and exiting the home
 Moving around within the home
 Using the furniture and equipment at home (table, storage space, lighting, outdoor play equipment, etc.)
 Moving around outside the home (backyard, grounds)

6. Mobility

Moving around streets and sidewalks (including crossing streets)
 Moving around on slippery or uneven surfaces (snow, ice, grass, gravel, etc.)
 Riding a bicycle (as means of transportation, for leisure, etc.)
 Being a passenger in a vehicle (car, bus, taxi, etc.)

7. Responsibilities

Recognizing the value of coins and bills and using them correctly
 Managing pocket money (savings, small purchases)
 Using a bank card and an automated teller machine (ATM)
 Shopping, running errands (choosing and paying for merchandise)
 Respecting other people's property and rights (personal effects, rules of conduct)
 Taking charge of himself/herself, standing up for own rights
 Helping out at home (doing a service for parent or other family members)

8. Relationships

Maintaining a loving relationship with parents
 Maintaining a loving relationship with other members of immediate family (brothers, sisters, etc.)
 Maintaining a loving relationship with other relatives (grand parents, cousins, etc.)
 Maintaining friendly or other social ties with other young people (school, recreational activities, etc.)
 Maintaining social ties with adults (teachers, instructors, etc.)

9. Community Life

Participating in the activities of community groups, student association, etc. (e.g. scouts, class committees)
 Participating in religious or spiritual activities

10. School

Getting to school, entering, moving around in the school (including carrying a school bag)
 Taking part in learning activities at school (workshops, classes, assignments)
 Taking specialized classes (PE, music, etc.)
 Using school facilities (e.g. cafeteria, school yard, gym, etc.)
 Doing homework
 Taking part in school activities (extra-curricular activities, outings, field day, etc.)

11. Recreation

Taking part in sports or recreational activities (sports and games, outdoors recreational activities)
 Playing individual or group games, indoors or outdoors (card games, ball games, video games)
 Attending sporting events (baseball, football, etc.)
 Taking part in artistic, cultural, or craft activities (music, dance, arts and crafts, etc.)
 Attending artistic or cultural events (concerts, movies, theatre, etc.)
 Taking part in tourist activities (traveling, visiting natural and historic sites, etc.)
 Getting to, entering and moving around in local recreational facilities (library, municipal recreation center, etc.)
 Using local recreational facilities (library, municipal recreation center, etc.)

