

Gaps in Parental Understanding of Sleep Disturbances During Maintenance Therapy for Pediatric Acute Lymphoblastic Leukemia

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Abstract

Background: Acute lymphoblastic leukemia (ALL) is the most common cancer in childhood, with survival rates approaching 90%. Sleep disturbance is common among ALL patients, often developing during the initial stages of chemotherapy treatment. While there have been significant efforts to understand and intervene in this issue during survivorship, there is far less research on children who are actively receiving treatment. In the current study, we sought to better understand the parent's experience in the sleep domain during maintenance therapy, including their perceptions of how their child's medical team had managed sleep disturbances, and recommendations for how to improve sleep management. **Method:** Fifteen parents of pediatric ALL patients (aged 4–12 years) completed semistructured interviews. Interview content was analyzed using a multistage thematic analysis. **Results:** Parents consistently expressed feeling unprepared to manage the sleep disruptions that arose during treatment, often reporting that they did not recall being told this would be a side effect. They were enthusiastic about learning how to improve their child's sleep, though they did not want pharmacotherapeutic interventions or additional medical/psychosocial appointments to address this. **Conclusion:** Despite consistent provider communication on sleep, parents report limited knowledge of the issue. This provides an obvious intervention target to improve treatment-related sleep disturbances. Clear messaging may help direct parents' attention and expectations regarding their child's treatment and potential for disturbed sleep, possibly in the form of a behavioral intervention that empowers parents with information about how to support their child's sleep health while they are undergoing treatment for ALL.

Keywords

sleep health, pediatric cancer patients, acute lymphoblastic leukemia, maintenance therapy, qualitative interviews, pediatric cancer, leukemia, symptoms, qualitative research

Introduction

Acute lymphoblastic leukemia (ALL) is the most common cancer in childhood (Siegel et al., 2022). Approximately 3,000 children are diagnosed with ALL in the United States annually. As 5-year survival rates for childhood ALL currently approach 90% (Bonaventure et al., 2017), interventions to reduce the long-term morbidity of therapy and to support families in managing both the acute toxicities and late effects of therapy are paramount (Landier et al., 2015).

Sleep disturbance is one of the most common challenging symptoms for pediatric cancer patients, both during and following treatment. These issues often develop during the intense initial stages of chemotherapy treatment (Steur, Kaspers, et al., 2020), exacerbated by a

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hospital environment and medical procedures that are not conducive to good sleep (Fidler et al., 2022; Lee et al., 2017). For children with ALL whose chemotherapy treatment lasts for 2 to 3 years, their sleep often continues to suffer throughout therapy due to chemotherapy regimens that include pulsed administration of glucocorticoids (particularly dexamethasone) that are highly disruptive to children's sleep/wake patterns (Daniel, Li, et al., 2016; Hinds et al., 2007; Matthews et al., 2014; Rogers et al., 2014; Steur, Grootenhuis, et al., 2020). One study concluded that 87% of children receiving ALL maintenance therapy had problematic sleep (Zupanec et al., 2010).

Maintenance therapy is a prolonged period of less intensive treatment during which a more routine pattern of daily activities reemerges, and families begin to consider ways in which they can improve their children's quality of life. In relation to sleep, parents play a critical role in potentially attenuating the impact that cancer treatments can have on the child's sleep (Kim et al., 2020; McCarthy et al., 2016). There is consistent evidence that behavioral treatments for pediatric insomnia are effective (Zhou & Owens, 2016). Yet, despite the high prevalence of disordered sleep among pediatric ALL patients, there has been limited study of the feasibility and efficacy of these evidence-based interventions among pediatric ALL patients, or pediatric cancer patients, in general (Zupanec et al., 2017). Importantly, we are not aware of any intervention tailored specifically to the needs of pediatric ALL patients. Tailoring intervention content to the needs of ALL patients is essential as standard behavioral approaches to treating pediatric insomnia do not provide guidance on issues fundamental to why a child cannot sleep (e.g., pulsed corticosteroid chemotherapy), nor do they help parents recognize that while some of the coping strategies (e.g., cosleeping) implemented during a child's cancer treatment may be helpful to alleviate immediate challenges, these behaviors often reinforce a child's sleep disturbance in survivorship (Daniel, Schwartz, et al., 2016).

To address this clear gap in the literature, we sought to better understand their child's sleep during maintenance therapy, how sleep disturbances had been managed by the medical team, and what recommendations parents had for improving how sleep is managed by the multidisciplinary medical team for future families by conducting semistructured interviews with parents of pediatric ALL patients receiving maintenance chemotherapy.

Method

This was a single-center study that enrolled children at Dana-Farber/Boston Children's Cancer and Blood Disorders Center who were receiving chemotherapy on the Dana-Farber Cancer Institute (DFCI) ALL

Consortium phase III randomized clinical trial 16-001 (clinicaltrials.gov ID: NCT03020030). DFCI 16-001 enrolled children with de novo ALL aged 1 to <22 years from 2016 to 2022 at eight participating U.S. and Canadian centers. Chemotherapy treatment on DFCI 16-001 includes approximately 1 month of inpatient induction chemotherapy to induce leukemia remission, followed by 2 years of outpatient chemotherapy. The maintenance phase of therapy includes 1 year of repeating, every 3-week cycles consisting of oral pulsed dexamethasone on days 1 to 5 of each cycle, oral 6-mercaptopurine on days 1 to 14 of each cycle, and IV methotrexate on days 1, 8, and 15 of each cycle.

Sample

Patients were eligible to participate if the following criteria were met: (a) de novo ALL enrolled on DFCI 16-001, (b) in the maintenance phase of chemotherapy and had completed at least two cycles of maintenance, (c) child aged 4 to 12 years, and (d) English-speaking primary caregiver (parent/guardian). Patients from low-socioeconomic status (SES) households, defined as household income <200% Federal Poverty Level (FPL) or the presence of at least one household material hardship (HMH; food, housing, utility, or transportation insecurity), were intentionally oversampled as children of lower SES are at elevated risk for sleep impairments (more frequent sleep/wake interruptions; Buckhalt et al., 2007), dysfunctional sleep patterns (Marco et al., 2012), less total sleep (Peña et al., 2016), and may be underrepresented in research (Scheurer et al., 2018). Between May 2021 and April 2022, 18 eligible parents were approached for participation; 17 (94%) consented to participation of whom 15 contributed evaluable data to form the analytic cohort.

Procedure

Study staff obtained oncology provider permission to approach eligible patients. Parents/guardians of eligible patients were approached by study staff while in the outpatient oncology clinic. The details of the study were explained to the parent/guardian and participants provided verbal consent/assent. Participating parents/guardians were instructed to maintain a sleep diary for their child to document their sleep patterns over a 3-week cycle of maintenance chemotherapy. The sleep diary was completed and then used as a starting point for discussion during a semistructured interview with the Principal Investigator (ESZ). Families received a \$15 Amazon gift card as appreciation for interview participation. As the primary aim of this study was exploratory, enrollment ceased when additional interviews (data) did not lead to any new emergent themes in the conversations

(Hennink et al., 2017). The decision to seek thematic code saturation was made as the goal of this study was to first understand the breadth of family experiences in the context of sleep and how we could better support them (Saunders et al., 2018). Study procedures were approved by the Institutional Review Board of the DFCL.

Analytic Plan

Study investigators (ESZ and KB) drafted a semistructured interview guide that was reviewed by a qualitative methodologist for completeness and comprehensibility. Sample questions from the interview include:

1. What do you see as being the most important sleep problems for children and families during treatment?
2. Have you implemented any strategies specifically to try and help your child's sleep?
3. As a parent, what kind of resources would you like to have to help with your child's sleep?

A single investigator with qualitative interview experience (ESZ) conducted the interviews, which were recorded, transcribed, and then analyzed using a multi-stage thematic analysis that combined prefigured and emergent codes (Kiger & Varpio, 2020). The initial coding framework structure was developed based on literature reviews of sleep health in pediatric ALL patients and the investigators' clinical experience. The finalized codebook was then applied to transcripts, with the coding structure refined throughout data collection to capture additional emerging themes. Once the coding structure was finalized, all transcripts were recoded using the final version of the coding structure. Subsequently, a review of the coded data was performed to identify overarching connections between the most salient codes. Finally, we focused on identifying key patterns, concepts, contexts, and themes within our data to characterize the key elements of the child's sleep during maintenance therapy, how these issues had been managed by his/her medical team, and what recommendations parents had for improving how sleep management. NVivo software was used to assist transcript coding, following COREQ guidelines (Supplemental Appendix A).

Results

Study patients were a majority female ($n = 9$; 60%), White ($n = 13$; 87%), and non-Hispanic ($n = 14$; 93%), and a mean of 5.8 years ($SD = 1.4$; Table 1). Nearly half of the children lived in a poverty-exposed household (either low-income [$<200\%$ FPL] or at least one domain of HMH; $n = 7$; 47%). At the time of their parent's study interview, patients were a mean of 1.5 years post-ALL diagnosis, and on average 8.3 months into

Table 1 Child and Parent Demographics and Characteristics ($N = 15$)

Child characteristics	<i>M</i>	<i>SD</i>	<i>n</i>	%
Age at enrollment (years)	5.8	1.4		
Gender				
Male			6	40
Female			9	60
Race				
Black			1	7
White			13	87
Asian			1	7
American Indian/Alaskan Native			0	0
Native Hawaiian or other Pacific Islander			0	0
Ethnicity				
Hispanic			1	7
Non-Hispanic			14	93
Months since remission	16.1	5.2		
Months since the start of maintenance therapy	8.3	5.2		
Parent characteristics			<i>n</i>	%
Marital status				
Married			12	80
Single/widowed/separated			3	20
Education				
High school or less			2	13
Trade/some college/college/postgrad			13	87
Poverty exposed			7	47
Household material hardship			2	13
Low-income			1	7
Both HMH and low-income			4	27

maintenance therapy. Parents were mostly married ($n = 12$; 80%).

Overall, parents described feeling insufficiently prepared for managing sleep disturbances during maintenance treatment. Below, and in Table 2, key themes and corresponding subthemes are presented, along with exemplar quotes.

Parent–Provider Communication Gaps

Parents recognized that chemotherapy consistently impacted their child's sleep. This was primarily driven by the 5 days of pulsed dexamethasone, with sleep during the first week being notably worse than in weeks two and three of each chemotherapy cycle. As a consequence, parents report that they may accommodate their child's sleep in certain ways, such as allowing them to take a daytime nap. Exemplar quote highlighting the predictable pattern of impact:

the first week of treatment he is drowsy, I have to keep him awake when he is at school ... by the third day, he will even out and won't wake up angry.

Table 2 Key Themes and Exemplar Quotes Related to Sleep Health in Pediatric Patients With Acute Lymphoblastic Leukemia

Theme	Subtheme	Exemplar quotes	Number of times referenced
Parent-provider communication gaps	Predictable pattern of impact	<ul style="list-style-type: none"> • ID01 “the first week of treatment he is drowsy, I have to keep him awake when he is at school ... by the third day, he will even out and won’t wake up angry.” • ID05 “during her dex week she wants us to put her to bed rather than going to bed herself.” • ID10 “it doesn’t kick in until 2 days after, then he doesn’t sleep for 3 nights.” • ID11 “it is the first 4–5 days after steroids.” • ID12 “it is a wave, week 1 is bad sleep, week 2 feels like the sleep is better and their personality comes back, week 3 they continue to sleep better but they are fatigued as they recover.” • ID13 “during her steroid week, she will take a nap every day which causes her to stay up later at night.” 	12
	Families are unprepared	<ul style="list-style-type: none"> • ID01 “we have not been given any information about sleep.” • ID03 “the doctors and nurses gave us this list of possible side effects, but there is no resolution ... finding out more information is kind of just me and my husband bringing it up.” • ID11 “no one said anything about how tired she would be and the naps, I wish someone had told us.” • ID13 “sleep was never something we talked about through treatment ... they should tell us about the importance of it.” • ID16 “no one mentioned it, I had to bring it up and they were like ‘oh was she on steroids when she kept waking up?’” 	15
	Information that is clear, to the point, and actionable should be provided as a tangible resource	<ul style="list-style-type: none"> • ID04 “something for us to look at when we are home.” • ID05 “a meeting is a lot of work.” • ID07 “I am one big ball of ADD, the chances of me remembering anything are slim, I need something I can hold on to and look at when needed.” • ID08 “I would want information to educate myself ... I am on a computer every day, that would be helpful for a lot of people.” • ID11 “I consider myself an older generation, I like things I can print out and hang on the fridge.” • ID12 “if I don’t have something in my hands I will forget it.” • ID17 “as parents, we get a lot of different messages, there is just so much information to process ... it needs to be on one page, like a plan.” 	11

(continued)

Table 2 (continued)

Theme	Subtheme	Exemplar quotes	Number of times referenced
Deficits in parent knowledge about sleep	Normalize the experience	<ul style="list-style-type: none"> • ID10 “this must happen to so many parents ... I made the mistake of going in there and laying down with him to get him back to sleep, you want to be there to comfort them, so that he knows that he will be okay, it is hard to say no because of everything he is going through.” • ID12 “warn us to be mentally aware this might be happening and that it is okay for it to be happening, say ‘hey you can expect this, don’t panic.’” 	8
	More in-depth information is needed	<ul style="list-style-type: none"> • ID02 “they mentioned you can try a warm bath or a cup of warm milk, these things I already thought of by myself.” • ID03 “I want information ... more insight as opposed to just telling someone this is normal.” • ID07 “there were heart palpitations on steroids and it made sleep harder ... we worked to relax before bed.” • ID08 “I want to be educated about sleep, I want to learn different techniques, things we can do that are more than standard information.” • ID13 “let families know how different medications can impact their sleep ... methotrexate makes her tired, and she feels fatigued the second day and will nap.” • ID14 “the vincristine made her constipated, she could not sleep at night because her tummy hurt.” 	9
	Parent recommendations	<ul style="list-style-type: none"> • ID01 “keep the pillow cases washed, blankets washed ... you have to keep things comfortable ... customize it to how they sleep, there is trial and error.” • ID04 “try to do as much prep work as you can ahead of time ... we have to give him fluids at night and he urinated through his pull-ups, so you have to plan to restrict fluid before bed ... we make sure he is on a bed pad and put clothes out ahead of time, and try to get him changed as fast as we can in the middle of the night when he wets himself.” • ID07 “I would suggest keeping a routine, even on the nights it seems hard, it might mean getting creative.” • ID11 “she was given a sleep mask by her Girl Scout troop, it was a lifesaver for her in the hospital, so she uses it at home now whenever has trouble sleeping.” • ID12 “routine, making everything a routine has helped, this is a grind and you have to take it one 3 week cycle at a time ... to help 	8

(continued)

Table 2 (continued)

Theme	Subtheme	Exemplar quotes	Number of times referenced
		we made a laminated schedule that could be checked off.”	
		• ID14 “families need to plan and divide up responsibilities ahead of time so they don’t have to decide in the middle of the night: it is called deciding before the deadline.”	
		• ID16 “the uncertainty of her treatments made her need me more, it is like having a newborn, don’t pack your days during weeks with a steroid burst, plan to be lacking sleep.”	
	Avoiding more medications	• ID02 “I felt like her body was taking in so much, I did not want to add anything to it, like medications.”	4
		• ID05 “they kept suggesting melatonin ... I don’t want to try it.”	
		• ID08 “I hate that she is on clonidine.”	

Despite the predictability (based on chemotherapy exposure) and prevalence of these sleep issues, they either did not recall being provided any information about sleep disruptions as a side effect of chemotherapy, or viewed any information communicated about sleep as being lost amidst the significant amount of health information that they had to process. While many participants spoke highly of their child’s oncology team and the extent of their communication about possible side effects of treatment, none believed that they were sufficiently prepared to deal with sleep disruptions that they attributed to ALL therapy. Exemplar quote highlighting that families are unprepared: “sleep was never something we talked about through treatment ... they should tell us about the importance of it.”

Consistently, participants expressed both a desire for more information about sleep health and a request that such information does *not* require an additional medical appointment. Several participants requested that this information be as direct as possible, with an action plan to concretely guide families in the event of sleep impairments. It was suggested that such information could be provided in a summary format available for them to refer to “on the fridge” at home when needed. Three participants reported that having online resources could be beneficial. Exemplar quote highlighting parent information needs: “I would want information to educate myself ... I am on a computer every day, that would be helpful for a lot of people.”

Deficits in Parent Knowledge About Sleep

Participants expressed a desire for their oncology team to normalize how common sleep disturbances are for children during maintenance treatment. They reported

feeling overwhelmed with managing all of the issues that may arise for their child during treatment and wanted to be reassured that they were not doing anything to worsen the situation. Exemplar quote highlighting the parent’s desires to normalize the experience: “warn us to be mentally aware this might be happening and that it is okay for it to be happening.”

In addition, parents indicated that when it came to sleep, the information they recalled being provided was inadequate, focusing primarily on information that they believe they could have read online. They expressed a desire for information that was more in-depth and evidence-based, including more clarity on the sleep-impairing side effects of the chemotherapy agents administered during treatment. Exemplar quote highlighting the parent’s wishes for more in-depth information: “they mentioned you can try a warm bath or a cup of warm milk, these things I already thought of by myself.”

Parents provided a number of recommendations for strategies that they had discovered were helpful. They benefited significantly from creating a plan for their daily activities that was mindful of their child’s treatment-related side effects, and committing to sticking to that plan, even when it was difficult to do so in the moment. Additional recommendations were made by parents to ensure that the child’s sleep environment was as comfortable as possible, with specific examples related to the child’s bedding/pillows. Exemplar quote highlighting parent recommendations:

Try to do as much prep work as you can ahead of time ... we have to give him fluids at night and he urinated through his pull-ups ... we make sure he is on a bed pad and put clothes out ahead of time, and try to get

him changed as fast as we can in the middle of the night when he wets himself.

In their discussion of nonbehavioral strategies, participants expressed a desire to avoid additional medications (prescribed or over the counter) to manage their child's sleep. Because of the number of other medications that parents saw their child take, they felt that it was important to avoid nonmedically necessary medications as best as possible. Exemplar quote highlighting parents' desires to avoid more medications: "I felt like her body was taking in so much, I did not want to add anything to it, like medications."

Discussion

In our qualitative study seeking to better understand the sleep-related experiences of families of children receiving maintenance therapy for ALL, parents identified modifiable issues in how treatment-associated disruptions to sleep health are communicated and managed. All families expressed feeling unprepared to manage the sleep disruptions that arose during treatment, often reporting that they did not recall this side effect being mentioned by their medical team. Families were consistently enthusiastic about learning how to improve their child's sleep health and provided clear suggestions on how to improve communication and care delivery informed by their experiences.

It is widely recognized that steroids during chemotherapy are a major contributor to poor sleep, with patterns of disruption that are consistent with our findings (Daniel, Li, et al., 2016; van Hulst et al., 2021). At our institution, oncologists routinely discuss the expected side effects of each chemotherapy agent at the time of consent to initial therapy, including sleep disruptions related to dexamethasone. Parents are additionally provided with standardized teaching sheets for each chemotherapy agent, which include information about common side effects. During the year of maintenance therapy, anticipated side effects and both pharmacologic and nonpharmacologic management strategies are discussed at the start of repeating chemotherapy cycles in the outpatient clinic by the oncology provider as well as a nurse navigator. Notably, standard practice does not include repeat provision of written information to be referenced at home by families. The fact that parents consistently reported having difficulty recalling provider discussions on the subject of sleep, or retention of information in this domain, provides an obvious target for healthcare delivery intervention strategies to improve family understanding and management of this distressing chemotherapy side effect.

This gap is one that parents are eager to fill. Similar to adult cancer populations, patients and their families want to learn more about how to improve their sleep (Zhou et al., 2019). Further, parents of pediatric cancer patients

are experienced as healthcare advocates for their children (Carpenter et al., 1992; Sisk et al., 2021), so it is not surprising that they are keen to learn more about sleep. Prior literature has demonstrated that families are often aware their behaviors may be effective at addressing short-term challenges (e.g., cosleeping during treatment to reduce nighttime wakings) but can cause long-term problems (e.g., the child continues to cosleep several years after therapy has ended; Kim et al., 2020). However, they lack the knowledge and toolkit to be able to balance their short-term needs with their long-term goals.

With respect to receiving further information on improving their child's sleep, it was clear that families were suffering from treatment fatigue, which has been documented in other studies with similar populations (Fletcher, 2010). Despite acknowledging the importance of sleep, parents expressed little enthusiasm to take on additional appointments with clinicians to discuss how to improve their child's sleep. In multiple clinical settings, there are increasing efforts to develop brief interventions that offer efficient means of addressing sleep problems (Erickson et al., 2005; Zhou et al., 2020). In our study, families desired materials that were to the point and provided clear directions as to actionable steps to follow. This request for information delivery format is similar to the well-established general pediatric management of patients with asthma. Asthma action plans are simple, individualized worksheets that provide caregivers with instructions for triaging symptoms into zones for action with concrete steps to take to address asthma symptoms and prevent symptoms from worsening (Ring et al., 2011). This approach to symptom education and management for asthma is highly prevalent (over 50% of children with asthma are provided with one; Simon & Akinbami, 2016) and effective. When used, asthma action plans significantly reduce acute care visits and improve asthma symptom scores (Zemek et al., 2008).

Families were clear in wanting more information than the sleep hygiene tips they were typically provided when expressing concern about their child's sleep. Sleep hygiene is typically comprised of strategies that encourage good sleep, such as avoiding electronics before bedtime. While sleep hygiene is the most commonly administered nonpharmacological treatment for insomnia, it has been proven to be ineffective as a monotherapy (Stepanski & Wyatt, 2003) and was the only behavioral therapy that the American Academy of Sleep Medicine advised against initiating as a monotherapy (Edinger et al., 2021). The effective strategies that parents shared in our interviews resembled the structured approaches common in behavioral treatments for pediatric insomnia used for typically developing children (Zhou & Owens, 2016). For example, one important recommendation was around the importance of making, and consistently keeping to, a plan for their child's sleep. Families of

pediatric ALL patients are well-versed in following a routine when it comes to their child's medical treatments—including 2 years of oral chemotherapy administration at home; applying an analogous structured approach to sleep management may thus be both familiar and effective.

We acknowledge some limitations of this work. This study involved participants who were willing to participate in a study about sleep during maintenance treatment. Thus, selection bias, including parents with greater available time or bandwidth, may influence our results. Next, we focused on a younger patient population aged 4 to 12 years. As sleep changes during normal development, and some research suggests that the sleep of older children may be differentially affected by steroid treatments (van Hulst et al., 2021), our findings may not apply to older patients with ALL. Finally, while we successfully recruited patients from a diverse socioeconomic background—including a cohort with over half of the participants living in a low-income household—the racial/ethnic composition of our sample was predominantly non-Hispanic White, likely due to enrollment of an exclusively English-speaking cohort. Cancer caregiving challenges are magnified by factors such as poverty, substandard access to healthcare, and language/cultural barriers (Alfano et al., 2019; Goodheart, 2012), which may impact their ability and bandwidth to learn more about how to help their child sleep better.

Implications for Nursing Practice and Research

Bedside nurses and advanced practice nurses play critical roles in managing the side effects of treatment for pediatric ALL patients. At many hospitals, the nursing staff, rather than medical oncologists, are the providers who are primarily responsible for the day-to-day support of families as they seek to understand and help the patient cope with the sequelae of maintenance therapy. As symptoms experienced by children with cancer rarely occur in isolation, nursing staff who encounter issues related to fatigue, pain, and/or depression should consider evaluation for possible sleep disturbances (Rodgers et al., 2016). If poor sleep arises, oncology nurse navigators could offer psychoeducation and direct patients and families to evidence-based resources to help children with ALL sleep better during their treatments.

Conclusion

Families of pediatric ALL patients report they are not “hearing” the message that their medical providers are sharing about treatment-related sleep disruptions during cancer treatment. Given how prevalent sleep disturbances are for this population, it is imperative that we improve

how this vital information is communicated. Nursing staff will likely play an important role in supporting families in this domain. We encourage researchers to continue exploring how sleep may be differentially impacted in families of ALL patients from varying socioeconomic backgrounds.

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Supplemental material

Supplemental material for this article is available online.

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