

THE RELATIONSHIP BETWEEN CHILD SLEEP QUALITY AND CHILD HEALTH-  
RELATED QUALITY OF LIFE DURING PEDIATRIC CANCER TREATMENT:  
TESTING PARENT STRESS AS A MODERATOR

By

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## THESIS ABSTRACT

The Relationship between Child Sleep Quality and Child Health-Related Quality of Life  
during Pediatric Cancer Treatment: Testing Parent Stress as a Moderator

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Recent medical advances have contributed to increased rates of childhood cancer survivorship (Ward et al., 2014) and addressing the psychosocial functioning of patients and their families is more relevant today than in previous decades. Children and adolescents with chronic health conditions, such as acute lymphoblastic leukemia, report lower health-related quality of life (HRQL) from initial diagnosis through the two to three-year-long maintenance phase of treatment (Earle & Eiser, 2007; Meeske, Katz, Palmer, Burwinkle & Varni, 2004). Both increased parent stress (Hamner, Latzman, Latzman, Elkin & Majumdar, 2015) and poor child sleep quality (van Litsenburg et al., 2011) can negatively contribute to child HRQL. Assessing modifiable components of HRQL can inform clinical practice and intervention development aimed at improving child and family outcomes. This study evaluated the relationship between child sleep quality and child HRQL, and assessed parent stress as a moderator of this relationship. Thirty-eight participants were parents of children (ages three through twelve) who were undergoing cancer treatment. Data assessing child sleep quality, child HRQL and parent stress was collected through parent self-report and child proxy-report questionnaires.

Results showed that parent stress is not a moderator on the relationship between child sleep quality and child HRQL, however, parent age and parent stress remained significant variables to consider when evaluating child HRQL. Factors related to child sleep quality and parent stress, and clinical implications of study findings are discussed. Future research directions are offered.

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## **Introduction**

### **Overview**

Evaluating child functioning is a core component of assessing overall child well-being. Health-related quality of life (HRQL) refers to the assessment of the physical and psychosocial functioning of children with chronic health conditions, such as cancer (Varni et al., 2003). Sleep quality has emerged as an important, modifiable component of health-related quality of life. Poor sleep quality is linked to poor child functioning (Steuer et al., 2016), and poor parent sleep quality (Daniel et al., 2018). Assessing child HRQL from a family perspective offers insight into the interplay between child and parent factors. Parent stress is an area of functioning that is heightened throughout child cancer diagnosis and treatment (Klassen et al., 2011). Parent stress greatly affects child functioning (Hamner et al., 2015), and has been shown to be malleable to intervention (Sulkers et al., 2015). For parents with high stress, as child sleep quality decreases, so too does child HRQL. This study aims to, first, evaluate the relationship between child sleep quality and child HRQL and, then, assess whether parent stress is a moderator of this relationship. This assessment allows for the identification of salient, modifiable components of child health-related quality of life for children on cancer treatment, which may bolster child and family outcomes.

Increasingly effective cancer treatments have resulted in high rates of 5-year cancer survivorship (69%) (Ward, DeSantis, Robbins, Kohler & Jemal, 2014) especially among children with leukemia. Continued assessment of the psychosocial health of children with cancer and their parents is crucial in identifying patient and parent needs and promoting healthy adjustment in parents caring for a child with a chronic health

condition (Cousino & Hazen, 2013; Eiser and Morse, 2001). When a child is diagnosed with cancer, parent, and overall family functioning is greatly affected (Kazak, 1989). Specifically, the impact of increased parent stress permeates all aspects of the home environment and family life (Cousino & Hazen, 2013) and high levels of parent stress can contribute to poor child health-related quality of life (HRQL) (Hamner et al., 2003). Assessing HRQL of patients and their families is crucial to improving family functioning (Varni, Burwinkle, Seid & Skarr, 2003). Child sleep quality has emerged as another important facet of child health-related quality of life, especially for children with a chronic health condition (Zupanec, Jones & Stremler, 2010; van Litsenburg et al., 2011; Hinds et al., 2007). Identifying the impact of child sleep quality and parent stress on child HRQL can guide sleep- and stress-related interventions for children undergoing cancer treatment. This study aims to evaluate the relationship between child sleep quality and child health-related quality of life, as well as explore parent stress as a moderator of this relationship.

Annual reports by the American Cancer Society indicate increasing rates of 5-year cancer survivorship. In 2011, the annual report indicated a 69% 5-year cancer survivorship rate with varying differences across patient race, gender, age at diagnosis and cancer diagnosis. Cultural shifts (i.e., reduced rates of smoking), increased preventative measures (i.e., regular cancer screenings), and medical advances (i.e., the development of targeted therapies), have largely accounted for decreased rates of mortality (Siegel, Miller & Jemal, 2016).

For young children and adolescents, on average, 1 in 408 children will be diagnosed with cancer before age 15. Acute Lymphoblastic Leukemia (ALL) is the most

common type of childhood cancer, accounting for 26% of pediatric cancer diagnoses. In 1975, ALL had a 57% 5-year survival rate; however, today, ALL has a 91% 5-year survival rate (Ward et al., 2014). Reduced mortality of children diagnosed with ALL is due to medical advances, increased clinical trial participation, increased awareness of susceptible genetic conditions (such as Down Syndrome) and preventative measures, including limited radiation exposure on fetuses (Childhood Acute Lymphoblastic Leukemia Treatment, 2017; Siegel, Miller & Jeman, 2016). As noted by Barakat and colleagues (1997), there has been a recent shift in the diagnosis of childhood ALL from a once fatal diagnosis to a chronic health condition. Due to this shift towards prolonged life-expectancy, promoting high health-related quality of life from initial diagnosis through treatment and into survivorship may improve long-term psychosocial outcomes for patients and their families.

### **Acute Lymphoblastic Leukemia**

ALL is a type of blood-based cancer, characterized by a proliferation of lymphoblasts (unhealthy, immature white blood cells) in the bone marrow. The build-up of unhealthy cells prevents the production and maturation of healthy white blood cells, which are the body's primary means of fighting infection. Furthermore, the proliferation of lymphoblasts may force the cancer cells to enter the bloodstream and spread throughout the body, potentially leading to metastases. Symptoms of ALL typically include frequent bruising or bleeding, and painful bones and joints (Childhood Acute Lymphoblastic Leukemia Treatment, 2017).

**Treatment.** Following diagnosis, ALL treatment consists of three phases: induction, consolidation, and maintenance, with treatment variations across cancer risk

categorization (Pui & Evans, 2006). The first phase, induction, consists of intense chemotherapy to eradicate leukemia cells. This phase typically lasts one month in the hospital with routine tests to monitor white blood cell counts. The second phase, consolidation, consists of continued chemotherapy to destroy lingering cancer cells, which may go undetected in blood work. This stage lasts several months consisting of multiple in-hospital treatments with routine monitoring by the medical team. Once cancerous cells are destroyed, patients enter remission and begin the final stage of treatment, maintenance. Maintenance treatment aims to maintain remission and typically consists of monthly outpatient chemotherapy treatments for two to three years. During this stage of treatment, patients are reintegrated into regular family life and school routine (Pui & Evans, 2006).

The monthly chemotherapy administered during the maintenance phase of ALL treatment may hinder a child's return to daily life, largely due to medication-related side effects. Side effects of chemotherapy frequently include fatigue (Hinds et al., 2007) and adverse psychological side effects, including depressive symptoms (Stuart, Segal & Keady, 2005). The monthly chemotherapy treatments take place over the course of five days. These treatment days can disrupt family and patient routines, and side effects from the chemotherapy, such as sleep problems, may persist during off-treatment days (Hinds et al., 2007). The adverse effects of chemotherapy on a child's sleep behaviors can negatively impact a child's HRQL during treatment (Steuer et al., 2016). Follow up studies show that ALL survivors may be at risk for neuropsychological deficits related to the late effects of cancer treatment on the child's developing brain tissue. Compared to their healthy peers, childhood cancer survivors are more likely to have educational



deficits (due to cancer treatment), lower rates of marriage and lower rates of having their own children (due to concerns over future child health) (Langeveld, Stam, Grootenhuis & Last, 2002).

### **Child Sleep Quality**

Child sleep quality has been shown to significantly impact parent stress level (Meltzer & Mindell, 2007) and is an important component of HRQL. Sleep quality is typically measured through subjective self- or proxy-report measures. Child sleep can also be measured as objective variables, such as latency to fall asleep, hours spent asleep, daytime sleepiness, and symptoms of sleep disordered breathing (Owens et al., 2000). Sleep can be measured through questionnaires, such as the Child Sleep Habits Questionnaire (CSHQ) (Owens et al., 2000), or sleep diaries, where parents record nightly child sleep habits. Devices such as actigraphy (watch-like movement trackers) or polysomnography (a sleep study in a lab) are also utilized as objective sleep measures (Markovich, Gendron, & Corkum, 2015). In general, researchers support multi-method approaches when evaluating sleep habits. The CSHQ, however, is a well-established and widely used measure in screening for child sleep problems and the presence of sleep disorders (Markovich et al., 2015). Previous research indicates that poor child sleep affects both child functioning (Sadeh, Gruber, & Raviv, 2002; Hinds et al., 2007) as well as overall family functioning (Meltzer & Mindell, 2007). In healthy children, poor sleep quality (defined as few hours of sleep) was significantly related to negative affect, poor daytime functioning (Vriend et al., 2012) and poor HRQL (Hart, Palermo & Rosen, 2005).

**Sleep Quality in Children with Cancer.** Children undergoing cancer treatment report more sleep problems than their healthy peers, although there is little consensus on which key aspects of sleep are most intrusive to functioning. Sleep problems during treatment have been shown to negatively impact HRQL (Steuer et al., 2016). For children in the maintenance phase of ALL treatment, disrupted child sleep is related to poor parent sleep quality (Daniel et al., 2018). Survivors of childhood cancer continue to report high rates of sleep disturbances in the years following the completion of therapy (Meeske, Siegel, Globe, Mack & Bernstein, 2005), which can even persist into adulthood (Mulrooney et al., 2008). Identifying and treating sleep problems early may protect patients from later sleep-related decrements in HRQL.

Children undergoing ALL maintenance therapy frequently report short sleep duration, repeated night awakenings and overall poor sleep efficiency (Hinds et al., 2007). Sleep efficiency is the percentage of time spent asleep while in bed. For instance, a child who is in bed for 8 hours and asleep for 4 of those 8 hours, has 50% sleep efficiency. Furthermore, studies support the notion that cancer treatment protocol and the use of corticosteroids, which are standard in ALL treatment, can negatively impact sleep behaviors and child HRQL (Daniel, Li, Kloss, Reilly & Barakat, 2016; Pound et al., 2012; Steuer et al., 2016). Children in the maintenance phase of ALL treatment continue to exhibit regular sleep problems and fatigue following the initial diagnosis and treatment (Gedaly-Duff, Lee, Nail, Nicholson & Johnson, 2006; Walter et al., 2015), which often results in poor HRQL (van Litsenburg et al., 2011). Understanding the associations between sleep quality and child HRQL, and the potential moderation of parent stress on

the relationship, may offer insights into the modifiable components of cancer treatment and help to promote high child HRQL and increased family functioning.

### **Health-Related Quality of Life**

Evaluating child well-being is a crucial component in assessing overall health and functioning. Measuring health-related quality of life (HRQL) is a means of assessing patient well-being in the context of a chronic health condition. HRQL refers to the evaluation of the physical and psychosocial functioning of patients with chronic health conditions (Varni et al., 2003). Assessing HRQL informs clinicians and the medical team of deficits in child functioning (Pickard, Topfer & Feeny, 2004).

**HRQL of Children with Chronic Health Conditions.** Parents of children with chronic health conditions, such as obesity and cancer, generally report lower child HRQL than parents of healthy children. Such reports may be due to the children's physical limitations in activities due to their health condition or related to peer bullying (Schwimmer, Burwinkle & Varni, 2003; Smith et al., 2013). Studies have recognized the value in assessing both child self-reports as well as proxy-reports of HRQL during treatment for chronic health conditions (Varni, Seid & Kurtin, 2001).

**HRQL of Children in ALL Treatment.** For children undergoing cancer treatment, regular chemotherapy can result in mood swings, increased anxiety and adverse somatic symptoms, such as increased reports of nausea and pain. These medication-related side effects can negatively impact child HRQL (Pound et al., 2012). Furthermore, during the first year after the diagnosis, high levels of parent stress have been linked to reports of poor child HRQL (Pierce et al, 2016).

Cancer diagnosis, treatment, and management can significantly disrupt the functioning of both children with ALL as well as their families. Children are required to undergo surgery, chemotherapy, and a host of rigorous treatment-related procedures including bone marrow biopsies, and needle sticks. Sung and colleagues (2011) conducted a study assessing the HRQL of children in the maintenance phase of ALL treatment. Results showed no change in reports of pain and hurt when comparing children before maintenance treatment to those currently in maintenance treatment. In addition to routine outpatient treatments and medication side-effects, children in the maintenance phase of ALL treatment are also coping with the transition back into the school setting. Across age groups, reintegrating into school is accompanied by a host of social anxieties (Earle & Eiser, 2007; Sung et al., 2011). While physical limitations due to treatment (i.e., fatigue) may contribute to challenges children face during the transition, Earle and Eiser (2007) found that supportive parents, teachers and school administration can help ease the process. School-age children and adolescents may also be at risk for poor HRQL due to increased illness-related worry (Meeske et al., 2004), problems in school and heightened frustration related to the prolonged disease management associated with ALL treatment (Earle & Eiser, 2007).

Data gathered through child self-report indicate that children in ALL treatment report similar rates of pain before, and during, the maintenance phase of treatment (Sung et al., 2011). This study also suggested that child HRQL and functioning does not change across the different phases of treatment. As such, continued assessment of child HRQL, and identification of potentially modifiable areas of functioning can aid in intervention development and promotion of high HRQL during, and after, cancer treatment.

## **Parent Stress**

Parent stress is an important aspect of family life which greatly contributes to children's functioning. Parent stress is typically defined as the distress that arises when trying to meet the demands of parenthood (Deater-Deckard, 1998). Parent stress has been associated with poor family functioning (Hoven, Anclair, Samuelsson, Kogner & Boman, 2008) and, in the presence of significant impairments of parental coping and stress management, negative effects on child psychosocial health (Mullins et al., 2016). Parent stress has also been associated with negative parent-child interactions (McKay, Pickins, & Stewart, 1996) as well as poor general well-being of parents and children (Abidin, 1992). Intervention development aimed at reducing parent stress for parents of children with chronic health conditions continues to show progress (Hoff et al., 2005; Kazak et al., 2005).

**Parent Stress in Children with Cancer.** Parents of children with chronic health conditions are at risk for high levels of stress. Initial parent reports of anxiousness, depression or uncertainty during treatment can persist for years following the completion of treatment (Vrijmoet-Wiersma et al., 2008). Parents, especially single parents, of children with chronic health conditions may experience elevated stress due to treatment-related factors, such as maintaining family functioning for siblings and establishing new parenting guidelines for the child with cancer (Granek, 2012). Interventions aimed at reducing parent stress early in cancer treatment can bolster parent functioning, even for parents who seem to be coping well with disease management (Sulkers et al., 2015). Heightened parent stress, specifically chronic parenting stress, has been shown to predict

poor child HRQL, physical functioning, and psychosocial functioning (Hamner et al., 2015).

Parents of children undergoing ALL treatment experience high levels of stress, especially during the first year of treatment (Klassen et al., 2011). Given the significant stress associated with caring for a child with cancer, evaluating parent functioning and adjustment following cancer diagnoses and throughout treatment is crucial to promoting high family functioning. Following the completion of cancer treatment, approximately 10-30% of parents, particularly mothers, meet full criteria for posttraumatic stress disorder (PTSD) diagnosis. Up to 95% of mothers meet Criteria B (recurrent thoughts and re-experiencing the trauma of diagnosis and treatment), 30% meet Criteria C (avoidance of thinking of the trauma or avoidance of stimuli associated with the trauma) and 53% meet Criteria D (increased arousal, such as hyper-vigilance) (Best, Streisand, Catania & Kazak, 2001; DSM-IV; Kazak et al., 2001). These statistics may be underreported, as parents who are consenting to take part in research studies may be coping better (i.e., less avoidance of cancer-related research) than those who refuse participation (Best et al., 2001). Parents who do not meet criteria for PTSD still tend to report distressing thoughts, feelings of avoidance and anxiety and, in general, have higher levels of posttraumatic stress than healthy controls (Best et al., 2001).

### **Child- and Family-related Covariates**

Assessing the impact of child, family and illness variables on HRQL can aid clinicians and researchers in identifying those at risk for decrements in health-related quality of life during cancer treatment. A study conducted by Sung and colleagues (2011), analyzed the HRQL of children aged 2 through 18 undergoing ALL treatment.

Results showed that older children tended to report lower PedsQL scores (poorer health-related quality of life) than younger children. One study, by Meeske and colleagues (2004), found that duration in ALL treatment was correlated with quality of life, such that children farther along in treatment reported higher HRQL.

Research evaluating child sleep found that older child age was often associated with changes across several sleep domains, such as greater sleep efficiency (Vriend et al., 2012) and delayed sleep onset (Sadeh, Raviv, & Gruber, 2000). When compared to healthy children, younger children on ALL treatment reported significantly more sleep problems, while older children did not significantly differ (Van Litsenburg et al., 2011)

Klassen and colleagues (2008) assessed the predictors of poor parent HRQL in parents of children with cancer. Results showed that parent age was predictive of better parent physical health such that younger parents reported higher parent HRQL. Parents with high HRQL themselves tended to report higher health-related quality of life for their child in proxy-ratings (Eiser, Eiser & Stride, 2005). This finding is especially relevant for this proposed study given that child data was collected by proxy-parent reports.

Additional studies indicate that households with higher SES report higher HRQL across the PedsQL domains (Sung et al., 2011), which may be due to the association between high SES and low parent stress (Klassen et al., 2011).

### **Gaps in Literature**

The risk and resistance model (Wallander & Varni, 1998) offers a framework to understand the interplay of chronic health condition variables, parent and family adjustment, and patient psychosocial adjustment. The model identifies parent stress as an important component when assessing family functioning and adjustment to disease-

management. Wallander and Varni (1998) call for additional research assessing parent stress across a range of time since diagnosis to offer a more comprehensive understanding of longitudinal parent adjustment. Research aimed at identifying the components and influences of child adjustment and HRQL outside of illness variables, such as the stressors associated with the return to daily life or school reintegration, would strengthen the model and inform clinical practice (Wallander & Varni, 1998).

Parent stress (Hamner et al., 2015) has been shown to impact child HRQL. High parent stress is associated with poor child psychosocial adjustment in pediatric cancer and a greater number of depressive symptoms in children with chronic health conditions, such as sickle cell disease and juvenile rheumatoid arthritis (Cousino & Hazen, 2013). Poor child psychosocial adjustment can persist for several years following baseline testing (Cousino & Hazen, 2013).

Parent social and emotional support, as well as, prior exposure to traumatic events, can be predictors of parent stress level (Chang et al., 2004). Caregivers without their own social supports (such as those without reliable transportation or those facing financial challenges paying home and hospital bills) may be unable to maintain their child's cancer treatment regimen and family routines. Continued assessment of the predictors and effects of stress is essential given that parent stress has been shown to affect parent psychopathology (Goodyer, Wright & Altham, 1988) as well as family functioning (Hoven et al., 2008).

Prior research has assessed the mechanisms by which parent stress impacts child functioning. High stress (often a result of limited parenting knowledge, minimal caregiver social support or poor caregiver coping skills) is related to poor parenting



(Deater-Deckard, 1998). Poor parenting is defined as harsh or authoritarian parenting, lack of parental involvement with the child or an insecure attachment style (Deater-Deckard, 1998). Poor parenting may impact the parent-child relationship, child functioning, and child coping with disease management. Parents with high stress may also exhibit depressive symptoms, potentially leading to poor parenting behaviors such as minimal responsiveness or little involvement with their child (Downey and Coyne, 1990). Poor parenting and low-quality parent-child relationships may result in a poor home environment, such as a lack of bedtime routines and poor sleep quality, and reduced child HRQL. In contrast, parents with low stress may offer their child high-quality parent-child relationships and a stable home environment, whereby parent stress may minimally impact child sleep quality and child HRQL. In sum, prior research suggests a significant impact of poor caregiver functioning on child functioning, especially for parents of children with chronic health conditions.

Given the prevalence of sleep disorders and reports of poor sleep quality by children undergoing ALL maintenance treatment, continued evaluation of child sleep may inform the development of sleep-related interventions and improve child HRQL during, and after, treatment. Prior research has yet to assess the relationship between child sleep quality and child HRQL with parent stress as the moderator. It was expected that high parent stress would amplify the child sleep quality and HRQL relationship such that high parent stress would be associated with poor child sleep quality and poor child HRQL. Low parent stress would have a minimal effect on the relationship between child sleep quality and HRQL. This study aimed to assess the impact of parent stress on the

relationship between child sleep quality and child health-related quality of life, important components of this population's long-term health and functioning.

A secondary aim of this study was to evaluate the family system and associations between parent and child variables for children on ALL treatment. This analysis can help to identify families who may benefit from additional psychosocial support. If parent stress is a moderator of the relationship between child sleep and child HRQL, then clinical interventions should primarily aim to reduce parent stress to improve child HRQL. If parent stress is not a moderator, then child sleep (rather than parent stress) is more closely associated with child HRQL, and interventions should target improving child sleep quality.

Additional research on the impact of chronic health conditions on family functioning and, more specifically, the parent-sibling relationship is crucial in identifying at-risk families and providing necessary support (Wallander & Varni, 1998). Research indicates that mothers tend to spend more individual time with their child with a chronic health condition than with the child's healthy sibling (Quittner & Opiari, 1994). There are mixed results when reporting the quality of life of siblings of children with chronic health conditions (Havermans et al., 2011; Sharpe and Rossiter, 2002). Children in single-child families have more parental attention, involvement, and information exchange than families with multiple children (Falbo & Polit, 1986; Gewirtz & Gewirtz, 1965; Hilton, 1967). Additional research on family member relationships throughout cancer treatment may aid in identifying children at risk for poor HRQL and inform targeted intervention development. Assessing the significance of the presence of siblings

versus only children on parent stress and HRQL may inform clinical practice in identifying families who may benefit from additional support.

### **Research Aims**

**Aim 1:** To describe reports of child sleep quality, parent stress and child health-related quality of life during ALL treatment, as measured by the Child Sleep Habits Questionnaires (CSHQ), the Parent Experience of Child Illness Questionnaire (PECI) and the Pediatric Quality of Life Inventory (PedsQL). Also, to identify relevant covariates, including child and family variables.

**Hypothesis 1:** It was expected that scores of child sleep would be greater in this sample than scores of normative values. It was also expected that scores of parent stress and child HRQL in this sample will be similar to scores of normative values.

*Hypothesis 1a:* It was hypothesized that parents of children in this sample would report more sleep problems on the CSHQ when compared to normative values of healthy children.

*Hypothesis 1b:* It was hypothesized that parents of children in this sample would report similar scores on the PedsQL when compared to normative values of children undergoing cancer treatment.

*Hypothesis 1c:* It was hypothesized that parents of children in this sample would report similar scores on the PEGI when compared to normative values of parents of children undergoing cancer treatment.

*Hypothesis 1d:* It was hypothesized that children without siblings, younger child age, younger parent age, and greater number of months in cancer treatment would be correlated with lower scores on the PEGI and higher scores on the PedsQL. It

was hypothesized that older child age would be related to lower scores on the CSHQ.

**Aim 2:** To assess the relationship between child sleep quality on the Child Sleep Habits Questionnaires and child health-related quality of life score on the Pediatric Quality of Life Inventory.

**Hypothesis 2:** It was expected that lower sleep disturbance scores reported on the Child Sleep Habits Questionnaires (few sleep problems) would be correlated with high scores on the Pediatric Quality of Life Inventory (high child health-related quality of life).

**Aim 3:** To assess the interaction of parent stress on the relationship between child sleep quality and child health-related quality of life.

**Hypothesis 3:** It was expected that parent stress would be a moderator on the relationship between child sleep quality and child HRQL.

*Hypothesis 3a:* It was hypothesized that parent stress would be a moderator of the relationship between child sleep quality and child HRQL. For parents with high stress, as child sleep quality increases, so too would child HRQL. For parents with low stress, as child sleep quality increases, child HRQL would remain unchanged.

### **Significance**

The purpose of this study is to, first, gain a better understanding of the interactions between parent and child variables with components of HRQL for children undergoing cancer treatment and, second, identify whether parent stress is a moderator of the relationship between child sleep quality and child HRQL. Children diagnosed with a chronic health condition are at risk for a host of future medical and psychosocial disorders due to treatment-related effects. Both sleep and stress have been shown to be

modifiable factors which, following interventions, can lead to significant improvements in overall functioning (Hiscock, Bayer, Hampton, Ukoumunne & Wake, 2008; Hoff et al., 2005; Kazak et al., 2005). Identifying modifiable factors present during cancer treatment will undoubtedly aid children and families in promoting high HRQL and coping with potential disease-related impairments. Since ALL has transitioned from a once fatal diagnosis into a chronic health condition, promoting better psychosocial functioning and higher HRQL during treatment is crucial for children's long-term functioning (Barakat et al., 1997).

## Method

### Participants

This prospective study was an analysis of archival data. Participants were recruited based on medical eligibility and through the tumor registry of The Children's Hospital of Philadelphia. Clinical staff and the patient's medical team were consulted to further confirm child eligibility for participation. Eligible children were aged three through twelve ( $M=6.72$ ,  $SD=2.48$ ) who were diagnosed with Acute Lymphoblastic Leukemia (ALL) and were in the maintenance phase of treatment. Majority of children were male (60%,  $n=23$ ) and children were, on average, 12.10 months ( $SD=8.49$ ) from diagnosis. Most children ( $n=24$ , 63.2%) were Caucasian, 2 children were African American (5.3%), 3 children were Asian (7.9%), 5 children endorsed more than one race (15.8%), 1 child was Hispanic/Latino (2.6%) and 3 children identified as "other" race/ethnicity (7.9%). Children were excluded if they had prior cranial radiation, pre-existing genetic conditions (i.e., Down Syndrome), prior neurological impairments, or relapsed ALL (Daniel et al., 2016).

Participants were composed of parent-child dyads with parents completing questionnaires as child-proxies. Research assistants (RAs) approached eligible families during in-hospital visits to the outpatient clinic to obtain parent consent, and patient assent when applicable (participants older than eight years old). RAs worked with parents to complete paperwork during the visit to ensure complete data collection. Of the original sample ( $n=81$ ), 38 caregivers completed measures relevant to the current proposal. Caregivers were aged 20 through 52 ( $M=36.63$ ,  $SD=6.65$ ) and 71% of caregivers were mothers ( $n=27$ ). 60% of caregivers were married ( $n=23$ ), 13% divorced ( $n=5$ ) and 13%

were either separated, never married or other. Majority of families ( $n=32$ ) had multiple children in the home.

## **Procedures**

RAs approached families as they arrived in the outpatient clinic for monthly cancer treatments and administered the questionnaires in clinic. Should families endorse suicidal or homicidal behaviors, trained clinicians were available to further assess caregiver and family functioning.

## **Measures**

### **Predictor: Child Sleep Habits Questionnaire**

**Background.** For this study, child sleep was evaluated using the Child Sleep Habits Questionnaire (CSHQ; Appendix A; Owens, Spirito, & McGuinn, 2000). The CSHQ was developed and assessed on both a typically functioning community sample ( $n=469$ ) of school-aged children ( $M= 7.6$  years, range: 4 to 10 years), as well as a clinical sample of children ( $n=154$ ,  $M=6.8$  years old) presenting in clinic for sleep-related disorders (Owens et al., 2000). While the CSHQ is not typically used with the pediatric cancer population, this measure allows for analysis across a host of sleep disorder domains, including sleep anxiety, parasomnias (sleepwalking, nightmares, bed-wetting and other abnormal nighttime behaviors) and daytime fatigue.

Construct validity of the CSHQ was assessed by comparing the community sample to the clinical sample. The clinical participants used for questionnaire development were children who had been diagnosed with a behavioral sleep disorder, parasomnias or sleep-disordered breathing. The clinical sample reported higher scores than the community sample on all but one questionnaire item. Internal consistency

reported a Cronbach's alpha of .68 (community sample) and .78 (clinical sample). While the clinical sample reported a somewhat low value of internal reliability, some heterogeneity can be expected when evaluating a construct with many facets (Streiner, 2003). The CSHQ measures overall sleep problems across 8 domains, not all of which may be endorsed by a clinical population with a sleep disorder. For example, children who struggle with bedtime routine and bedtime resistance may not endorse items related to sleep disordered breathing. 2-week test-retest reliability scores ranged from .62-.79 (Owens et al., 2000).

For this study, sleep quality theoretically ranged from poor to excellent. Parents completed the CSHQ based on child sleep disturbances and sleep behaviors in the past week. The measure includes 33 items, such as "child falls asleep within 20 minutes after going to bed" and "child sleepwalks during the night," and is composed of eight subscales, which include bedtime resistance, sleep duration, and night wakings. Parents respond to items on a scale of either 3 ["usually" (5-7 nights per week), 2 ["sometimes" (2-4 nights per week)] or 1 ["rarely" (0-1 night per week)]. Several items were reverse scored and total score ranged from 33 to 99. Higher scores indicated higher rates of sleep disturbances with scores above 41 indicating the presence of a sleep disorder (Owens et al., 2000).

**Limitations.** Limitations of the CSHQ, as suggested by Owens and colleagues (2000), include parent response biases, inaccurate retrospective reports and the potential lack of sleep disorder diagnosis in the community sample. Utilizing a mixed-method approach and incorporating a sleep diary or actigraphy reports into data collection may reduce retrospective biases. Previous studies compared the CSHQ to objective sleep



measurements, such as actigraphy, and found mixed results indicating the need for further development of accurate measures of child sleep habits (Markovich et al., 2015).

### **Outcome: Pediatric Quality of Life Inventory**

**Background.** For this study, child health-related quality of life was measured by the Pediatric Quality of Life Inventory (PedsQL; Appendix B; Varni, Seid, & Rode, 1999). Child HRQL theoretically ranged from poor to excellent. The PedsQL assesses health-related quality of life in children (ages 2 through 18) and is a valid and frequently used measure when assessing HRQL in children with chronic health conditions (Eiser & Morse, 2001; Varni, Burwinkle, Katz, Meeske & Dickinson, 2002). To reduce effects of child age on the ability to accurately self-report HRQL, this study utilized parent proxy rating of child HRQL, a valid alternative assessed during measure development (Varni et al., 2002).

The PedsQL was developed by testing health-related quality of life domains in a group of healthy children (n=683) and groups of children with acute (n=207) and chronic (n=730) health conditions. Raters were asked to reflect on behaviors within the past month and rated 23 items, such as “In the past five days, how much of a problem has your child had with walking more than one block,” on a scale of zero (never a problem) to four (almost always a problem). The questionnaire assesses functioning across four domains including physical, emotional, social and school functioning. All items are reverse scored, transformed into a zero to one hundred scale and then calculated as a total score. Higher total scores on the PedsQL indicate greater HRQL (Varni, Seid, & Rode, 1999).

**Validity.** Internal consistency was tested using Cronbach's alpha where total score of parent ratings reported an alpha of .90. Construct validity was assessed using one-way ANOVA across the three groups (healthy children, acutely ill children, and chronically ill children). The PedsQL distinguished between healthy controls and acutely/chronically ill children, specifically when assessing morbidity and illness burden. The researcher's hypothesis was supported and healthy children reported higher HRQL than children in the acute or chronic health condition groups (Varni et al., 1999).

**Limitations.** The researchers noted that the PedsQL has several limitations (Varni et al., 1999). Self-reports are inherently susceptible to response biases, such as acquiescence bias, social desirability biases, and demand characteristics. These biases may be reduced by the presence of an RA during questionnaire administration to ensure a thorough understanding of survey items and completion of all measures. Prior to questionnaire administration, RAs emphasized the de-identification of questionnaire responses, such that participant name was not associated with participant responses. Furthermore, previous studies indicate that parents of children with chronic health conditions may underreport health-related quality of life when compared with parent reports of healthy controls (Upton, Lawford & Eiser, 2008). Supplemental comparison of the PedsQL to objective measures of HRQL (such as physical fitness and vital sign measurements) will further strengthen this questionnaire (Varni et al., 1999).

### **Moderator: Parent Experience of Child Illness**

**Background.** Parent stress is typically defined as the negative response felt by parents as they accommodate to the demands of the parental role (Deater-Deckard, 1998). The definition of parental stress varies across studies including slight emotional strain

from caregiving demands or post-traumatic stress disorder-type symptoms (Vrijmoet-Wiersma et al., 2008). For the purposes of this study, the definition of stress mirrored the definition as suggested by Bonner and colleagues (2006). Parental stress and uncertainty refer to the impaired short- or long-term feelings and/or fears associated with the uncertainty of illness treatment and future effects (Bonner et al., 2006).

For this study, parent stress was the moderating variable and theoretically ranged from low to high. This variable was operationalized through the Parent Experience of Child Illness Questionnaire (PECI; Appendix C; Bonner et al., 2006). The Peci is designed to assess caregiver concerns and the emotional resources of caregivers of children with chronic health conditions. The Peci was developed and assessed by the Pediatric Neuro-Oncology and Hematology-Oncology units of a major medical center with participants (n=149, aged 1 through 18) who were either in-treatment (57.1%) or had recently completed treatment for a brain tumor.

**Guilt and Worry Subscale.** Similar to the primary study, this proposed secondary data analysis utilized the short-form eleven items of the guilt/worry subscale of the Peci with total scores ranging between zero and forty-four. Parents rated items, such as “I worry that I may be responsible for my child’s illness in some way” and “I worry that my child’s illness will worsen/return,” on a scale of zero (never) to four (always). High scores on the Peci indicated high levels of parent stress. The guilt/worry subscale is highly related to parental stress and guilt/worry is frequently a source of reduced overall quality of life (Rosenberg et al., 2016). Analysis of internal consistency of the guilt/worry subscale yielded a Cronbach’s alpha of .89 (Bonner et al., 2006). Construct validity of the guilt/worry subscale was evaluated through correlational analysis with

participant reports on three measures, Brief Symptom Inventory (BSI), Caregiver Strain Questionnaire (CGSQ) and Impact of Events Scale (IES). The guilt/worry subscale correlates with the Anxiety ( $r=.36, p<.004$ ) and Depression ( $r=.37, p<.004$ ) domains of the BSI, the Internalized Subjective Burden domain of the CGSQ ( $r=.60, p=.008$ ), and the Intrusion ( $r=.51, p=.003$ ), Avoidance ( $r=.39, p<.013$ ) and Impact on Family Scale ( $r=.38, p=.003$ ) domains of the IES.

### **Demographics**

Initial data on demographic and illness variables were gathered through self-report measures and electronic medical records. The demographic questionnaire assessed child health history, family variables (including the number of children in the household) and parental health history (Appendix D).

**Barratt Simplified Measures Status.** Socioeconomic status was determined through the Barratt Simplified Measures Status questionnaire, which is a version of the Hollingshead Four Factor Form of Social Status (Hollingshead, 1975). The measure assesses SES based on caregiver education and occupation (Appendix E; Barratt, 2006).

**Medical Records.** Patient health records were reviewed to determine participant eligibility and identify the number of months in cancer treatment.

### **Data Analysis**

Initial data analysis consisted of assessing child, family and illness variables. Independent sample t-tests were conducted to compare scores on the PEGI, PedsQL, and CSHQ with normative values. Normative values were derived from results obtained during measure development. Pearson correlations were used to evaluate the relationship between the predictor variable of child sleep quality (total score of CSHQ) and outcome

variable of child health-related quality of life (total score on PedsQL). Regression analysis evaluated whether parent stress (total score on guilty/worry subscale of PEGI) was a moderator of the relationship between child sleep quality and child HRQL.

**Analysis for Aim 1.** To assess the first aim, descriptive statistics evaluated child, family and illness variables. Child variables included child age, child gender and time (months) in treatment. Family variables included parent age, parent gender, parent socioeconomic status and number of children in the household. Pearson correlation was used to test the relationships between covariates and child HRQL. Independent samples t-tests compared total scores on child sleep quality and child health-related quality of life in this sample to normative values. An independent samples t-test was also conducted on sample mean of reports of parent stress and normative value mean.

**Analysis for Aim 2.** Van Litsenburg and colleagues (2011) evaluated child sleep and child quality of life during the maintenance phase of ALL treatment in a sample of Dutch children. Results showed a moderate correlation between child sleep quality and child HRQL ( $r = -.6, p = .01$ ). It was expected that child sleep and child health-related quality of life will yield a medium effect size. With alpha set at .05, observed power to detect moderate correlations was 44.68 (Faul, Erdfelder, Lang, & Buchner, 2007). Prior research assessing caregiver stress and parent-report of child health-related quality of life demonstrated a significant negative relationship ( $\beta = -.32$ ) (Mullins et al., 2016). It was expected that parent stress and child health-related quality of life will yield a medium effect size. With alpha set at .05, observed power to detect moderate correlations was 44.68 (Faul, Erdfelder, Lang, & Buchner, 2007). Pearson correlation was used to analyze

the relationship between reports of child sleep problems with child health-related quality of life.

**Analysis for Aim 3.** Moderation analysis through hierarchical multiple regression was conducted to assess whether parent stress was a moderator of the relationship between child sleep quality and child health-related quality of life. Regression, rather than SEM, is the ideal method for moderation analysis when working with small sample sizes (Holmbeck, 1997). Child sleep quality scores and parent stress scores were mean centered around a score of 0 to reduce the threat of multicollinearity (Aiken & West, 1991). Hierarchical multiple regression was used to predict health-related quality of life by entering child sleep score and parent stress score in the first step and, next, entering the interaction of child sleep score and parent stress score. Post-hoc probing, as described by Holmbeck (2002), was used to plot regression lines and assess the significance of simple slopes to further evaluate the interaction.

### **Human Subjects Rights and Welfare**

#### **Informed Consent**

Study participant's rights and welfare were preserved through continued research staff integrity standards and Children's Hospital of Philadelphia IRB protocol. Participants were initially screened for eligibility through a hospital tumor registry and trained research staff then approached participants during in-hospital clinic visits. Participants were composed of parent-child dyads. Parents or guardians completed informed consent and all research questionnaires. Participants for this study were a vulnerable population, children between the ages of three and twelve who were undergoing ALL treatment, and child assent was obtained when applicable (children over

eight years old). Parent-child dyads could request participation termination at any time without penalty of compromised current or future CHOP medical care. All data were collected by self-report questionnaires, including demographic and social status surveys.

### **Risks of Participation**

For this study, the benefits outweighed the risks of participation and participation did not involve more than minimal risk. Participation benefits included parking validation and contribution to continued data collection of this population to identify future research directions. Possible risks of participation included discomfort or distress that may arise due to the nature of the information being gathered through the questionnaires. Hospital clinicians were available to address any participation discomfort and referral to long-term psychological services was provided should be deemed necessary by clinical or research staff.

### **Confidentiality**

Any accessed electronic medical record information was contained within the secure hospital system. Although there was a possibility of a breach of confidentiality, procedures were in place to reduce the chances of a breach from happening. Questionnaires did not contain any identifying information and names were not stored with participant ID numbers. Study computer documents were password protected and remained on the CHOP system. Hard copies of questionnaires were stored in a locked cabinet in CHOP, which was only accessible by the principal investigator and approved research staff. Following the publication of study results, all identifying information will be appropriately destroyed. This study has IRB approval by both The Children's Hospital of Philadelphia and Rutgers University- Camden. A data share agreement is in place

between The Children's Hospital of Philadelphia and Rutgers University- Camden, to allow for analysis of de-identified data.



## Results

### Correlations Among Variables

To evaluate Aim 1, first descriptive statistics for child, family and illness variables were assessed. The relationship between covariates and child health-related quality of life was then analyzed using Pearson correlation (Table F). Older caregivers reported higher SES ( $r=.39, p<.05$ ) and higher child health-related quality of life ( $r=.37, p<.05$ ). Parent stress was positively correlated with parent report of child health-related quality of life ( $r=-.38, p<.05$ ). While the relationship between siblings in the home and the number of reported sleep problems did not reach significance ( $F=(1,36)=.72, p=.40$ ), children with siblings were reported to have higher health-related quality of life ( $M=84.13, SD=13.58$ ) than children without siblings ( $M=74.82, SD=15.48$ ).

In this sample, younger child age was positively related to the number of reported sleep problems ( $r=-.43, p<.01$ ). Fathers tended to report fewer child sleep problems [ $F=(1,36)= 4.78, p=.03$ ] and greater child HRQL [ $F=(1,36)= 5.29, p=.03$ ] than mothers. Subscales of child sleep problems were not related to total child HRQL score or physical HRQL score. Child sleep anxiety ( $r=-.33, p=.04$ ) and parasomnias ( $r=-.37, p=.02$ ) were negatively associated with child psychosocial HRQL.

### Comparison of Variables to Normative Values

For Aim 1, t-tests were performed to evaluate sample reports of child sleep problems and child health-related quality of life with normative values. There was a significant difference in reports of child sleep problems (scores on Child Sleep Habits Questionnaire) between this sample ( $M=44.08, SD=6.99$ ) and the normative values ( $M=56.20, SD=8.90$ ) (Owens et al., 2000) such that the current sample reported a lower

number of sleep problems;  $t(37)=-10.68, p<.01$ . In this sample, a majority of participants ( $n=23, 60.5\%$ ) endorsed a Child Sleep Habits Questionnaire score above 41, which is the clinical cut-off score used to identify the presence of significant sleep problems (Owens et al., 2000). Additionally, there was a significant difference in reports of child HRQL (Pediatric Quality of Life Inventory) in this sample ( $M=82.66, SD=14.09$ ) and the sample evaluated during measure development ( $M=71.61, SD=16.79$ ), such that this sample reported greater health-related quality of life;  $t(37)=4.83, p<.01$ . A t-test was used to evaluate the relationship between sample report of parent stress with normative values. There was no significant difference in reports of caregiver stress (score on the Parent Experience of Child Illness) between this sample ( $M=1.89, SD=.78$ ) and the sample assessed during measure development ( $M=1.72, SD=.77$ ) (Bonner et al., 2006);  $t(37)=1.42, p=.16$ .

### **Moderation Analysis**

To support Aim 2, Pearson correlation was used to assess the relationships between child sleep quality and reports of child health-related quality of life. In this sample, there was no significant relationship between sleep quality and health-related quality of life ( $r=-.26, p>.05$ ) (Appendix F).

For Aim 3, hierarchical multiple regression was performed to assess the interaction of parent stress on the relationship between child sleep quality and child health-related quality of life (Holmbeck 1997, 2002). Child sleep score and parent stress score were first mean centered around a score of zero. Parent age remained a significant predictor of child health-related quality of life and was entered into step 1 of the model. The centered variables of child sleep score and parent stress score were entered in step 2.

The interaction of the centered child sleep score and parent stress score scores were entered into step 3 of the model predicting child HRQL (Appendix G). The moderation model accounted for 29% of the variance of child health-related quality of life scores and was significant [ $R^2=.29$ ,  $F(4, 33)=3.37$ ,  $p=.02$ ] (Appendix G), although the individual predictors were not significant (Appendix H). Post-hoc probing revealed non-significant simple slopes [High stress:  $t(4)=.284$ ,  $p=.778$ , Low stress:  $t(4)=-1.91$ ,  $p=.065$ ] (Appendix I).

## **Discussion**

Recent medical advances have resulted in high rates (91%) of 5-year survivorship following diagnoses of Acute lymphoblastic leukemia (ALL) (Ward et al., 2014). As such, evaluating the psychosocial functioning of children on cancer treatment, as well as their parents, is crucial in identifying patient and family needs to promote family functioning (Cousino & Hazen, 2013; Eiser and Morse, 2001). Child sleep quality has emerged as an important component of child health-related quality of life (HRQL), especially for children with a chronic health condition (Zupanec, Jones & Stremler, 2010; van Litsenburg et al., 2011; Hinds et al., 2007). Furthermore, heightened and prolonged parenting stress has been shown to predict poor child functioning and HRQL (Hamner et al., 2015). This study aimed to identify modifiable components of child HRQL for children undergoing ALL treatment.

Results did not suggest that child sleep quality was related to child HRQL, although prior research does support this relationship (Hart et al., 2005; Hinds et al., 2007; Steur et al., 2016). Consistent with prior research (van Litsenburg et al., 2011; Zupanec, Jones & Stremler, 2010), younger child age was associated with a greater number of sleep problems, suggesting that younger children may be more susceptible to sleep-related dysfunction than older children. Furthermore, domains of child sleep problems, specifically sleep anxiety and parasomnias, were related to poor HRQL, as previously reported by van Litsenburg and colleagues (2011). Given the significant, possibly traumatic, impact of cancer diagnosis and management on psychosocial functioning (Bruce, 2006), it is possible that child anxiety and stress may be related to sleep problems (Wright, 2011), such as bed wetting and nightmares (Levin & Nielsen,

2007), as reported in the parasomnia domain of the Child Sleep Habits Questionnaire. Early screening of sleep problems for children on cancer treatment may improve both child sleep and child HRQL during treatment and into survivorship.

When comparing the child health-related quality of life scores in this sample to normative values, unexpectedly, this sample's scores were significantly higher than normative values of children on cancer treatment. This may, in part, be due to the fact that children in this sample were younger ( $M=6.7$  years,  $SD=2.48$ ) than children in the normative value sample ( $M=8.2$  years). As Sung and colleagues (2011) note, younger child age is often associated with higher reports of HRQL. Furthermore, families in this sample reported higher socioeconomic status ( $M=46.99$ ,  $SD=10.58$ ) than families in the normative value sample ( $M=35$ ). Prior research suggests that higher SES is related to higher scores on child HRQL (Sung et al., 2011). Data collection on child HRQL took place at the beginning of a chemotherapy cycle, where children had not received chemotherapy for the previous 28 days. Given this timing, parents may have reported higher health-related quality of life than data collected at various time points during chemotherapy cycles. Additionally, small sample sizes and large standard deviations on the Pediatric Quality of Life Inventory for both this sample ( $n=38$ , PedsQL  $SD=14.09$ ) as well as the sample used for measure development and validation ( $n=61$ , PedsQL  $SD=16.79$ ) may have resulted in sampling biases. Further research with larger samples of HRQL for children in the maintenance phase of ALL treatment may support study findings.

As expected, results showed a significant difference in reports of child sleep problems in this sample compared to healthy controls. However, parents in this sample

reported fewer sleep problems (lower scores on the Child Sleep Habits Questionnaire) than healthy controls. Prior research suggests that children on cancer treatment report significant disruptions in sleep routine and overall poor sleep quality (Gedaly-Duff et al., 2006; Hinds et al., 2007; Walter et al., 2015; van Litsenburg et al., 2011). This finding may be related to the nature of data collection, specifically the single-reporter, subjective and retrospective parent report of child sleep behaviors. Continued research on the reliability of parent report with objective sleep measures is needed (Markovich et al., 2015). Study results highlight that, in this sample, mothers of young children reported the greatest number of sleep problems.

While children in this sample reported fewer sleep problems than healthy controls, a majority of children in this sample reported clinically significant sleep problems and the average child sleep score for this sample was higher than the clinical cut-off of 41. These findings suggest the presence of significant sleep problems. This unexpected report of child sleep quality in a sample of children with cancer may also be related to the response shift phenomenon. Response shift refers to the under-reporting of specific concerns, a process which may occur as individuals adjust to the demands of a cancer diagnosis and disease management. Typically, this is observed with reports of HRQL in samples of adults and children with cancer (Brinksma, Tissing, Sulkers & Kamps, 2014). Brinksma and colleagues (2014) conducted a study assessing response shift of HRQL in children undergoing cancer treatment. Significant response shift in reports of HRQL was observed for both child self-report as well as parent proxy-reports. This may be one explanation as to why reports of sleep quality are lower than normative values.

While in this study, the interaction model was not significant, results did suggest a trend that for parents with low stress, high child sleep quality was associated with higher child HRQL. Identifying and supporting parents with low stress may promote better child outcomes. These findings also suggest that for parents with high stress, child sleep quality was not related to child HRQL. Continued research in identifying salient, modifiable components of child HRQL is crucial for parents with high stress. Within the model predicting child HRQL, Parent age remained a significant independent predictor. Consistent with prior research (Eiser, Eiser & Stride, 2005), older parent age was related to higher reports of child HRQL. Identifying families who may be at risk for poor child HRQL, such as young parents, can aid the treatment team in providing early psychosocial support to promote child, parent and family outcomes.

Correlational analysis highlighted the negative relationship between parent stress and reports of child health-related quality of life. Findings suggest that decreased parent stress is associated with increased reports of child HRQL. This is consistent with prior research on the impact of parent stress on child functioning and HRQL (Abidin, 1992; Drotar, 1997; Hamner et al., 2015). Parents of children on cancer treatment, particularly young mothers, may be at risk for increased stress throughout treatment. Targeted psychosocial support, specifically through monitoring and addressing stress in young parents, may improve child outcomes.

### **Study Limitations**

There were several potential limitations with study findings. Questionnaire administration in the hospital clinic setting, rather than in the participant's home, may impact parent reports of stress and child HRQL (Meeske et al., 2004). A common

limitation inherent in data collection is social desirability biases (Adams, Soumerai, Lomas & Ross-Degnan, 1999), whereby parents may report inaccurate scores on questionnaires in order to provide socially appropriate answers. The measures in the proposed study were self-administered and, as reviewed by the RA during the consent process, the participant survey answers were de-identified. These procedures may contribute to reduced social desirability biases (Nederhof, 1985). By completing data with an RA present to answer questions and encourage measure completion, response biases may have been overcome. Furthermore, parent reports on questionnaires are a subjective, single reporter account of behaviors; supplemental objective measures and multi-method approaches may strengthen study results.

Finally, this study has a small sample size ( $n=38$ ), which reduces data analysis power and generalizability. However, given the potential impact within the family system on child HRQL, continued research in this population is crucial to improving child and caregiver functioning.

### **Future Directions**

Future research directions should continue to assess modifiable components of child health-related quality of life for children on cancer treatment. Assessing child, parent and family factors that contribute to child HRQL may aid in identifying families who can benefit from targeting psychosocial support. Administering interventions to families who report high parent stress or child sleep problems, such as parent education on healthy sleep routines, may promote higher child HRQL. Future research should aim to include larger sample sizes to enhance generalizability, and incorporate multi-method approaches in order to strengthen study findings, and better assess variables, such as child sleep.



Continued psychosocial research in the pediatric oncology population is crucial to improving outcomes for children, both on treatment and in survivorship, as well as their families.

## Appendix A

### Child's Sleep Habits Questionnaire (CSHQ; Owens, Spirito, & McGuinn, 2000)

The following statements are about your child's sleep habits and possible difficulties with sleep. Think about the past week in your child's life when answering the questions. If last week was unusual for a specific reason (such as your child had an ear infection and did not sleep well or the TV set was broken), choose the most recent typical week.

Answer **USUALLY** if something occurs **5 or more times** in a week

Answer **SOMETIMES** if it occurs **2-4 times** in a week;

Answer **RARELY** if something occurs **never or 1 time** during a week.

Also, please indicate whether or not the sleep habit is a problem by circling "Yes," "No," or "Not applicable (N/A)."

#### **Bedtime**

Write in child's bedtime:

	<i>Usually (5-7 nights)</i>	<i>Sometimes (2-4 nights)</i>	<i>Rarely (0-1 night)</i>	<i>Problem? (circle)</i>
1. Child goes to bed at the same time at night				Yes No NA
2. Child falls asleep within 20 minutes after going to bed				Yes No NA
3. Child falls asleep alone in own bed				Yes No NA
4. Child falls asleep in parent's or sibling's bed				Yes No NA
5. Child needs parent in the room to fall asleep				Yes No NA
6. Child struggles at bedtime (cries, refuses to stay in bed, etc.)				Yes No NA
7. Child is afraid of sleeping in the dark				Yes No NA
8. Child is afraid of sleep alone				Yes No NA

#### **Sleep Behavior**

Child's usual amount of sleep each day: \_\_\_\_\_ hours and \_\_\_\_\_ minutes  
(combining nighttime sleep and naps)

	<i>Usually (5-7 nights)</i>	<i>Sometimes (2-4 nights)</i>	<i>Rarely (0-1 night)</i>	<i>Problem? (circle)</i>
9. Child sleeps too little				Yes No NA
10. Child sleeps the right amount				Yes No NA
11. Child sleeps about the same amount each day				Yes No NA
12. Child wets the bed at night				Yes No NA
13. Child talks during sleep				Yes No NA
14. Child is restless and moves a lot during sleep				Yes No NA
15. Child sleepwalks during the night				Yes No NA
16. Child moves to someone else's bed during the night (parent, brother, sister, etc.)				Yes No NA
17. Child grinds teeth during sleep (your dentist may have told you this)				Yes No NA
18. Child snores loudly				Yes No NA
19. Child seems to stop breathing during sleep				Yes No NA
20. Child snorts and/or gasps				Yes No NA
21. Child has trouble sleeping away from home (visiting relatives, vacation)				Yes No NA
22. Child awakens during night screaming, sweating, and inconsolable				Yes No NA
23. Child awakens alarmed by a frightening dream				Yes No NA

**Waking During the Night**

	<i>Usually (5-7 nights)</i>	<i>Sometimes (2-4 nights)</i>	<i>Rarely (0-1 night)</i>	<i>Problem? (circle)</i>
24. Child awakes once during the night				Yes No NA
25. Child awakes more than once during the night				Yes No NA
Write the number of minutes a night waking usually lasts:				

**Morning Waking**

Write in the time of day child usually wakes in the morning: -

	<i>Usually (5-7 nights)</i>	<i>Sometimes (2-4 nights)</i>	<i>Rarely (0-1 night)</i>	<i>Problem? (circle)</i>
26. Child wakes by him/herself				Yes No NA
27. Child wakes up in negative mood				Yes No NA
28. Adults or siblings wake up child				Yes No NA
29. Child has difficulty getting out of bed in the morning				Yes No NA
30. Child takes a long time to become alert in the morning				Yes No NA
31. Child seems tired				Yes No NA

**Daytime Sleepiness**

During the past week, your child has appeared very sleepy or fallen asleep during the following (check all that apply):

	1 Not Sleepy	2 Very Sleepy	3 Falls Asleep
Watching TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Riding in car	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix B

The Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Rode, 1999).

## Directions

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem each one** has been for **your child** during the past **one month** by circling:

**0** is it is **never** a problem

**1** if it is **almost never** a problem

**2** if it is **sometimes** a problem

**3** is it is **often** a problem

**4** if it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

In the past ONE month, how much of a problem has your child had with...

<b>Physical Functioning (problems with...)</b>	<b>Never</b>	<b>Almost Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
1. Walking more than one block	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores, like picking up his or her toys	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4

<b>Emotional Functioning (problems with...)</b>	<b>Never</b>	<b>Almost Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

<b>Social Functioning (problems with...)</b>	<b>Never</b>	<b>Almost Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
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1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

<b>School Functioning (problems with...)</b>	<b>Never</b>	<b>Almost Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with school activities	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4

## Appendix C

## Parent Experience of Child Illness (PECI; Bonner et al., 2006)

Directions: This questionnaire is concerned with the thoughts and feelings related to parenting a child who is living with or has experienced a chronic illness. Read each statement and then try to determine how well it describes your thoughts and feelings over the past month.

	Never	Rarely	Sometimes	Often	Always
1. I feel guilty because my child became ill while I remained healthy	0	1	2	3	4
2. I worry that I may be responsible for my child's illness in some way	0	1	2	3	4
3. I worry then it any minute, things might take a turn for the worse	0	1	2	3	4
4. I think about whether or not my child will die	0	1	2	3	4
5. I am afraid of this diagnosis occurring in another member of my immediate family	0	1	2	3	4
6. I trust myself to manage the future whatever happens	0	1	2	3	4
7. When my child is playing actively, I find myself worried that s/he will get hurt	0	1	2	3	4
8. I worry that my child's illness will worsen or return	0	1	2	3	4
9. I worry about something bad happening to my child when s/he is out of my care	0	1	2	3	4
10. I wake up during the night check on my child	0	1	2	3	4
11. When I'm not with my child, I find myself thinking about whether or not s/he is okay	0	1	2	3	4

## Appendix D

## Demographic Information

**Background Information and Developmental History Questionnaire****Please answer all questions to the best of your ability.**

<b>Identifying Information</b>	
Child Current Age:	Age: _____
Child's Race/Ethnicity (Check <u>ALL</u> that apply):	<input type="checkbox"/> White <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Black or African American <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> Hispanic <input type="checkbox"/> Other
<b>Family Information</b>	
Parent/Guardian (1)  <input type="checkbox"/> Biological Mother/Father <input type="checkbox"/> Step Mother/Father <input type="checkbox"/> Adoptive Mother/Father <input type="checkbox"/> Grandmother/Grandfather <input type="checkbox"/> Other Relative <input type="checkbox"/> Other Non-Relative	Race/Ethnicity: (check that <u>ALL</u> that apply):  <input type="checkbox"/> White <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Hispanic <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> Black or African American <input type="checkbox"/> Hispanic <input type="checkbox"/> Other: _____
Parent/Guardian (2)  <input type="checkbox"/> Biological Mother/Father <input type="checkbox"/> Step Mother/Father <input type="checkbox"/> Adoptive Mother/Father <input type="checkbox"/> Grandmother/Grandfather <input type="checkbox"/> Other Relative <input type="checkbox"/> Other Non-Relative	Race/Ethnicity: (check <u>ALL</u> that apply):  <input type="checkbox"/> White <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Hispanic <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> Black or African American <input type="checkbox"/> Hispanic <input type="checkbox"/> Other: _____
The Child's Biological Parents are:	<input type="checkbox"/> Married <input type="checkbox"/> Divorced <input type="checkbox"/> Separated <input type="checkbox"/> Widowed <input type="checkbox"/> Never Married <input type="checkbox"/> Other (please explain):



Please list all brothers and sisters, including full, half and step-siblings.	<u>Relationship</u>   	<u>Age</u>   	<u>Living with child now?</u> <input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes	
<b>Pregnancy and Birth History</b>				
Did the child's mother have any health problems during her pregnancy with the child?	<input type="checkbox"/> No <input type="checkbox"/> Yes (please describe):			
The baby was born:	<input type="checkbox"/> Full-Term <input type="checkbox"/> Premature (____ weeks early) <input type="checkbox"/> Late (____ weeks late) Birth Weight:      lbs.      oz.			
Were there any delivery complications or birth defects noted?	<input type="checkbox"/> No <input type="checkbox"/> Yes (please describe):			
Were there any problems in the first year of life?	<input type="checkbox"/> No <input type="checkbox"/> Yes (please describe):			
<b>Developmental History</b>				
Please indicate the age when your child:	Crawled _____ Walked alone _____ Spoke first words _____ Fully bladder trained _____			
<b>Temperament and Social</b>				
Has the child experienced: (check <u>ALL</u> that apply)	Difficult to comfort Sleep problems Fussy/Irritable Unhappy Lack of Affection High-energy Shy/Cautious	<u>1<sup>st</sup> year of life</u> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<u>This year</u> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<u>Ongoing</u> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Medical and Oncology History</b>				
Oncology Diagnosis:	Diagnosis: _____ Date of Diagnosis: _____			
List any other serious illnesses, injuries, hospitalizations, or surgeries:	<input type="checkbox"/> None      or      list incidents with dates: _____ _____			
Any head injuries?	<input type="checkbox"/> No <input type="checkbox"/> Yes (please describe):			
Has the child ever had:	<input type="checkbox"/> Seizures or Epilepsy <input type="checkbox"/> Loss of Consciousness <input type="checkbox"/> Tics/Twitching <input type="checkbox"/> Exposure to Toxins <input type="checkbox"/> Lead Poisoning			

	<input type="checkbox"/> Asthma
Current other medications other than chemotherapy:	Medication: _____ Dose: _____ Reason: _____ Medication: _____ Dose: _____ Reason: _____
Has a medical professional ever diagnosed your child with Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD)	<input type="checkbox"/> No <input type="checkbox"/> Yes  If yes, does your child take medication for ADD/ADHD? <input type="checkbox"/> No <input type="checkbox"/> Yes Medication name and dose: _____
Has your child ever been diagnosed with any of the following sleep disorders (check all that apply)?	<input type="checkbox"/> Obstructive Sleep Apnea <input type="checkbox"/> Restless Legs Syndrome <input type="checkbox"/> Periodic Limb Movements of sleep <input type="checkbox"/> Narcolepsy <input type="checkbox"/> Insomnia <input type="checkbox"/> Other Sleep Disorder (please list): _____
Does your child snore?	<input type="checkbox"/> No <input type="checkbox"/> Yes
<b>Child's Education</b>	
Child's current school:	School Name: _____  <input type="checkbox"/> Public <input type="checkbox"/> Private Grade: _____

## Appendix E

## The Barratt Simplified Measure of Social Status (BSMSS; Barratt, 2006)

Circle the appropriate number for your Mother's, your Father's, your Spouse / Partner's, and your level of school completed and occupation. If you grew up in a single parent home, circle only the score from your one parent. If you are neither married nor partnered circle only your score. If you are a full time student circle only the scores for your parents.

Level of School Completed	Mother	Father	Spouse	You
Less than 7 <sup>th</sup> grade	3	3	3	3
Junior high / Middle school (9 <sup>th</sup> grade)	6	6	6	6
Partial high school (10 <sup>th</sup> or 11 <sup>th</sup> grade)	9	9	9	9
High school graduate	12	12	12	12
Partial college (at least one year)	15	15	15	15
College education	18	18	18	18
Graduate degree	21	21	21	21

Circle the appropriate number for your *Mother's*, your Father's, your Spouse / Partner's, and your occupation. If you grew up in a single parent home, use only the score from your parent. If you are not married or partnered circle only your score. If you are still a full-time student only circle the scores for your parents. If you are retired use your most recent occupation.

Occupation	Mother	Father	Spouse	You
Day laborer, janitor, house cleaner, farm worker, food counter sales, food	5	5	5	5
Garbage collector, short-order cook, cab driver, shoe sales, assembly line	10	10	10	10
Painter, skilled construction trade, sales clerk, truck driver, cook, sales	15	15	15	15
Automobile mechanic, typist, locksmith, farmer, carpenter, receptionist,	20	20	20	20
Machinist, musician, bookkeeper, secretary, insurance sales, cabinet	25	25	25	25
Supervisor, librarian, aircraft mechanic, artist and artisan, electrician, administrator, military	30	30	30	30
Nurse, skilled technician, medical technician, counselor, manager, police and fire personnel, financial manager, physical,	35	35	35	35
Mechanical, nuclear, and electrical engineer, educational administrator, veterinarian, military officer, elementary,	40	40	40	40

Physician, attorney, professor, chemical and aerospace engineer, judge, CEO, senior manager, public official,	45	45	45	45
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#### Level of School Completed Scoring

1	If you grew up with both parents add <u>Mother</u> + <u>Father</u> and divide by 2. If you grew up with one parent enter that score to the right.		
2	If you are married or partnered add <u>Spouse</u> + <u>You</u> and divide by 2. If you live alone enter <u>Your</u> score to the right.		
3	Double your score from line 2. If you are a full-time student leave this blank.		
4	If you are a full-time student enter only your parents' score. Add line 1 and line 3 then divide by 3 (three) for a <b>TOTAL EDUCATION</b>		

#### Occupation Scoring

1	If you grew up with both parents add <u>Mother</u> + <u>Father</u> and divide by 2. If you grew up with one parent enter that score to the right.		
2	If you are married or partnered add <u>Spouse</u> + <u>You</u> and divide by 2. If you live alone enter <u>Your</u> score to the right.		
3	Double your score from line 2. If you are a full-time student leave this blank.		
4	If you are a full-time student enter only your parents' score. Add line 1 and line 3 then divide by 3 (three) for <b>TOTAL OCCUPATION</b>		

#### TOTAL Score

Add <b>TOTAL EDUCATION</b> + <b>TOTAL OCCUPATION</b> : Score should be between 8 and 66	
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## Appendix F

**Table 1**

*Correlations Among Child, Family and Illness Covariates with PEGI, PedsQL and CSHQ*

	<u>Mean (SD)</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>
1. Child Age [3-12 years]	6.72 (2.48)	.32*	-.08	-.02	-.03	.06	-.43**
2. Caregiver Age [20-52 years]	36.63 (6.65)	-	-.20	.39*	-.31	.37*	-.09
3. Time Since Diagnosis (months)	12.10 (8.49)	-	-	-.19	-.12	-.09	-.04
4. Barratt Social Status Score	46.99 (10.58)	-	-	-	-.41**	.11	-.01
5. PEGI Score	1.89 (0.78)	-	-	-	-	-.38*	-.25
6. PedsQL Score	82.66 (14.09)	-	-	-	-	-	-.26
7. CSHQ Score	44.08 (6.99)	-	-	-	-	-	-

*Notes.* \* $p < .05$ . \*\* $p < .01$ .

## Appendix G

	<u>Variable</u>	<u>R<sup>2</sup></u>	<u>SE of the Estimate</u>	<u>ΔR<sup>2</sup></u>	<u>ΔF</u>	<u>Sig. F Change</u>	<u>df1</u>	<u>df2</u>
Model 1	Parent Age	.14	13.29	.14	5.61*	.02	1	36
Model 2	CSHQ, PECI	.25	12.82	.10	2.33	.11	2	34
Model 3	CSHQ x PECI	.29	12.57	.05	2.38	.13	1	33

*Notes.* \*p<.05. \*\*p<.01.

## Appendix H

Table 1					
<i>Hierarchical Multiple Regression Analysis Predicting HRQL</i>					
		B***	B Standard Error	<i>t</i>	<i>p</i>
1	Constant	54.16	12.22	4.43	.00
	Parent Age	.78*	.33	2.37	.02
2	Constant	61.51	12.41	4.96	.00
	Parent Age	.58	.33	1.73	.09
	CSHQ	-.34	.33	-1.10	.28
	PECI	-4.54	2.93	-1.55	.13
3	Constant	57.23	12.47	4.59	.00
	Parent Age	.67*	.33	2.01	.05
	CSHQ	-.44	.31	-1.42	.17
	PECI	-4.45	2.87	-1.55	.13
	CSHQ x Peci	.72	.47	1.54	.13
Notes. *p<.05. **p<.01. ***B= Unstandardized Beta Coefficients.					

## Appendix I

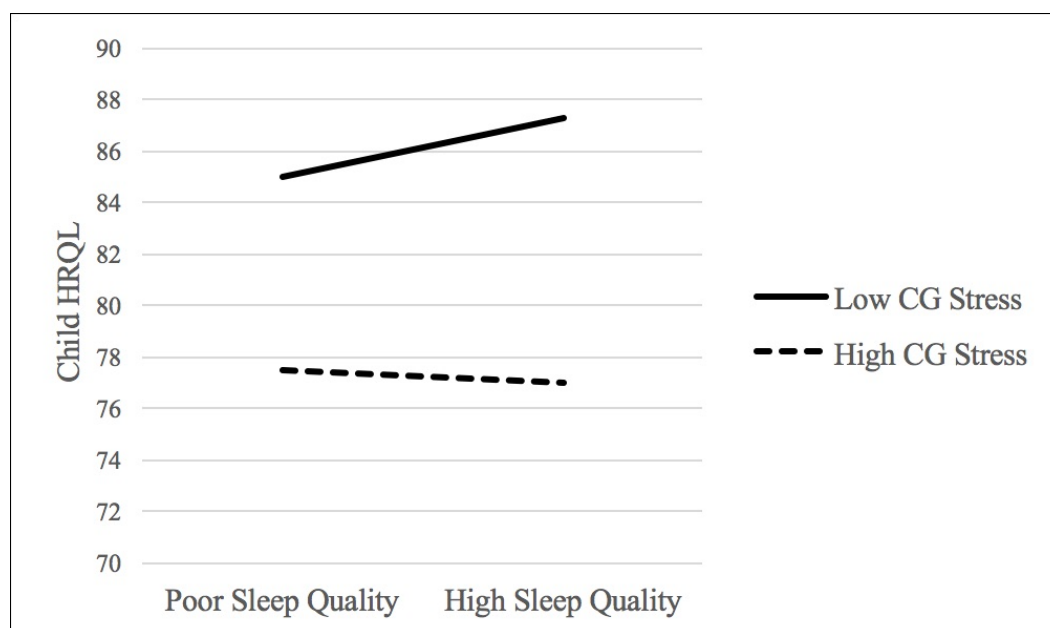


Figure 1. Child sleep quality and child HRQL moderated by caregiver stress.



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