

Sleep Disturbance in Caregivers of Children With Respiratory and Atopic Disease

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Abstract

Objective To examine sleep patterns and sleep disturbances in caregivers of children with chronic illness. **Methods** Caregivers of children with atopic dermatitis (AD, $n = 35$), asthma (AS, $n = 27$), atopic dermatitis and asthma (AD + AS, $n = 57$), ventilator assistance (VENT, $n = 61$), or typically developing (HEALTHY, $n = 63$) completed the Pittsburgh Sleep Quality Index, the Insomnia Severity Index, and three items examining reasons for parent sleep disruption. **Results** Compared with healthy families, caregivers of children with chronic illness reported poorer sleep quality, more symptoms of insomnia, and chronic partial sleep deprivation. VENT and AD caregivers had higher rates of sleep disruptions due to caregiving, whereas AS caregivers reported more sleep disruptions from stress about the child's health. **Conclusions** Deficient and poor-quality sleep in caregivers of children with chronic illness may have a significant impact on their health and well-being, as well as caregiving responsibilities. These data provide important information for pediatric psychologists working with these families.

Key words: children; chronic illness; parents; sleep.

Sleep Disturbance in Parents of Children With Chronic Illnesses

Chronic illnesses in children can adversely impact the child's health-related quality of life (Bender, 1995; Chamlin et al., 2005; Daud, Garralda, & David, 1993; Merikallio, Mustalahti, Remes, Valovirta, & Kaila, 2005). Yet, to better understand the impact of chronic illness on family functioning, one must consider the child's larger and dynamic social-ecological framework (Bronfenbrenner, 1979), including parents and the child's health care team (Kazak, Simms, & Rourke, 2002). For example, a child's chronic illness often requires significant caregiving from a parent, which not only changes the parent's role within the family, but also impacts the parent's functioning. As the parent becomes more exhausted and overwhelmed, this may impact his/her ability to carry out normal activities of daily living, make important medical decisions, and/or care for not only the affected child but other children in the home. While it may not

be possible to change many of the child's caregiving requirements, other modifiable factors that contribute to parent functioning are important to consider.

For children with chronic illnesses, one such factor is the role of deficient or disrupted parent sleep. While there are an increasing number of studies that have examined the relationship between a child's illness and child sleep (Lewandowski, Ward, & Palermo, 2011), less attention has been focused on the relationship between child illness and parent sleep (Meltzer & Moore, 2008). In particular, relatively little research has directly examined sleep patterns and sleep disturbances among parents of children with chronic illnesses, and of the few studies that have been completed, differences across medical populations has rarely been considered. This latter issue is important because while it may be obvious that parents of children with chronic illnesses do not sleep owing to stress and caregiving requirements, not all pediatric chronic illnesses have the same level of nocturnal caregiving requirements. In this

study, we considered populations of children with known nocturnal caregiving requirements, namely atopic dermatitis, asthma, and ventilator assistance.

Caring for a child with chronic atopic dermatitis requires substantial time and effort, which may extend into the night hours. Specifically, owing to the increase in itching that occurs near bedtime and primarily in the first 3 hr of the night (Hon et al., 2006), parents are often required to sleep near their children to prevent scratching that can result in bleeding and infection. Research examining quality of life in parents of children with atopic dermatitis has consistently identified parental sleep loss as one of the most significant variables that reduces parental quality of life and family functioning (Alvarenga & Caldeira, 2009; Al Shobaili, 2010; Aziah, Rosnah, Mardziah, & Norzila, 2002; Beattie & Lewis-Jones, 2006; Lewis-Jones, Finlay, & Dykes, 2001; Ricci, Bendandi, Bellini, Patrizi, & Masi, 2007; Su, Kemp, Varigos, & Nolan, 1997).

There are also studies demonstrating that parents of children with asthma experience sleep disruptions, either owing to caregiving or worry that results in overnight monitoring. This can range from occasional night wakings in parents of children with asthma (Moore, David, Murray, Child, & Arkwright, 2006) to “harrowing experiences” in which mothers of children with asthma stay up through the night watching their child struggle to breathe (Cheezum et al., 2013; Horner, 1997). Further, parental reports of their own sleep quality and sleep duration have been significantly correlated with the severity of their child’s asthma (Yuksel et al., 2007).

For parents of children who require ventilator assistance, parents are often required to provide medical care during the night owing to the child’s technology needs, which results in frequent night wakings and poorer sleep quality for parents (Andrews & Nielson, 1988; Kirk, 1998). Additionally, preliminary research comparing sleep among parents of different respiratory illnesses (including asthma and ventilator assistance) suggests that the impact on parent sleep may differ between child illness groups (Meltzer & Mindell, 2006; Yilmaz et al., 2008).

Parents of children with chronic illnesses clearly demonstrate poorer sleep than parents of healthy children. Differences between illness groups, as well as the level of severity and reasons for sleep disruptions, however, need further investigation. Many studies have been limited by the use of a single item to identify sleep problems and/or the lack of comparison with both groups of healthy children and children with other chronic illnesses (Aziah, Rosnah, Mardziah, & Norzila, 2002; Beattie & Lewis-Jones, 2006; Lewis-Jones et al., 2001; Su et al., 1997). In studies of parents of children with asthma and ventilator assistance, only a small number have included validated questionnaires

(Meltzer & Mindell, 2006; Paddeu et al., 2015; Yilmaz et al., 2008; Yuksel et al., 2007).

Finally, not all sleep disruptions are equal. Some parents may wake to provide medical care for their child and return to sleep quickly and easily, while others may wake up during the night or be unable to return to sleep owing to stress about the child’s illness. Thus, it is important to consider whether caregivers meet the clinical criteria for insomnia, which is defined as difficulty initiating or maintaining sleep (American Academy of Sleep Medicine, 2014). Required medical caregiving is not something a psychologist can change, but when caregivers are having difficulties sleeping owing to stress, cognitive-behavioral therapy for insomnia can provide parents with strategies that may improve sleep quantity and quality.

The primary aim of this study was to use established and validated sleep measures to directly assess sleep quality and symptoms of insomnia in caregivers of children with atopic dermatitis (AD), asthma (AS), both AD and asthma (AD + AS), and ventilator assistance (VENT), and typically developing children (HEALTHY). We hypothesized that compared with HEALTHY families, caregivers of children with chronic illness would have poorer sleep quality and more symptoms of insomnia. The secondary aims of this study were to examine differences in caregiver sleep between illness groups, as well as to explore reasons why caregiver sleep may be disrupted.

Methods

Participants and Procedure

Participants were part of two studies of sleep in parents of children with chronic illness. Both studies were approved by the institutional review boards at the medical centers where data were collected. All participants provided written informed consent.

Study 1

Study 1 included families of ventilator-assisted children (VENT, $n = 61$) who were identified through three different home care/case management programs and families of healthy, typically developing children (HEALTHY, $n = 63$) who were identified through peer nomination and community newspaper advertisements. Participants completed questionnaires during a home visit between November 2008 and May 2011. Data were not collected during the summer. While the reason for VENT varied (e.g., severe lung disease, neurodegenerative illness), all children were considered to have moderate to severe illness.

Study 2

Study 2 included families of children with AD only ($n = 35$), AS only ($n = 27$), or both AD and AS (AD +

AS, $n = 57$) who were identified during their participation in a 2-week day hospital program at a medical research center. Participants completed questionnaires during a scheduled time with a research assistant at the medical center during the first 2 days after admission, between August 2011 and October 2012. Caregivers of 10 school-aged Study 2 participants completed questionnaires during the summer/school holidays. However, no differences in primary sleep outcomes were found between caregivers who completed questionnaires during the school year versus the summer/holidays. All children in Study 2 had active, moderate to severe illness at the time of the study.

Exclusion criteria for both studies included caregivers who reported a diagnosed sleep disorder (e.g., insomnia) or limiting chronic health condition (e.g., chronic pain), were employed in a night shift position, or were non-English speaking. Families in the HEALTHY group were also excluded if the identified child had a chronic illness or developmental disorder that would interfere with sleep. Seventy-seven percent of participating caregivers were female, 80% were White, with a mean of 15.6 years of education (range: 10–20 years). Caregivers were primarily parents (97% parents, four grandmothers [3 HEALTHY, 1 VENT] and two other relatives [both VENT]), and 87% were married. For children, the average age was 8.7 years ($SD = 5.1$), 59% were female, and 75% were White. Complete demographic information (by group) is presented in Table I.

Measures

Pittsburgh Sleep Quality Index

The Pittsburgh Sleep Quality Index (PSQI; Buysse, Reynolds, Monk, Berman, & Kupfer, 1989) is a

well-validated 19-item self-report instrument that assesses sleep disturbance in adults. The PSQI provides a global score, with higher scores indicating poorer sleep quality, and a total score of ≥ 5 indicative of significant sleep disruption. The PSQI has demonstrated good reliability and validity (Mollaveya et al., 2016; Buysse et al., 1989). The PSQI total score was the primary outcome variable of interest, with secondary variables of interest including reported Bedtime, Sleep Onset Latency, Wake Time, and Total Sleep Time.

Situational Specific Sleep Disruptions

One limitation of the PSQI is that it does not query situational specific sleep disruptions related to children and stress. However, there currently are no validated questionnaires that address these specific issues. Thus, three additional items were added to allow for an exploration of reasons for caregiver sleep disruptions. Specifically, participants were asked about sleep disruptions owing to “attending to your child’s health needs,” “stress related to your child’s health,” and “stress not related to your child’s health” (Meltzer & Mindell, 2006). Caregivers were asked to answer these questions related to the identified study child. Response choices were the same Likert choices as the other PSQI sleep disturbances items. These items were not included in the PSQI subscale or total scores, but rather examined individually.

Insomnia Severity Index

The Insomnia Severity Index (ISI; Bastien, Vallieres, & Morin, 2001) is a seven-item self-report instrument that evaluates the severity of problems with sleep onset, sleep maintenance, and early morning awakenings; satisfaction with current sleep pattern, interference with daily functioning, noticeable

Table I. Demographic Variables by Illness Group [Mean (SD) or Percent (n)]

Variable	AD	AS	AD + AS	VENT	HEALTHY	$F, \chi^2, \text{ or } LR$	p
Caregiver age ^{a, b}	34.63 (5.76) $R = 22-45$	41.07 (8.02) $R = 23-53$	38.53 (8.36) $R = 23-62$	43.50 (7.52) $R = 28-60$	41.55 (6.40) $R = 29-58$	$F(4,238) = 9.62$	<.001
Caregiver sex (% female)	83% (29)	85% (23)	86% (49)	72% (44)	65% (41)	$\chi^2(4) = 9.99$.04
Caregiver race (%)						$LR(16) = 26.72$.23
White	83% (29)	96% (26)	75% (43)	75% (46)	79% (50)		
Black	9% (3)	0% (0)	12% (7)	15% (9)	8% (5)		
Other	9% (3)	4% (1)	12% (7)	10% (6)	13% (8)		
Caregiver years of education ^c	15.94 (2.14)	16.07 (1.96)	15.37 (1.82)	14.85 (2.38)	16.00 (1.65)	$F(4,238) = 3.58$.007
Marital status (% married)	97% (34)	89% (24)	82% (47)	82% (50)	90% (57)	$\chi^2(4) = 7.47$.11
Relationship to child (% parent)	100% (35)	100% (27)	98% (56)	95% (58)	95% (60)	$LR(8) = 9.90$.27
Child’s age ^{a, d}	3.74 (3.193) $R = 1-13$	10.22 (5.13) $R = 1-17$	7.74 (5.33) $R = 1-19$	10.55 (4.51) $R = 4-19$	10.02 (4.43) $R = 4-20$	$F(4,238) = 15.22$	<.001
Child’s gender (% female)	60% (21)	56% (15)	65% (37)	54% (33)	57% (36)	$\chi^2(4) = 1.63$.80
Child’s race (% White)	75% (26)	93% (25)	68% (39)	72% (44)	73% (46)	$LR(16) = 31.12$.18

Note. AD = atopic dermatitis only; AS = asthma only; AD + AS = both atopic dermatitis and asthma; VENT = requiring ventilator assistance; HEALTHY = typically developing children.

^aAD < all other groups.

^bAD + AS < VENT, HEALTHY.

^cVENT < AD, AS, HEALTHY.

^dAD + AS < AS, VENT, HEALTHY.

impairment owing to sleep disruptions, and distress caused by sleep problems. The ISI has been shown to have adequate reliability and validity (Bastien et al., 2001). A score of ≥ 15 is suggestive of clinically significant insomnia.

Data Analytic Plan

Demographic differences between illness groups were compared using a multivariate analysis of variance for continuous variables and nonparametric tests (Pearson chi-square or Likelihood ratio) for categorical variables. Differences between illness groups on measures of caregiver sleep were conducted using multivariate analyses of covariance (MANCOVA), with primary outcome variables the total scores on the PSQI and the ISI, and secondary outcome variables bedtime, sleep onset latency, wake time, and total sleep time. Logistic regression was used to examine predictors of the following: poor sleep quality (scoring >5 on the PSQI), clinically significant symptoms of insomnia (scoring ≥ 15 on the ISI), chronic deficient sleep (reporting an average total sleep time <6 hr/night), and waking more than once per week for: (1) caregiving, (2) child illness-related stress, (3) general stress. A conservative p -value of .01 was used to control for multiple comparisons.

Results

Preliminary Analyses

Group means or frequencies for all demographic variables are presented in Table I. Significant group differences were found for caregiver age, caregiver years of education, and child age. Thus, these variables were included as covariates in all analyses. There were more mothers than fathers in the sample; however, there were no significant differences found between mothers and fathers for any of the continuous sleep outcome variables.

Group Differences on Continuous Outcome Variables

Means, standard deviations, and F statistics for sleep outcomes are reported in Table II for the MANCOVA comparing all five groups. A significant difference was found between groups for both the PSQI total score (partial $\eta^2 = .13$) and the ISI total score (partial $\eta^2 = .13$). Secondary outcome variable differences were also found between groups for bedtime (partial $\eta^2 = .07$), sleep onset latency (partial $\eta^2 = .06$), and total sleep time (partial $\eta^2 = .09$).

HEALTHY Versus Illness Groups

Post hoc analyses show that HEALTHY caregivers reported better global sleep quality ($p < .001$) and fewer symptoms of insomnia ($p < .001$) than all other illness groups. In addition, HEALTHY caregivers reported a significantly earlier bedtime compared with AD + AS ($p = .004$) and VENT caregivers ($p = .001$), a shorter sleep onset latency compared with AS caregivers ($p = .001$), a longer total sleep time compared with AD ($p = .001$), AD + AS ($p < .001$), and VENT caregivers ($p < .001$).

Comparison Between Illness Groups

No significant difference was found between illness groups for the PSQI total score or the ISI total score. The only differences between illness groups on secondary outcomes were that VENT caregivers reported a later bedtime than AS caregivers ($p = .006$), and AS caregivers had a longer sleep onset latency than AD caregivers ($p = .004$).

Predictors of Categorical Sleep Outcomes

For all outcome variables, models included covariates (caregiver age, caregiver years of education, child age, and caregiver sex), as well as group membership (with HEALTHY considered the control group). Models for

Table II. Means (SE) and Differences Between Illness Groups on Sleep Outcomes

Sleep outcome	AD	AS	AD + AS	VENT	HEALTHY	F
PSQI total score ^a	9.13 (0.65)	9.27 (0.69)	9.54 (0.49)	8.69 (0.46)	6.19 (0.46)	7.99**
ISI total score ^a	11.61 (1.09)	11.31 (1.15)	12.05 (0.81)	10.93 (0.79)	6.30 (0.76)	8.67**
Typical bedtime ^{b,c}	22:59 (0:13)	22:37 (0:13)	23:16 (0:10)	23:22 (0:09)	22:38 (0:10)	4.42*
Sleep onset latency (min) ^{d,e}	16.40 (3.22)	30.37 (3.39)	22.96 (2.39)	21.77 (2.26)	16.65 (2.25)	3.62*
Typical wake time	06:36 (0:12)	06:14 (0:13)	06:30 (0:09)	06:11 (0:09)	06:19 (0:09)	0.68
Total sleep time (hr) ^f	5.88 (0.22)	6.47 (0.23)	5.99 (0.17)	5.95 (0.16)	6.79 (0.16)	5.60**

Note. ANCOVA model controls for child age, caregiver age, and caregiver years of education. AD = atopic dermatitis only; AS = asthma only; AD + AS = both atopic dermatitis and asthma; VENT = requiring ventilator assistance; HEALTHY = typically developing children.

^aHEALTHY < all other groups.

^bHEALTHY < AD + AS, VENT.

^cAS < VENT.

^dHEALTHY < AS.

^eAD < AS.

^fHEALTHY > AD, AD + AS, VENT.

*Significant differences between groups, $p < .01$.

**Significant differences between groups, $p < .001$.

each outcome variable, including the coefficient for the constant and odds ratios, can be found in Table III.

Poor Sleep Quality (PSQI > 5)

The full logistic regression model was statistically significant, $\chi^2(8) = 33.33$, $p < .001$. Caregivers of all illness groups were more likely to have poor sleep quality compared with HEALTHY caregivers, with odds ratios ranging from 3.99 (AS) to 5.07 (AD + AS).

Clinically Significant Insomnia (ISI > 15)

The full logistic regression model was statistically significant, $\chi^2(8) = 24.92$, $p = .002$. Caregivers of all illness groups were more likely to have clinically significant symptoms of insomnia compared with HEALTHY caregivers, with odds ratios ranging from 6.19 (VENT) to 10.76 (AD + AS) caregivers.

Total Sleep Time <6 Hr

The full logistic regression model was statistically significant, $\chi^2(8) = 22.37$, $p = .004$. Caregivers of all illness groups were more likely to average <6 hr of sleep per night compared with HEALTHY caregivers, with odds ratios ranging from 4.34 (VENT) to 8.60 (AD).

Waking Due to Medical Caregiving for Child

The full logistic regression model was statistically significant, $\chi^2(8) = 105.08$, $p < .001$. Caregivers of all illness groups were more likely to wake at least once a week for medical caregiving, with odds ratios ranging from 5.44 (AS) to 22.08 (VENT).

Waking Due to Stress About Child's Health

The full logistic regression model was statistically significant, $\chi^2(8) = 102.84$, $p < .001$. Caregivers of all illness groups were more likely to wake at least once a week due to stress about the child's health, with odds ratios ranging from 44.83 (VENT) to 239.88 (AS).

Waking Due to General Stress

The full logistic regression model predicting night wakings at least once a week due to general stress was not statistically significant, $\chi^2(8) = 9.60$, n.s. This suggests that there is no difference in the frequency of waking due to general stress between parents of children with chronic illnesses and HEALTHY parents.

Discussion

As expected, this study demonstrated that caregivers of children with chronic illness reported poorer sleep quality and more symptoms of insomnia than caregivers of healthy children. Results from the present study demonstrate clear sleep impairment in

Table III. Logistic Regression Models for Predictors of Categorical Sleep Outcome Variables

Predictor variable	B (SE)	OR (95% CI)
PSQI < 5		
Caregiver age	0.001 (0.03)	1.00 (0.94–1.07)
Years of education	–0.19 (0.09)	0.83 (0.69–0.99)
Child age	–0.06 (0.05)	0.94 (0.86–1.03)
Caregiver sex	–0.72 (0.42)	0.49 (0.21–1.12)
AD	1.50 (0.61)	4.48 (1.37–14.68)
AS	1.39 (0.55)	3.99 (1.35–11.82)
AD + AS	1.62 (0.48)	5.07 (1.97–13.05)
VENT	1.47 (0.45)	4.35 (1.79–10.55)
ISI > 15		
Caregiver age	0.006 (0.03)	1.01 (0.95–1.06)
Years of education	–0.02 (0.08)	0.98 (0.84–1.15)
Child age	–0.04 (0.05)	0.96 (0.88–1.05)
Caregiver sex	0.24 (0.42)	1.27 (0.56–2.88)
AD	2.01 (0.73)	7.45 (1.77–31.34)
AS	1.89 (0.74)	6.61 (1.54–28.37)
AD + AS	2.38 (0.66)	10.76 (2.93–39.49)
VENT	1.82 (0.67)	6.19 (1.65–23.22)
Total sleep time <6 hr		
Caregiver age	0.02 (0.03)	1.02 (0.97–1.08)
Years of education	–0.10 (0.08)	0.91 (0.78–1.06)
Child age	–0.03 (0.05)	0.97 (0.89–1.06)
Caregiver sex	–0.55 (0.39)	0.58 (0.27–1.24)
AD	2.15 (0.68)	8.60 (2.26–32.70)
AS	1.58 (0.71)	4.84 (1.21–19.34)
AD + AS	2.07 (0.61)	7.90 (2.40–26.06)
VENT	1.47 (0.61)	4.34 (1.30–14.42)
Wake at least once/week due to care giving		
Caregiver age	–0.03 (0.03)	0.98 (0.92–1.03)
Years of education	–0.2 (0.08)	0.98 (0.83–1.15)
Child age	–0.16 (0.05)	0.85 (0.78–0.93)
Caregiver sex	0.76 (0.42)	2.15 (0.94–4.89)
AD	2.44 (0.62)	11.41 (3.40–38.36)
AS	1.69 (0.61)	5.44 (1.65–17.96)
AD + AS	2.79 (0.54)	16.31 (5.71–46.58)
VENT	3.10 (0.54)	22.08 (7.68–63.50)
Wake at least once/week due to stress about child's health		
Caregiver age	–0.01 (0.03)	0.99 (0.93–1.04)
Years of education	–0.02 (0.08)	0.99 (0.85–1.15)
Child age	–0.03 (0.05)	0.97 (0.89–1.06)
Caregiver sex	0.40 (0.40)	1.49 (0.68–3.27)
AD	3.81 (0.83)	44.91 (8.77–229.98)
AS	5.48 (0.95)	239.88 (37.27–1544.09)
AD + AS	3.93 (0.78)	50.87 (11.08–233.52)
VENT	3.80 (0.78)	44.83 (9.80–205.08)
Wake at least once/week due to general stress		
Caregiver age	–0.02 (0.02)	0.98 (0.94–1.03)
Years of education	–0.07 (0.07)	0.93 (0.81–1.07)
Child age	0.06 (0.04)	1.06 (0.98–1.14)
Caregiver sex	0.03 (0.33)	1.03 (0.54–1.98)
AD	0.70 (0.49)	2.02 (0.77–5.29)
AS	1.04 (0.48)	2.82 (1.10–7.26)
AD + AS	0.68 (0.40)	1.98 (0.90–4.33)
VENT	0.52 (0.39)	1.67 (0.78–3.60)

Note. Reference group for caregiver sex is fathers; reference group for all illness groups is HEALTHY.

caregivers of children with chronic illness compared with parents of healthy children. These results are consistent with the literature documenting sleep disruptions in parents of chronic illness (Meltzer & Mindell,

2006; Moore et al., 2006; Heaton et al., 2006; Yuksel et al., 2007). While intuitive, this study is one of the first to compare caregiver sleep for a variety of illness groups at one time to both a healthy comparison group and to each other. In addition, this study contributes a preliminary examination of possible reasons for caregiver sleep disruptions, highlighting the fact that sleep disruptions are influenced by illness characteristics and nocturnal caregiving requirements.

Differences were found for global sleep quality between caregivers of healthy children and all illness groups, but there was no difference between the illness groups. More research is needed, but one possible explanation is that these validated measures do not capture the unique caregiving requirements or stressors that may disrupt sleep. However, the mean values reported in this article highlight the significant sleep disruptions experienced by all caregivers of children with chronic illness.

For insomnia, all four illness groups reported significantly higher mean scores on the ISI compared with caregivers of healthy children, suggestive of clinically significant insomnia. However, the factors that contribute to insomnia, namely caregiving responsibilities and stress, must be considered, as it is unlikely caregivers of children with chronic illness have “typical” insomnia. Although all four illness groups were significantly more likely to fall above the clinical cutoff for insomnia, this was most notable for caregivers of children with combined AD and AS. For these caregivers, night wakings that result in elevated insomnia symptoms are commonly owing to caregiving requirements, which can include nighttime skin care (e.g., moisturizing or wet-wrap therapy) preventing children from scratching their skin, and monitoring children’s breathing quality.

While previous studies have highlighted sleep disruptions in parents of children with AD, this is one of the first to specifically consider the significant level of nocturnal caregiving in this population. Not surprisingly, caregivers of children with VENT were the most likely to wake for nocturnal caregiving (e.g., responding to monitor’s alarms, airway clearance). Yet, caregivers of children with AD were also 11–16 times more likely than healthy caregivers to wake to care for their children. Researchers have demonstrated the benefits of night nursing support for families of children with VENT on daytime functioning (Meltzer, Burroughs, & Downs 2010), and results from the present study suggest families of children with AD may benefit from similar support.

Although cognitive-behavioral therapy for insomnia cannot change nocturnal caregiving requirements, this well-established empirically supported treatment can address the significant stress associated with caring for a child with a chronic illness. While caregivers

in all illness groups reported significant nocturnal stress related to their child’s health, it was notable that caregivers of children with AS were most likely to report this cause of sleep disruption. Previous research has documented poor sleep in parents of children with AS (Yuksel et al., 2007; Yilmaz et al., 2008) but has not identified reasons behind the sleep disruption. Results from the current study suggest that stress and worry are significant factors for caregivers of children with AS. Modified cognitive behavioral therapy for insomnia has been shown to improve sleep quality and quantity in caregivers of adults with chronic illness (Carter, 2006; Cohen & Kuten, 2006; McCurry, Logsdon, Vitiello, & Terri, 1998) and may be beneficial to pediatric caregivers as well. Although it may not be possible to alter nighttime caregiving requirements, brief interventions such as relaxation training could be used to help caregivers return to sleep more quickly. Interventions to improve child sleep, such as improved illness management and behavioral strategies to help children develop and maintain healthy sleep habits, may also improve caregiver sleep.

Beyond sleep quality and reasons for sleep disruptions, it was notable that the mean reported total sleep time for caregivers of children with AD (both with and without AS) and VENT was 48–60 min less per night than caregivers of healthy children. Further, caregivers of children with chronic illness were four to eight times more likely to average <6 hr of sleep per night compared with caregivers of healthy children. This is particularly important as chronic partial sleep deprivation (regularly obtaining ≤ 6 hr) has been shown to cause negative mood, increased fatigue, and impaired performance (Banks & Dinges, 2011; Van Dongen, Maislin, Mullington, & Dinges, 2003). In addition, deficient sleep has been linked to increased weight gain (Markwald et al., 2013) and risk of illness (Cohen, Doyle, Alper, Janicki-Deverts, & Turner, 2009). The current study findings of deficient sleep are comparable with a previous study with parents of ventilator-assisted children (Meltzer & Mindell, 2006) and studies documenting up to 1 hr of sleep loss for parents of children with AD (Moore et al., 2006; Su et al., 1997).

The study’s limitations identify avenues for future research. First, the assessment of sleep outcomes in this study was conducted using self-report only. Further, the PSQI and ISI are related measures, and thus, it is possible that responses on the ISI were influenced by participants completing the PSQI. Future research should examine caregiver sleep using objective measures of sleep patterns (such as actigraphy) that would remove the potential for biased reporting. Second, this study was limited by its cross-sectional design and the lack of control for sleep issues before the onset of the child’s illness. Further, data were not

collected related to time since child's illness diagnosis. Longitudinal studies would provide additional information regarding the onset of sleep difficulties in caregivers as well as the relationship of sleep disturbance to illness course and severity. Third, the majority of caregivers were White and did not have any diagnosed sleep disorders, and thus, results may not be generalizable to all caregivers. In addition, the VENT group included children with a variety of illnesses that may also limit generalizability. Despite these limitations, this study provides important information regarding sleep disruptions in caregivers of children with chronic illness, using reliable and valid measures of sleep disturbance across multiple illness groups and healthy controls.

The role of a pediatric psychologist in addressing caregiver sleep is clear, as caregiver functioning is an important factor in the well-being of the child. Caregivers who are chronically sleep-deprived may have increased difficulty managing their emotions with regard to their child's illness and behavior, may be less able to implement and monitor medical interventions appropriately, and may be less equipped to set appropriate expectations for their child's behavior and adherence. Pediatric psychologists can provide important interventions to support not only the child, but the caregivers and family structure as a whole. Pediatric psychologists should also work with medical and multidisciplinary teams to help physicians and other health care providers understand the impact of caregiver sleep deprivation, especially with regard to treatment adherence and decision-making.

In sum, the present study contributes to the existing literature by providing additional evidence for sleep disturbance among caregivers of children with chronic illness. This study also identifies differences between caregivers of children with chronic illnesses with regard to reasons for sleep disruption (e.g., caregiving responsibilities vs. stress related to the child's health) and clearly identifies the severity of these sleep disruptions using established cutoffs for clinical impairment. Although more research is clearly needed, caregiver sleep should be a priority for pediatric psychologists working with families affected by pediatric chronic illness.

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