

# Sleep Disruptions in Parents of Children and Adolescents with Chronic Illnesses: Prevalence, Causes, and Consequences

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**Objective** Provide a comprehensive review of the existing literature on the prevalence, causes, and consequences of sleep disruptions in parents of youth with chronic illnesses. **Methods** A comprehensive literature search of PsychInfo, MEDLINE, and CINAHL for articles related to sleep in parents of youth with chronic illnesses yielded 59 potential articles, with 19 meeting inclusion criteria. **Results** Parents of children with eczema were the most commonly studied group. The prevalence of sleep disruptions was 15–86%. Potential causes of parent sleep disruptions included nighttime caregiving, monitoring of the child's illness, and stress related to the child's illness. Consequences included poor sleep quality, depression, and anxiety. **Conclusions** Parents of youth with chronic illnesses experience sleep disruptions, providing a potential mechanism to explain elevated rates of negative daytime functioning found in previous studies. To provide interventions and support for these parents, additional research is needed to address the limitations of the existing literature.

**Key words** caregivers; children; chronic illness; parents; sleep.

The number of children with chronic illnesses (a health condition lasting at least 12 months or at the time of diagnosis is likely to last at least 12 months) has been estimated between 5 and 9.4 million in the United States (Child and Adolescent Health Measurement Initiative, 2005; National Center for Health Statistics, 2006). Parents of these children have reported elevated rates of depression, anxiety, and parenting stress (Breslau, Staruch, & Mortimer, Jr., 1982; Hauenstein, 1990; Quittner & DiGirolamo, 1998), as well as poorer health (Brehaut et al., 2004; Raina et al., 2005), compared to parents of children without a chronic illness. In addition to typical parenting responsibilities, parents are also required to become medical caregivers, not only during the day, but also at night. Nighttime caregiving, and/or worries about the child's illness, can result in sleep disruptions, including poor sleep quality and shorter sleep quantity for parents. As most parents were functioning competently prior to their child's diagnosis (Kazak, 2001), chronic sleep disruptions are a potential mechanism to explain the elevated rates of negative mood, stress, and health outcomes reported by parents. However, little is known about the relationship

between a child's illness and parent sleep and daytime functioning.

Sleep disruptions are not unique to children with chronic illnesses, with 25–40% of the general pediatric population also experiencing sleep problems (Owens, 2005). Parent sleep disruptions are clearly linked to night wakings in infants, with recent studies and population surveys also demonstrating the relationship between children's sleep patterns, parent sleep, and parent daytime functioning in children of all ages. A national survey of sleep in children ages 0–10 years reported that 14% of children woke at least once a week requiring parent help (National Sleep Foundation, 2004). Further, 49% of the parents reported losing an average of at least 30 min of sleep each time they needed to attend to their child. In a group of children seen in a pediatric sleep clinic, child sleep disruptions were a significant predictor of maternal daytime sleepiness (Boergers, Hart, Owens, Streisand, & Spirito, 2007). Child sleepiness was also related to both mothers' and fathers' daytime sleepiness. A study of mothers of typically developing children found significant differences for both mood and parenting stress between mothers

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of children with and without significant sleep disruptions (Meltzer & Mindell, 2007). Child sleep quality was also found to be a significant predictor of maternal sleep quality, with maternal sleep quality significantly predicting maternal daytime functioning. These recent studies are examples of the link between child sleep disruptions and parent sleep and functioning.

Compared to healthy children, children with chronic illnesses often have more night wakings requiring parental attention during the night, yet few studies have directly examined sleep quantity and sleep quality in these parents. A number of studies have found sleep disruptions in children with chronic illnesses. For example, compared to healthy children, more sleep disruptions have been reported for children with epilepsy (Cortesi, Giannotti, & Ottaviano, 1999), juvenile rheumatoid arthritis (Bloom et al., 2002), HIV (Franck et al., 1999), and headaches (Bruni et al., 1997; Heng & Wirrell, 2006; Miller, Palermo, Powers, Scher, & Hershey, 2003). In addition, parents have reported that symptoms of or events caused by a child's illness also disrupt the child's sleep, including coughing or wheezing in children with asthma (Diette et al., 2000; Fiese, Winter, Sliwinski, & Anbar, 2007; Mitchell, Adams, & Murdock, 2005; Sotir, Yeatts, Miller, & Shy, 2006), itching in children with eczema (Chamlin et al., 2005; Daud, Garralda, & David, 1993; Lewis-Jones, Finlay, & Dykes, 2001; Moore, David, Murray, Child, & Arkwright, 2006), or pain or hospitalization in children with cancer (Davies, Whitsett, Bruce, & McCarthy, 2002; Gedaly-Duff, Lee, Nail, Nicholson, & Johnson, 2006; Hinds et al., 2007; Hockenberry-Eaton et al., 1998). Ironically, the fact that many parents are aware of, and able to report on, their child's sleep disruptions may suggest that the parent's sleep is also disrupted. While there is a growing body of literature on sleep disruptions in children with chronic illnesses (which is not comprehensively reviewed here), fewer studies have examined sleep in parents of these children.

A number of studies have directly examined sleep in caregivers of adult patients (Carter, 2003; Flaskerud, Carter, & Lee, 2000; Happe & Berger, 2002; McKibbin et al., 2005; Wilcox & King, 1999). Overall these studies have found significantly elevated rates of sleep disturbances, and a relationship between sleep problems, depressive symptoms, and daytime fatigue. To our knowledge there has not been a review of the literature on sleep in parents/caregivers of children and adolescents with chronic illnesses. With the strong emphasis on family centered care for youth with chronic illnesses, it is essential to understand mechanisms such as chronic sleep disruptions that may contribute to the physical and

mental health of parents who have children or adolescents with chronic illnesses.

### **Purpose of this Review**

The primary objective of this article is to provide a comprehensive review of the prevalence, causes, and consequences of sleep disruptions in parents of children/adolescents with chronic illnesses. Based on this review, we will propose areas of need for future studies focusing on sleep in parents of children/adolescents with chronic illnesses, and provide clinical implications for psychologists and health care professionals working with these populations.

### **Methods**

Two literature searches were performed using Cumulative Index to Nursing & Allied Health (CINAHL), MEDLINE, and PsychInfo on the topic of sleep in parents of youth with chronic illnesses. The following keywords were used in the first search: (a) sleep; (b) parent-caregiver child-caregiver pediatric; and (c) chronic disease-chronic illness-chronic health-chronic problems. In the second search, the first two terms were combined with individual chronic illnesses (Table 1). Additional studies were found using references listed within the articles.

**Table 1.** Chronic Illness Terms Included in Literature Search

Asthma
Atopic dermatitis—Eczema
Burns
Cancer
Cardiovascular—Heart
Chronic otitis media
Chronic regional pain syndrome—Reflex sympathetic dystrophy
Cystic fibrosis
Diabetes
Epilepsy—Seizure disorder
Headache—migraine
Hemophilia
Hepatic—hepatitis
HIV—AIDS
Irritable bowel syndrome—Crohn's—Collitis—Recurrent abdominal pain
Juvenile rheumatoid arthritis
Kidney—renal—nephrology
Muscular dystrophy
Obesity
Sickle cell disease
Stroke
Traumatic brain injury—Acquired brain injury
Ventilator—Technology dependent—Mechanical ventilation

The articles included in this review met the following criteria: (a) the study sample included more than one youth with a chronic illness (ages 0–18 years), (b) there was a direct measure of parent sleep problems or disruptions, and (c) the study was published in English. Exclusion criteria included (a) no measure or report on parent sleep, (b) single subject case reports, and (c) study was not published in a peer-reviewed publication (e.g., dissertation).

## Results

A total of 681 abstracts were considered from the original search that included all articles published through June 2007. Most of these studies did not meet the inclusion criteria and were eliminated, with 51 articles selected for full review. Review of the references of these articles yielded an additional eight articles, for a total of 59 articles that were selected for full review. Forty studies were excluded, primarily because the study focused only on child sleep, resulting in the 19 studies included in this review (Table 2). As many of these studies did not include any type of control group, and none included an intervention, statistical approaches to integrating the data in this review (e.g., meta-analysis) were not used.

### Overview of the Literature

In the 19 studies reviewed, parents of children with eczema (or atopic dermatitis) were the most commonly studied population ( $n = 6$ ), followed by children/adolescents with diabetes or cancer ( $n = 4$  each), technology dependency ( $n = 3$ , including mechanical ventilation, feeding pumps, or dialysis), asthma or epilepsy ( $n = 2$  each), and cystic fibrosis (CF) or chronic otitis media ( $n = 1$  each). Only three of the studies included a control or comparison group of parents of healthy children, although four studies compared two different illness groups. Several studies did not provide demographic information about parents (including parent sex), but of those that did, 71% (10/14) included fathers in their reports. Children and adolescents in the reviewed studies ranged in age from infancy through 22 years, with the majority of studies focusing on toddlers through school-aged children (~2–11 years).

Fourteen studies were identified as “quantitative” in that they provided some type of statistical data (e.g., means, frequencies, ANOVAs). “Qualitative” studies used well-defined methodology to identify themes in parents of children with chronic illnesses. Only one study used an objective measure of sleep (actigraphy), demonstrating the feasibility of this approach in parents of children

with cancer. “Sleep disruptions” was the term most commonly used in these studies, but there is no standardized definition of this term across studies. Since many studies used a single item or qualitative methodology to identify sleep disturbances, the following terms have also been included under the umbrella of “sleep disruptions” for this review (all related to the child’s illness): sleep interruption, sleep loss, sleep disturbances, sleep issues, insufficient sleep, and chronic sleep deprivation. To integrate this literature, we identified the prevalence, the potential causes, and the consequences of sleep disruptions in parents of children with chronic illnesses.

### Prevalence of Sleep Disruptions

Prevalence rates of sleep disruptions in parents of children with chronic illnesses ranged from 15% to 86%. Much of this variation is accounted for by the different methodologies, time of assessment, or illness. For example, one study of children with eczema reported that 15% of parents chose sleep issues as the most bothersome aspect of their child’s illness. However, they did not assess the number of parents who thought sleep issues were bothersome (Chamlin et al., 2005). Alternatively, another study of parents of children with eczema reported an 86% prevalence rate of sleep disturbances, but only during an eczema flare. Data were not provided for how many parents experienced sleep disturbances when the child’s eczema was well-managed (Reid & Lewis-Jones, 1995). In between these two studies, Arvola et al. (2000) found that sleep disturbances were a primary concern for 54% of parents prior to treatment of eczema, and 34% of parents after treatment. Qualitative studies used the following terms to describe the prevalence of sleep disturbances: *all*, *most*, or *many* of the parents (Horner, 1997; Sullivan-Bolyai et al., 2003, 2004).

The lack of studies with a control or comparison group made it difficult to assess if the prevalence of sleep disruptions in parents of children with chronic illnesses was greater than in parents of healthy children. The few studies that did include a control group reported mixed prevalence rates, mostly due to varying illnesses. Meltzer and Mindell (2006) found the prevalence of sleep disruptions due to caregiving in mothers of ventilator-dependent children (VDC) to be significantly higher compared to mothers of healthy children (52 vs. 9%), while sleep disruptions due to caregiving did not significantly differ for mothers of children with CF compared to mothers of healthy children (26 vs. 9%). However, the prevalence of sleep disruptions due to stress related to the child’s

**Table 2.** Articles Included in Literature Review

Citation	Subjects	Child Age <sup>a</sup>	Illness(es)	Methodology	Control group(s)	Results
Andrews & Nielson (1988)	74 mothers	Infants	Technology dependent	Quantitative: Single question about family problems	None	Sixty-two percent reported interruption in sleep due to false monitor alarm.
Arvola, Tahvanainen, & Isolauri (2000)	81 parents	M = 5 months, range = 1.5–15 months	Atopic eczema	Quantitative: Questionnaire designed for study, question on problems in the care of the infant before and after treatment	None	Sleep loss one of most important problems reported by parents, a moderate to severe concern for 54% of parents before treatment and 34% after treatment. Parent fatigue reported to be 50% before treatment and 44% after treatment.
Asmussen, Olson, & Sullivan, (1999)	14 mothers and fathers (n of each not given)	range = infant to 9 years	Chronic otitis media	Qualitative: Themes of impact on parents	None	Sleep one aspect of parents life that was disrupted.
Boman, Lindahl, & Bjork (2003)	146 mothers, 118 fathers <sup>b</sup>	M = 5.8 years <sup>c</sup> , range = infant to 21 years	Cancer	Quantitative: Parent Psychological Distress in Childhood Cancer (5-item sleep disturbances scale)	None	A total of 47.1% of parents reported sleep disturbances, higher level of sleep disturbance if shorter time since diagnosis and child on active treatment.
Boman, Viksten, Kogner, & Samuelsson (2004)	373 mothers, 301 fathers	range = 0 to 16 years	Cancer (n = 264) and diabetes (n = 203)	Quantitative: Parent Psychological Distress in Childhood Cancer (5-item sleep disturbances scale)	General population (n = 208)	Sleep disturbances did not differ between the three groups. Sleep disturbances related to time since diagnosis, with disturbances maintained for diabetes group and improved in cancer group over time.
Chamlin et al. (2005)	270 families, both mothers and fathers (specific n not given)	M = 16.0 months, range = 1.5 to 71.4 months	Atopic dermatitis	Quantitative: Childhood Atopic Dermatitis Impact Scale (3-item sleep scale)	None	“Sleep issues” was the most bothersome thing about AD for 14.8% of parents (#3 on list of 24 items for full sample).
Cottrell & Khan (2005)	50 mothers	M = 3.6 years	Epilepsy	Quantitative: Pittsburgh Sleep Quality Index, Beck Depression Inventory, Dyadic Adjustment Scale, SF-36	None	Mothers slept an average of 4.5 hr, and woke ~3 times/night to check on child. Night wakings and sleep quality each related to increased maternal depression, poorer sleep quality, poorer marital satisfaction, and poorer parent health.
Ferrell, Rhiner, Shapiro, & Dierkes (1994)	21 mothers, 10 fathers	M = 11.6 years, range 5–22 years	Cancer	Qualitative: Themes related to impact of child’s pain on the family	None	Sleep deprivation common theme. Sleep loss due to mental and emotional burden or required physical care of child’s pain.

Gedaly-Duff et al. (2006)	Seven mothers, Six fathers	M = 11 years, range = 8–16 years	Cancer (ALL)	Quantitative: Three day sleep diary, actigraphy, VAS for fatigue	None	Mothers slept an average of 7 hr and fathers an average of 6 hr. Mothers had 8.8% wake after sleep onset and fathers had 14.3% WASO. Actigraphy recorded awakenings were 16.9 for mothers and 19.7 for fathers. Average fatigue score of 45 for mothers and 50 for fathers (range 23–63).
Heaton, Noyes, Sloper, & Shah (2006)	34 mothers, 12 fathers	M = 8.4 years, range = 16 months–19 years	Technology dependent	Quantitative and qualitative: Frequency of sleep disruptions, themes related to the incidence, reasons, and effects of sleep disruptions	None	All families experienced sleep disruptions, 22/36 regularly ( $\geq 2$ nights/week), five families when child was ill, one family if night support not provided. Reasons for sleep disruptions included equipment problems, turning child, checking devices, attending to child's pain/vomiting due to machine. Effects included tiredness and exhaustion, as well as limited socializing and work.
Horner (1997)	12 families	Range = 6–18 years	Asthma	Qualitative: Themes on uncertainty prior to child's diagnosis	None	All of the mothers reported staying up through the night watching their child struggle to breath. "Mothers portrayed these nocturnal episodes as harrowing experiences" (p.661). The need to be vigilant led to "wearing out" (p.661).
Lawson, Lewis-Jones, Finlay, Reid, & Owens (1998)	34 mothers, 34 fathers	Median = 3.2 years, range = 6 months –10 years	Atopic dermatitis	Quantitative: Dermatitis Family Impact questionnaire (one sleep and one fatigue questionnaire)	None	Sixty-three percent of children had sleep disturbances (difficulties settling child and nighttime waking requiring parental help), with 64% of parents reporting frustration and exhaustion due to sleep problems.
Lewis-Jones et al. (2001)	89 parents	M = 2.0 years	Atopic dermatitis	Quantitative: Family Dermatitis Index (FDI), Infants Dermatitis QOL Index, Infants Behavioural Checklist	Children attending local daycare (n = 22, < 4 years)	Sleep disturbance was the highest scoring question for parents, followed by tiredness or exhaustion. Forty-three percent of infants with AD had frequent night wakings compared to 4.5% of controls.
Meltzer & Mindell (2006)	71 mothers	M = 7.5 years, range = 3–14 years	Ventilator dependent (VENT, n = 29), cystic fibrosis (CF, n = 42)	Quantitative: Pittsburgh Sleep Quality Index, 24-Hr Sleep Patterns Inventory, Center for Epidemiological Studies – Depression Scale, Iowa Fatigue Scale, Child Health Questionnaire	Peer-nominated healthy children (HEALTHY, n = 47)	VENT woke ~45 min earlier and slept 1 hr less (~6.3 hr), had more night wakings and poorer sleep quality, longer sleep onset latency, and generally more sleep problems than other groups. Sleep disturbances due to nighttime caregiving (52% VENT, 26% CF, 9% HEALTHY) and stress related to child's illness (38% VENT and CF, 2% HEALTHY). Sleep quality found to mediate relationship between child health status and maternal depression and fatigue.

(continued)

Table 2. Continued

Citation	Subjects	Child Age <sup>a</sup>	Illness(es)	Methodology	Control group(s)	Results
Moore et al. (2006)	55 mothers, 37 fathers	Median = 5 years, range = 6 months–11 years	Eczema ( <i>n</i> = 26), asthma ( <i>n</i> = 29)	Quantitative: Questions about frequency and duration of parent night wakings due to the child, Hospital Anxiety and Depression Scale	None	Mothers spend 39 min and fathers 45 min per night attending to child with eczema, 0 min for asthma. Number of times sleep disturbed by child double that of asthma. Maternal depression in the eczema group related to nighttime sleep disruptions (OR 7.9 for > 3 night wakings in past 2 nights compared to mothers who had no night wakings). Sleep disturbances also related to anxiety in both mothers (OR 4.6) and fathers (OR 4.9).
Reid & Lewis-Jones (1995)	45 parents	M = 25 months, median = 20 months	Atopic eczema	Quantitative: Structured inter- view questions about when and where child falls asleep, frequency and duration of night wakings in parents	None	During an eczema flare, sleep disturbance reported for 86% of the nights (M = 2.7 wakings/night). Parents lost an average of 2.6 hr of sleep per night. 48% of parents brought child to bed as a management strategy for eczema flares.
Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey (2003)	28 mothers	M = 2.9 years	Diabetes	Qualitative: Themes related to mothers' management behaviors of child's diabetes, and the meanings mothers attributed to them	None	"The fear and need to be constantly vigilant led to sleep deprivation for many of the parents." (p. 25) Constant vigilance resulted in chronic sleep deprivation, with some mothers reporting that "the only way they could get any rest was to have the child sleep with them." (p. 26).
Sullivan-Bolyai, Knafl, Tamborlane, & Grey (2004)	14 mothers, 7 fathers	M = 7 years, range = 2–11 years	Diabetes	Qualitative: Themes related to parents response to placing child on insulin pump	None	In the quality of life theme, most parents reported that "sleep returned to normal" with the insulin pump (p. 321).
Williams et al. (2000)	334 parents	M = 9.4 years, range = 3–17 years	Epilepsy ( <i>n</i> = 179), diabetes ( <i>n</i> = 155)	Quantitative: Questions about sleeping arrangements before and after diagnosis, question about reason for co-sleeping	None	Twenty-two percent of children with epilepsy and 8% of children with diabetes changed to a less independent sleeping arrangement following diag- nosis. Twenty-four out of 25 parents of child with epilepsy reported co-sleeping due to concern about child's epilepsy. Three out of 13 parents of child with diabetes reported co-sleeping due to concern about child's diabetes.

<sup>a</sup>If the mean was not reported in the study, the median is provided.<sup>b</sup>This includes one stepmother and one stepfather.<sup>c</sup>Age at time of diagnosis, age during study not given.

illness for both mothers of VDC and children with CF (each 38%) was significantly higher compared to mothers of healthy children (2%).

In determining the prevalence of sleep disruptions, healthy children may not always be the most appropriate control group, with significant differences in caregiving demands occurring across pediatric illnesses. To examine disease specific differences, several studies compared two illness groups. For example, while no specific prevalence data of sleep disturbances was given, parents of children with eczema had a median sleep loss of 78 and 90 min (mothers and fathers, respectively) over 2 nights compared to a median of 0 min for both mothers and fathers of children with asthma (Moore et al., 2006), suggesting a higher rate of sleep disturbances in parents of children with eczema. Whereas night coughs and wheezing may be more periodic for children with asthma, itching may be more constant in children with eczema.

### **Potential Causes of Sleep Disruptions in Parents**

Four potential causes of parent sleep disruption were identified. First, parents of children/adolescents with chronic illnesses are often required to provide care for their child's illness or pain during the night (Ferrell et al., 1994; Heaton et al., 2006; Lawson et al., 1998; Lewis-Jones et al., 2001; Meltzer & Mindell, 2006; Moore et al., 2006; Reid & Lewis-Jones, 1995). Four of these seven studies focused on youth with eczema, highlighting the disruptive nature of the child's nighttime itching on parent sleep. Second, a child's illness often requires monitoring by parents during the night. This was reported by parents of youth with diabetes (Sullivan-Bolyai et al., 2003; Williams et al., 2000), epilepsy (Williams et al., 2000), and asthma (Horner, 1997). Third, sleep disruptions in parents can result from false monitor alarms, in particular for children/adolescents who are technology dependent (Andrews & Nielson, 1988; Heaton et al., 2006; Meltzer & Mindell, 2006). Finally, the stress of caring for youths with a chronic illness can disrupt sleep (Boman et al., 2003, 2004; Ferrell et al., 1994; Meltzer & Mindell, 2006). For example, Ferrell et al. (1994) found in a group of parents of children and adolescents with cancer that "the mental and emotional burden of all that was happening made it impossible to sleep" (p. 377). In a study comparing children with cancer and diabetes, sleep disruptions were related to time since diagnosis, with improvement in sleep for parents of youth with cancer over time, but not diabetes (Boman et al., 2004). The authors suggest this is due to either changes in caregiving duties at night and/or less stress as the child's health improves.

### **Consequences of Sleep Disruptions**

Three studies directly examined the relationship between child sleep disruptions and both parent sleep and daytime functioning. Using validated questionnaires (e.g., Beck Depression Inventory), a relationship was found between sleep disruptions and depression in mothers of children with eczema (Moore et al., 2006), and a relationship between sleep quality and depression has been found in mothers of children with epilepsy (Cottrell & Khan, 2005) and VDC (Meltzer & Mindell, 2006). In addition, using the Hospital Anxiety and Depression Scale, Moore et al. (2006) found a significant relationship between sleep disruptions and anxiety in both mothers and fathers of children with eczema. Finally, Cottrell et al. (2005) reported a relationship between poor sleep quality and decreased marital satisfaction as well as poor health in mothers of children with epilepsy.

Fatigue has also been related to sleep disturbances in parents of children with eczema (Arvola et al., 2000), asthma (Horner, 1997), and VDC (Meltzer & Mindell, 2006). For parents of youth with diabetes, epilepsy, and eczema, changing to a less independent sleeping arrangement (i.e., co-sleeping) has been reported either following the child's diagnosis, or as an intervention to help children sleep during the night (Reid & Lewis-Jones, 1995; Sullivan-Bolyai et al., 2003; Williams et al., 2000). While co-sleeping is more common in infants and toddlers than older children, these studies included children of all developmental age groups. Reid and Lewis-Jones (1995) found that 48% of parents brought their child with eczema (mean = 25 months) to bed as a management strategy for eczema, compared to 15.1% of a national prevalence sample of infants and toddlers (National Sleep Foundation, 2004). Similarly, Williams et al. (2000) reported that 22% of preschool and school-aged children with epilepsy, and 8% of youth with diabetes changed to a less independent sleeping arrangement after diagnosis, compared to a national prevalence of 7.6% for preschool and school-aged children.

Qualitatively, mothers in one study reported that watching their child struggling to breathe during the night was "harrowing" (Horner, 1997, p. 661). Frustration and exhaustion due to sleep problems (both their own and their child's) has also been reported by parents of children with eczema (Lawson et al., 1998; Lewis-Jones et al., 2001) and technology dependency (Heaton et al., 2006).

### **Discussion**

The studies reviewed provide preliminary data to support the idea that sleep disruptions may provide a mechanism

that contributes to the negative psychosocial and health outcomes experienced by parents of youth with chronic illnesses, providing a potential area for intervention. Together, the studies reviewed demonstrate that sleep in parents of youth with chronic illnesses is disrupted, and that a relationship exists between child sleep, parent sleep, and parent daytime functioning. However, many of the reviewed studies have methodological limitations that restrict our ability to draw definitive conclusions about the prevalence, causes, and consequences of sleep disruption in this population. In order to provide the most effective and beneficial interventions for parents of youth with chronic illnesses, more research is needed. The limitations outlined subsequently provide a clear avenue for future research in this area.

### **Defining and Measuring Parent Sleep**

In sleep research, the primary variables of interest can be operationally defined. Constructs include total sleep time (number of hours of sleep), sleep onset latency (number of minutes to fall asleep at bedtime), night wakings (the frequency and duration of wakings between sleep onset and sleep offset), and sleep quality (a subjective rating of how well the person felt they slept). Only 5 of the 13 quantitative studies included one of these variables (Cottrell & Khan, 2005; Gedaly-Duff et al., 2006; Meltzer & Mindell, 2006; Moore et al., 2006; Reid & Lewis-Jones, 1995). The other studies investigated sleep interruption, sleep loss, disrupted sleep, sleep disturbance, tiredness, exhaustion, sleep issues, and night wakings. Studies that were more qualitative in nature provided themes related to interrupted sleep, sleep deprivation, the stress of nighttime caregiving and disrupted sleep. This wide variety in terminology makes comparisons across studies difficult. It is recommended that future studies measure constructs of sleep that can be operationally defined, improving both the specificity of the variables, and the ability to generalize information across studies.

Along with well-defined variables, future studies should include validated measures of sleep quantity and quality, including questionnaires [e.g., Pittsburgh Sleep Quality Index (PSQI), Children's Sleep Habits Questionnaire (CSHQ)], actigraphy, and polysomnography (PSG). While PSG is considered the gold standard for measuring sleep architecture and physiological sleep disorders such as obstructive sleep apnea or narcolepsy, questionnaires and actigraphy are the more common approach used to measure sleep patterns, sleep quantity, and sleep quality. Two recent studies included an empirically validated

sleep questionnaire (PSQI) (Cottrell & Khan, 2005; Meltzer & Mindell, 2006), and one feasibility study included actigraphy (Gedaly-Duff et al., 2006). The majority of the studies reviewed looked at parent sleep either as an incidental variable found during interviews regarding the impact of the child's illness on the family or as a single item question [e.g., over the last week, how much effect has your child having eczema had on the sleep of others in the family? (Lawson et al., 1998; Lewis-Jones et al., 2001)]. The use of validated questionnaires and actigraphy in future studies would help to clarify the relationship between a youth's chronic illness and sleep patterns and parental sleep and daytime functioning.

### **Longitudinal Data**

None of the studies reported included longitudinal data, allowing us to only interpret the results as "potential causes" and preventing us from drawing directional conclusions about the "consequences" of sleep disruptions. Longitudinal studies are needed to identify the direct causes of sleep disruptions and to elucidate the direction of the consequences of sleep disruptions. Since all of the studies reviewed only included correlational or descriptive data, we cannot definitively identify the direction of these relationships. Yet, because there is a relationship, future studies should consider sleep disruptions as a potential mechanism to explain the negative daytime functioning in parents of children and adolescents with chronic illnesses.

### **Control Group**

Only three studies reviewed included a control or comparison group of healthy youth (Boman et al., 2004; Lewis-Jones et al., 2001; Meltzer & Mindell, 2006). With almost 40% of adults in the United States sleeping <7 hr per night (National Sleep Foundation, 2002), more information is needed about whether sleep differs between parents of children and adolescents with and without chronic illnesses.

Furthermore sleep duration, sleep quality, and reasons for sleep disruptions may differ not only between parents of youth with and without a chronic illness, but may also differ between illnesses, highlighting the importance of selecting an appropriate control group. For example, illness factors such as disease severity or duration that may impact child and caregiver sleep have not been well defined. Only one study reviewed investigated the relationship between the child's disease duration and parent sleep, reporting changes in sleep over



time for both caregivers of youth with cancer or diabetes (Boman et al., 2004). These changes differed by disease group, with one group improving and the other not changing (or getting worse). Disease-specific sleep disruptors and common sleep disruptors across conditions should be considered separately, and appropriate control groups are needed to disentangle these effects on parent sleep.

### ***Consideration of Child Age***

Finally, developmental issues related to sleep problems should be examined more directly in future research. The age range of children included in this review was infancy through 22 years. In healthy children and adolescents, sleep is known to change with developmental stages. For example, night wakings are common in young children, while parents are less involved with adolescent sleep. Thus, the relationship between parent and child sleep disruptions may be influenced by the child's age. Only one study in this review examined whether sleep disturbances in children were age appropriate (e.g., similar or different compared to a control group), finding night wakings to occur 10 times more often in preschoolers with eczema compared to healthy preschoolers (Lewis-Jones et al., 2001). Future studies should have narrower age ranges, or include analyses to examine for developmental differences in sleep.

### ***Relationship between Child Sleep and Parent Sleep***

Four potential causes of parent sleep disruptions were identified: nighttime caregiving, monitoring the child's illness, equipment alarms, and caregiver stress. However, another limitation of the existing literature is that the relationship between child sleep and parent sleep has not been well established in this population. For example, few studies have shown a relationship between child sleep quantity and parent sleep quantity, or child sleep disruptions and parent sleep quality. Although the common belief is that parent sleep is related to the child's illness or disorder in terms of caregiving responsibilities, stress or worry related to the child's illness could also cause additional sleep disruptions. Future studies should specifically identify sources of sleep disruption in parents. In the few studies that have shown a relationship between parent and child sleep, this finding is associational. Thus, the direction of the relationship between child sleep, parent sleep, and parent daytime functioning cannot be concluded. Longitudinal studies that follow

families over the course of the child's illness would help to clarify the relationship between these variables.

### ***Consequences of Sleep Disruptions on Daytime Functioning***

Findings from three studies (Cottrell & Khan, 2005; Meltzer & Mindell, 2006; Moore et al., 2006) suggested that disrupted parent sleep was related to depression, anxiety, health, and marital satisfaction. Additional studies identified fatigue and exhaustion to be negative consequences of sleep disruptions. There is a strong need for more research on the impact of sleep disruptions on daytime functioning in parents of children with chronic illness, which is highlighted by findings from the experimental sleep literature. For example, at least one study has found that sleeping <6 hr per night over 14 days produced severe cognitive impairments and that participants were unaware of such a decline in functioning (Van Dongen, Maislin, Mullington, & Dinges, 2003). Chronic insufficient sleep has also been associated with increased sleepiness and mood disturbance (Dinges et al., 1997). Notably, such deficits may persist for several days even after sufficient sleep is obtained (Belenky et al., 2003).

These findings are critical because as parents become medical caregivers in the home, they are required to make a number of decisions about their child's health care on a regular basis. Studies of physicians and nurses have shown an increase in medical errors with sleep loss (Balas, Scott, & Rogers, 2006; Richardson et al., 1996; Scott, Hwang, & Rogers, 2006). Thus, children's health and well-being may be compromised by the lack of consistent and sufficient sleep in parents. Future studies of functioning in parental caregivers should include measures of mood, psychological functioning, neurobehavioral performance, and health. Again, longitudinal studies would clarify the role of sleep disruptions in the daytime functioning of parents of children and adolescents with chronic illnesses.

### ***Interventions to Improve Parent Sleep***

None of the studies reviewed included an intervention to improve parent sleep. While more empirical evidence is needed to precisely demonstrate the relationship between a child's illness and parent sleep, interventions are needed that address both parent and child sleep disruptions. Brief interventions in adult caregivers have shown improvements in sleep quality and quantity using modified cognitive behavioral therapy for insomnia approaches (Carter, 2006; Cohen & Kuten, 2006; McCurry, Logsdon, Vitiello, & Teri, 1998). It is likely that

similar types of interventions would also benefit pediatric caregivers. Although some nighttime caregiving requirements cannot be changed, interventions such as relaxation training could be utilized to address parental stress related to the child's illness, enabling parents to fall asleep or return to sleep more quickly.

Interventions to improve child sleep may also improve parent sleep. This would include improved illness management (e.g., reduce itching, night coughs, or decrease pain) and behavioral strategies (e.g., consistent sleep schedule, regular bedtime routine) to help children develop and maintain healthy sleep habits. Additionally, it has been suggested that pharmacological treatments in combination with behavioral approaches may be beneficial for children with chronic illnesses or pain, or during hospitalization (Owens et al., 2005). While there are currently no FDA approved medications for pediatric insomnia, one study found promising effects of melatonin use in children with epilepsy, significantly decreasing total sleep problems (Gupta, Aneja, & Kohli, 2004).

### Clinical Implications

It is clear that interventions to improve sleep in youth with chronic illness and their parental caregivers need to be developed, tested, and utilized. Along with standard interview questions about mood and functioning, it is recommended that psychologists and other healthcare providers ask children and adolescents with chronic illnesses and their parents about sleep quantity and quality. One study recommended that changes in sleep locations following diagnosis (e.g., child now sleeps in parent's bed) may be indicative of greater stress related to the child's illness, providing an indirect way of assessing the family's coping (Sullivan-Bolyai et al., 2003). For reported sleep problems, practitioners can provide education around healthy sleep habits and consequences of insufficient sleep. Respite care is an intervention that is currently available and can be recommended to families. For example, parents of children with technology dependency have reported that the greatest benefit of overnight respite care is being able to sleep (Heaton et al., 2006). In the adult literature, the use of overnight respite care has also shown promising results (Bramwell, MacKenzie, Laschinger, & Cameron, 1995).

### Summary

This review of the existing literature shows elevated rates of sleep problems, multiple potential causes

(e.g., child's pain, nighttime medical care, caregiver stress) of parent sleep disruptions, and consequences to parent daytime functioning, including negative mood and increased fatigue. Together these studies suggest a need for interventions designed to improve sleep in parents of youth with chronic illnesses, allowing them to function optimally during the day while caring for their child.

There remain a number of areas to be addressed in future research. To better understand the prevalence, causes, and consequences of sleep disruptions in parents of children and adolescents with chronic illnesses, longitudinal studies with clearly defined sleep variables, validated and/or objective measures of sleep, age/developmental considerations, and control groups are needed. With this information, interventions that ultimately improve parent sleep should be developed and tested. Such interventions in turn may alleviate some of the stress, negative mood, and caregiver burden experienced by parental caregivers.

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