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The relationship between child and caregiver sleep in acute lymphoblastic leukemia maintenance

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Abstract

Purpose—The purposes of this study are to describe sleep quality and sleep disturbance among caregivers of children in the maintenance phase of acute lymphoblastic leukemia (ALL) and to examine the relationship between sleep quality, child sleep disturbance, and caregiver guilt and worry.

Methods—Caregivers of 68 children with ALL, ages 3 to 12 years old, completed measures of caregiver guilt and worry, caregiver sleep quality, and child's developmental history and sleep habits. Demographic and treatment correlates of poor caregiver sleep were examined, and caregiver guilt and worry was tested as a moderator between child and caregiver sleep.

Results—More than half of caregivers (55.9%) reported clinically significant poor sleep and less than 40% were obtaining adequate sleep durations. Caregiver sleep was significantly related to child age at diagnosis, child sleep, and caregiver guilt and worry. Caregiver guilt and worry did not moderate the relationship between child sleep and caregiver sleep.

Conclusions—Poor sleep is common in caregivers of children with cancer. Further research on the timing of sleep interventions and the most effective intervention targets are needed to maximize caregiver functioning during a child's cancer treatment. Targeted interventions seeking

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to improve caregiver sleep should be directed towards caregivers of children diagnosed in early childhood, caregivers of children with poor sleep, and caregivers with high guilt and worry.

Keywords

Sleep disturbance; Sleep quality; Parental caregivers; Acute lymphoblastic leukemia

Childhood chronic illnesses increase caregiver stress, which may pose a risk to the child's quality of life and adaptation— particularly in the case of pediatric cancer [1]. Across pediatric chronic health conditions, caregivers report elevated parenting stress [2], depression [3], high anxiety during and after treatment [4], increased fatigue [5], poorer health [6], and more disrupted sleep [7] compared to parents of children without a chronic illness. Furthermore, sleep disturbances related to nighttime caregiving [8], hypervigilance and illness monitoring [9], the presence of the child in the bed [10], emotional stress [11], and child sleep disruption [12] are extremely common for caregivers of children with chronic health conditions. Caregiver sleep disturbances, marked by short sleep, low sleep efficiency (percent of time in bed spent asleep), and poor sleep quality, may serve as a modifiable risk factor for negative physical and psychosocial outcomes experienced by these caregivers.

Caregivers of children with cancer potentially face an increased risk for sleep disruption due to the severity of the diagnosis relative to other illnesses, the life threatening and intense treatments which may result in high caregiver demands [13], and the significant impact of cancer on child sleep [14–17]. Managing acute symptoms and side effects of intensive treatment, providing medical care at home, and hospital admissions [18] can result in erratic sleep schedules, night time awakenings, and environmental disruptions to the caregiver's sleep. Because children with cancer exhibit longer sleep onset latency [16, 17], low sleep efficiency [19], less restful sleep [17], and more problematic sleep behaviors [15], caregivers' sleep may be further disrupted by increased demands in managing the child's sleep. Many caregivers report needing to co-sleep with children out of necessity in order to manage their child's needs, often resulting in reduced sleep quality for children and parents [20]. The regular disruptions to the caregiver's sleep may create maladaptive sleep behaviors to compensate for frequent awakenings such as short sleep times, increased napping, or co-sleeping, which may perpetuate caregiver sleep disturbances throughout the child's treatment.

In addition to the physical demands on caregivers of children with cancer, psychosocial stressors related to the child's diagnosis, such as uncertainty about the disease, anxiety, and depression can also play a role in disrupting caregiver sleep [21]. For example, mothers caring for children in acute lymphoblastic leukemia (ALL) maintenance report more subjective symptoms of insomnia than controls despite evidencing similar sleep patterns by actigraphy estimates [15], and qualitatively, they report trouble sleeping throughout the child's treatment [22]. Qualitative research with mothers of children in ALL maintenance has indicated that about half of the mothers in the study reported that worries increased at night and contributed to poor sleep throughout the child's treatment [22]. Caregiver stress, and specifically worry, may play an important role in the genesis and maintenance of sleep

disturbances in families of children with cancer. Furthermore, worry may interact with poor child sleep to further decrease caregiver sleep quality. Because worry may be modifiable, understanding the role it plays in caregiver sleep is important to improving outcomes and informing intervention targets.

The current study examines caregiver sleep during ALL maintenance to identify factors that contribute to disrupted sleep with the intention of informing clinical practice and future intervention development. The maintenance phase of ALL is the third, final, and longest phase of treatment, lasting for 2 to 3 years, during which time patients cycle on and off corticosteroids [23]. Interim side effects of corticosteroids include mood disturbance and irritability [24], pain [25], increased fatigue [26], and sleep disturbances, such as poor sleep quality and increased night awakenings [26, 27]. The variable nature of ALL maintenance treatment and the long duration of this treatment stage may result in prolonged disruption to the family's routines and sleep. With improvements in treatments and health outcomes for ALL, research focused on improving health-related quality of life of children and families during treatment is increasingly important. Optimal caregiver functioning is essential to maximize child quality of life during treatment. Little research has described sleep in caregivers of children with cancer [15], despite the demonstrated relationships between sleep and caregiver psychosocial functioning in other chronic health conditions [7, 28]. Further, because the maintenance phase of treatment is long and often is a time that families return to school and work, maximizing the caregiver's ability to sleep can be essential to improving the caregiver's functioning.

The aims of the study were to (1) describe sleep patterns and sleep quality in caregivers of children with ALL in maintenance treatment; (2) identify factors associated with caregiver sleep disturbances; and (3) examine parent guilt and worry as a moderator between child and caregiver sleep. We hypothesized that caregivers of children with ALL would report poor sleep habits relative to previously published samples of both non-caregivers and caregivers of children with other illnesses. For caregivers with greater sociodemographic, psychosocial stress, and more disrupted child sleep, we hypothesized that sleep quality would be lower. We also hypothesized that caregiver guilt and worry would moderate the relationship between child and caregiver sleep when controlling for significant sociodemographic factors related to caregiver sleep. The purpose of this moderation was to better understand whether caregiver guilt and worry is a viable intervention target when seeking to improve caregiver sleep (if caregiver guilt and worry is a significant moderator) or whether intervention efforts should be aimed at improving child sleep (if there is a main effect for child sleep on caregiver sleep, but no moderation). Post hoc exploratory analyses were conducted to examine the role of significant sociodemographic factors in this moderation to better understand how guilt and worry impact family sleep in different subgroups of patients.

Method

Participants

Participants were 68 caregivers (one per child) recruited during their child's outpatient oncology visits. Caregivers were eligible if they spoke English and met inclusion criteria for the parent study that aimed to prospectively describe sleep patterns and quality of life during

steroid courses in ALL maintenance [27]. Inclusion criteria included caring for a child between the ages of 3 to 12 years old with a primary diagnosis of ALL, at least 1 month into the maintenance phase of treatment, and taking corticosteroids (dexamethasone or prednisone). Children were being treated according to the following chemotherapy protocols: AALL0232, AALL0331, AALL07P4, and AALL0932, with mercaptopurine, methotrexate, vincristine, and corticosteroid pulses. This age range was selected to coincide with the peak incidence of ALL diagnoses, but to limit the inclusion of infants and adolescents who have different treatments, prognoses, and developmental characteristics that may influence sleep. Potential participants were identified through a cancer registry and verified via the hospital electronic medical records system. For the current study, 204 children were assessed for eligibility and 93 did not meet eligibility criteria (e.g., prior diagnosis of genetic syndromes, neurological impairment, cranial radiation treatment, or relapsed ALL). Eighty-one participants were approached for the current study before completing treatment or aging out of the study, 13 caregivers declined participation (10 due to lack of interest, 3 due to lack of time), and 68 enrolled.

Procedure

The study was approved by the appropriate Institutional Review Boards, and recruitment occurred from May 2010 to October 2014. Research assistants approached families at the child's oncology appointment, explained the study, and obtained informed consent from the caregiver. Caregivers completed study measures during the clinic visit.

Measures

Medical chart review—Medical records were reviewed to confirm inclusion and exclusion criteria, date of diagnosis, month in maintenance treatment, treatment protocol, and time since diagnosis.

Developmental history questionnaire—Caregivers completed a brief form regarding the child's medical and developmental history and family demographic variables. Child age and gender, relationship to the caregiver, caregiver age, marital status, and number of children in the home were used in the current analyses.

Barratt simplified measure of social status (BSMSS)—This measure is a simplified version of the Hollingshead Four Factor Form of Social Status [29] used to estimate social class through parents' and grandparents' education and occupations [30]. Higher scores indicate higher social status (ranging from 8 to 66). The BSMSS has been used previously in pediatric cancer [31].

The abbreviated Children's Sleep Habits Questionnaire (CSHQ)—The CSHQ is a 33-item parent report questionnaire assessing the child's sleep habits and disturbances for the past week [32], which was a week prior to taking corticosteroids. Caregivers rate the frequency of sleep behaviors on a 3-point Likert scale of "usually" (5–7 times per week) to "rarely" (0–1 time per week). The CSHQ yields a total score, with higher scores indicating more sleep disturbances. Total scores of 41 or higher indicate clinically significant sleep disturbances. Internal consistency was acceptable for the current sample ($\alpha = .78$).

Parent Experience of Child Illness (PECI)—This measure assesses parent/caregiver stress related to caring for a child with a chronic illness during the past week. Caregivers completed the 11-item “Guilt & Worry” subscale of the PEGI, rating each item on a 5-point Likert-type scale (range = 0–4), where a higher mean score indicates greater guilt and worry [33]. Reliability in the current sample was acceptable ($\alpha = .87$). Items assess guilt about the diagnosis (e.g., “I feel guilty because my child became while I remained healthy”) and worry about the child and family’s health (e.g., “I worry that my child’s illness will worsen/return”).

Pittsburgh Sleep Quality Index (PSQI)—The PSQI is a well-validated, 19-item self-report questionnaire that measures sleep quality and disturbance in adults over the past 1 month [34]. The PSQI total score ranges from 0 to 21, with a higher score indicating worse sleep quality and scores > 5 indicating clinically significant sleep disturbances (i.e., a “poor sleeper” [34]). The seven component scores (sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbances, sleep medications, and daytime dysfunction) are used to compute the total score. Reliability for the PSQI was acceptable ($\alpha = .79$).

PSQI-Addendum—Sleep disturbances specific to caregiving are not captured on the PSQI; thus, an Addendum to the PSQI was created to assess how caregiving impacts the parent’s sleep as has been done previously in other studies of caregivers of children with chronic health conditions [7, 28]. The caregiver was asked two additional questions: to rate how often in the past month they have experienced trouble sleeping due to (1) stress from the child’s health and (2) attending to the child’s health needs. Items are scored on the same 4-point scale as the PSQI, ranging from “not during the past month” to “3 or more times per week.” Caregivers also reported how much their sleep has changed since the cancer diagnosis.

Statistical analyses

Descriptive statistics for current caregiver sleep (PSQI components, PSQI Addendum) and child sleep (CSHQ) were calculated. One-sample *T* tests were used to compare the current sample to previously published values on each instrument [28, 33, 34]. To understand which caregivers exhibit more disrupted sleep, Pearson correlations were used to examine the relationship between caregiver sleep (PSQI Total Score) with demographic (child age at diagnosis, age on study, caregiver age, Barrett Social Status, number of siblings in the home, average age of siblings living in the home) and time in maintenance treatment. The relationship between caregiver guilt and worry with risk group was also tested. Caregiver sleep was also compared between the two steroid groups (prednisone and dexamethasone) and the child’s disease risk group. Sociodemographic characteristics of the child and caregiver that were significantly related to caregiver sleep (at $p = .05$) were included as covariates. Pearson’s correlations were also used to examine the relationship between caregiver sleep quality, caregiver guilt and worry, and child sleep disturbance. To understand whether caregiver guilt and worry moderated the relationship between child sleep and caregiver sleep, a hierarchical regression was conducted using covariates and mean-centered CSHQ and PEGI as step one and the interaction between CSHQ and PEGI as step two with caregiver sleep quality as the outcome (PSQI total score). Post hoc probing was conducted

according to the methods of Holmbeck [35]. Specifically, t tests of simple slopes were examined for the relationship between parent and child sleep at different levels of parenting stress.

Post hoc analyses were conducted to understand if guilt and worry moderated the relationship between child and caregiver sleep at different child ages of diagnosis because age at diagnosis (which was included in the initial moderation analyses as a covariate) was a significant predictor in the primary moderation models. A multiple additive moderation model was conducted using the PROCESS macro for SPSS testing guilt and worry and child age as moderators between child and caregiver sleep [36]. A sample size of 67 was needed to achieve power of 0.80 to detect moderate correlations (correlations of 0.3), with alpha of .05 [37]. Observed power for guilt and worry as a moderator between parent and child sleep (3 tested predictors with 1 covariate in the model) was 74% to detect a medium effect size ($f^2 = .15$). For the analysis examining child age and guilt and worry as moderators (5 predictors in the model), observed power to detect a medium effect size ($f^2 = .15$) was 64% [38].

Results

Description of caregiver variables

Sample characteristics are presented in Table 1, and caregiver sleep quality is presented in Table 2. The average PSQI score was above the clinical cutoff of 5 ($M = 7.00$, $SD = 4.13$), with more than half of caregivers identified as “poor” sleepers (55.9%) based on this cutoff. Caregivers reported spending on average 6.4-h asleep ($SD = 1.33$) and were in bed for 7.7 h ($SD = 1.26$), with 26.5% of caregivers reporting an average of < 6 h of sleep per night over the past month. Mean sleep efficiency was 83% (normal > 85%), and the average sleep latency was 22 min, with 19.1% taking 30 min or longer to fall asleep. All but three caregivers reported experiencing sleep disturbance within the past month. Caregiver guilt and worry was similar between child disease risk groups [$F(2, 65) = 2.10$, $p = .131$].

Correlates of caregiver sleep

Caregivers who endorsed more sleep difficulties had children diagnosed at younger ages ($r = -.26$, $p = .031$); however, caregiver sleep was not related to child’s current age, caregiver age, length of time in maintenance treatment, SES, the number of children living in the home, or the average age of children in the home (Table 3). Caregiver sleep did not differ by the steroid the child was taking during maintenance [$F(1, 66) = 0.14$, $p = .709$] or between risk groups [$F(2, 65) = 1.03$, $p = .362$]. PSQI scores also did not differ between white and minority caregivers [$F(1, 66) = 0.23$, $p = .631$], gender of the child [$F(1, 66) = 1.43$, $p = .235$], or gender of the caregiver [$F(1, 66) = 2.98$, $p = .089$]. The PSQI total score was significantly positively correlated with child sleep disturbance, ($r = .26$, $p = .030$) and caregiver guilt and worry ($r = .24$, $p = .049$).

Caregiver guilt and worry as a moderator between child and caregiver sleep

Because child age at diagnosis was related to caregiver sleep quality, this variable was entered as a covariate into the first step of the regression model. The model predicting

caregiver sleep quality was significant [$F(4, 67) = 3.64, p = .010$], with child sleep disturbance (unstandardized $\beta = .266, p = .040$) and caregiver guilt and worry (unstandardized $\beta = .163, p = .169$), explaining 19% of the variance in caregiver sleep. The interaction between child sleep and caregiver guilt and worry did not reach significance (unstandardized $\beta = -.23, p = .072$). Post hoc probing suggested that for parents with high stress, child and caregiver sleep were not related (unstandardized $\beta = 0.38, t = 0.46, p = .648$) but for parents with lower stress, parent and child sleep were positively related (unstandardized $\beta = 0.30, t = 2.51, p = .015$).

The post hoc analysis including child age at diagnosis as a moderator rather than a covariate increased the model fit to explain 26% of the variance in caregiver sleep [$F(5, 62) = 4.27, p = .002$]. There was a significant interaction between age and child sleep disturbances (unstandardized $\beta = -.06, p = .020$) but not caregiver guilt and worry and child sleep disturbances (unstandardized $\beta = -.16, p = .083$) in predicting caregiver sleep. Specifically, for children diagnosed at younger ages, there was a positive relationship with greater caregiver sleep disturbances related to greater child sleep disturbances; however, the strength of this relationship decreased in children diagnosed at older ages. Although not significant, in children with better sleep, higher guilt and worry was related to poorer caregiver sleep quality. A scatter plot of the relationships is presented in Fig. 1.

Discussion

Caregivers of children with ALL are at risk for poor sleep, which can persist into maintenance treatment when many families expect a return to normalcy. Although the overall measure of sleep disturbance indicates that caregivers of children in ALL maintenance are similar to parents of children without chronic health conditions, a substantial portion of the current sample report short poorly consolidated sleep, symptoms of insomnia, and daytime dysfunction related to poor sleep. Specifically, 60% of the current sample reported inadequate sleep time, 50% reported poor sleep efficiency, almost 20% reported prolonged sleep onset latencies, and almost 70% indicated that sleepiness impairs daytime functioning.

Caregivers reported significantly higher PSQI total scores indicating poorer sleep than previously published norms of healthy adults (Buysse et al. [34]: control group mean = 2.67; $t(118) = 7.11, p < .001$), but similar levels to a previously published sample of caregivers of healthy children (Meltzer and Booster [28]: healthy caregiver PSQI: 6.19, SE = 0.46, $t(129) = 1.18, p = .238$). These similarities between caregivers of children in ALL maintenance and caregivers of healthy children are consistent with prior research [15] that found higher rates of insomnia symptoms in ALL caregivers despite similar sleep parameters. Similarities between caregivers of children with ALL in maintenance treatment and caregivers of healthy children [28] may be due to the PSQI not reflecting awakenings related to caregiving and parenting stress. For approximately 50–60% of the current sample, stress about the child's illness and caregiving impact sleep at least once per week. These are likely additional disruptions to sleep beyond those experienced by caregivers of children without chronic health conditions.

The National Sleep Foundation recommends 7–9 h of sleep for adults [39], but less than 40% of the current sample reports sleep durations in this range. It was striking that over 25% of caregivers reported less than 6 h of sleep per night. Sleep durations of 6 h or less are consistently associated with negative health outcomes including higher incidences of diabetes mellitus, hypertension, cardiovascular disease, coronary heart disease, obesity, and all-cause mortality [40]. Additionally, short sleep may also impact caregivers' mental health and care provision.

Of the 55% of caregivers that are classified as “poor sleepers,” 47% report “somewhat worse” sleep since their child's diagnosis and 21% report “much worse” sleep since their child's diagnosis, suggesting that the child's cancer diagnosis is the precipitating factor for the poor sleep quality evidenced in this study. Results are consistent with prior qualitative studies [22]. Families may expect sleep to return to normal in maintenance therapy as families are in their own homes and the child's medical treatment is somewhat predictable; however, results from our study suggest that awakenings for caregiving and stress related to the child's health persist for many families. Some awakenings may be inevitable—for example, awakening to administer medication—but other awakenings such as when the child comes into the caregiver's room may be amenable to intervention.

The persistence of caregiver guilt and worry at moderate to high levels in a subset of caregivers is concerning; however, levels reported in this sample are similar to previously published levels of families of children with brain tumors on and off treatment (current sample: $M = 1.89$, $SD = 0.76$; Bonner et al. [33]: $M = 1.72$, $SD = 0.77$; $t(214) = 1.59$, $p = .112$). Treatments targeting parent adjustment have shown promise in improving child outcomes [41]. Reductions in caregiver guilt and worry could result in improved caregiver sleep, indirectly impacting child quality of life. Caregiver guilt and worry was not, however, a significant moderator between child and caregiver sleep. It is possible that sleep quality and guilt/worry are more disruptive earlier in treatment and parents adjust to worries over time. Longitudinal study of caregiver sleep across treatment phases of ALL is warranted to examine the dynamic of sleep quality and parenting stress. Alternatively, other psychosocial factors not measured in the current study may have been more relevant to caregiver sleep quality. For example, past literature has demonstrated correlations between caregiver sleep and depression [42], fatigue [8], and general parental stress [2]. Understanding underlying cognitive processes that affect caregiver sleep may provide intervention targets for cognitive behavioral interventions intended to improve family outcomes in pediatric oncology.

Child age at diagnosis was a significant moderator of the relationship between child and caregiver sleep, indicating that for children diagnosed at younger ages, child and caregiver sleep are positively related but for children diagnosed at older ages (> 6) child sleep has a negligible impact on caregiver sleep. Although not significant, the role of caregiver guilt and worry appears to be somewhat more salient for children diagnosed at younger ages with fewer sleep problems. For this subset of caregivers, higher parent guilt and worry may explain sleep disturbances rather than child sleep explaining these disturbances.

Limitations

Findings add to the scant literature on sleep disturbance in caregivers of children with cancer, but limitations should be noted. Future studies should include a greater diversity of caregivers, as the current sample was primarily Caucasian mothers. Information about possible caregiver sleep disorders was not collected. Thus, it is possible that symptoms of a sleep disorder may have contributed to caregiver sleep. The study is also limited in the reliance on cross-sectional single reporter self-report for all variables; the complementary use of actigraphy would allow for verification of sleep characteristics in both children and caregivers. Measures also incorporated different time frames (1 week for the CSHQ and PEGI, 1 month for the PSQI), which may have impacted the relationships among variables. Longitudinal study of caregiver sleep is needed to truly understand predictors and the progression of caregiver sleep. Using parent report of child sleep also has limitations in the age range under study. Specifically, parents may be less accurate in reporting on older, more independent children than younger children who necessitate more parental involvement in child sleep. Power was moderate to test exploratory moderator models; thus, the null results should be replicated to further evaluate caregiver guilt and worry as a moderator between child and parent sleep.

Implications for clinical practice and future interventions

Sleep should be assessed in all children and families presenting to pediatric oncology; however, some families may be at greater risk for poor caregiver sleep. Specifically, caregivers of children diagnosed in early childhood, caregivers of children with poor sleep, and caregivers with significant guilt and worry related to the child's cancer diagnosis are at greatest risk of poor sleep. For caregivers of young children not exhibiting sleep problems, it may be important for interventions to target guilt and worry to improve caregiver sleep. Interventions intending to improve caregiver sleep should focus on supporting caregivers in obtaining an adequate amount of sleep and minimizing nocturnal disruptions, such as helping caregivers plan medication dosing schedules that have the least impact on sleep schedules and encouraging caregivers to consider the impact of the child's sleeping location on the caregiver's ability to obtain adequate sleep.

Finally, for some caregivers, interventions aimed at treating symptoms of insomnia may be necessary. From the general insomnia literature, cognitive processes are an essential factor in the maintenance of insomnia [43]. Caregiver guilt and worry may be a unique cognitive process for caregivers of children with cancer that contributes to maintaining poor sleep quality across the cancer continuum. Interventions that address caregiver stress, specifically targeting the "uncontrollable" elements of pediatric cancer, may prove efficacious in improving caregiver sleep. Problems-solving interventions such as Surviving Cancer Competently Intervention Program [44] and Bright Ideas [45] focus on differentiating the controllable and uncontrollable elements in pediatric cancer and providing families with workable strategies to shift the focus away from the uncontrollable in an effort to improve parental efficacy and overall family outcomes. The relationship between caregiver and child sleep may be bidirectional; thus, offering parent and child treatment in tandem may be the most effective way to improve caregiver sleep. Promising research addressing child sleep

concerns in ALL suggests that a sleep hygiene and relaxation intervention is feasible and may reduce nocturnal awakenings and increase sleep duration [46].

Overall, the current study provides much needed insight into sleep quality and sleep disturbance in caregivers of children with ALL in maintenance therapy. Study findings highlight the need for further research focused on caregivers of children with cancer to better understand the progression of caregiver sleep disturbances over time, as well as to delineate the most effective interventions to improve caregiver sleep.

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Abbreviations

ALL	Acute lymphoblastic leukemia
PECI	Parent Experience of Child Illness
CSHQ	Children's Sleep Habits Questionnaire
PSQI	Pittsburg Sleep Quality Index

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Fig. 1.

Scatter plot of age and caregiver guilt/worry as moderators of the relationship between child and caregiver sleep. The relationship between child sleep and caregiver sleep are depicted at low, moderate, and high caregiver worry (depicted by x's, squares, and circles, respectively) within younger, average, and older children (indicated by panels **a**, **b**, **c**, respectively)

Table 1**Demographic information**

	<i>n</i> (%)
Caregiver characteristics (<i>N</i> = 68)	
Age (mean + SD, years)	35.87 ± 6.91
Gender	
Male	15 (22.1)
Female	53 (77.7)
Race	
Caucasian	59 (86.8)
Asian	4 (5.9)
Black or African American	2 (2.9)
Other	1 (1.5)
More than one race/ethnicity	2 (2.9)
Hispanic/Latino	7 (10.2)
Marital status	
Not currently married/other	24 (35.3)
Currently married/partnered	44 (64.7)
BSMSS education	
Partial high school	2 (2.9)
High school graduate	11 (16.2)
Partial college (< 1 year)	20 (29.4)
College education	17 (25)
Graduate degree	17 (25)
BSMSS (mean + SD)	45.98 ± 10.63
Additional number of children living in home	
0	11 (16.2)
1	28 (41.2)
2	18 (26.5)
3	8 (11.8)
4 or more	3 (4.4)
Average age of siblings living in home	7.4 (4.5)
Child characteristics (<i>N</i> = 68)	
Age (mean + SD, years)	6.24 ± 2.27
Gender	
Male	40 (58.8)
Female	28 (41.2)
Race/ethnicity	
Caucasian	52 (76.5)
Asian	3 (4.4)
Black or African American	5 (7.4)
Other	2 (2.7)

	<i>n</i> (%)
More than one race	6 (8.8)
Hispanic/Latino	7 (10.3)
Risk group	
Low	2 (2.9%)
Standard	43 (63.2%)
High	23 (33.8%)
Age at diagnosis (mean + SD, years)	4.54 ± 2.31
Month in maintenance (mean + SD, months)	12.61 ± 9.15
Time from diagnosis to maintenance (mean + SD, months)	7.90 ± 2.17

Table 2

Caregiver sleep characteristics

PSQI sleep variables	<i>n</i> (%)	<i>M</i> ± <i>SD</i> , range
PSQI-total score		7.00 ± 4.13, 0–17
Good (≤ 5)	30 (44.1%)	
Poor (> 5)	38 (55.9%)	
Sleep quality		
Very good	10 (14.7%)	
Fairly good	30 (44.1%)	
Fairly bad	24 (35.3%)	
Very bad	4 (5.9%)	
Sleep duration (hours per night)		6.4 ± 1.33, 3–10
7	27 (39.7%)	
<7 and ≥ 6	23 (33.8%)	
<6	18 (26.5%)	
Sleep latency (minutes)		22.03 ± 17.65, 0–60
0 and ≤ 15	35 (51.5%)	
>15 and ≤ 30	20 (29.4%)	
>30 and ≤ 60	13 (19.1%)	
Sleep efficiency		82.96 ± 14.46, 43.9–100
85	34 (50%)	
< 85 and ≥ 65	24 (35.3%)	
< 65	10 (14.7%)	
Sleep disturbances		
Not during past month	3 (4.4%)	
1 and ≤ 9	47 (69.1%)	
> 9 and ≤ 18	16 (23.5%)	
>18	2 (2.9%)	
Bed time		Mode = 11:00 PM
Earlier than or at 11:00 PM	46 (67.6%)	
Later than 11:00 PM	22 (32.4%)	
Wake time		Mode = 7:00 AM
Earlier than or at 7:00 AM	47 (69.2%)	
Later than 7:00 AM	21 (30.8%)	
Sleep medication		
Not during past month	53 (77.9%)	
Less than once per week, or more	15 (22.1%)	
Daytime dysfunction		
Not during past month	21 (30.9%)	
Less than once per week, or more	47 (69.1%)	
PSQI Addendum sleep variables		
Past month, trouble sleeping because of:		

Attending to child's health needs		
Not during past month	32 (47.1%)	
Less than once per week, or more	27 (39.7%)	
3 times per week	9 (13.2%)	
Stress related to child's health		
Not during past month	27 (39.7%)	
Less than once per week, or more	31 (45.5%)	
3 times per week	10 (14.7%)	
Current overall sleep quality compared to before cancer Dx		
Better now	3 (4.4%)	
Same	30 (44.1%)	
Worse now	35 (51.4%)	
Child sleep habits		
CSHQ sleep variables	<i>n</i> (%)	<i>M</i> ± <i>SD</i> range
CSHQ total sleep disturbance		45.44 ± 7.44, 33–73
> 41	46 (67.6%)	
41	22 (32.4%)	

Table 3
Pearson correlations of demographic factors, caregiver guilt and worry, and caregiver and child sleep

	1	2	3	4	5	6	7	8	9	10
1. Child age at diagnosis	1.00	<i>0.94</i>	<i>0.33</i>	-0.25	-0.02	-0.07	-0.49	-0.11	-0.20	-0.26
2. Child age at study	<i>0.94</i>	1.00	<i>0.35</i>	0.06	0.01	-0.06	<i>0.48</i>	-0.11	-0.25	-0.23
3. Caregiver age at study	<i>0.33</i>	<i>0.35</i>	1.00	-0.08	<i>0.42</i>	0.04	<i>0.48</i>	-0.34	-0.14	-0.27
4. Months in maintenance treatment	-0.25	0.06	-0.08	1.00	-0.02	0.11	-0.12	0.05	-0.03	0.04
5. Barrett Social Status total score	-0.02	0.01	<i>0.42</i>	-0.02	1.00	0.01	-0.06	-0.26	-0.10	-0.13
6. Number of siblings in home	-0.07	-0.06	0.04	0.11	0.01	1.00	0.07	-0.14	-0.19	-0.13
7. Average age of siblings in home	<i>0.49</i>	<i>0.48</i>	<i>0.48</i>	-0.12	-0.06	0.07	1.00	-0.02	-0.06	-0.11
8. PECCI guilt and worry	-0.11	-0.11	-0.34	0.05	-0.26	-0.14	-0.02	1.00	0.22	<i>0.24</i>
9. CSHQ child sleep disturbance	-0.20	-0.25	-0.14	-0.03	-0.10	-0.19	-0.06	0.22	1.00	<i>0.27</i>
10. PSQI global caregiver sleep	-0.26	-0.23	-0.27	0.04	-0.13	-0.13	-0.11	<i>0.24</i>	<i>0.27</i>	1.00

Italicized items are significant at $p < .05$