

Parental Behaviors, Emotions at Bedtime, and Sleep Disturbances in Children with Cancer

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Abstract

Background Poor sleep is common for children during cancer treatment, but there is limited understanding of the nature of children's sleep throughout the treatment trajectory. The current exploratory study used an explanatory sequential mixed method approach to examine quantitative associations among sleep problems in children with cancer, parental behavior, and children's sleep hygiene, with follow-up qualitative characterizations of children's sleep across cancer treatment stages. **Procedure** Eighty parents of children with cancer (aged 2–10 years; in active treatment, maintenance treatment, or off treatment) completed an online survey querying the child's sleep quality (Sleep Disturbance Scale for Children—Disorders of Initiating and Maintaining Sleep subscale) and behaviors (Child Sleep Hygiene Scale) and sleep-related parenting behaviors (Parental Sleep Strategies). A subsample ($n = 17$ parents) participated in qualitative interviews to better characterize the processes of children's sleep and parents' sleep-related behaviors. **Results** Children's sleep quality, sleep hygiene, or parental sleep strategies were not significantly different by cancer treatment groups. Greater sleep disturbance in children was associated with their parents' tendency to accommodate the child's bedtime requests. Qualitatively, cancer treatment-related anxiety in both children and parents influence the onset of these disruptive sleep behaviors. **Conclusion** Parents' sleep-related behaviors affect children's sleep during cancer treatment. Parents' accommodation may start during active treatment to alleviate cancer-related challenges, and these behaviors may continue into maintenance therapy and off treatment to reinforce sleep disturbance. Behavioral interventions targeting unhelpful parental behaviors may improve sleep in children with cancer during and after cancer treatment.

Key words: parental behavior; psychosocial; sleep.

Introduction

As the 5-year childhood cancer survival rate has increased to an estimated 85.2% (Noone, Howlader, Krapcho, & Cronin, 1975-2015), research and clinical care have increasingly focused on addressing the long-

term impairments related to cancer and its treatments, including sleep problems. Impaired sleep in children treated for cancer is associated with depression and anxiety (Daniel, Kazak, et al., 2016), negative neurocognitive outcomes (Clanton et al., 2011), and

decreased quality of life (van Litsenburg et al., 2011). Although the child's treatment intensity and sleep health vary across the cancer trajectory, scant research has explored sleep across different treatment stages.

Sleep problems are common in children *newly diagnosed with cancer* (Jacob, Hesselgrave, Sambuco, & Hockenberry, 2007). Within a hospital setting, environmental factors such as bright lighting and elevated noises are related to sleep disruptions (Park et al., 2014; Stickland, Clayton, Sankey, & Hill, 2016), and frequent nighttime medical activities (e.g., dispensing medications and monitoring) contribute to greater bedside noises, shorter sleep time, more nighttime awakenings, and more fatigue in children who are inpatient for cancer treatment (Hinds, Hockenberry, Rai, et al., 2007; Linder & Christian, 2012; Lee, Narendran, Tomfohr-Madsen, & Schulte, 2017). Children diagnosed with cancers that require *maintenance therapy* (e.g., acute lymphoblastic leukemia) often continue to experience difficulties with their sleep (Daniel, Schwartz, Mindell, Tucker, & Barakat, 2016; Hinds, Hockenberry, Gattuso, et al., 2007). These sleep difficulties can persist into *survivorship* without appropriate treatment (Daniel et al., 2019; Cheung et al., 2017; Clanton et al., 2011; Zhou, Manley, Marcus, & Recklitis, 2016; Zhou & Recklitis, 2014).

Parents of children with cancer are responsible for setting and enforcing routines and/or rules as they relate to the child's sleep behaviors, though limited literature has examined family factors that may directly impact the sleep of pediatric cancer patients. In response to their child's cancer treatment, families may change their sleep-related behaviors in ways that are more accommodating to the child's requests (Williams & McCarthy, 2014). Previous literature has demonstrated that the challenges of caring for a child with cancer can impact the parents' ability to set and enforce rules (Vance & Eiser, 2004). For example, children undergoing cancer treatment who consume food and drinks past bedtime, and those who co-sleep end up reporting worse sleep (Williams, Lamb, & McCarthy, 2014; Zupanec, Jones, & Stremler, 2010).

Although parental behavior is critical in shaping children's sleep, a limited number of studies have examined parents' role in the context of cancer. The current study aims to address this gap by examining how sleep problems emerge and change across different stages of cancer treatment as they relate to parental sleep behaviors. Our explanatory, mixed methods approach examined behavioral factors associated with sleep problems in children across the treatment trajectory. The quantitative portion of the current study aims to (a) examine associations among sleep problems in children with cancer, parental behavior, and sleep hygiene throughout the cancer treatment (active, maintenance, and off treatment); and (b) evaluate

aspects of children's sleep (demographic factors, sleep hygiene, and sleep-related parental behaviors) associated with sleep problems during and after cancer treatment. Using an explanatory sequential mixed method design (Creswell & Plano Clark, 2018), the current study uses qualitative data to inform interpretation of the quantitative results. Based on previous studies that investigated children's sleep during the maintenance phase of ALL (Williams & McCarthy, 2014; Zupanec, Jones, & Stremler, 2010), we hypothesized that side effects of cancer and related treatment may increase parents' engagement in accommodating behaviors during bedtime, which would be negatively associated with sleep hygiene and children's sleep. We also hypothesized that these parental behaviors change during the course of treatment.

Materials and Methods

Sample and Recruitment

Parents of children with cancer were recruited through various online communities and email listservs related to pediatric oncology (e.g., Momcology, Pediatric Oncology Survivors listserv, Pediatric Cancers Online Support Group listserv) or by re-contacting parents who had previously participated in a cancer research study in our lab (Long et al., 2017). Parents were eligible to participate in the current study if the following criteria were met: (a) parent has a child aged 2–10 years who had been diagnosed with pediatric cancer, (b) child had active cancer treatment within the past 6 months, (c) parent is fluent in English, and (d) parent is currently living with the child with cancer. The sample focused on children ages 2–10 years to remove the unique developmental considerations of sleep during early childhood or adolescence. Bereaved parents were excluded from study enrollment.

Procedure

Parents were screened for eligibility and, if eligible, completed informed consent online. Parents then completed online questionnaires through REDCap (Harris et al., 2009), a secure web application for managing and storing online surveys and databases. Ninety-nine parents initiated the survey, but those with incomplete demographic data ($n = 19$) were excluded. The current analyses are of 80 parents who had children in active treatment, maintenance treatment, or who were off treatment (Table I). At the end of the quantitative survey, parents were asked if they would be interested in completing a 30–45 min telephone interview that would expand on topics addressed in the survey. Of the 80 participants who completed the survey, 49 agreed to be contacted about the interview. Enrollment in the qualitative sub-study was stopped after 17 interviews, once thematic saturation was

Table I. Demographic Characteristics of the Study Sample

| | Total sample (N = 80) | In active treatment (N = 31, 38.75%) | In maintenance (N = 30, 37.50%) | Off treatment (N = 19, 23.75%) | p-value ^a |
|-----------------------------------|--------------------------|---|------------------------------------|-----------------------------------|----------------------|
| Child's age, mean ± SD | 5.06 ± 2.22 | 5.38 ± 2.53 | 4.47 ± 2.11 | 5.47 ± 1.71 | 0.18 |
| Child's gender (female), n (%) | 34 (42.50) | 14 (45.16) | 14 (46.67) | 6 (31.58) | 0.54 |
| Child's race, n (%) | | | | | 0.10 |
| White | 68 (84.99) | 27 (87.10) | 25 (83.33) | 16 (84.21) | |
| Asian | 2 (2.50) | 0 (0.00) | 0 (0.00) | 2 (10.53) | |
| Other | 3 (3.75) | 0 (0.00) | 2 (6.67) | 1 (5.26) | |
| More than one race | 7 (8.75) | 4 (12.90) | 3 (10.00) | 0 (0.00) | |
| Child's ethnicity, n (%) | | | | | 0.98 |
| Hispanic/Latino | 5 (6.25) | 2 (6.45) | 2 (6.67) | 1 (5.26) | |
| Non-Hispanic/non-Latino | 75 (93.75) | 29 (93.55) | 28 (93.33) | 18 (94.74) | |
| Cancer type, n (%) | | | | | 0.36 |
| Blood cancers | 62 (77.50) | 24 (77.42) | 26 (86.67) | 12 (63.26) | |
| Central nervous system | 18 (22.50) | 7 (22.58) | 4 (13.33) | 7 (36.84) | |
| Parent's relation to child, n (%) | | | | | 0.19 |
| Mother | 79 (98.75) | 31 (100.00) | 30 (100.00) | 18 (94.74) | |
| Father | 1 (1.25) | 0 (0.00) | 0 (0.00) | 1 (5.26) | |
| Parent's age, mean ± SD | 36.43 ± 5.09 | 36.97 ± 4.96 | 35.67 ± 5.22 | 36.74 ± 5.25 | 0.59 |
| Parent's marital status, n (%) | | | | | 0.51 |
| Single | 1 (1.25) | 0 (0.00) | 1 (3.33) | 0 (0.00) | |
| Married | 75 (93.75) | 30 (96.77) | 27 (90.00) | 18 (94.74) | |
| Cohabiting | 3 (3.80) | 0 (0.00) | 2 (6.67) | 1 (5.26) | |
| Re-married | 1 (1.25) | 1 (3.23) | 0 (0.00) | 0 (0.00) | |

^ap-values represent statistical significance between the three cancer treatment groups.

reached. Interviews were conducted by one doctoral-level psychologist with expertise in qualitative methods and two graduate-level psychology students who were closely supervised on qualitative interviewing techniques. Interviews were recorded, transcribed verbatim, then cleaned and checked for accuracy by the research team. Participants were not compensated for their participation. Study procedures were approved by the Institutional Review Board of Boston University.

Measures

Sleep Disturbance Scale for Children—Disorders of Initiating and Maintaining Sleep subscale

The 7-item Disorders of Initiating and Maintaining Sleep subscale (DIMS) subscale assessed the child's difficulties with initiating and/or maintaining sleep, with higher scores indicating worse sleep (Bruni et al., 1996). Although this scale was originally validated in children aged six and up, the current measure was included in the current study because it covered a wide range of common sleep problems that are present in the age range of our sample. Each item reflected an area of sleep difficulty, and parents' responses on the frequency of each item were summed to calculate the total DIMS score (Bruni et al., 1996).

Child Sleep Hygiene Scale

Sleep hygiene in children was measured using the Child Sleep Hygiene Scale (CSHS), a 22-item questionnaire (Harsh, Easley, & LeBourgeois, 2002). The CSHS includes six subscales: *Cognitive* (engaging in

alerting non-sleep activities that keep children awake such as TV or video games), *Physiological* (consuming a high quantity of liquids or caffeinated drinks, playing rough, and complaining about being hungry), *Emotional* (feeling upset or worried), *Environmental* (sleeping in a room with light, cold/hot temperature, or loud noises; in an uncomfortable bed; or in an environment where someone smokes), *Bedtime Routine* (not engaging in behaviors that are relaxing before bedtime or not having a calming bedtime routine), and *Sleep Stability* (being put into bed after falling asleep, staying up past the bedtime, not getting out of bed at the same time each morning). Total score can be obtained by summing all items. For all subscale scores and the total score, higher scores indicate better sleep hygiene.

Parental Sleep Strategies

Behaviors parents use to put their children to sleep were measured using the Parental Sleep Strategies (PSS), a six-question scale developed and used by pediatric sleep medicine experts (McCarthy, Bastiani, & Williams, 2016). Parents rated how often they used the following strategies to get their children to sleep and resettle their children if they woke up in the middle of sleep: co-sleeping, food and drink in the bed or bedroom, provision of bedtime routines, use of sleep medication, television in the bed or bedroom, and comforting activities (e.g., rocking/holding the child, lying with the child to re-settle them). The item "use of controlled crying" (graduated extinction or Ferber method) was not included in the current analyses due

to the reduced likelihood that this would be relevant for older children in our sample. In order to represent parental use of ineffective strategies that were identified in previous literature, presence of behaviors that are known to interfere with children's sleep (e.g., co-sleeping or watching television) was defined as the parent responding "Sometimes," "Often," or "Always" to the described behavior. Consistent bedtime routines are known to promote sleep in children in the general population, and therefore, a lack of consistent bedtime routines was considered an ineffective strategy (Owens, Palermo, & Rosen, 2002). Use of each ineffective strategy was summed to yield the total PSS score (range 1–6). Higher scores reflect increased use of ineffective parental sleep-related behaviors.

Semi-Structured Interview

A semi-structured interview guide was developed by the research team to build on quantitative findings and gather more information on the timing and nature of processes linking parent behaviors and child sleep in pediatric cancer. The interview questions were designed to reflect the current study's aim to explore changes in sleep, sleep hygiene, and sleep-related parent behaviors across the cancer trajectory. Open-ended questions addressed child sleep patterns during different phases of cancer (e.g., "Tell me about your child's sleep during active cancer treatment"), changes in bedtime routines across phases (e.g., "How were bedtime rules similar pre- to post-cancer? How were they different?"), and parent sleep-related behaviors across phases (e.g., "Which aspects of the sleep routine or environment were controllable at the hospital? In what ways were your child's bedtime routines same/different at the hospital?"). Specific probes and follow-up questions were asked to expand parents' response (e.g., "You mentioned it was more difficult to control sleep environment during hospitalization. What aspects of the hospital setting made it more difficult?").

Quantitative Data Analysis

The preliminary analyses included comparing sum scores of all continuous measures (DIMS, CSHS, and PSS) and demographic factors by different treatment status groups (*Active Treatment*, *Maintenance*, and *Off Treatment*) using analysis of variance. Associations between these continuous outcome measures were analyzed using the multiple regression analyses, with child's age and gender as covariates. Next, hierarchical multiple regression was used to examine predictors of child sleep disturbance (DIMS) in the total sample. Age, gender, and cancer type (blood cancer vs. other types) were entered into Step 1, children's sleep hygiene (CSHS) was entered into Step 2, and sleep-related parental strategies (PSS) was entered into

Step 3. Analyses were performed using SAS 9.4 (SAS Institute Inc., Cary, NC). A $p < .05$ was considered to be statistically significant.

Qualitative Data Analysis

Qualitative interviews were coded by two graduate-level psychology students with oversight by a doctoral-level psychologist with expertise in qualitative methods and pediatric cancer. Interviews were coded using a coding structure that was developed based on *a priori* research questions (i.e., changes in sleep, sleep hygiene, and sleep-related parent behaviors across the cancer trajectory). The initial coding structure included codes related to each section of the interview guide, which corresponded to quantitative findings (e.g., description of sleep quality during inpatient treatment; identification of reasons for maintaining bedtime consistency). The coding structure was refined throughout data collection to capture additional emerging themes. Once the coding structure was finalized, all transcripts were re-coded using the final version of the coding structure. Coders met weekly to discuss questions about the application of codes. Twenty percent of transcripts were double coded, and inter-coder concordance (Morse, Barrett, Mayan, Olson, & Spiers, 2002) was calculated to be 90%. Qualitative themes were analyzed using an applied thematic analysis approach (Guest, MacQueen, & Namey, 2011).

Results

Quantitative Findings

Participant Characteristics

The parents who participated in the online survey were primarily female (98.75%) with a mean age of 36.43 years ($SD = 5.09$). The children with cancer were approximately half male ($n = 46$, 57.50%) and primarily White/Caucasian ($n = 68$, 85.00%) with a mean age of 5.06 years ($SD = 2.22$). Children were on active treatment ($n = 31$), maintenance therapy ($n = 30$), or off treatment ($n = 19$). There were no significant differences in children's demographics by treatment status (all $p > .10$; Table I).

Children's Sleep and Parental Behaviors by Treatment Group

Mean levels of sleep disturbance in children (DIMS), children's sleep hygiene (CSHS) and subscales, and PSS did not significantly differ by treatment group (all p 's $> .05$; Table II). When different sleep variables were compared by cancer type, children with blood cancer had better general sleep hygiene ($p = .01$) and were less likely to engage in cognitively stimulating activities prior to bedtime (engaging in alerting non-sleep activities that keep children awake such as TV or

Table II. Comparison of Outcome Measures by Treatment Groups

| | Total sample (N = 80) | In active treatment (N = 31, 38.75%) | In maintenance (N = 30, 37.5%) | Off treatment (N = 19, 23.8%) | SS | Mean square | F-value | p-value ^a |
|----------------------------------|--------------------------|---|-----------------------------------|----------------------------------|--------|-------------|---------|----------------------|
| Child's sleep disturbance (DIMS) | 17.20 ± 6.17 | 18.06 ± 6.49 | 15.67 ± 5.73 | 18.21 ± 6.16 | 113.10 | 56.55 | 1.50 | 0.23 |
| Parental sleep strategies (PSS) | 2.89 ± 1.18 | 3.00 ± 1.10 | 2.80 ± 1.32 | 2.84 ± 1.12 | 0.66 | 0.33 | 0.23 | 0.79 |
| Child's sleep hygiene (CSHS) | 4.82 ± 0.44 | 4.80 ± 0.33 | 4.85 ± 0.47 | 4.82 ± 0.55 | 0.05 | 0.03 | 0.13 | 0.88 |
| CSHS subscales | | | | | | | | |
| Cognitive | 4.46 ± 1.00 | 4.32 ± 1.03 | 4.64 ± 0.99 | 4.39 ± 0.98 | 1.71 | 0.85 | 0.85 | 0.43 |
| Environmental | 5.74 ± 0.36 | 5.75 ± 0.41 | 5.79 ± 0.31 | 5.65 ± 0.36 | 0.24 | 0.13 | 0.92 | 0.40 |
| Bedtime routine | 4.49 ± 1.28 | 4.40 ± 1.25 | 4.43 ± 1.34 | 4.71 ± 1.27 | 1.25 | 0.63 | 0.38 | 0.69 |
| Physiological | 4.73 ± 0.63 | 4.80 ± 0.54 | 4.72 ± 0.69 | 4.63 ± 0.70 | 0.33 | 0.17 | 0.41 | 0.67 |
| Emotional | 5.04 ± 0.88 | 5.02 ± 0.97 | 5.07 ± 0.77 | 5.03 ± 0.94 | 0.04 | 0.02 | 0.03 | 0.97 |
| Sleep stability | 4.49 ± 0.40 | 4.48 ± 0.50 | 4.47 ± 0.34 | 4.54 ± 0.33 | 0.06 | 0.03 | 0.18 | 0.84 |

^ap-values represent statistical significance between the three cancer treatment groups.

Table III. Comparison of Outcome Measures by Cancer Type

| | Blood cancer (N = 62) | Other cancer type (N = 31) | Unadjusted p-value | Adjusted p-value ^a |
|----------------------------------|--------------------------|-------------------------------|--------------------|-------------------------------|
| Child's sleep disturbance (DIMS) | 16.89 ± 5.89 | 18.28 ± 7.14 | 0.40 | 0.40 |
| Parental sleep strategies (PSS) | 2.76 ± 1.17 | 3.33 ± 1.14 | 0.07 | 0.06 |
| Child's sleep hygiene (CSHS) | 4.89 ± 0.40 | 4.58 ± 0.48 | 0.02 | 0.01 |
| CSHS subscales | | | | |
| Cognitive | 4.67 ± 0.87 | 3.74 ± 1.18 | 0.004 | 0.0006 |
| Environmental | 5.78 ± 0.35 | 5.60 ± 0.39 | 0.09 | 0.09 |
| Bedtime routine | 4.56 ± 1.25 | 4.25 ± 1.40 | 0.41 | 0.41 |
| Physiological | 4.77 ± 0.65 | 4.58 ± 0.58 | 0.25 | 0.36 |
| Emotional | 5.06 ± 0.82 | 4.97 ± 1.09 | 0.76 | 0.72 |
| Sleep stability | 4.54 ± 0.35 | 4.33 ± 0.54 | 0.06 | 0.06 |

^ap-value after adjusting for child's age and gender.

video games) compared to children with other types of cancer ($p = .0006$ for the cognitive subscale of the CSHS; [Table III](#)). Children's sleep disturbance and PSS were not significantly different by cancer type (p 's $\geq .06$).

Associations Between Sleep Hygiene and Sleep

Quality

Good child sleep hygiene (higher CSHS) was marginally associated with less sleep disturbance (DIMS) in the entire sample after adjusting for child's age, gender, and cancer type ($\beta = -3.08$, $p = .07$).

Associations Between Parenting Behaviors and Sleep

Quality

Parents' increased tendency to accommodate their child's bedtime requests with ineffective strategies (PSS) was associated with greater sleep disturbance in children (DIMS) across the entire sample ($\beta = 2.50$, $p < .0001$). Child's age, gender, cancer type, sleep hygiene (CSHS), and PSS were not significantly associated with children's sleep disturbance (DIMS) in univariate regression analyses. In hierarchical regression analyses ([Table IV](#)), children's sleep disturbance

was not significantly accounted for by age, gender, and cancer type (Step 1), nor by children's sleep hygiene (Step 2). However, higher levels of ineffective PSS (Step 3) significantly predicted higher levels of children's sleep disturbance, independently of child age, cancer type, or sleep hygiene ($p < .0001$).

Qualitative Findings

Qualitative interviews were conducted with 16 mothers and 1 father. Children discussed in the interviews were 2- to 9-year-old (mean age = 4.65 ± 2.17), and 58.82% were female. They were diagnosed with leukemia ($n = 13$) or solid tumors ($n = 4$). Children were in active treatment ($n = 3$), maintenance treatment ($n = 8$), or off treatment ($n = 6$) at the time of the qualitative interview.

Cancer Treatment Disrupts Child Sleep

Parents reported poor sleep in their children across treatment phases ([Figure 1](#)). Similar to the quantitative findings, parents described frequent nighttime awakenings, particularly when in the hospital, which contributed to disrupted sleep schedules and increased daytime naps. A mother of an 8-year-old boy with a

Table IV. Summary of Hierarchical Regression Analysis for Variables Predicting Children’s Sleep Disturbance (DIMS)

| | Model 1 | | Model 2 | | Model 3 | |
|--|---------|----------|---------|----------|----------|----------|
| | β | <i>p</i> | β | <i>p</i> | β | <i>p</i> |
| Age | −0.13 | .67 | −0.20 | .55 | 0.04 | .90 |
| Gender (female vs. male) | −0.01 | .99 | −0.34 | .82 | −0.23 | .86 |
| Cancer type (blood cancer vs. other types) | −1.42 | .40 | 0.48 | .77 | −0.71 | .66 |
| Children’s sleep hygiene (CSHS) | | | −3.08 | .07 | −2.32 | .13 |
| Sleep-related parental strategies (PSS) | | | | | 2.41 | <.0001 |
| R ² | 0.01 | | 0.05 | | 0.25 | |
| F for change in R ² | | | 3.33 | | 19.15*** | |

****p* < .0001.

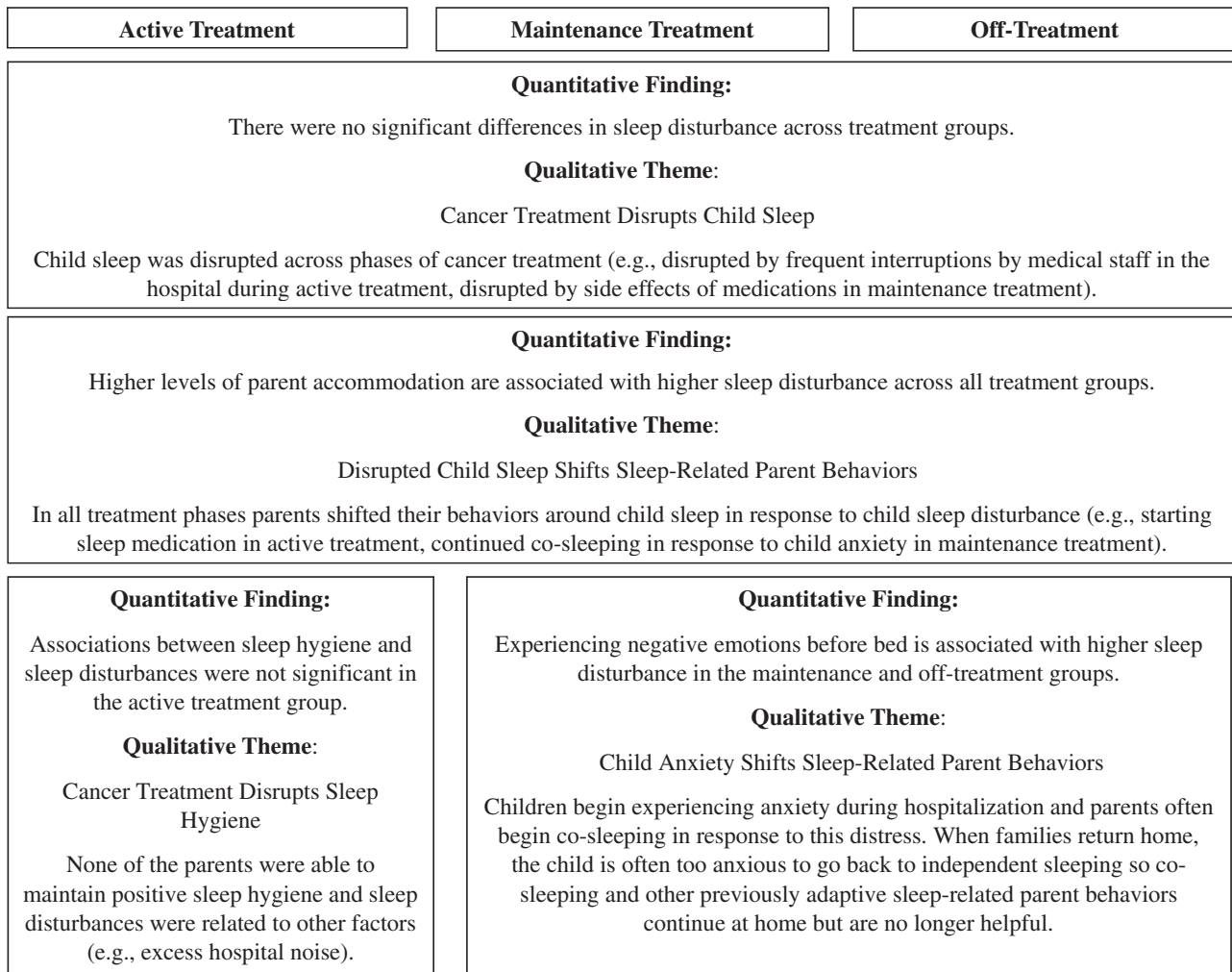


Figure 1. Links between quantitative and qualitative findings.

blood cancer described, “He woke more frequently. It’s difficult to know whether it was environmental, as in there’s always a lot of noise going on—or whether... it’s the medication and how terrible the medication makes you feel... You’re exhausted, but it’s a different exhaustion when you’re exhausted because you’re sick, compared to if you’ve been moving around.” As active treatment continued at home, parents described continued frequent night

awakenings and daytime fatigue due to the side effects of medications (e.g., steroids). A mother of a 3-year-old boy with a blood cancer reported, “He came home and was on the steroids for the 29 days for induction which completely messes up their sleep. And he would wake up hungry in the middle of the night. So, he would try to sleep and some nights he would do very well, and other nights, he’d be up at 2 o’clock eating pizza and he couldn’t go back to sleep.” In addition,

parents described an increase in their child's anxiety during active treatment once returning home after hospitalization which made falling asleep more difficult, particularly when a caregiver was not present (Figure 1).

Cancer Treatment Impacts Sleep Hygiene

Parents described having very little control over conditions that could affect their child's sleep during active treatment, particularly while in the hospital (Figure 1). A mother of a 3-year-old boy with a blood cancer reported, "We do our best to still keep [sleep routines regular], you know, you go to bed at this time, you get up at this time, but at the hospital you are kind of at the whims of what time they can get your medicines to you." Excessive noise and light, medication administration schedules, and frequent interruptions by medical staff during the night made regular bedtimes and wake times difficult in the hospital. At home during active treatment, the majority of parents noted that steroid medications made children hungry during the night, which disrupted sleep and prevented normal sleep periods.

Disrupted Child Sleep Shifts Sleep-Related Parent Behaviors

Parents described a variety of changes in their behaviors to improve disrupted child sleep during cancer treatment (Figure 1). During hospitalization, some parents allowed children to nap whenever possible to make up for disrupted sleep at night due to interruptions by medical staff or excess hospital noise. A mother of a 10-year-old girl with a solid tumor described, "In the hospital, everything's so different. . .so it was just about getting sleep whenever she could, regardless of the time of day or night." Other parents tried to keep a consistent sleep schedule to maintain good sleep hygiene and improve sleep, or they played music or audiobooks as a way to block out noise and help their child relax before bed. During active treatment both in the hospital and at home, some parents gave their child sleeping medications (e.g., melatonin) to counteract medication-related (e.g., steroids) sleep disruptions. A mother of an 8-year-old girl with blood cancer described, "As steroids got worse and treatment got worse, she started taking melatonin and Benadryl for a while. So that, that helped, but it didn't really solve the problem [of disturbed sleep]."

Child Anxiety Shifts Sleep-Related Parent Behaviors

Most parents indicated that their child became anxious during active treatment in the hospital; this anxiety also occurred amongst children who were at home during active and maintenance treatment phases. A mother of a 3-year-old boy with a blood cancer described, "He was terrified out of his mind. He had just

been put through so many pokes, and needles, and invasive procedures, and X-rays, and CT scans. He had surgery and he's getting poked all the time." Parents described shifting their behaviors around child sleep during active treatment due to child anxiety (e.g., fear of sleeping alone) and continuing these new behaviors into maintenance treatment (Figure 1). A mother of a 3-year-old boy with a blood cancer described, "What had happened in the hospital was traumatic. And he just wanted someone there. And then in the hospital, he wanted me to lay with him in his bed. . .So I think it sort of started from that. And then when we got home, he just wanted someone there, all the trauma he's gone through." Most parents reported co-sleeping in response to child anxiety in the hospital, and many described having difficulty transitioning back to independent sleeping at home due to child anxiety around sleeping alone that had not existed prior to the cancer diagnosis. Although the majority of shifts in parent sleep-related behaviors (e.g., co-sleeping) were adaptive during active treatment, parents reported that these new behaviors continue into maintenance and off treatment where they were no longer helpful (Figure 1).

Discussion

The current study examined children's sleep hygiene and PSS at different stages of a child's cancer treatment and assessed how these factors may be associated with cancer-related sleep disturbance. Consistent with previous research (McCarthy et al., 2016), our data suggest that parents of children with cancer report high levels of child sleep disturbance across all treatment phases. However, contrary to our hypothesis, our quantitative findings indicate that the levels of sleep disturbances, children's sleep hygiene practices, and their parents' sleep behaviors are comparable across treatment stages. Our qualitative findings support this finding and further clarify that many of the ineffective sleep-related behaviors utilized by parents (e.g., co-sleeping) may start in active treatment, particularly during an inpatient stay, and continue through maintenance and off treatment. Furthermore, our qualitative findings suggest that returning home during maintenance treatment and after treatment ends may be associated with continued emotional distress that negatively impacts child sleep. Both sleep-related parent behaviors and children's sleep hygiene have implications for the child's overall sleep quality during and after active cancer treatment. Considering the finding that many sleep-related parent behaviors and disrupted sleep start during inpatient treatment and continue into outpatient, it may be particularly important to begin to address sleep behaviors in the hospital,

especially during the transition from inpatient to outpatient treatment.

Sleep-Related Parenting Strategies

Current findings indicate that children experienced greater sleep disturbance when parents were engaging in sleep-related parental behaviors that are known to be ineffective in the general population. In particular, our quantitative data indicate that children's sleep disturbance was strongly associated with increased number of parental accommodating behaviors (e.g., co-sleeping or engaging in comforting activities) that are generally discouraged by sleep experts for long-term use due to their propensity to maintain sleep disturbances and prevent the development of adaptive sleep strategies (Bathory & Tomopoulos, 2017). Our qualitative findings emphasize that parents found it to be nearly impossible to maintain good sleep hygiene during hospitalization, consistent with previous findings (Daniel, Schwartz, et al., 2016). Our quantitative findings also show that parents across the different treatment groups engaged in a similar number of accommodating behaviors and that parental accommodating behaviors significantly contributed to children's sleep disturbance, independent of children's age, cancer type, and sleep hygiene. However, it is unclear whether parents engaged in accommodating behaviors as a response to their children's worse sleep and/or if worse sleep was a negative consequence of initiating these sleep-related parenting behaviors. Although the directionality of this relationship could not be clarified in the quantitative results, parents reported qualitatively that many accommodating behaviors (e.g., sleep medications) were often initiated in active treatment in response to sleep disturbances. Based on this finding, it may be hypothesized that accommodating behaviors may arise during active and maintenance treatment and are maintained following treatment, then prolonging sleep disturbances to the off treatment stage. Treatment for the pediatric cancer population may include educating parents on when certain behaviors (e.g., co-sleeping) are helpful in the short-term and when and how to switch to more appropriate behaviors that are better for long-term sleep health outcomes.

Anxiety and Accommodating Behaviors

In addition to highlighting parental responses to sleep disturbances, our qualitative findings suggest that children's sleep disturbances and parents' accommodating sleep-related behaviors may create a feedback loop and have a bidirectional relationship. For example, co-sleeping may begin initially to decrease child anxiety and improve child's sleep while in the hospital. However, as the child finishes treatment and/or returns home, these behaviors then reinforce sleep

disturbances as parents continue to co-sleep or utilize comforting activities in response to their child's behavioral or emotional disturbances (Williams & McCarthy, 2014). As parents utilize more comforting activities, children rely more on parents during bedtime. Parents' efforts are understandable in the context of active treatment or hospitalizations, given that changes in sleep-related parent behaviors may be adaptive and helpful initially. Although this pattern has been discussed in the context of child anxiety disorders (Peterman, Carper, & Kendall, 2015), to our knowledge, this is the first paper to begin to illustrate changes in sleep-related parent behaviors specifically in response to child anxiety during pediatric cancer treatment.

Parents may also engage in more accommodating behaviors at bedtime due to their own distress when their child is being treated for a life-threatening illness (Gellerstedt, Medin, & Karlsson, 2014). Their increased use of accommodating behaviors is consistent with prior data indicating higher use of behavioral and pharmacological accommodations to try to manage children's sleep disturbances during active treatment (Lee et al., 2017). Parents' distress may be exacerbated by both their child's pain/anxiety and fear of relapse and loss of clinical support, as the few months immediately following completion of treatment are one of the most anxiety-provoking times for cancer patients and their family members (Hobbie et al., 2010; Kunin-Batson et al., 2016). As parents struggle to manage their own distress, they may be less able to tolerate their child's distress, rendering them more willing to try any short-term strategy available to them to try to improve their child's sleep, even those which are less desirable in the long-term (Armstrong, Covington, Unick, & Black, 2018; McCarthy et al., 2016; Onen, Onen, Courpron, & Dubray, 2005).

Sleep Hygiene

Children's sleep hygiene was examined separately from sleep-related parent behaviors, given that there are multiple components associated with children's sleep (e.g., behavioral, environmental, cognitive, and emotional). In the current study, children's sleep hygiene was not significantly associated with children's sleep in quantitative analyses. This is potentially because the Children's Sleep Hygiene Scale was not developed for this specific population, and therefore may not fully capture the sleep hygiene in children with cancer (e.g., hospital experiences, medication side effects). However, consistent with previous research (Williams & McCarthy, 2014; Hinds, Hockenberry, Rai, et al., 2007), qualitative findings highlight uncontrollable environmental (e.g., hospital room set-up) and physiological factors (e.g., side

effects from steroids) that might override the positive impact of good sleep hygiene on sleep outcomes. Parents reported difficulties with controlling aspects of sleep hygiene throughout cancer treatment, although some factors had a larger impact during certain treatment stages (e.g., excessive noise in the hospital).

Strengths, Limitations, and Future Directions

The current study was the first to evaluate child sleep disturbances, sleep-related parent behaviors, and sleep hygiene in all three phases of cancer treatment for children. Findings illuminated sleep disturbances across various cancer stages and clarified parents' impact on children's sleep during cancer treatment. Our mixed methods approach was well suited to this exploratory study given our limited knowledge of processes linking sleep and behavior in children with cancer and the complementary nature of quantitative and qualitative findings. Some of the qualitative findings were not as clearly reflected in the quantitative data, which may be due to difficulty applying survey responses in the current sample. For example, the DIMS, which was used as our main outcome measure was validated in children 6 years or older, and its potential lack of applicability to younger children in our sample may have limited our findings within the qualitative analyses. The addition of the qualitative findings illustrated the impact of cancer treatment on children's sleep and parents accommodating sleep-related behaviors.

Despite these strengths, we also acknowledge limitations of our study. One main limitation is the small subgroups of patients in different treatment stages, which may have limited our power to detect meaningful differences across the treatment groups. The study might also face potential challenges to generalizability as our sample mostly consisted of mothers and primarily individuals from non-Hispanic White backgrounds. Furthermore, the method of recruitment may have created a potentially biased sample due to self-selected inclusion from listserv recruitment. Unavailable information regarding response rates from each recruitment source made it difficult to understand how this may have restricted generalizability. There are also limitations associated with the measures used in the current study. The measures included were subjective, rather than objective, assessments of the child's sleep. Sparse information on the validation of CSHS and PSS in the general and pediatric cancer populations, as well as limited data supporting the applicability of the DIMS for the age range of our sample, might have contributed to some of null findings in our quantitative analyses. Lastly, the cross-sectional design of the current study and the lack of measurement of parental adjustment to cancer treatment limited our interpretation of the observed results. This study is

exploratory in nature and findings from the current study should be viewed as a first step in understanding the processes linking sleep disturbance, parenting strategies, and sleep hygiene in children with cancer at various treatment stages. Future studies with larger, more diverse samples, collecting objective data in longitudinal follow-up may better elucidate the nature and directionality of relationships between sleep-related parent and child behaviors and their effects on child's sleep.

Clinical Implications

There are known health consequences of chronically disrupted sleep in children with cancer (Daniel, Schwartz, et al., 2016), which underscores the importance of early identification and intervention for poor sleep. Our findings highlight that sleep-related parent behaviors may start as adaptive or responsive to the environmental challenges during active treatment, but these behaviors may reinforce sleep disturbance over time. Many sleep-related parenting behaviors are potentially modifiable through evidence-based interventions (e.g., extinction strategies, positive bedtime routines), especially as families move into maintenance and off treatment. In particular, parents of children with cancer may benefit from learning adaptive behavioral strategies to promote healthy sleep in their child and problem-solving strategies to identify and address barriers to implementing behavioral sleep strategies (e.g., parental distress). Finally, children with cancer and their parents may benefit from learning skills to cope with strong emotions during or following active cancer treatment as it may additionally improve sleep quality in children with cancer.

Conclusion

The current study highlights the importance of sleep-related parent behaviors on child sleep disruptions in children with pediatric cancer in various stages of treatment (active, maintenance, and off treatment). We identify accommodating parental behaviors, child and parent psychological factors, and environmental factors that contribute to the challenge of improving children's sleep within this population. Current findings lay the groundwork for future research to better understand and address sleep disturbances in children with cancer, with the long-term goal of improving sleep in children with cancer and their families.

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