Impact of a Child’s Chronic Illness on Maternal Sleep and Daytime Functioning

Lisa J. Meltzer, PhD; Jodi A. Mindell, PhD

Background: Chronic illness may not only directly impact the sleep of a patient but also indirectly impact the sleep of the family members who provide nighttime care. For parents of children with chronic illnesses, few studies have examined sleep disruptions that may account for elevated rates of depression and fatigue. Our objectives were to examine sleep patterns and causes of sleep disturbances in caregivers of children with and without chronic illnesses and to determine whether sleep mediates the relationship between a child’s chronic illness and daytime functioning in caregivers.

Methods: A total of 118 mothers of children with ventilator dependency (VENT), cystic fibrosis (CF), or healthy children (HEALTHY) completed a series of self-reported measures during a structured telephone interview, including the Pittsburgh Sleep Quality Index, the 24-Hour Sleep Patterns Interview, the Child Health Questionnaire–General Health Scale, the Center for Epidemiological Studies–Depression Scale, and the Iowa Fatigue Scale.

Results: Ventilator dependency caregivers reported an earlier morning wake time and shorter total sleep time than both CF and HEALTHY caregivers. In addition, VENT caregivers reported more night wakings and poorer sleep quality than HEALTHY caregivers. Frequent sleep disruptions for VENT caregivers were due to nighttime caregiving, while almost 40% of both VENT and CF caregivers reported sleep disruptions due to stress related to their child’s health. Finally, caregiver sleep quality was found to mediate the relationship between child health and caregiver depression and fatigue.

Conclusions: Sleep in caregivers of children with chronic illnesses, in particular ventilator dependency, is significantly disrupted, resulting in chronic partial sleep deprivation. Owing to the level of attention and care required by these children, interventions and support for caregivers to improve their sleep quality and quantity are necessary.

Arch Intern Med. 2006;166:1749-1755

FAMILY CAREGIVING HAS BECOME A CENTRAL PART of our health care system, with more than 25 million informal caregivers providing approximately 80% of all long-term services and supports for family members across the life span. While the services provided by family caregivers are conservatively estimated to be worth $257 billion, caregivers put their own health and well-being at risk. For example, depression and other psychiatric illnesses have been reported in over 35% of caregivers (compared with a lifetime prevalence in women of about 21%). Recent studies have also shown that caregiving can have a significant negative impact on physical health and life expectancy. Caring for a family member or loved one with a chronic illness is not only a daytime job but can require a significant amount of work during the night, resulting in sleep disruption and chronic partial sleep deprivation, with 60% to 95% of caregivers reporting poor sleep quality owing to caregiving. Much of the scientific literature and surveys of caregiving populations have focused on caregivers of adult patients (age >18 years), with less emphasis on caregivers of pediatric populations. However, up to 20% of school-aged children are estimated to have a chronic medical condition, translating to approximately 12 million children younger than 18 years with a chronic illness. Caring for a child with a chronic illness goes above and beyond the responsibilities of raising a healthy child. Studies have reported higher rates of depression and anxiety in parents of children with chronic health conditions or disabilities compared with parents of healthy children. However, it is important to consider that most parents were functioning competently prior to assuming the role of caregiver. This highlights the importance of studying mechanisms such as sleep deprivation that may contribute to the depression and negative psychological functioning reported by caregivers of patients with chronic illnesses.
In general, sleep in caregivers has been understudied in the literature. For caregivers of adult patients, a small number of studies have demonstrated a relationship between sleep quality and/or sleep quantity and measures of caregiver burden and daytime functioning (eg, depression), with most studies focusing on dementia and adult patients with cancer. In a study of caregivers of adult patients with cancer, 95% of caregivers reported sleep problems, and more than 50% of the caregivers were at risk for clinical depression. Higher rates of sleep disturbances have also been found in caregivers of patients with Parkinson disease and caregivers of recently deceased patients. A study of female caregivers of people with AIDS, age-related dementia, and advanced-stage cancer found a relationship between distressing emotions and sleep problems. Finally, a study of primary caregivers of hospice patients found that 27% of caregivers were getting less than 4 hours of sleep per night, while the rest of the caregivers reported insufficient sleep.

The relationship between sleep and caregiving in pediatric populations has also received limited attention. Parents of children with epilepsy and diabetes reported changing sleeping arrangements (eg, increased child cosleeping with parents) following diagnosis, as well as increased sleep deprivation due to multiple night wakings to check on their children. Parents of children with severe atopic eczema were found to spend approximately 40 to 45 minutes per night attending to their child’s health-related needs. For children who are ventilator dependent, over 60% of parents complain of regular sleep disruptions from false monitor alarms and waking to turn their child, check machines, or attend to their child’s pain, vomiting, or other health-related needs. In terms of daytime functioning, parents of children with asthma reported missing work due to caring for children with asthma during the night. Together, these studies suggest that a child’s illness may significantly disrupt parental sleep.

While a few pediatric caregiver studies have found a relationship between the child’s illness and caregiver sleep, the impact of these sleep disruptions on parental daytime functioning has not been explored. Laboratory-based studies have shown that stress may cause poor sleep, with disrupted sleep resulting in negative mood, increased daytime stress, and more limited daytime functioning. However, the question remains whether sleep disruptions are associated with the negative outcomes so commonly found in parents of children with chronic illnesses. Thus, the aims of the present study were to (1) examine sleep patterns in caregivers of children with and without chronic illnesses, (2) examine causes of sleep disturbances in caregivers, and (3) determine whether sleep mediates the relationship between a child’s chronic illness and daytime functioning in caregivers.

### METHODS

#### PARTICIPANTS

A total of 154 mothers of children aged 3 to 14 years (mean age, 7.3 years) were invited to participate in this study, including 40 mothers of children with ventilator dependency (VENT), 54 mothers of children with cystic fibrosis (CF), and 50 mothers of children without a chronic illness (HEALTHY). Nineteen mothers declined to participate (10 VENT, 8 CF, and 1 HEALTHY), stating they were either too busy (n = 11) or not interested (n = 8). In addition, interviews with 7 mothers (1 VENT, 4 CF, and 2 HEALTHY) were never completed owing to conflicts with the mothers’ schedules. This resulted in the final sample of 118 mothers (29 VENT, 42 CF, and 47 HEALTHY).

During recruitment, we asked each family to identify the primary caregiver in the home. Only 3 fathers were identified in this role (1 VENT, 2 CF); thus, we chose to include only mothers in the current analyses. This is consistent with prior research that notes that mothers are most likely to be the parent who attends to a child’s nighttime awakening. Participants were 96% white and ranged in age from 26.7 to 52.7 years (mean ± SD age, 38.3 ± 5.6 years). Most (82.2%) had completed some postsecondary education, and 89.9% were married. Thirty-one percent of the participants worked outside the home part-time, and 33% worked outside the home full-time. Seventy-five percent of the mothers had additional children other than the identified study child in the home (ages 6 months to 21 years). Twenty-five mothers (21%) (7 VENT, 7 CF, and 11 HEALTHY) were taking a psychotropic medication.

#### PITTSBURGH SLEEP QUALITY INDEX

The Pittsburgh Sleep Quality Index (PSQI) is a well-validated 19-item self-report instrument that measures sleep disturbances in adults. The PSQI provides a global score ranging from no sleep difficulty to severe difficulties and includes 7 subscale scores (sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, sleep medications, and daytime dysfunction). Multiple studies have reported good reliability of the PSQI (Cronbach α > 0.8). In addition to sleep continuity variables, the PSQI inquires about the frequency of different reasons for sleep disruptions (not in the past week, less than once a week, once or twice a week, 3 or more times a week). Because 1 item on the PSQI has potential overlap with both depression and fatigue (“keeping your enthusiasm to get things done”), all analyses were run with and without this item. No differences were found; thus, all reported analyses include all items from the PSQI.

Based on open-ended questions in a pilot study about caregiver sleep in pediatric populations, 3 additional items inquiring about reasons why participants had trouble sleeping over the previous week were added (attending to your child’s health needs, stress related to your child’s health, and stress not related to your child’s health). Participants responded using the same Likert choices as the other PSQI sleep disturbances questions. These items were evaluated individually and were not included in the PSQI subscale or total scores.

#### 24-HOUR SLEEP PATTERNS INVENTORY

The 24-hour Sleep Patterns Inventory (SPI) is a telephone interview that asks participants 12 questions about their sleep patterns over the past 24 hours, including bedtime, sleep onset latency, night wakings (frequency and duration), morning wake time, and overall sleep quality. Four telephone interviews were conducted over a 2-week period, with 2 weekday interviews and 2 weekend interviews completed for each participant. These interviews last less than 5 minutes each. This measure has been shown to be valid and feasible compared with a 2-week sleep diary.
CHILD HEALTH QUESTIONNAIRE, GENERAL HEALTH PERCEPTION SCALE

The Child Health Questionnaire is a 50-item measure that was developed as a health-related quality-of-life measure for children that assesses parent perception of a child's physical, emotional, and social well-being. It has been normalized on different chronic illnesses as well as healthy populations of children. The General Health Perception Scale has 4 items. Low scores indicate that the parent believes that the child has poor health that will likely get worse, and high scores indicate that the parent believes that the child is in excellent health, which will continue. A recent population-based study demonstrated that this scale has excellent reliability (Cronbach α > 0.70) and is able to discriminate between populations of children with asthma, headaches, problems with hearing, and no health conditions.

CENTER FOR EPIDEMIOLOGICAL STUDIES–DEPRESSION SCALE

The Center for Epidemiological Studies–Depression Scale (CES-D) is a 20-item measure that asks participants to rate items on a 4-point Likert scale with responses ranging from 1 (never) to 4 (most of the time). The CES-D responses are summed, with higher scores indicating more depressive symptoms. The CES-D has consistently shown adequate internal reliability (Cronbach α > 0.86) in studies of caregivers. Because 1 item on this scale asks about sleep disturbances, all analyses were conducted both with and without this item. There were no differences in the results; thus, all reported findings include the full 20 items.

IOWA FATIGUE SCALE

The Iowa Fatigue Scale is an 11-item measure of daytime fatigue and functioning over the past month. The Iowa Fatigue Scale assesses fatigue in terms of cognitive function, energy level, and productivity and provides a total score, with a higher score indicating greater fatigue. This measure has good internal consistency (Cronbach α = 0.90) and is correlated with other measures of daytime fatigue (r > 0.90). While the Iowa Fatigue Scale is correlated with the PSQI Daytime Functioning Scale (r = 0.68), the PSQI scale includes only 2 items, while the Iowa Fatigue Scale measures multiple dimensions of fatigue.

PROCEDURE

This study was approved by the institutional review board at a large tertiary care children's hospital. Families with ventilator-dependent children were identified by a home-care program that provides case management, education, support, and nursing for over 150 families in the region. Families with children with cystic fibrosis were identified by members of the Cystic Fibrosis Center of the children's hospital, which cares for over 200 children with cystic fibrosis. The healthy comparison sample was identified through peer nomination, with mothers of children in the chronic illness groups identifying an acquaintance who had a child of the same sex and similar age. Seventy percent of the mothers who completed the initial structured telephone interview identified a comparison family (n = 30). Participants in all 3 groups were excluded if they had a diagnosed sleep disorder, if their child had a diagnosed sleep disorder, if they did not have access to a telephone, and/or if English was not their primary language.

Participants received a letter inviting them to participate in the study and explaining the purpose and procedure of the study. This was followed up by a telephone call from the principal investigator, who screened the mothers for eligibility, obtained verbal consent, and scheduled a time for the initial telephone interview. During the initial telephone interview, participants completed measures of sleep, child health, and caregiver daytime functioning. During the 2 weeks after the initial telephone interview, participants also completed four 24-hour SPIs, 2 asking them to recall weekday sleep, and 2 asking them to recall weekend sleep.

DATA ANALYSES

Preliminary analyses were conducted to evaluate whether there were any demographic differences between the 3 caregiving groups that would need to be controlled for when conducting between-group analyses. These included analysis of variance.
and χ² tests. Similar analyses were conducted to determine whether sleep patterns, daytime functioning, and reasons for sleep disruptions differed between the 3 caregiver groups. To examine the differences in reasons for sleep disruptions, the responses on the PSQI were consolidated from 4 to 2 options (less than once a week and at least once a week), which distinguished the ongoing presence of a sleep disruption from an occasional sleep disturbance.

In this study, we predicted that caregiver sleep quality (as measured by the PSQI Global Score) would mediate the relationship between child health status and caregiver daytime outcomes (depression and fatigue). A mediating variable is one that attempts to explain the relationship between the predictor and the criterion variable. 4 As stipulated by Baron and Kenny, 4 3 multiple regression analyses were used to test the following 4 conditions: (1) the predictor variable (child health status) must be significantly associated with the hypothesized mediator (caregiver sleep quality); (2) the predictor variable (child health status) must be significantly associated with the dependent measure (depression and fatigue); (3) the mediator (caregiver sleep quality) must be significantly associated with the dependent measure (depression and fatigue); and (4) the impact of the predictor (child health status) on the dependent measure (depression and fatigue) is less after controlling for the mediator (caregiver sleep quality). Prior to running the mediation model analyses, all demographic variables were entered into the regression equations.

RESULTS

DEMOGRAPHIC DIFFERENCES

Descriptive sample data are summarized in Table 1. The only significant demographic difference between the 3 caregiver groups was for race (χ² = 8.90, P = .01). While there were 4 black VENT mothers, there were no black mothers in the CF group because cystic fibrosis is a disease that occurs primarily in whites. Thus, race was controlled for in all analyses.

SLEEP-WAKE PATTERNS

The first aim of this study was to examine sleep patterns in mothers of children with and without a chronic illness. Based on the 24-hour SPI, there were no significant differences among the 3 groups in terms of bedtime or sleep onset latency (Table 2). However, significant differences were found for morning wake time, total sleep time, night waking frequency, and sleep quality. As listed in Table 2, post hoc analyses (Tukey honestly significant difference test) indicate that the VENT group awakened earlier in the morning and had a shorter total sleep time than both the CF and HEALTHY groups. In addition, the VENT caregivers had significantly more night wakings and poorer sleep quality than the HEALTHY group.

Sleep patterns were also examined using the PSQI, with significant differences found between the groups for sleep quality, sleep latency, sleep duration, and sleep efficiency. As listed in Table 2, post hoc analyses (Tukey honestly significant difference test) indicated that the VENT group reported poorer sleep quality than the HEALTHY group as well as longer sleep latency and shorter total sleep time than both the CF and HEALTHY groups. Both the VENT and CF mothers reported poorer sleep efficiency than the HEALTHY group. While sleep disturbances did not differ among the 3 groups, this scale did not include the 3 additional items related to sleep disruptions (caregiving, stress about child’s health, and general stress).

Table 2. Sleep-Wake Patterns and Daytime Functioning in Caregivers

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>VENT</th>
<th>CF</th>
<th>HEALTHY</th>
<th>F Score</th>
<th>P Value</th>
</tr>
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<tbody>
<tr>
<td>24-Hour SPI</td>
<td></td>
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<tr>
<td>Bedtime†</td>
<td>22.55 ± 74 (20:00-1:27)</td>
<td>23.14 ± 63 (21:30-2:00)</td>
<td>23.11 ± 50 (21:21-1:21)</td>
<td>0.89 .41</td>
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<tr>
<td>Wake time‡‡</td>
<td>6.21 ± 39 (3:03-7:30)</td>
<td>7.07 ± 68 (4:50-10:00)</td>
<td>7.01 ± 46 (5:57-10:00)</td>
<td>6.89 .001</td>
<td></td>
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<tr>
<td>Sleep onset latency, min</td>
<td>24.90 ± 18.7 (5.0-71.4)</td>
<td>17.74 ± 18.0 (0.5-90.0)</td>
<td>17.56 ± 12.9 (0.0-57.9)</td>
<td>2.16 .12</td>
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<tr>
<td>Night waking frequency§</td>
<td>3.99 ± 0.9 (0-3)</td>
<td>1.12 ± 0.9 (0-3)</td>
<td>0.85 ± 0.7 (0-3)</td>
<td>3.43 .04</td>
<td></td>
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<tr>
<td>TST, h</td>
<td>6.31 ± 12.3 (3.8-8.4)</td>
<td>7.28 ± 9.9 (5.0-9.8)</td>
<td>7.34 ± 9.9 (5.2-9.8)</td>
<td>11.05 .&lt;.001</td>
<td></td>
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<tr>
<td>Sleep quality (1-5 scale)§</td>
<td>3.33 ± 0.7 (1.9-5.0)</td>
<td>3.73 ± 0.7 (2.5-5.0)</td>
<td>3.82 ± 0.7 (1.9-4.9)</td>
<td>4.19 .02</td>
<td></td>
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<tr>
<td>PSQI¶</td>
<td></td>
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<td></td>
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<tr>
<td>Sleep quality‡</td>
<td>1.45 ± 0.7 (0-3)</td>
<td>1.29 ± 0.6 (0-3)</td>
<td>1.00 ± 0.7 (0-3)</td>
<td>4.08 .02</td>
<td></td>
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<tr>
<td>Sleep latency‡</td>
<td>1.52 ± 0.9 (0-3)</td>
<td>1.05 ± 0.7 (0-3)</td>
<td>0.89 ± 0.9 (0-3)</td>
<td>5.75 .004</td>
<td></td>
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<tr>
<td>Sleep duration‡</td>
<td>2.28 ± 0.8 (1-3)</td>
<td>1.45 ± 1.0 (0-3)</td>
<td>1.32 ± 0.9 (0-3)</td>
<td>11.12 .&lt;.001</td>
<td></td>
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<tr>
<td>Sleep efficiency§</td>
<td>1.17 ± 1.2 (0-3)</td>
<td>0.71 ± 0.9 (0-3)</td>
<td>0.23 ± 0.6 (0-3)</td>
<td>10.22 .&lt;.001</td>
<td></td>
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<tr>
<td>Sleep disturbances</td>
<td>1.31 ± 0.7 (0-3)</td>
<td>1.14 ± 0.4 (1-2)</td>
<td>1.15 ± 0.5 (0-2)</td>
<td>1.16 .32</td>
<td></td>
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<tr>
<td>Sleep medications</td>
<td>0.62 ± 1.0 (0-3)</td>
<td>0.60 ± 1.1 (0-3)</td>
<td>0.34 ± 0.7 (0-3)</td>
<td>1.18 .31</td>
<td></td>
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<tr>
<td>Daytime functioning‡</td>
<td>1.72 ± 0.9 (0-3)</td>
<td>1.12 ± 0.8 (0-3)</td>
<td>1.00 ± 0.9 (0-3)</td>
<td>6.57 .002</td>
<td></td>
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<tr>
<td>Global score‡</td>
<td>10.07 ± 3.7 (2-18)</td>
<td>7.36 ± 3.8 (2-17)</td>
<td>5.94 ± 3.2 (1-15)</td>
<td>12.98 .&lt;.001</td>
<td></td>
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<tr>
<td>Depression§</td>
<td>15.10 ± 9.5 (1-36)</td>
<td>10.83 ± 8.9 (0-36)</td>
<td>9.28 ± 8.5 (0-35)</td>
<td>3.92 .02</td>
<td></td>
</tr>
<tr>
<td>Fatigue¶</td>
<td>31.34 ± 5.2 (20-38)</td>
<td>28.40 ± 6.1 (17-46)</td>
<td>26.40 ± 7.1 (12-43)</td>
<td>5.50 .005</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: CF, mothers of children with cystic fibrosis; HEALTHY, mothers of healthy children; PSQI, Pittsburgh Sleep Quality Index 37; SPI, Sleep Patterns Inventory; TST, total sleep time; VENT, mothers of children with ventilator dependency.

*Unless otherwise indicated, data are reported as mean ± SD (range).
†Bedtimes and wake times are expressed as times on the 24-hour clock; standard deviations are expressed in number of minutes.
‡Significant difference between VENT and both CF and HEALTHY.
§Significant difference between VENT and HEALTHY.
¶Significant difference between CF and HEALTHY.
§§Higher scores indicate more negative functioning.
SLEEP DISRUPTIONS

To examine reasons for sleep disturbances in caregivers’ analyses, were conducted to compare the reasons why caregivers woke at least once a week using the PSQI. As seen in the Figure, a significant difference was found for caregiving during the night ($\chi^2 = 17.7, P < .001$), with 52% of the VENT group reporting waking at least once a week to perform nighttime caregiving duties, compared with 26% of CF and 9% of the HEALTHY groups. A significant difference was also found for disruptions to sleep caused by stress related to the child’s health ($\chi^2 = 20.1, P < .001$), with 38% of both the VENT and CF groups waking at least once a week, compared with only 2% of the HEALTHY groups. No difference was found between the groups for disruptions of sleep caused by general stress ($\chi^2 = 0.91, P = .64$).

DAYTIME FUNCTIONING

One-way analysis of variance was performed to examine differences in depression and fatigue among the 3 caregiver groups. Significant differences were found between groups for depression, fatigue, and PSQI daytime functioning. As listed in Table 2, post hoc analyses (Tukey honestly significant difference test) indicated that the VENT group had significantly more symptoms of depression and fatigue and poorer daytime functioning than the HEALTHY group.

MEDIATION MODEL

Prior to testing the mediation model, demographic variables were entered to determine if any variable needed to be controlled in further analyses. None of the demographic variables listed in Table 1 were significant predictors of either model. To test whether caregiver sleep quality (as measured by the PSQI Global Score) mediated the relationship between child health status and caregiver daytime functioning, 2 series of regression analyses were conducted (1 for depression and 1 for fatigue) (Table 3). Following the Baron and Kenny approach, the partial correlation coefficient showed a significant association between (1) child health status and caregiver sleep quality ($r = 0.44; P < .001$); (2) child health status and depression ($r = 0.35; P < .001$) and child health status and fatigue ($r = 0.38; P < .001$); (3) caregiver sleep quality and depression ($r = 0.57; P < .001$) and caregiver sleep quality and fatigue ($r = 0.64; P < .001$). The association between child health status and depression ($\beta = 0.11$; $P = .01$) was reduced to a nonsignificant level ($\beta = 0.04$; $P = .15$) after controlling for caregiver sleep quality. Similarly, the association between child health status and fatigue ($\beta = 0.09$; $P < .001$) was reduced to a nonsignificant level ($\beta = 0.03$; $P = .11$) after controlling for caregiver sleep quality.

The purpose of this study was to investigate disrupted sleep patterns as a potential explanation for caregiver depression and fatigue in caregivers of children with chronic illnesses. In this sample, we found that VENT mothers had higher rates of impaired sleep patterns and shorter total sleep time than CF and HEALTHY mothers. Furthermore, poor sleep quality was shown to mediate the relationship between the child’s health and both caregiver depression and fatigue. Although causation cannot be assumed because of the cross-sectional design of this study, the child’s health was associated with poorer caregiver sleep quality and greater symptoms of depression and fatigue. Along with coping and adjustment to the child’s illness, limited social interactions, and uncertainty about the future due to the child’s illness, the disrupted sleep patterns identified in this study provide an additional explanation for why parents of children with chronic illnesses experience greater negative physical and psychosocial outcomes. In addition, the mediation model provides evidence that the impact of a chronic illness on sleep and functioning extends well beyond the patient to the caregiver who is responsible for the child’s health care and nighttime caregiving.

The mean self-reported total sleep time in the VENT group was 1 hour less than that in the CF and HEALTHY groups. This was in part due to the earlier morning wake time as well as the higher frequency of night wakings, which is consistent with previous studies of caregivers of ventilator-dependent children. However, when we asked about reasons for sleep disruptions, we were surprised that almost 40% of both VENT and CF caregivers reported waking at least once a week due to stress related to the child’s health (rather than actual caregiving responsibilities). This result provides an area for further investigation and potential intervention. Several studies have demonstrated that a brief cognitive behavioral intervention could be used to improve overall sleep quality and/or shorten prolonged night wakings in caregivers of adult patients, which is likely to be applicable to caregivers of pediatric patients.

One significant consequence of the shorter self-reported total sleep time found in caregivers is chronic partial sleep deprivation, which can negatively impact mood, fatigue, and performance. As seen in this study, it is possible that the changes in mood following chronic illness...
partial sleep deprivation may have resulted in an increased report of depression and fatigue in caregivers. Laboratory-based studies have also shown that sleep deprivation adversely affects performance and decision making, including multitasking, flexible thinking, risk assessment, insight, and communication. These abilities rely heavily on executive functioning and are each a part of day-to-day caregiving responsibilities.

Several limitations in both the measurement and participants in this study must be noted and suggest future directions for research in this area. In terms of measurement, this study was limited by having all measures completed by a single reporter (the caregiver). Future studies should include an objective measure of sleep patterns (e.g., actigraphy) that would allow for an unbiased examination of sleep patterns. In addition, this approach could provide more accurate information about sleep onset latency, since differences in measurements in this study (continuous 24-hour SPI vs categorical PSQI) provided different results in terms of caregivers reporting difficulties with sleep onset. Along with an objective measure of sleep, additional reporters of mood and functioning (e.g., physician or spouse) should be included in future research. Finally, this study measured sleep patterns and daytime functioning at only 1 point in time. Many caregivers remarked that their sleep patterns in particular become much worse when their child is more acutely ill (e.g., respiratory virus in the winter). This would suggest that caregivers of children with chronic illnesses may have greater sleep disruptions than those reported here, which indicates the need for studies that monitor caregiver sleep patterns over time.

In terms of participants, the study was limited by the homogeneous sample that heavily favored educated white women. Thus, the generalizability of these results to broader populations remains to be determined. In particular, additional caregivers in the home (e.g., fathers) should also be included in future studies, since their sleep and daytime functioning may also be negatively impacted by their child’s chronic illness. Furthermore, while use of psychotropic medications were reported in this study, we did not collect information on caregiver health status. The relationship between caregiving, health, sleep, and daytime functioning is complex, yet it is likely that these variables are related. Thus, additional studies should include caregiver health status when examining caregiving, sleep, and mood. Finally, there was potentially a self-selection bias in terms of mothers who agreed to participate, with higher rates of refusal in the 2 illness groups. However, as most of those who refused stated they were “too busy” to participate, it is likely this study underestimates the impact of the child’s illness on maternal sleep, mood, and functioning.

In conclusion, while a chronic illness may impact or disrupt a child’s sleep, caregiver sleep patterns are also significantly disrupted by nighttime caregiving demands and stress related to the child’s illness. Frequent and ongoing disruptions to sleep may result in chronic partial sleep deprivation in caregivers. With the increasing rates of informal or family caregiving in our population across the lifespan, it is essential to monitor the sleep, health, and well-being of caregivers of patients with chronic health conditions.

Accepted for Publication: June 9, 2006.
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Table 3. Regression Models for Depression and Fatigue on Child Health Status and Caregiver Sleep Quality*

<table>
<thead>
<tr>
<th>Equation</th>
<th>Predictor: child health</th>
<th>Outcome: caregiver sleep quality</th>
<th>Beta (SE)</th>
<th>R²</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td>-0.06 (0.01)</td>
<td>-0.44</td>
<td>0.19</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td>-0.11 (0.03)</td>
<td>-0.35</td>
<td>0.12</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td>1.38 (0.57)</td>
<td>0.57</td>
<td>0.33</td>
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<td>4†</td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Child health</td>
<td></td>
<td>-0.04 (0.03)</td>
<td>-0.12</td>
<td>0.33</td>
</tr>
<tr>
<td></td>
<td>Caregiver sleep quality</td>
<td></td>
<td>1.25 (0.20)</td>
<td>0.52</td>
<td></td>
</tr>
</tbody>
</table>

*In all equations, caregiver sleep quality was measured by the Pittsburgh Sleep Quality Index global score.
†Represents the partial correlation for each variable.
‡For the final model of each outcome, the values are for the final 2-variable regression model, with the adjusted R² reported.
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