Support Care Cancer (2015) 23:393–401
DOI 10.1007/s00520-014-2356-3

ORIGINAL ARTICLE

Changes in sleep and fatigue in newly treated pediatric oncology patients

Valerie McLaughlin Crabtree · Amanda M. Rach · Kriston B. Schellinger · Kathryn M. Russell · Teresa Hammarback · Belinda N. Mandrell

Received: 19 August 2013 / Accepted: 21 July 2014 / Published online: 13 August 2014

Abstract
Background Fatigue has been reported as one of the most distressing symptoms in oncology patients, yet few have investigated the longitudinal course of sleep and fatigue in newly diagnosed pediatric oncology patients.
Procedure To longitudinally assess presence and changes of sleep complaints and fatigue, we administered questionnaires designed to measure sleep complaints, sleep habits, daytime sleepiness, and fatigue to parents of pediatric oncology patients ages 2–18 and to pediatric oncology patients, themselves, ages 8–18 within 30 days of diagnosis (n=170) and again 8 weeks later (n=153).
Results Bedtimes, wake times, and sleep duration remained relatively stable across the first 8 weeks of treatment. Sleep duration and fatigue were not related for the entire sample, though children's self-reported sleep duration was positively correlated with fatigue only at the baseline time point. Parent reports of fatigue significantly decreased for leukemia patients but remained rather high for solid tumor and brain tumor patients.
Conclusions Because fatigue remained high for solid tumor and brain tumor patients across the initial 8 weeks of treatment, this may highlight the need for intervention in this patient population.

Keywords Solid tumor · Brain tumor · Leukemia/lymphoma · Symptoms · Parent-child agreement

V. M. Crabtree (✉) · K. M. Russell
Department of Psychology, St. Jude Children's Research Hospital, 262 Danny Thomas Place, Mail Stop 101, Memphis, TN 38105, USA
e-mail: Valerie.crabtree@stjude.org

A. M. Rach
Department of Psychology, University of Memphis, Memphis, TN, USA

K. B. Schellinger
Family Health Centers, San Diego, CA, USA

T. Hammarback
Children's Healthcare of Atlanta, Atlanta, GA, USA

B. N. Mandrell
Division of Nursing Research, St. Jude Children's Research Hospital, Memphis, TN, USA

Introduction

Childhood cancer 5-year survival rates have increased dramatically from approximately 58 % in 1975 to 80 % in 2003 [1]. Because of the increased likelihood of survival, focus on improved quality of life has increased. In particular, one important contributor to quality of life that has received attention is sleep and fatigue.

Fatigue and sleep disturbances have consistently been found to be among the most frequent symptoms experienced by both adult and pediatric oncology patients [2–5]. Many factors contribute to fatigue among on-therapy oncology patients, including disease process, treatment modality [6], frequent nocturnal awakenings in hospitalized patients [3], and poor sleep quality [5]. Fatigue can be distinguished from sleep disturbances in that cancer-related fatigue is a daytime symptom that is defined by The Clinical Practice Guidelines in Oncology of the National Comprehensive Cancer Network (NCCN) as "a distressing persistent subjective sense of physical, emotional, or cognitive tiredness or exhaustion related to cancer or cancer treatments that is not proportional to recent activity and interferes with daily function" [7]. Sleep disturbances, on the other hand, refer to difficulties initiating or maintaining sleep that can, in turn, contribute to daytime fatigue.

Sleep disturbances and fatigue are of particular concern to oncology patients not only because they may negatively

impact immune functioning and healing [8] but also because they negatively impact treatment adherence, daily functioning, social activities, depressive symptoms, behavior problems, and overall quality of life [2, 6, 9, 10]. In particular, children undergoing maintenance treatment for acute lymphoblastic leukemia have been shown to have poorer quality of life associated with overall impaired sleep including difficulty initiating and maintaining sleep as well as with daytime sleepiness [10]. Thus, sleep and fatigue may impact both physical and mental well-being in pediatric oncology patients, making these important variables to understand.

In addition to the importance of cancer on children's sleep and fatigue, previous research suggests that socioeconomic status (SES) may contribute to increased risk for sleep-disordered breathing. Lower SES has been found to be significantly related to obstructive sleep apnea in children, even after controlling for other health variables such as prematurity and obesity [11, 12]. Although the relation between SES and sleep problems has not yet been examined with pediatric oncology patients, given the relation of SES to sleep-disordered breathing in children with other medical conditions, we sought to explore this variable in the current study.

Limitations of previous research and study aims

Although sleep and fatigue in pediatric oncology patients has received increased attention in recent years, many questions remain. First, while diagnosis is related to unique treatment-related factors that may impact sleep and daytime alertness, the majority of research has included children with acute lymphoblastic leukemia (ALL) or CNS tumors, which account for only half of childhood cancer patients. Thus, this exploratory study included three diagnostic groups (leukemia/lymphoma, solid tumor, and CNS tumor) to better understand the impact of a cancer diagnosis, treatment-related factors, and potential differences in sleep and fatigue among pediatric oncology patients. Second, few studies have prospectively addressed sleep complaints in a cross section of pediatric oncology patients at the time of diagnosis [13], and studies that have explored sleep complaints across time during treatment have had methodological limitations such as small sample size and low statistical power [14]. As fatigue and sleep interventions are developed, it is important to discern fatigue and sleep disturbance that may have been influenced by disease in comparison to disturbances that are treatment related. Therefore, this exploratory study assessed sleep disturbance and fatigue at two time points, within 30 days of a cancer diagnosis and 8 weeks after the initial assessment.

Methods

Participants

Study participant demographics are presented in Table 1. One hundred seventy parents of children (87 boys) between the ages of 2 and 18 (M_{Age}=7.71 years, SD=4.4) and 81 children between the ages of 8 and 18 were asked to complete questionnaires within 30 days of diagnosis (time 1), and of these, 153 parents and 68 children again completed questionnaires 8 weeks after the initial assessment (time 2). Seventeen participants were unable to complete the time 2 assessment due to the inability of the study team to contact the participant within the study time window of 8 weeks (±2 weeks) of initial assessment. There were no differences in diagnosis, age, gender, SES, or steroid use in those who participated at only time 1 and those who participated at both time points. Participant diagnoses were categorized into three disease groups: leukemia/lymphoma (n=70), solid tumor (n=50), and CNS tumor (n=50). Eighty percent of those invited to participate consented, and those who did not consent typically were "passive refusals," in which they verbally agreed but then did not return completed questionnaires. No significant differences in participants and passive refusers were found with respect to age, gender, or diagnosis. Those who agreed to participate were significantly more likely to be Caucasian than African American or other races (χ^2=6.25, p<0.05). Half of the participants at time 1 were taking steroids (including dexamethasone, methylprednisolone, prednisolone, prednisone, and hydrocortisone) in the immediate period prior to

Table 1 Demographic characteristics of participants

	N	Percentage
Gender		
Boys	87	51
Girls	83	49
Racial Background		
African American	31	18
Asian American	2	1
Caucasian	128	75
Multiracial	7	4
Other	2	1
Age Group		
2–5 years	69	41
6–12 years	72	42
13–18 years	29	17
Diagnosis		
Brain Tumor	50	29
Leukemia	70	41
Solid Tumor	50	29

data collection, while only 11 % were taking steroids immediately prior to the data collection at time 2. The study was approved by the Institutional Review Board of St. Jude Children's Research Hospital, and parents provided informed consent to participate.

Instruments

Parents of children newly diagnosed with cancer completed an abbreviated version of the Kosair Sleep Questionnaire [15], and the Childhood Cancer Fatigue Scale—Parent Version (CCFS) [16]. Additionally, parents of children ages 2–12 completed the Children's Sleep Hygiene Scale (CSHS) [17]. Children and adolescents ages 8–18 completed the Children's Report of Sleep Patterns (CRSP) [18]. Finally, socioeconomic status was calculated using a modified version of the Barratt Simplified Measure of Social Status (BSMSS) [19].

Kosair Sleep Questionnaire The Kosair Sleep Questionnaire is a 39-item parent report measure of demographics and children's sleep disturbances. It has been validated for use in children to identify daytime and nighttime behaviors consistent with symptoms of sleep-disordered breathing, daytime sleepiness, and restless sleep. The instrument has demonstrated good sensitivity and specificity for parents reporting sleep-disordered breathing symptoms in their children "frequently" or "almost always" [15]. The Kosair is designed such that parents are provided with a forced choice of a range of bed and wake times (e.g., 8:00–9:00 pm, 9:00–10:00 pm; 7:00–7:30 am, after 7:30 am). The measure was abbreviated for the current study to include 20 items focused on sleep schedule, restless sleep, and symptoms of sleep-disordered breathing in an effort to reduce participant burden in a newly diagnosed pediatric oncology sample. Items that were removed were related to parasomnias, nightmares, and daytime somnolence to allow for focus on the items with demonstrated effective psychometric properties.

Childhood Cancer Fatigue Scale The CCFS is a 17-item parent report measure of fatigue specific to children with cancer [16]. Items related to fatigue are rated by the parent on a 5-point Likert scale from "not at all" (1) to "always" (5), with possible scores ranging from 17 to 85, and higher scores corresponding to more fatigue. The measure has demonstrated good psychometric properties with an internal consistency estimate of 0.88 and item to total correlations ranging from 0.34 to 0.069. The CCFS has demonstrated construct validity with strong correlations between parent and child self-report of fatigue. For the current study sample, at time point 1, the CCFS had a Cronbach's α of 0.92, with item to total correlations ranging from 0.40 to 0.80. At time point 2, Cronbach's α=0.84, with item to total correlations ranging from 0.31 to 0.62.

Children's Report of Sleep Patterns The CRSP is a 60-item self-report measure of sleep patterns, sleep hygiene, and sleep disturbances in children ages 8–18 years. Children respond to items considering both the previous night and a typical night. Items are rated on a five-point scale from "never" to "always," and three modules including sleep patterns, sleep hygiene, and sleep disturbance are calculated. Validity and reliability have been established separately for children and adolescents, and participants in this sample served as a subset of the validation sample for the CRSP. In children ages 8–12, Cronbach's alpha for most sleep disturbances scales were acceptable ranging from 0.70 to 0.76. The two-item Parasomnia scale has a Cronbach's alpha of 0.64 [18]. Test-retest reliability correlations >0.80 were present for all indices other than the Restless Legs Scale with a test-retest correlation index of 0.65 [18]. In adolescents, the modules had moderate to acceptable reliability with Cronbach's alphas ranging from 0.54 for the two-item Parasomnia scale to 0.77 in the Insomnia scale [20]. The CRSP also includes a sleepiness scale (Cronbach's alpha= 0.77) that was utilized in the current study for purposes of assessing child self-reported daytime sleepiness [21].

Barratt Simplified Measure of Social Status SES was estimated using an adaptation of the BSMSS [19]. Although the complete BSMSS formula is calculated using scores from grandparents and parents, the formula was modified for use in this study as only parent data were available for this sample. The BSMSS calculates a proxy of SES based on occupational prestige and parental level of education. Level of education is rated on a 3- to 21-point scale while occupation is rated on a 5- to 45-point scale. For two parent families in which both parents were employed, a score was obtained by averaging father and mother scores. For two parent families in which only one parent was employed, a score was calculated for only that parent. Scores for single parent families were based on a calculation for the parent who participated in the research study. Therefore, the possible scores ranged from 4 to 33. In this sample, the range of scores was 4.25 to 33.00 (M=19.68, SD=7.11), indicating that individuals from diverse socioeconomic backgrounds were included in the sample.

Statistical analysis

To examine changes in bed time and wake time from time 1 to time 2, it was necessary to first compute a midpoint time from the time intervals indicated on the Kosair, CRSP, and ASHS. For example, a parent reporting a bedtime between 9:00 pm and 10:00 pm had a midpoint score of 9:30 pm, and a child reporting a bedtime between 8:30 pm and 9:00 pm had a midpoint score of 8:45 pm. Repeated measures ANOVAs were used to examine changes in bed time midpoint, wake time midpoint, and sleep duration separately by child and parent report. Because bed time, wake time, and sleep

duration norms vary by developmental level, these ANOVAs were performed separately for participants 2–5 years (parent report only), 6–12 years (child and parent-reported data for 8–12 years), and 13–18 years (adolescent and parent report). All relationships between demographic variables (gender, race, SES) and fatigue scores were found to be nonsignificant. Pearson correlations between parent and child report were used at each time point for the two older age groups to assess agreement in bed time, wake time, and sleep duration. Change scores were calculated for both parent-reported fatigue as measured by the CCFS and child-reported daytime sleepiness as measured by the sleepiness scale of the CRSP. An ANOVA was used to examine differences in change in fatigue and sleepiness by diagnostic group.

Results

Changes in bedtime, wake time, and sleep duration

Table 2 includes child and parent report of bedtime and wake time at baseline (time 1) and 8 weeks from initial assessment (time 2). At time 1, the mode bedtime reported by both children for the entire sample was between 9:00 and 9:59 pm with a wake time between 6:00 and 6:29 am. Parents reported mode bedtimes (36.5 %) for the entire sample between 8:00 and 9:00 pm with rise times between 7 and 7:30 am. Of note, nearly as many parents reported mode bedtimes between 9:00 and 10:00 pm (33.5 %). The mode bedtime at time 2 as reported by children was unchanged from time 1; however, parents reported later bedtimes at time 2, and both child and parent report indicated that the children's mode wake time surpassed the 7:30 am wake time reported at time 1. At both time points, as expected, bedtimes were reported to be later for the older than the younger age groups. Multivariate analyses were conducted to determine change in reported bedtime, wake time, and sleep duration from time 1 to time 2. Prior to this analysis, the relation of steroid use to bedtime and wake time at time 1 and time 2 and the relation of SES to sleep change scores were found to be nonsignificant, and thus were not included as a covariate. Young children, ages 2 to 5, were reported to have significantly later bedtime and wake time at time 2 when compared to time 1 ($F(3, 37)=4.01$, $p<0.05$). Parents of children ages 6–12 also reported significantly later bedtime and wake time at time 2 ($F(3, 41)=3.51$, $p<0.05$), though children did not self-report later bedtimes or wake time. Conversely, adolescents self-reported later bedtime and wake time at time 2 ($F(3, 21)=4.99$, $p<0.01$), though their parents did not report changes in bedtime and wake time over time.

Table 3 includes child and parent reports of sleep duration at time 1 and time 2. At time 1, for the overall sample, children reported sleeping an average of 9.0±1.1 h per night (range 6.75–11.75), and parents reported that their child slept 9.7±1.0 h per night (range 6.75–12.0). At time 2, children reported sleeping 8.9±1.3 h per night (range 6.0–12.0), and parents reported that their child slept 9.5±1.1 h per night (range 6.0–11.75). Steroid use was not significantly related to sleep duration at either time point, and no significant time 1 to time 2 changes in sleep duration were reported by either parents or children. As expected, adolescents reportedly slept less than did younger children at both time points and by both parent and child report (See Table 3). When potentially sedating agents (including antiemetics, anticholinergics, antiepileptics, benzodiazepines, and opioids) were investigated as potential contributors to sleep habits, no relation was found with bedtime, wake time, or sleep duration.

Table 2 Modal bed time & wake time (hour intervals)

	Time 1		Time 2	
	Bed Time	Wake Time	Bed Time	Wake Time
Children all ages				
Child report	9:00–9:59	6:00–6:29	9:00–9:59	after 7:30
Parent report	8:00–9:00	7:00–7:30	9:00–10:00	after 7:30
Children 2–5				
Child=no report	–	–	–	–
Parent report	8:00–9:00	7:00–7:30	9:00–10:00*	after 7:30*
Children 6–12				
Child report	9:00–9:59	7:00–7:29	9:00–9:59	after 7:30
Parent report	8:00–9:00	6:30–7:00	9:00–10:00*	after 7:30*
Children 13–18				
Child report	9:00–9:59	6:00–6:29	10:00–10:59	after 7:30
Parent report	9:00–10:00	6:00–6:30	9:00–10:00**	after 7:30**

* p < .05; ** p < .01

Table 3 Mean sleep duration in hours

	Time 1			Time 2		
	M (SD)	Range	p	*M* (SD)	Range	*p*
Child Report	8.97 (1.06)	6.75–11.75		8.94 (1.28)	6.00–12.00	
Gender			0.399			0.291
Boys	9.06 (1.08)	6.75–11.75		8.68 (1.23)	6.00–11.00	
Girls	8.86 (1.05)	6.75–11.00		9.07 (1.21)	6.00–12.00	
Age Group			<0.001			0.009
2–5 years	–	–		–	–	
6–12 years	9.33 (0.99)	7.25–11.75		9.27 (1.28)	6.00–12.00	
13–18 years	8.38 (0.91)	6.75–10.00		8.35 (0.94)	6.00–9.75	
Diagnosis			0.344			0.922
Leukemia	8.99 (1.12)	6.75–11.00		8.85 (0.71)	7.75–10.25	
Solid Tumor	8.78 (1.11)	6.75–11.75		8.75 (1.45)	6.00–11.00	
Brain Tumor	9.21 (0.90)	7.75–10.75		9.16 (1.45)	6.00–12.00	
Steroid Use			0.209			0.916
Yes	9.08 (1.06)	6.75–11.75		8.63 (1.25)	6.75–11.00	
No	8.85 (1.04)	6.75–11.00		8.93 (1.23)	6.00–12.00	
Parent Report	9.67 (0.99)	6.75–12.00		9.47 (1.07)	6.00–11.75	
Gender (Child)			0.788			0.617
Boys	9.46 (1.00)	6.75–12.00		9.41 (0.98)	6.00–11.25	
Girls	9.68 (1.01)	7.00–11.75		9.49 (1.15)	6.00–11.75	
Age Group			<0.001			0.003
2–5 years	9.93 (0.93)	7.75–11.75		9.63 (1.17)	6.00–11.75	
6–12 years	9.75 (0.77)	8.00–12.00		9.61 (0.86)	8.00–11.25	
13–18 years	8.77 (1.20)	6.75–12.00		8.64 (0.97)	6.00–10.00	
Diagnosis			0.295			0.908
Leukemia	9.78 (0.89)	7.75–12.00		9.43 (0.85)	7.75–11.00	
Solid Tumor	9.42 (1.09)	6.75–12.00		9.38 (1.22)	6.00–11.75	
Brain Tumor	9.92 (1.01)	7.25–11.75		9.55 (1.21)	6.00–11.25	
Steroid Use			0.176			0.312
Yes	9.56 (0.92)	6.75–12.00		8.97 (0.65)	8.00–10.00	
No	9.77 (1.07)	7.00–12.00		9.51 (1.10)	6.00–11.75	

Sleep problems

At time 1, parental report of sleep problems as measured by the Kosair indicated that 12 % of children snored, 19 % did not sleep through the night, 20 % were restless sleepers, 1 % stopped breathing during the night, and 9 % had enuresis. At time 2, 4 % snored, 12 % did not sleep through the night, 13 % experienced restless sleep, no children stopped breathing during the night, and 10 % continued to have enuresis.

McNemar and paired *t* tests were used to evaluate the change in sleep problems from time 1 to time 2. The reduction of the number of children reported as snoring was significant (McNemar test=137, $p<0.05$); however, decreases in not sleeping through the night, restless sleeping, stopping breathing, and enuresis were not significant. Decreases in snoring were not significantly related to diagnostic group, gender, age, SES category, or steroid use at either time point.

Fatigue

Mean fatigue scores as reported on the Childhood Cancer Fatigue Scale at time 1 and time 2 are presented in Table 4. Steroid use, chemotherapy, and radiation therapy were not significantly associated with fatigue scores at either time point and were not associated with change in fatigue score from time 1 to time 2. Results from the ANCOVA analysis (controlling for gender, age, and SES) indicated a significant effect of diagnosis on cancer fatigue change scores over the first 8 weeks of treatment, $F(2, 110)=5.44$, $p<0.01$. Children diagnosed with leukemia/lymphoma were found to have

Table 4 Mean fatigue scores (CCFS) at time 1 and time 2 and mean fatigue change scores across groups

		Time 1 *M* (SD)	Time 2 *M* (SD)	Change *M* (SD)
Diagnostic Group	$F(2, 110)=5.44$, $p<0.01$			
Leukemia		48.45 (12.75)	38.72 (9.94)	8.76 (12.56)
Solid Tumor		44.41 (10.95)	42.09 (9.69)	0.56 (12.86)
Brain Tumor		43.90 (13.32)	41.79 (8.59)	1.58 (12.74)
Analysis Covariates				
Gender	$F(1, 110)=1.17$, $p=0.28$			
Boys		46.00 (12.08)	37.76 (9.54)	5.97 (13.05)
Girls		45.77 (13.05)	43.48 (8.71)	2.44 (13.11)
Age group	$F(1, 110)=0.01$, $p=0.91$			
2–5 years		46.88 (11.57)	40.26 (9.95)	5.58 (13.47)
6–12 years		43.90 (11.90)	40.71 (9.30)	1.86 (11.91)
13–18 years		48.43 (10.82)	41.64 (9.48)	6.29 (12.85)
SES category	$F(1, 110)=2.34$, $p=0.13$			
1		43.95 (11.63)	41.58 (9.91)	2.10 (11.57)
2		44.55 (14.82)	39.88 (8.78)	2.44 (14.91)
3		47.36 (10.30)	40.07 (8.20)	6.28 (8.97)
4		45.29 (12.70)	39.78 (11.28)	4.52 (16.25)

ANCOVA results in this table correspond to impact of diagnostic group on fatigue change scores, with gender, age group, and SES entered as covariates. Higher scores indicate more fatigue

significantly reduced parent-reported fatigue scores on the CCFS ($M_{Change}=8.76$) from time 1 to time 2 compared to children diagnosed with solid tumors ($M_{Change}=0.56$) or brain tumors ($M_{Change}=1.58$; Fig. 1). Interestingly, this did not correspond to a significant mean change in child-reported daytime sleepiness on the CRSP over the 8-week period, $F(5, 40)=0.87$. However, it is important to note that this measure was only completed by children 8 years or older (n=81), and of this group, only 46 participants had data at both time points to be included in this analysis. Furthermore, no statistically significant relationships between change in fatigue and several sleep-related variables, including insomnia, sleep hygiene, bedtime, wake time, total sleep time, or restless sleep were found.

Relation of sleep duration and fatigue

Pearson correlations were run to determine the relation of sleep duration and fatigue at both time points. At time 1, there were no significant correlations between parent or child report of sleep duration and fatigue ($r=0.12$, $p>0.05$ child; $r=0.04$, $p>0.05$ parent). Similarly, there were no significant correlations between parent or child report of sleep duration and fatigue at time 2 ($r=0.12$, $p>0.05$ child; $r=0.09$, $p>0.05$

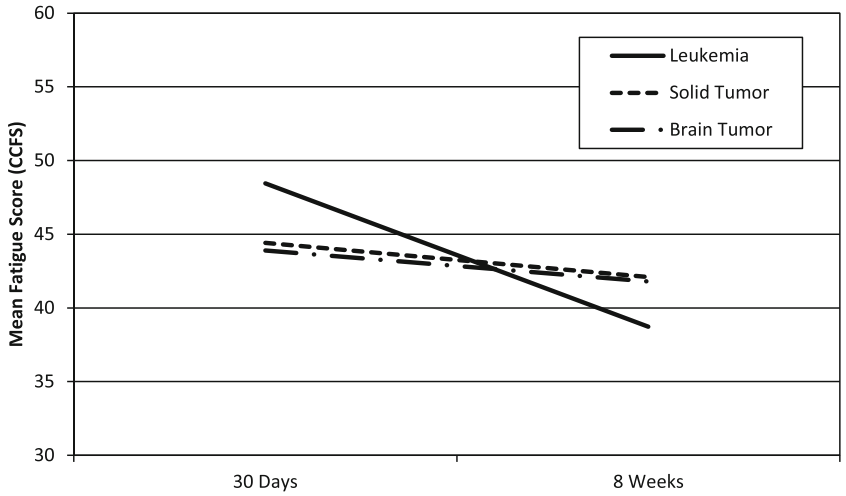

Fig. 1 Change in childhood cancer fatigue scores by group

parent). When exploring the correlations by age group, children ages 6–12 did show a significant positive correlation between self-reported sleep duration and fatigue at time 1 only (r=0.31, p<0.05). At time 2, self-reported sleep duration and fatigue were not significantly correlated in this age group (r= 0.27, p>0.05).

Discussion

This study was the first to our knowledge to evaluate sleep duration and fatigue longitudinally in a cross section of pediatric oncology patients with a wide variety of diagnoses. Because sleep and fatigue are related but distinct concepts, it is important to delineate if poor sleep is contributing to daytime fatigue or if daytime fatigue is a separate entity to be treated with daytime interventions. Over the first 8 weeks of treatment in this newly diagnosed pediatric oncology sample, both bedtimes and wake times became significantly later while sleep duration was not reported to change. Interestingly, this finding of later bedtime and wake time across the initial portion of treatment was reported by parents in young children and school-aged children and by self-report in adolescents. School-aged children did not self-report changes in bedtime and wake time across treatment, and the parents of adolescents did not report changes in bedtime and wake time. This likely points to a developmentally typical finding in which parents may be more accurate reporters of bedtime and wake time in preschool and school-aged children, while adolescents may be able to better report their own sleep patterns. As such, the importance of obtaining self-reported sleep habits from adolescents, even those on active treatment for cancer, is underscored. Later bedtimes and wake times from time 1 to time 2 are likely reflective of changes in schedule for these patients who are typically not in school while receiving cancer-directed therapy. Although their schedules appear delayed, their overall sleep duration is not reported to change, and younger children were reported to have longer nighttime sleep (on average 9–10 h) than school-aged children (on average 9 h), who were reported to sleep longer than adolescents (on average 8.5 h). Of note, the adolescents in our sample were reportedly obtaining more sleep each night than the average of 7.6 h per night reported in the 2006 National Sleep Foundation Sleep in America Poll [22].

With sleep duration within the recommended range for age, rates of fatigue were high in the newly diagnosed patients near the time of diagnosis. Although the sleep duration was not reported to change and snoring actually decreased across the first 8 weeks of treatment, parent-reported fatigue only improved for the leukemia/lymphoma group, with the solid tumor and brain tumor groups reporting significant fatigue both at time of diagnosis and again 8 weeks into treatment. It is unclear why snoring significantly decreased across the 8 weeks of treatment to below the mean rates of 7 % of healthy children who are reported to snore [23], as it had no association with diagnosis or steroid use, which might have been explanatory related to decreased inflammation. The mean fatigue scores reported in the current sample were somewhat higher than the mean of 41 reported in the original validation sample of the CCFS [16]. It is important to note that 51 % of the validation sample for the CCFS was recruited within 6 months of oncology diagnosis with an even longer time since diagnosis for the remainder of the sample [16]. While the results may not be directly comparable, this may lend support for higher fatigue earlier in the diagnosis and treatment process.

It is interesting to note the significant reduction of fatigue in the leukemia/lymphoma sample with no improvement in fatigue for the solid tumor or brain tumor patients, with all groups reporting similar fatigue at time of diagnosis. The fatigue experienced by leukemia/lymphoma patients at diagnosis is likely related to their disease burden and subsequent anemia, infection, and bleeding; however, these symptoms have been shown to dramatically reduce during the initial month of therapy [24, 25]. The solid tumor and brain tumor patients, on the other hand, continue to demonstrate similar fatigue to baseline as they undergo additional treatment options including surgery and radiation. The ongoing fatigue throughout the initial portion of treatment, which has previously been reported as one of the most distressing symptoms by patients [3, 5], points to the need for empirically validated interventions to reduce fatigue in these patient groups. For the overall group, sleep duration and fatigue were not significantly related at either time point. Thus, the interventions to address fatigue may need to focus more on daytime activity rather than targeting nighttime sleep.

While these findings are important, several limitations must be delineated. First, only 29 adolescents were included in the sample, which may have limited our statistical power to detect changes in this group over time. Additionally, potential participants were more likely to agree to participate if they were Caucasian than other racial backgrounds. This may limit the generalizability of findings to other races and/or ethnicities. Although we are able to ascertain that fatigue significantly decreases for children in the Leukemia/Lymphoma group, we unfortunately do not have an established score to indicate clinically significant fatigue in this sample. As a result, we are limited in our ability to determine if the statistically significant reduction in fatigue corresponds with a clinically significant reduction in fatigue in this sample. We further did not collect data on number of inpatient days preceding the questionnaire completion. Thus, we cannot draw conclusions related to the child's sleeping environment that may have potentially contributed to fatigue. Furthermore, all of the data collected in the study were subjective reports without actigraphy,

polysomnography, or other objective assessment of sleep. While it is important that both parents and children (8 years of age and older) were permitted to provide their assessment of the child's sleep and fatigue, objective actigraphy data would have expanded the confidence to interpret typical bed times, wake times, and sleep duration. It is important to recognize, however, that while actigraphy can yield more accurate assessments of sleep, parent report correlates significantly with actigraphy with respect to sleep onset, sleep offset, and total sleep time [26, 27]. Furthermore, we did not include an assessment of daytime sleep, which limits our ability to understand how much sleep children are obtaining in a 24-h period. In addition, because the final choice option on the Kosair regarding wake times does not include an end time (after 7:30 am), we are unable to directly ascertain just how late a portion of our sample was regularly sleeping. Finally, as we only obtained fatigue and sleep complaint ratings at two time points, we are limited in our ability to make conclusions about the trajectory of fatigue across treatment in pediatric oncology patients. Future studies could help elucidate this trajectory by measuring fatigue and sleep complaints at multiple time points and later in the treatment course.

Sleep and fatigue in pediatric oncology patients has primarily been descriptive in nature thus far. While the current study is also descriptive, exploratory, and subjective in nature, the findings describe previously unknown changes in sleep and fatigue during the initial intensive portion of treatment in newly diagnosed pediatric oncology patients. Fatigue in solid tumor and brain tumor patients remains relatively high, while sleep duration reportedly remains stable. This provides support for the need to focus interventions on daytime activity, rather than nighttime sleep, in an effort to reduce the very distressing symptom of daytime fatigue in this patient population.

Acknowledgments The authors wish to acknowledge the work of Nancy West, MSN, RN for data entry and Julie Ormsby, MS, RN for assistance with data collection. We also would like to acknowledge the efforts of the patients and their families in participating in this study during a significantly distressing time immediately following diagnosis.

Conflict of interest The authors have no real or perceived conflicts of interest in this manuscript.

References

1. Jemal A, Siegel R, Xu J, Ward E (2010) Cancer statistics, 2010. CA Cancer J Clin 60(5):277–300. doi:10.3322/caac.20073
2. Ancoli-Israel S, Rissling M, Neikrug A, Trofimenko V, Natarajan L, Parker B, Lawton S, Desan P, Liu L (2012) Light treatment prevents fatigue in women undergoing chemotherapy for breast cancer. Support Care Cancer 20(6):1211–1219. doi:10.1007/s00520-011-1203-z
3. Hinds P, Hockenberry M, Rai S, Zhang L, Razzouk B, McCarthy K, Cremer L, Rodriguez-Galindo C (2007) Nocturnal awakenings, sleep environment Interruptions, and fatigue in hospitalized children with cancer. Oncol Nurs Forum 34(2):393–402. doi:10.1188/07.onf.393-402
4. Kim B, Chun M, Han E, Kim D-K (2012) Fatigue assessment and rehabilitation outcomes in patients with brain tumors. Support Care Cancer 20(4):805–812. doi:10.1007/s00520-011-1153-5
5. Zupanec S, Jones H, Stremler R (2010) Sleep habits and fatigue in children receiving maintenance chemotherapy for ALL and their parents. J Pediatr Oncol Nurs 27(4):217–228. doi:10.1177/1043454209358890
6. Erickson J, Beck S, Christian B, Dudley W, Hollen P, Albritton K, Sennett M, Dillon R, Godder K (2010) Patterns of fatigue in adolescents receiving chemotherapy. Oncol Nurs Forum 37(4):444–455. doi:10.1188/10.onf.444-455
7. Network NCC (2012) NCCN practice guidelines for cancer-related fatigue. http://www.nccn.org/professionals/physician_gls/pdf/fatigue.pdf
8. Mandrell BN, Wise M, Schoumacher RA, Pritchard M, West N, Ness KK, Crabtree VM, Merchant TE, Morris B (2012) Excessive daytime sleepiness and sleep-disordered breathing disturbances in survivors of childhood central nervous system tumors. Pediatr Blood Cancer 58(5):746–751. doi:10.1002/pbc.23311
9. Hockenberry M, Hooke M, Gregurich M, McCarthy K, Sambuco G, Krull K (2010) Symptom clusters in children and adolescents receiving cisplatin, doxorubicin, or ifosfamide. Oncol Nurs Forum 37(1):E16–E27. doi: 10.1188/10.onf.e16-e27
10. van Litsenburg R, Huisman J, Hoogerbrugge P, Egeler RM, Kaspers G, Gemke R (2011) Impaired sleep affects quality of life in children during maintenance treatment for acute lymphoblastic leukemia: an exploratory study. Health Qual Life Outcome 9(1):25
11. Spilsbury JC, Storfer-Isser A, Kirchner HL, Nelson L, Rosen CL, Drotar D, Redline S (2006) Neighborhood disadvantage as a risk factor for pediatric obstructive sleep apnea. J Pediatr 149(3):342–347. doi:10.1016/j.jpeds.2006.04.061
12. Brouillette RT, Horwood L, Constantin E, Brown K, Ross NA (2011) Childhood sleep apnea and neighborhood disadvantage. J Pediatr 158(5):789–795.e781. doi:10.1016/j.jpeds.2010.10.036
13. Rosen GM, Shor AC, Geller TJ (2008) Sleep in children with cancer. Curr Opin Pediatr 20(6):676–681. doi:10.1097/MOP.1090b1013e328312c328317ad
14. Hooke M, Garwick A, Gross C (2011) Fatigue and physical performance in children and adolescents receiving chemotherapy. Oncol Nurs Forum 38(6):649–657. doi:10.1188/11.onf.649-657
15. Montgomery-Downs H, O'Brien L, Holbrook C, Gozal D (2004) Snoring and sleep-disordered breathing in young children: subjective and objective correlates. Sleep 27(1):87–94
16. Hockenberry MJ, Hinds PS, Barrera P, Bryant R, Adams-McNeill J, Hooke C, Rasco-Baggott C, Patterson-Kelly K, Gattuso JS, Manteuffel B (2003) Three instruments to assess fatigue in children with cancer: the child, parent and staff perspectives. J Pain Symptom Manag 25(4):319–328. doi:10.1016/S0885-3924(02)00680-2
17. LeBourgeois MK, Harsh J (2001) A new research instrument for measuring children's sleep. Sleep 24:A213
18. Meltzer LJ, Biggs S, Reynolds A, Avis KT, Crabtree VM, Bevans KB (2012) The Children's Report of Sleep Patterns (CRSP): a self-report measure of sleep for school-aged children. Sleep Med 13(4):385–389. doi:10.1016/j.sleep.2011.12.004
19. Barratt W (2006) The Barratt simplified measure of social status (BSMSS) Measuring SES
20. Gamble HL, Meltzer LJ, Rach AM, Biggs S, Reynolds A, Crabtree VM (2012) Validation of a self-report measure of sleep patterns in adolescents. Sleep 35:A357–358, Abstract supplement
21. Meltzer LJ, Biggs S, Reynolds A, Avis KT, Crabtree VM, Bevans KB (2012) The Children's report of sleep patterns—sleepiness scale: a

self-report measure for school-aged children. Sleep Med 13(4):385–389. doi:10.1016/j.sleep.2011.12.004
22. National Sleep Foundation (2006) Teens and Sleep. www.sleepfoundation.org. Accessed July 30, 2014
23. Lumeng JC, Chervin RD (2008) Epidemiology of pediatric obstructive sleep apnea. Proc Am Thorac Soc 5:242-252. http://www.sleepfoundation.org/sites/default/files/2006_summary_of_findings.pdf
24. Coustan-Smith E, Sancho J, Behm FG, Hancock ML, Razzouk BI, Ribeiro RC, Rivera GK, Rubnitz JE, Sandlund JT, Pui C-H, Campana D (2002) Prognostic importance of measuring early clearance of leukemic cells by flow cytometry in childhood acute lymphoblastic leukemia. Blood 100(1):52–58. doi:10.1182/blood-2002-01-0006
25. Panzer-Grümayer ER, Schneider M, Panzer S, Fasching K, Gadner H (2000) Rapid molecular response during early induction chemotherapy predicts a good outcome in childhood acute lymphoblastic leukemia. Blood 95(3):790–794
26. Iwasaki M, Iwata S, Iemura A, Yamashita N, Tomino Y, Anme T, Yamagata Z, Iwata O, Matsuishi T (2010) Utility of subjective sleep assessment tools for healthy preschool children: a comparative study between sleep logs, questionnaires, and actigraphy. J Epidemiol 20(2):143–149
27. Tremaine RB, Dorrian J, Blunden S (2010) Subjective and objective sleep in children and adolescents: measurement, age, and gender differences. Sleep Biol Rhythm 8(4):229–238. doi:10.1111/j.1479-8425.2010.00452.x