Published in final edited form as:

J Pediatr Nurs. 2014 ; 29(5): 410–421. doi:10.1016/j.pedn.2014.01.002.

Exploring Sleep-Wake Experiences of Mothers during Maintenance Therapy for Their Child's Acute Lymphoblastic Leukemia

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Abstract

A qualitative study was designed to explore sleep-wake experience of mothers of children in maintenance treatment for Acute Lymphocytic Leukemia. Interviews were conducted with 20 participants using open-ended, semi-structured questions and were transcribed verbatim. Two main themes emerged: "It's a whole new cancer world" and "I don't remember what it's like to have sleep." Mothers experience difficulty sleeping during their children's treatment, and expressed several serious issues. Although the mothers were able to employ various mechanisms to address sleep deprivation and disruption, interventions such as social support, journaling, spiritual guidance, and/or self-talk may be most beneficial.

Keywords

Acute Lymphocytic Leukemia; ALL; Sleep; Stress; Maintenance Treatment

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Presentation of preliminary analysis: Matthews, E.E., Neu, M., Laudenslager, M., Garrington, T., King, N. (June, 2011). Mother-Child Sleep Patterns During Maintenance Therapy for Acute Lymphocytic Leukemia (ALL). Poster presentation for the American Academy of Sleep Medicine and Sleep Research: Sleep. Minneapolis, MN.

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Background

Cancer is the second most common cause of death among children between the ages of one and fourteen in the United States. Leukemia accounts for approximately 25% of childhood cancer and acute lymphoblastic leukemia (ALL) comprises approximately 75 % of childhood leukemia cases. Current five-year survival rate for children with ALL is approximately 87 % (Bertolone & Landier, 2011; Siegel, Naishadham, D., & Jemal, A., 2013). Relapse-free survival is highest in children between ages one and ten years at diagnosis who have a total white blood cell count of less than 50,000 (Bertolone & Landier, 2011; Pieters and Carroll, 2008). If relapse occurs, it is most common in the first year off therapy but may occur as late as three years after therapy completion (Furlong et al, 2012).

Treatment for ALL ranges from two and a half for girls to three years for boys. The first six to eight months of treatment are intensive. As shown in Table 1, after the initial hospitalization for diagnosis and stabilization, the child must be brought to the clinic weekly for a multi-phased plan of oral, intravenous (IV), and intrathecal chemotherapy (Zupanec & Tomlinson, 2010). Parents face: their children's loss of body hair, potential infection resulting from bone marrow suppression, weight gain from increased appetite and fluid retention, insomnia, and adjustment to new routines and limitations in daily activities imposed by treatment. Parents must also prepare for possible late effects of therapy, such as cardiac toxicity, osteopenia/osteonecrosis, and neurocognitive/psychosocial sequelae (Furlong et al, 2012; Hobbie, Carlson, Harvey, Ruccione & Moore, 2011; Hooke, Garwick and Gross, 2011; Whitsett, Gudmundsdottir, Davies, McCarthy, & Friedman, 2008).

The initial, intensive months of treatment are followed by up to three years of maintenance therapy. "Maintenance" entails monthly clinic/hospital visits and less intensive chemotherapy, and bursts or "pulses" of steroid therapy (Pieters & Carroll, 2008). Most children resume normal activities during maintenance because they experience fewer serious side effects and lower risk of infection.

Sleep disturbance is a common and distressing problem for parents of children with leukemia and other cancers. Sufficient sleep is necessary for health and well-being of these parents (Mindell & Owens, 2010). Dealing with routine responsibilities, work, and school with treatment-related duties such as hospital visits and medication schedules tax logistical and emotional capacities of most parents of chronically ill children (Norberg & Green, 2007). This strain tremendously disturbs parents' sleep. For instance, tiredness and exhaustion also were reported by parents of children with mild to severe atopic dermatitis (Al Robaee & Shahzad, 2010). Maternal-child sleep onset ($r = .70$), and number of night awakenings ($r = .62$) are strongly related so mothers' sleep is even influenced when children have undefined sleep problems (Kalek et al., 2012). Compared to mothers of children with typical sleep patterns, mothers of children with sleep disturbance reported significantly poorer sleep quality, and more negative mood, parenting stress, fatigue, and daytime sleepiness (Meltzer & Mindell, 2007). Other consequences of sleep deprivation in adults are poorer performance in cognitive functioning (e.g., alertness, memory, attention, and learning ability), reduced dietary restraint, weight gain, and decreased driving ability leading to

motor vehicle accidents (Kahol et al., 2008; Markwald et al., 2013; Pizza, Contardi, Mondini, & Cirignotta, 2012).

Chronic stress and depression are associated with sleep quality and sleep deprivation is a contributor to poor adaptation to stressful situations and depression (Boelen & Lancee, 2013; Germain, 2013). McGrath and Philips (2008) reported parental stress due to their child's invasive treatment (e.g., toxicity of the chemotherapeutic drugs, injections, intravenous access, and spinal taps). Other factors associated with stress in mothers of children with cancer include appraisal of the child's distress, ability to cope with the illness, decreased family cohesion, uncertainty about the future, and change in daily role functioning (Rodriguez et al., 2011; Sloper, 2000). Fear of relapse or possible sequelae of cancer, and symptoms of depression (sadness, hopelessness, guilt or helplessness also have been reported (Norberg & Boman, 2008; Vrijmoet-Wiersma et al., 2008). In one study, 38% of mothers of children with cancer reported high to moderate stress and negative mood (Steele, Dreyer, & Phipps, 2004), while chronic stress as evidenced by intrusive thoughts, physiologic arousal, and avoidance was found in 68% of mothers during their child's cancer treatment (Kazak, Boevig, Alderfer, Hwang, & Reilly, 2005). Stress and depression in mothers of children with varied cancer diagnoses in the aforementioned studies were present months to several years after diagnosis.

Three qualitative studies addressed emotional states, striving for normality, and adaptation of parents of children with cancer. McGrath (2002) examined perspectives of 12 mothers and 4 fathers during initial stages of diagnosis and treatment for their child's ALL. Parent's insights suggest this period as highly stressful and overwhelming. Emotional states were expressed as: stress of uncertainty, shock of diagnosis, and feelings of being trapped in a difficult emotional roller-coaster ride (McGrath, 2002). In a study of 32 mothers of children recently diagnosed with ALL, Earle and colleagues (2006) interviewed mothers during the initial-treatment, maintenance, and near-conclusion phases of treatment. Mothers described struggling to maintain a normal life (as it was before the cancer diagnosis) for their family throughout the treatment period (Earle, Clarke, Eiser, & Sheppard, 2006). Fletcher (2011) described the experience of nine mothers of children with cancer, during and after diagnosis and treatment. Although four of the children died, mothers described benefits that emerged from the experience: 1) the importance of support from family, friends and employers; 2) discovering the opportunity to give something back to society ("when life gives you lemons"), and 3) learning to be positive in challenging circumstances ("finding the silver lining"). Taken together, these studies suggest an emotionally charged period during which parents struggle to adapt to physical and psychological demands.

Researchers who quantitatively studied sleep in parents of children with ALL found a higher number of nighttime awakenings in children with ALL ($n = 9$) than in healthy children. Their parents also had increased awakenings. The authors suggested that worry, changes in family life, and corticosteroids contributed to these sleep problems (Gedaly-Duff, Lee, Nail, Nicholson, & Johnson, 2006). Corticosteroids, a cornerstone of ALL maintenance, can result in distressing behavior such as belligerence and aggressiveness (McGrath & Rawson-Huff, 2010) and may alter sleep structure, leading to arousal and sleeplessness in children with ALL (Vgontzas & Chrousos, 2002).

Findings of a descriptive study of children aged 4–18 years ($n = 62$) in maintenance for ALL showed that sleep disturbance was pervasive in children and parents (Zupanec, Jones, & Stremler, 2010). Children's sleep disruption was associated with medication schedules and side effects, especially with dexamethasone. Parents facilitated their children's sleep by establishing a predictable routine, allowing them to sleep with someone, providing comforting activities (e.g., bath, song, story, stuffed animal), and furnishing bedtime snacks (Zupanec, et al., 2010).

Sleep deprivation in the general adult population has been shown to strongly impair human functioning including cognitive and motor performance (Pilcher & Huttcutt, 1996), and negatively affect anxiety, pain, fatigue, behavior, and mood (Institute of Medicine (US) Committee on Sleep Medicine and Research, 2006; Smaldone, Honig & Byrne, 2007). Even with partial sleep deprivation, these factors can impact daily functioning and impair performance in work, social, and parenting roles. Recent evidence suggests the cumulative long-term effects of sleep loss is negatively associated with several serious health issues, including an increased risk of obesity in adults and children, diabetes, cardiovascular disease and hypertension, anxiety symptoms, depressed mood, and alcohol use (Institute of Medicine (US) Committee on Sleep Medicine and Research, 2006). Moreover, sleep loss and disruption of the circadian system has been hypothesized to increase cancer risk because of disruption of the molecular mechanisms generating circadian rhythms or because of disruption of substances controlled by the circadian clock such as melatonin levels (Schernhammer et al., 2006; Sigurdardottir, et al., 2012; Straif et al., 2007).

Sleep deprivation in parents caring for a child diagnosed with cancer is a strong predictor of parents' psychological and physical well-being (Gedaly-Duff et al., 2006; Klassen et al., 2011). In a study of parental sleep experiences on a pediatric oncology unit, McLoone and colleagues reported that parents of children with cancer slept 5.7 hours ($SD = 1.8$) on average compared to control parents who reported sleeping 7.0 hours at home ($SD = 1.4$; $t = 4.3$, $p < 0.001$) (McLoone, Wakefield, Yoong, & Cohn., 2013). Parents described how lack of sleep impacted the care and emotional support they were able to give their children through their cancer treatment (McLoone et al, 2013).

The potential negative impact of impaired sleep in parents of children with ALL, and the paucity of studies examining sleep disturbances in mothers of children with ALL were the impetus for the current investigation. Exploring the coping measures that the mothers use to attain sleep could guide implementation or development of interventions to promote sleep. The aim of this study was to explore maternal perception of their sleep quality during maintenance treatment for their child's ALL, and to discover what sleep strategies mothers used to attain sleep, and/or cope with lack of sleep.

Research Methodology

This study was planned in conjunction with the clinical staff in the Oncology/Hematology unit, the site for recruitment. The judgment of the physicians and nurses in that unit was that maternal sleep definitely was disrupted during intense initial phases of treatment when the child was hospitalized or required frequent visits to the hospital. Because survival rate is

high for children with ALL and because the maintenance is less intense than initial treatment, the clinical and research team sought evidence of the frequency and severity of sleep disruption during this phase of treatment.

A qualitative descriptive approach with thematic analysis was used to allow mothers to express their emotions, feelings, and attitudes by relating their experiences in their own words (Vaismoradi, Turunen, & Bondas, 2013). “Thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within data (Braun & Clarke, 2006, pp79).” Thematic analysis is described as a flexible method in which identification of common threads that are recognized across a set of interviews occurs. Subtle shades of meaning or feeling can be discovered from the accounts of the participants (Braun & Clarke, 2006; Vaismoradi et al., 2013).

Sample

Mothers of children with ALL comprised the purposive sample. In this initial exploration, we enrolled only mothers for two reasons: 1) in the majority of families, mothers are the child’s primary caregivers and would be most affected by the child’s night awakenings and 2) to control for gender-related sleep differences. Mothers were eligible if they were the primary caregivers of the children, spoke and wrote English, and had children between three and twelve years of age who were receiving maintenance therapy and had no other concurrent illness or disability. Mothers were not eligible if they had a serious, unstable physical or mental illness.

Approval was obtained from the university Institutional Review Board and mothers signed informed consent. Then clinicians in the Oncology/Hematology unit of a metropolitan children’s hospital approached and screened potential participants. Brochures also were placed in the children’s hospital clinical areas. Mothers were compensated \$40 in recognition of their time and effort.

Data Collection

The principal investigators (PIs; MN, EM) and two research assistants, experienced in interviewing, used open-ended, semi-structured questions during in-depth, face-to-face interviews. Mothers were asked to describe their sleep during their children’s maintenance treatment. Researchers asked probing questions about the mothers’ sleep habits before the ALL diagnosis and coping mechanisms to manage sleep deprivation or induce sleep if mothers did not spontaneously discuss these topics. The researcher also asked clarifying questions to ensure comprehension of the mother’s statements and made field notes about the environment, emotions during the interview, and non-verbal behaviors.

Analysis

Interviews were transcribed verbatim by a paid, independent transcriptionist and the investigators individually read the transcripts several times to immerse themselves in the data. The PIs adopted a theoretical approach (Braun & Clarke, 2006) and focused on comments of the mothers relating to maternal sleep, factors mentioned that would interfere with quality sleep, and methods mothers used to obtain sleep or cope with lack of sleep.

Because the data set was relatively small and the researchers wanted to feel closely connected to the data, the researchers chose not to use qualitative data analysis software, and coded the interviews manually.

Each PI bracketed sections of each interview and labeled it with a code word that represented the meaning of the section. They each compiled a table of themes with statements made by the participants that supported each theme. Choice of themes or subthemes were based on whether a statement captured something of importance to the research question rather than the frequency of phrases or words (Braun and Clarke, 2008; Vaismoradi, et al., 2013). Initially, the study team met frequently to discuss interpretations of ongoing interviews and any unexpected information. In the few instances where there were differences, discussion continued until agreement was obtained. During this stage, closely connected themes were combined. Two themes were agreed upon that told the story of these mothers. The subthemes that comprised each theme were re-examined by both PIs as they compared and discussed interpretations and categories. The subthemes that best described the spirit of each theme and were consistent with the narrative of the mothers were identified.

Scientific Rigor—Methods to insure rigor followed suggestions of Lincoln & Guba (1985). Credibility was addressed by the ongoing discussion of the two investigators about the emerging themes. Interviewers summarized comments of the participants during the interviews and elicited feedback (member checking). Use of the mother's own words during data analysis helped preserve perspectives of the participants. Investigators addressed confirmability and dependability with an electronic audit trail that included raw data, field notes, and coding rationale. Transferability was strengthened by purposive sampling (Lincoln & Guba, 1985).

Results

Sample Characteristics

Thirty-five mothers of children with ALL were eligible. Twenty mothers agreed to participate in the interviews. Fifteen mothers (75%) were white, nonhispanic and five mothers were Hispanic. Sixteen mothers (80%) were married, two were separated or divorced, and two were never married. Maternal ages ranged from 23 to 49 years ($M = 33.5$). Eight mothers (40%) had at least a 4-year college degree, 4 mothers (20%) had a technical degree, and the remainder completed high school. Five mothers (25%) were employed full-time and three (15%) were employed part-time. Income ranged from less than \$20,000 to \$150,000 per year. Children ranged in age from 3.5 to 12 years ($M = 6.5$). Maintenance treatment was received by eleven children (55%) for 6 months or less; four children (20%) for 7–12 months; and 5 children (25%) for 17 to 24 months, thus, multiple periods of the maintenance treatment were represented.

Themes

Two main themes emerged: (a) “It’s a Whole New Cancer World” and (b) “I Don’t Remember What it’s Like to Have Sleep.” It’s a Whole New Cancer World contained four

sub-themes: (a) Losing Normality, (b) Being Off-Balance/Insecure, (c) Juggling Duties, and (d) Making Transitions. Although the New Cancer World theme did not specifically address maternal sleep, it enhanced understanding of issues that potentially influenced sleep, which led to the second theme, “I Don’t Remember What it’s Like to Have Sleep.” Four subthemes comprised the “I Don’t Remember Sleep” theme: (a) Sleeping Trouble before and after ALL, (b) Child Feeling Sick at Night, (c) Worrying, and (d) Coping with Exhaustion. Table 2 lists the themes and subthemes and maternal comments supporting the subthemes.

Theme 1: “It’s a Whole New Cancer World”

Mothers’ discussion of this theme established a sleep-disturbance context, and suggested that life had been substantially altered by ALL diagnosis and subsequent treatment. One mother aptly framed the situation, “It’s a whole new world again. We went from a normal life to this cancer world and now we’re going back into the regular world, but it’s not exactly cancer free – ‘cause we’ll always have that fear. So we’re going back into a normal world that’s not so normal.”

Losing normality was discussed by more than half of the mothers. Families lost friends and normal social structure soon after diagnosis: “We had a lot of close friends pull away from us. They didn’t know what to say or how to react.” Maintaining friendships was made even more difficult by mothers’ fears of exposing their children to infections, so they did not invite friends to their homes. Normal familial activities also changed: “It’s the simple things. Every weekend we’d go to the movies. ...the amusement park...we did a lot of things and now we don’t.” Because of the inability to take the child out to public places, normal daily scheduling broke down. Everyday activities like shopping had to be done at different times (i.e., late evening). Mothers needed to give thought to who would stay home with the child. As another mother said, “I grieve the loss of our normal life.”

Being off-balance or insecure was comprised of the new experience of being responsible for medication administration, financial difficulties, and the possibility of relapse, and at least one of these issues was mentioned by almost all of the mothers. Mothers revealed challenges of keeping track of medication regime changes, giving medications at “exactly the right times,” and administering potent medications with serious potential side effects. One mother expressed, “It’s scary how you just become immune to the question, ‘You do understand the risks, don’t you?’” Another dimension of being off-balance/insecure was financial. Mothers mentioned threats of job loss because of time taken off work, mortgage foreclosure, or possible relocation if they could not afford house payments. Paying for the child’s care was a prominent concern. Mothers acknowledged that maintenance was preferable to the first months of therapy, but worried that something else, such as relapse, would occur, “I heard about another child relapsing—I know it can happen. The nasty thing will always be in the back of my head.” A mother who had developed diabetes while her child was in maintenance treatment wondered, “What else is going to happen? It’s like waiting for the other shoe to drop.”

Juggling duties was discussed by over half of the mothers and was related to the “being off-balance/insecure” subtheme. The hospital was a regional center for cancer treatment and some families traveled more than an hour one way. Treatment lasted several hours, so a

clinic visit could occupy the entire day. One mother mentioned trips to the emergency department during the night if the child developed a fever or other signs of infection. Although more of a juggling feat during initial therapy, hospital visits remained an issue during maintenance. If the child had siblings, mothers had to schedule their activities around hospital visits. Night time visits to the hospital affected the family's sleep and in turn, next day activities. For mothers who could work at home, night hours may have been the only available time for "catch-up" work.

Making transitions included continuation of early transitions experienced soon after the ALL diagnosis and new transitions during maintenance. For example, alteration of sleeping arrangements began in many families at the onset of initial treatment. Seven mothers described their children as needing someone—sibling or parent—to sleep with them. All manners of sleeping arrangements were described. Sometimes the child's bed was moved to the living area of the house, or mothers stayed with the child until the child went to sleep, or the child slept with the parents. One mother related that both of her children brought blankets into the parents' room and slept on the floor.

Another form of transition involved five mothers' alteration of their work situation. Mothers took a lower paying/part-time job or began working. In one family, the father's income was the lesser of the two, therefore, the mother continued her full-time employment. These transitions were all difficult. One mother commented on how much she wanted to stay home and resume caregiving activities, "To quit my job and be at home would be the best gift in the world. When your baby is sick, he only wants his mom."

A third kind of transition was the children's time off and reentry into school discussed by several mothers. During early phases of treatment, children were unable to attend school. One mother related her child's explanation of her condition to her classmates upon returning to school, "On her first day back to school, she got a great reception from the kids. She was very straight-forward with them, yanked off her hat 'cause everybody was asking why she was wearing a hat. She said, 'so I'm losing my hair,' "and then, you know, question after question from all the kids. She explained it the best she could and just pretty much told them, 'This is who I am, I'm still the same person, and I'm just wonderful.' Another child began transitioned to online schooling during the early treatment phase and continued this schedule. His mother explained, "We don't have to worry about when he sleeps or takes medications."

Loss of friendships or family relationships that occurred during the initial phases of treatment remained lost for a few mothers, "Our friends have backed off." Conversely, another mother described development of new friendships with parents of children with cancer, "We know what they're going through." This mother explained that not only could she receive support from these other parents, but could also give her support to them.

Theme 2: "I Don't Remember What it's Like to Have Sleep"

I Don't Remember Sleep—Whether related to sleeping arrangements, work, school, or friendships, the aforementioned transitions contributed to an unsettling atmosphere that potentially interfered with maternal sleep. The post-ALL diagnosis environment forced

mothers to adapt to new demands. Comments of these mothers illustrated how little they did sleep and how tired they were: “I have not had a good night’s sleep since the diagnosis,” or “I get so tired that I collapse sometimes, or “I don’t remember what it’s like to have sleep.”

Trouble sleeping before, trouble sleeping after was true for some mothers. Typically sleep disturbances before their child was diagnosed with ALL were related to being a light sleeper, physical maladies like back or leg pain, or having young children in the household who were not sleeping through the night. These sleeping difficulties intensified after their child was diagnosed with ALL. Mothers waking to care for infants or young children now awakened even more often to check on the child with ALL, “I had a hard time falling asleep before. I would wake up once. Now, I am *always* checking on him.” One mother described her typical night: “The kids are out of control—really rambunctious—and my husband has left for his night shift. The kids are up 3–4 times before settling. I go to bed at midnight, the baby’s up at 1:30, then my daughter (with ALL) wakes up. The baby wakes up again at 3 AM but everyone is asleep by 4 AM. The baby is up again at 6AM, then it’s time to get up.”

Several mothers compared sleep during maintenance with experiences during the initial treatment, “I sleep better than during the initial treatments. If he’s not sick. I wake up once or twice. If he is sick I wake up a lot with panicky feelings.” Although most mothers discussed sleeping difficulties in terms of lack of sleep, one mother said she slept more than she did before and thought that perhaps she was using “sleep as an escape.”

Children being sick at night was an experience shared by all but three mothers who discussed discomfort that often kept the children and consequently, the mothers awake. Side effects of the medications occurred less often during maintenance, yet could still be severe and disrupt the child’s sleep. One child spent much of the night vomiting after a monthly treatment, “When she throws up we are awake all night, cleaning her up, changing her bedding, and giving her a bath. She still has times when she’s neutropenic and running fevers on top of getting chemo and we have to go to the hospital. When she isn’t doing well, I don’t sleep well.” A mother described her emotional distress knowing that her child was uncomfortable. “It bothers me when he hurts and I lay in bed feeling bad for him.” Children became agitated when on the steroid regimen that occurred every 5 weeks, so during that time they had difficulty sleeping or were hungry at night. “He wakes up in the middle of the night wanting to eat because of the steroids. They make him hungry, hungry, hungry and really, really whiny. He is a different person on the steroids. The rage inside him is unbelievable—like ‘roid rage. When he wants to eat, even if it’s at night, I feed him.”

Worries intensified at night for more than half of the mothers. Mothers worried about giving the medications correctly, “Every time we go back to the hospital, they always ask, ‘Is he off track? Did he have any gaps in his schedule?’ We never want to say that he did cause that kinda slows down his progress.” Some mothers, whose children were in the early months of maintenance, lamented the lack of improvement in their sleep, “I expected change, but nothing has changed. Sometimes I sleep real good, but sometimes I don’t because of what I’m worried about.” Financial worries, the child’s illness, and keeping up with their job or household duties seemed to fester while mothers were trying to sleep: “I worry about how we are going to pay our bills, losing my job or his job, who’s going to take him to the

hospital, did he take his pills, the children's health, things that need repairing, and all the things that need to be done and I do not have the energy to do them." Another mother said, "Things pile up at night. When my time comes and finally the kids are asleep and I'm by myself it's like, "oh crap, now I have to think."

Coping with exhaustion was a necessity for mothers to be able to function and was mentioned by all but three mothers. Consequences of exhaustion were described as being irritable, less patient with their children, sluggish, and less productive than they wished to be. One mother related: "If the kids push my buttons one too many times, I just lose it. The constant nagging gets to me." Other mothers felt more stressed at work after a poor night's sleep or felt that they lacked motivation to accomplish everything they should be doing. A variety of methods to cope with their tiredness were mentioned. Many mothers consumed some form of caffeine, although most stopped drinking caffeinated beverages in the afternoon to improve their likelihood of sleeping at night. To combat impatience, a mother related that she would "pray for patience." Others would "keep moving" to remain awake during the day. Although mothers tried to be positive they sometimes needed to "let loose and cry." One mother strongly advocated asking other for help, "My neighbors pick up my other children from school or buy a prepared dinner from the store if I get too busy or need to take her (ALL child) into the Emergency Department."

Mothers used several other coping mechanisms to attain sleep. Two sleep hygiene measures recommended by the National Sleep Foundation (National Center for Chronic Disease Prevention and Health Promotion, 2013) were routinely used: A strict schedule for going to bed and arising, and avoiding large meals before bedtime. Refraining from caffeine entirely or later in the day also was done. Strict schedules worked for some mothers, who carefully scheduled when to stop drinking caffeine, naps, eating, and going to bed. Mothers did not follow the National Sleep Foundation recommendation to avoid using the bedroom for reading, watching TV, or listening to music. In fact, most mothers applied those techniques to put themselves to sleep in or out of the bedroom. One mother watched television until she was "too sleepy to stay awake. Exercise also was common and ranged from regular exercise routines to household chores such as "scrubbing floors or cleaning closets."

Yoga, meditation, or prayer was used by some mothers to bring about a more positive mood, "I put my life in God's hands. He's taking care of it. He's got it under control. That really eases me." Many mothers mentioned "letting them [husband, relative or friend] help you." These mothers found it helpful to discuss their worries with another person, or to record their feelings in a journal, "I write in my Gratitude Journal every day to help me remember that good things are happening too." Some mothers found that accepting their situation helped them sleep. As one mother summarized, "I cannot control what will happen. I just love my kids and let them know that they're gonna be OK and just ride through it. There's nothing else that you can really do." One mother talked about how she tried to turn the situation into a positive one to improve her mood, "I try not to think, 'why me?' and instead think, 'what am I supposed to learn from this?'"

Discussion

When mothers were asked to describe their sleep during the maintenance phase of treatment, they first related issues that they had experienced during the child's illness ("It's a Whole New Cancer World"), suggesting that those issues were entwined with the mothers' perception of quality of sleep ("I Don't Remember What it's Like to Have Sleep"). Life changes that mothers encountered since the ALL diagnosis seemed to persist into the maintenance phase.

Loss of normality and its attendant lifestyle changes resulted in feelings of grief. Isolation from loss of friends and discontinuation of previously enjoyable family activities destabilized mothers of children with ALL. These findings differed from a Canadian study in which mothers of children with mixed hematologic malignancies, related that they had received tremendous support from friends and employers. Differences may be due to culture, community value system, or the probability that the children in the Canadian study had less-favorable prognoses (Fletcher, 2011). The isolation experienced by mothers in our study resulted in lack of support for many mothers, who also reported feeling "off-balance due to new treatment schedules, new responsibilities to provide potent medications to their children, and uncertainty about their children's recovery. These feelings were potential threats to sleep.

Financial issues were of particular concern to parents. Mothers voiced concerns about lower incomes due to parental job resignation or reduction in hours or employment to meet new familial time demands, but also because of the real fear they might lose their jobs entirely. As a result, parents of children with ALL found that disease-imposed conditions compounded financial problems. McGrath (2002) reported similar findings, but they were limited only to the very early stages of treatment for ALL.

Mothers became adept at juggling activities, similar to findings of Norberg & Green (2007). Juggling family activities, however, often came at the expense of sleep. Mothers were able to re-arrange schedules of family members, but their own work was done at night when they had some time alone.

With the exception of children returning to school, the transitions that began during the initial treatment phases remained. These transitions appeared to unravel normality (e.g., one or several children sleeping with the parents or the interruption of job/school). Some transitions, however, like loss of job may have long-term ramifications. A lost home or preferred job may be difficult to regain. Mothers in a previous study also described difficulty resuming life in terms of fitting into the community as they had before ALL (Earle et al., 2006). Friendships were tested and in some cases they were lost. On the other hand, one mother found new friends who also were experiencing ALL and another relied heavily on her friends to help with her other children or prepare dinner, suggesting hope for a return to normality.

Mothers did not verbally connect experiences described in their "Whole New Cancer World" with loss of sleep. Despite expressing that their lives were chaotic or the need to catch up with chores or work at night, they did not directly attribute those factors to their

loss of sleep. Other researchers reported that loss of support systems, financial strain, and the child's illness increased anxiety and depression resulting in sleep disruption (Greening & Stoppelbein, 2007; Meltzer & Mindell, 2007; Wakefield, McLoones, Butow, Lenthen & Cohn, 2011). In this current study, it was not until mothers lighted upon the second theme, "I Don't Remember What it's Like to Have Sleep", that they explicitly acknowledged that their sleep had been profoundly disturbed. Perhaps the connection of the experiences discussed in 'It's a Whole New Cancer World' with loss of sleep seemed too obvious to state, or these experiences were such a necessary part of their life with ALL that mothers did not consider verbalizing the resulting sleep loss. These experiences were ongoing and potentially stressful but were usually associated with daytime activities.

It was not until mothers focused on actual sleep disruptions, such as caring for the needs of a sick child at night or worries that prevented them from sleeping, that they discussed lack of sleep in conjunction with ALL. Nocturnal issues reported by mothers that disrupted sleep seemed to persist from the initial treatment period. Mothers with a history of sleep interruptions due to physical ailments or nocturnal caregiving of young children experienced the additional interruption of frequent awakenings, vomiting, and medication requirements associated with an ill child. Other factors that disturbed sleep were the child's steroid-induced hunger or worrying. This is in contrast to the findings of McGrath & Rawson-Huff (2010), who reported that the only parental stressor associated with ALL maintenance treatment was the child's aggressive and erratic behavior while receiving steroids. The difference might be due to the focus of the study. The focus of one study was stress (McGrath & Rawson-Huff, 2010) while this current study addressed sleep. Behavior of the children while on steroids was mentioned often as an unpleasant disruption to sleep but perhaps not dwelt upon because it was intermittent (5 nights per month). Worrying about a myriad of issues including children's well-being seemed more likely to cause sleep disruption on a continual basis rather than children's intermittent agitated behavior.

Mothers admitted to impatience with their family members and suboptimal performance at their jobs, which amplified their distress. This distress placed even more focus on the need to maximize the upcoming night's sleep to stop the downward spiral. The wide range of strategies to cope with fatigue and to obtain sleep suggested that pressure to sleep increased arousal and intensified rather than ameliorated the sleep problem. Some strategies were aimed at improving functioning during the day (caffeine, "keep moving"), others assisted sleep onset and quality at night (e.g., caffeine control), or facilitated a more positive mood (e.g., prayer, crying, positive journaling). An even greater variety of strategies were discussed as ways to attain sleep as the night wore on. Most mothers used basic sleep hygiene measures like eliminating caffeine and large meals before bedtime, and trying to have a set schedule for sleeping. Some mothers used denial and avoidance of their problems (e.g., reading, housework, television, exercise) while others journaled or talked with supportive others. Some mothers tried to improve their mood with meditation; schedules and back-up plans helped others.

Chronic sleep deprivation is a serious issue. Mothers mentioned some of their difficulties that arose from lack of sleep such as impatience, lack of productivity, feelings of stress, feeling ill, and collapse. Depressive symptoms were not specifically mentioned but

insomnia, sluggishness, fatigue, loss of energy, and diminished concentration also are symptoms of depression. The chronic nature of sleep deprivation could contribute to development of depression in mothers of children with ALL (Boelen & Lancee, 2013; Germain, 2013). Two of the mothers had diabetes. Although eating habits were not discussed by mothers in this study, reduced dietary restraint and obesity are associated with sleep deprivation (Chapman, Benedict, Brooks, & Schioth, 2012). Consumption of “comfort” foods high in carbohydrates, and weight gain could be especially detrimental to mothers with diabetes.

It seems imperative that mothers are assisted in their effort to attain sleep. The many strategies that mothers tried suggest interventions that could be investigated for mothers of ALL. Of the different therapeutic options available for insomnia, benzodiazepine-receptor agonists (BzRAs) and cognitive-behavioral therapy (CBT) are supported by the best empirical evidence (Morin & Benca, 2012). However, sleep disturbances in mothers of children with ALL often are due to caregiving responsibilities leading to lack of *opportunity* for sleep. Current sleep interventions such as sleep restriction and stimulus control, components of CBT for insomnia, may not be appropriate. Other components of CBT including sleep hygiene, cognitive therapy, and relaxation may need to be adapted and tested in parents of children with cancer. The two sleep hygiene measures (e.g., elimination of caffeine and large meals before bed, and scheduling of sleep time) endorsed by the National Sleep Foundation (National Center for Chronic Disease Prevention, 2013) were not adequate to promote sleep in this study. Mothers seemed unable to carry out the other recommendation – avoid using the bedroom for reading and watching TV- as those two activities were frequently used to go to sleep.

Other interventions that make use of maternal journaling, self-talk/self-regulation and spiritual support may decrease reliance on reading and watching TV as a means of attaining sleep. Attending to the needs of the child with ALL, other children in the family, work and household chores certainly must be done, but an intervention encouraging mothers to enlist the help of family and friends could ease the burden and decrease feelings of isolation. The variety of methods used by mothers in this study suggests that an individualized combination of strategies might be most effective and this is an important area for future research. Pediatric oncology teams who see the mothers on a regular basis could work with sleep experts to develop and implement appropriate interventions.

Limitations and Strengths

Participants in this study were socioeconomically diverse, but the sample was primarily Caucasian and did not include fathers. Further research with larger samples that includes fathers would allow comparisons to be made between parent gender, socioeconomic status, and ethnicity. The strength of this study was the in depth examination of sleep in mothers during their children’s maintenance treatment for ALL and coping strategies of the mothers. Although findings of other studies highlighted stresses, experiences, and factors that interfered with sleep in mothers of children with ALL (Earle et al., 2006; Fletcher, 2011; Gedaly-Duff et al., 2000; McGrath, 2002; McGrath & Rawson-Huff, 2010; Zupanec et al., 2010) they did not include the comprehensive description of how mothers attempted to cope

with sleep deprivation that was done in this study. The approaches to attain sleep by mothers in this study are important insights that can be used for investigation of much needed interventions.

Conclusions

Findings of this study indicate that sleep continues to be considerably disrupted in mothers during maintenance treatment for their child's ALL for a variety of reasons. Sleep deprivation can seriously impact health in the short and long-term (Steele et al., 2004). More research is needed to find ways to assist mothers to cope with all aspects of their child's illness, including attainment of sleep. Results from this study suggested there are varied coping mechanisms and an individual approach may be needed. Interventions that incorporate use of social support, journaling, spiritual guidance and/or self-talk may be most beneficial.

Acknowledgments

Funding: This research was supported by the CU Denver Clinical Translational Science Institute (1UL1RR014780) and Clinical Translational Research Center.

We would like to thank Tim Garrington, MD, Janie Kappius, Ann Ribe, Jane Ambro, Lacey Flemlee, Flori Legette, Kimberlee Horst, and Megan Duffy for their support with this project, and Jason Weiss for editing the manuscript. We also wish to thank Jacqueline Jones PhD RN for sharing her expertise in qualitative methodology.

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Table 1**Phases of Treatment for Standard Risk ALL**

Phase	Duration of Treatment and Goal of Therapy	Examples of commonly used chemotherapy agents (may vary by protocol and institution)
Induction	1 month Induce remission	IV vincristine, oral prednisone or dexamethasone, IV or IM pegaspargase, Intrathecal (IT) cytarabine initially then IT methotrexate
Consolidation	4–8 weeks Intensive CNS prophylaxis	IV vincristine, oral mercaptopurine, weekly IT methotrexate
Interim Maintenance	8 weeks Solidify remission and eradicate any remaining leukemia cells in the CSF and marrow	IV vincristine, IV methotrexate, monthly IT methotrexate, oral mercaptopurine, IM or IV pegaspargase
Delayed Intensification	8 weeks Intensify treatment to capture any resistant cells	 Oral dexamethasone or prednisone pulse, IV vincristine, IV doxorubicin, IM or IV pegaspargase, IV cyclophosphamide, oral thioguanine, IV or SC cytarabine
Maintenance	24 months -36 months Low intensity prolonged treatment to maintain remission	IV vincristine monthly, oral dexamethasone or prednisone pulses monthly, oral mercaptopurine daily, oral methotrexate weekly, IT methotrexate once per cycle

Table 2

Themes and Sub-themes with Exemplar Statements

Theme: It's a Whole New Cancer World	
Subtheme	Exemplar Statements
Losing Normality	<ul style="list-style-type: none"> “Our friends have backed off. I have to buy groceries late at night. I cannot take him (child) and I am always worried about bringing germs home.” “We live in a bubble. Friends can't come over. I cannot take her (ALL child) to the store. It affects the whole family every day. There are no movies, no dinners out. My other kids don't get attention when she is sick.”
Being Off-Balance/Insecure	<ul style="list-style-type: none"> “Not being on guard is when you get kicked in the butt.” “Go to bed, eat, take care of yourself, because you may not get another chance.”
	<u>Medication Administration</u>
	<ul style="list-style-type: none"> You go through so many treatment changes – maybe every 4 to 6 weeks. Now we have to get used to another routine. Before they gave the meds. Now we have to. We have to give the meds at just the right time. It is very stressful.”
	<u>Financial</u>
	<ul style="list-style-type: none"> We had to sell our house. With the medical bills and economy, I don't know if we can buy another one.” “I never know when I will need to miss work and lose pay. I am not sure what insurance will pay for and what we need to pay.”
	<u>Fear of Relapse</u>
	<ul style="list-style-type: none"> “I know that she can relapse, but there is only one more year left of treatment and she has not relapsed, so maybe she won't.” “It's still hard knowing that anything can happen.” “I don't think you ever get peace of mind back.”
Juggling Duties	<ul style="list-style-type: none"> “I have two kids in sports. I work. I have to drive the kids to school. The hospital is far away and I have to take him to treatments. I always am trying to figure out my time. It's very chaotic. We have to think about his (husband) job and my job and who is going to take him to the hospital and who is going to give him his pills.” “Now I have to think about when to schedule surgery for my knee – in between visits to the hospital or emergency trips to the hospital.”
Making Transitions	<u>Alteration of child's sleeping arrangements</u>
	<ul style="list-style-type: none"> “He was a good sleeper before ALL. During induction he would get stomach aches, leg pains, and mouth pain and would get up and sit in front of TV until 2 AM. He still wakes up at odd hours want wants to do something like eat, watch a movie and does not want to go back to bed. Now the other kids get up at night, too.” “He and his brother end up in the same bed. They have their own beds but he just needed somebody near him all the time. That's how it started. If he doesn't have someone near him he sleeps more restlessly. Sometimes all the kids end up in bed with us. Then my husband is the one who leaves and sleeps downstairs.”
	<u>Changing Work Situation</u>
	<ul style="list-style-type: none"> “I had to quit my job and take a lower paying one so that I could get him to treatments.” “I have to work now. My husband watches her from 4 AM to 10AM so that I can sleep before going to work.” “I had to switch to the night shift so that I could be home during the day with her.”
	<u>School</u>

- “He started back to school, but I’m always worried about other kids sneezing. I want to hand masks to everybody.”
- “He has been going to school online and is still doing that. We don’t have to worry about when he sleeps or take medications.”

Friendships

“Our extended family does not understand. My mother says, ‘He’s alive and that’s all that matters.’
“We have lost friends because they can’t come over.”

Theme 2: I Don’t Remember What it’s Like to Have Sleep

Sleeping Trouble Before and After ALL

Trouble Sleeping Before ALL and After

- “I was always a light sleeper. Now I hear everything. I wake up 5 or 6 times a night to check on him.”
- “I was diagnosed with diabetes a month before her ALL, so I was not sleeping well. I think the diabetes still impacts my sleep, but now that things are more relaxed, I am feeling a lot more pressure. Everything is now catching up with me.

Child Feeling Sick at Night

- “He’s up all night when he is taking steroids.”
- “When she is on steroids, she sleeps a lot during the day and is up all night.”
- I hear her toss and turn all night.”

Worrying

- “I had no sleep early in his treatment because of constant worry. I don’t see a big difference now. I still toss and turn a lot. I have a hard time falling asleep and wake up several times. Sometimes I have a hard time going back. I check on him – just making sure that he is OK.
- “My mind keeps going when I lay down. I think about everything that needs to be done and what’s going on the next day. It’s in the back of my mind-”I gotta do this tomorrow. I gotta do that tomorrow. He has to take this- just constant goin through my mind.”
- “I worry about work and when to do my household chores. I am overwhelmed with my life. We have financial problems too.”

Coping with Exhaustion

Consequences of Exhaustion

- “I feel more stressed. I don’t feel good. I get so tired. I get frustrated, argue about nothing, escalate situations and feel guilty. I am just surviving.”
- “I feel tired and want to rest but I have things to do laundry, cook. Clean.”
- “I am less patient, not clicking well mentally, not taking care of tasks. I forget things but know that I have to do them.”

Ways that mothers coped with exhaustion

Daily Functioning

- “I clean, walk, and read to stay awake.”
- “Crying helps me.”
- “I keep moving and drink coffee to stay awake during the day.”

General

- “My husband advised me to put a pad by my bed and write down things. He says, ‘if you can’t do anything about it, don’t think about it.’ and try to relax.”
- “No caffeine; I have tried yoga, but I am too tired to do it. Taking time for myself, like reading, puts me to sleep.”
- “I do not eat after 7 PM and go to bed at 9 PM. I read, watch TV, or take a bath before bed. Sometimes I work in the evening.”
- “I play on the computer.”
- “I listen to the radio or read to put me to sleep.”

Spiritual

- “I remind myself that ‘we’re taken care of. He’s taking care of it. He’s got it under control. That really eases me.”
- “Reading scripture and prayer are a regular thing in my life. I’ve had a much different relationship with my Heavenly Father since my son has been sick. I’ll talk things out in my mind a lot more during the day than I probably would have otherwise.”

Use of External Support

- I talk to my husband or a friend.”
- “I have a support system.” (stated by two mothers)
- “It helps me to talk to other parents to get their opinions and share mine.”
- “I talk to my family. Sometimes I go to the movies with my husband and friends. Letting loose and talking about it makes you feel better.”

Self Talk/Self regulation

- “I try to put my worrisome thoughts into perspective – ‘she’ll be OK.”
 - “I journal to see patterns.”
 - “I think to myself. ‘What’s the worst possible thing that can happen? It hasn’t happened yet – death – so I keep doin what I am doing and it won’t happen.”
 - “Sometimes I read or put things down on paper. I read them and tell myself to stop thinking about it. It’s a visual way of getting them out of my head. It’s on a piece of paper - see - you don’t have to have it in your head – you won’t forget it.”
 - “If I wake up panicky, I tell myself to calm down. I tell myself, ‘You know, things are actually going well and you don’t need to be freaked out so adjust and think more positively.’ ”
-