SLEEP QUALITY, STRESS, CAREGIVER BURDEN, AND QUALITY OF LIFE IN MATERNAL CAREGIVERS OF YOUNG CHILDREN WITH BRONCHOPULMONARY DYSPLASIA

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A DISSERTATION

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Mothers are usually the primary caregivers of young children with a chronic illness such as bronchopulmonary dysplasia (BPD), and may have no formal caregiver training. Children with BPD often require complex healthcare at home (complex medication regimens, oxygen via nasal cannula, Gastrostomy feedings, etc.), thus many maternal caregivers experience difficulty balancing the needs of their child with their own needs and other responsibilities. As such, maternal caregivers may report increased levels of stress and caregiver burden, as well as decreased quality of life (QOL). Additionally, a great number of maternal caregivers report poor sleep quality due to nighttime caregiving duties. The primary purpose of this study is to examine relationships between sleep quality, stress, caregiver burden, and QOL, as well as influences of these variables on QOL.

The sample consisted of 61 maternal caregivers, who were predominantly minority (67.2% African American) and had an average age of 29.59 years. The majority of maternal caregivers were single (62.3%), and 88.5% had a high school education or greater. The average age of the child with BPD was 13.93 months, and had been living at home for, on average, 8.79 months. Maternal caregivers reported sleeping less than 6 hours per night (average 5.8), and the majority (78.7%) reported disturbed sleep (as determined by a score of 5 or greater on the Pittsburgh Sleep Quality Index).
Significant Pearson’s correlations were found between sleep quality and depressive symptoms ($r=.529, p=.000$), stress ($r=.284, p=.027$), and inversely QOL ($r= -.292, p=.022$). Caregiver burden was significantly correlated with stress ($r=.326, p=.010$). Sleep quality ($p=.000, t=-3.757$) and depressive symptoms ($p=.011, t=2.635$) were found to be the most significant predictors of QOL using forced entry multiple linear regression in a model that explained 30% of the variance in QOL. Stress was not found to mediate the relationship between sleep quality and caregiver burden and QOL.

Improving sleep quality and depressive symptoms in maternal caregivers may help to improve QOL. Clinicians should assess caregiver’s sleep and provide education on the importance of sleep for overall health.

Keywords: Sleep Quality, Stress, Caregiver Burden, Maternal Caregivers, Bronchopulmonary Dysplasia, Quality of Life
DEDICATION

I dedicate this dissertation to my family, and my parents especially. Without their support, their patience, their understanding, their endless encouragement, their optimism, their humor, and their strength, I do not know how I would have survived this process. Mom and Dad, you always knew what to say, when to say it, and when it was best to just duck and cover. If anyone ever asks where I get it from…
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CHAPTER ONE

INTRODUCTION

While recent advances in healthcare treatments of premature or chronically ill infants have led to increased survival rates, these infants are still at risk for developing chronic illnesses, such as bronchopulmonary dysplasia (BPD) (Gracey, Talbot, Lankford, & Dodge, 2002). The rates of BPD have decreased over the years due to advanced treatments, though acuity and healthcare expenditures have increased, and infants with BPD are now spending longer in the NICU and requiring more complex care at home (Stroustrup & Trasande, 2010). The National Heart Lung and Blood Institute (NHLBI) reported that nearly 1 in 3 babies born with very low birth weight (less than 1,500 grams) will be diagnosed with BPD (National Heart Lung Blood Institute, 2009). In contrast, only 4 out of 1,000 births result in a child diagnosed with cerebral palsy (MassGeneral Hospital for Children, 2011). Gracey et al. (2002) estimated that there are as many as 7,200 new cases of BPD each year, the majority of these cases come as a result of healthcare treatments (ventilator, requiring oxygen) or lung immaturity (Gracey et al., 2002). Upon hospital discharge, many of these infants will have multiple co-morbidities and are sent home with complex healthcare treatment regimens. The primary caregiver,
usually the mother, is ultimately responsible for providing the healthcare treatments, monitoring, and general physical care of the child while at home, and she may have received little to no preparation prior to the child’s discharge (Singer et al., 2010). Caregivers often report poor sleep quality, and stress and burden are often high, leading, possibly, to overall poor quality of life (QOL) (Arafa, Zaher, El-Dowaty, & Moneeb, 2008; Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008; Meltzer, 2008).

BPD is a chronic illness, most commonly found in premature infants as a result of immature lungs or treatments in the NICU (such as ventilation or oxygen administration) (Gracey et al., 2002). The definition of BPD has undergone several changes throughout the years (Gracey et al., 2002), though most health providers now use the definition proposed by the National Institute of Child Health and Human Development, the NHLBI, and the Office of Rare Diseases (Jobe & Bancalari, 2001). A general definition of BPD is radiographic changes to the lungs over time, as well as the need for supplemental oxygen at a certain time post conceptual age (Gracey et al., 2002). Further, physiologic definitions include two different groups of infants. At 35-37 weeks’ postmenstrual age (the gestational age plus the chronological age), if the infant was treated with mechanical ventilation or continuous positive airway pressure (CPAP), or required supplemental oxygen of a concentration ≥ 30% with oxygen saturations of 90-96%, the infant is considered to have BPD without further testing (Walsh et al., 2004). In addition, infants needing supplemental oxygen < 30% at rest with oxygen saturations between 90-96% or supplemental oxygen ≥ 30% with oxygen saturations > 96% would undergo a stepwise,
timed reduction of oxygen to room air. Those infants who have failed to wean off of oxygen are considered to have BPD (Walsh et al., 2004).

In the clinical management of BPD, the condition is classified as mild, moderate or severe (Deakins, 2009). These classifications are often used in clinical management to determine healthcare treatments. Infants less than 32 weeks postmenstrual age presenting with specific clinical manifestations (such as tachypnea, increased work of breathing and retractions, hypercarbia, typically with a compensated respiratory acidosis, changes in chest x-ray, and in some cases, reactive airway disease and wheezing), requiring supplemental oxygen at 28 days of life, and who were weaned to room air by 36 weeks or at hospital discharge, are considered to have mild BPD (Jobe & Bancalari, 2001). Moderate BPD is defined as infants requiring < 30% continuous oxygen at 36 weeks postmenstrual age or at hospital discharge, and infants remaining on ≥ 30% oxygen and on CPAP are considered to have severe BPD (Jobe & Bancalari, 2001). Home healthcare treatment regimens for children with BPD often involve home oxygen therapy, pulse oximetry monitoring, specialized nutrition plans, complex medication schedules, nebulizer breathing treatments, and other therapies such as physical or occupational therapy due to developmental delays (Deakins, 2009; Holditch-Davis, Docherty, Miles, & Burchinal, 2001; Singer et al., 2010).

High levels of caregiving burden related to their child’s treatment are often reported by caregivers of chronically ill children and found to be related to their child’s diagnosis and complex care needs (Pederson, Parsons, & Dewey, 2004). Maternal caregivers of children requiring enteral nutrition have reported increased levels of caregiver burden, increased levels of stress, and sleep deprivation (less than 4-6 hours a
night of sleep), as well as poor quality of sleep (Calderon et al., 2010; Holditch-Davis, Miles, Burchinal, & Goldman, 2011). While studies of caregivers for adult family members post-stroke have repeatedly reported caregivers as having poor sleep or being sleep deprived (Rittman, Hinojosa, & Findley, 2009), few studies have examined sleep in caregivers of children (Meltzer, Boroughs, & Downes, 2010). Much of the focus of the research on sleep in caregivers has been on caregivers to adult family members (Meltzer & Mindell, 2006).

Along with burden, stress also influences a caregiver’s overall well-being and QOL (Lyon, 2000). Increased levels of burden and stress in caregivers of children requiring home enteral nutrition was found to be associated with significantly increased levels of anxiety and decreased QOL in caregivers (Calderon et al., 2010). In caregivers of children with cancer, stress was found to mediate the relationship between QOL and age, marital status, race, and educational status, so that increased stress led to decreased QOL (Witt et al., 2010). Reporting increased stress was also found to be related to decreased sleep quality in caregivers of children with developmental disabilities (Gallagher, Philips, & Carroll, 2010). However, the relationship between stress, caregiver burden, and sleep quality on overall QOL in caregivers of children has not been examined.

Sleep quality has been linked to several aspects of health, including stress, burden, and QOL (McEwan, 2006). For the purposes of this study, sleep quality was defined as reported sleep duration, habitual sleep efficiency, sleep disturbance, and use of sleep medications (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). Sleep quantity (which includes sleep restriction or sleep deprivation) may be an aspect of sleep quality;
however, sleep quality encompasses subjective perception of sleep, as well as quantity. A caregiver may report adequate hours of sleep, but may also report poor quality of sleep (Kravitz et al., 2003). Sleep deprivation has been shown to influence memory, with less sleep leading to poorer memory consolidation and short-term memory recall. Sleep quality may be influenced by a number of external and internal factors unrelated to caregiving, such as diet, medications, exercise, comorbid conditions (such as obstructive sleep apnea, insomnia, high blood pressure, or diabetes), hormonal activity within the body, and weight (Baker, Kahan, Trinder, & Colrain, 2007; K. A. Lee, Kaffke, & McEnany, 2000; Matthews et al., 2008). Age also plays an important role in sleep, with circadian rhythm changes occurring as a person ages (older adults often feel tired earlier, and wake up sooner than younger adults or adolescents) (Kripke et al., 2005).

In caregivers of children with special healthcare needs, sleep quality may be especially important, as caregivers are already at an increased risk for higher levels of stress and caregiver burden and adverse health outcomes (Thyen, Kuhlthau, & Perrin, 1999). While researchers of sleep in caregivers of adults convey that caregivers consistently report disrupted sleep and poor sleep quality, these relationships have not been examined for caregivers of children with chronic conditions, such as BPD (Meltzer & Mindell, 2006).

Previous studies have reported that caring for a child with BPD does result in increased stress and depressive symptoms in maternal caregivers (Holditch-Davis et al., 2001). A child with BPD will require home monitoring equipment, a specialized diet, and home oxygen (Deakins, 2009). Maternal caregivers of young children with BPD have reported increased feelings of stress and anxiety due to the demands of caring for
the child, including monitoring equipment, maintaining a feeding and medication regimen, and navigating an oftentimes complex healthcare environment (Singer et al., 2010). Compounded are feelings of isolation and increased depressive symptoms, as maternal caregivers have reported reluctance to leave the house, for fear of exposing their child to contagions (such as cold or flu viruses) and the fear of public scrutiny the maternal caregiver may face with a child on oxygen (a visible and noticeable trait) (Jackson & Vessey, 1996; Singer, Yamashita, Lilien, Collin, & Baley, 1997).

Background of Study

Many children diagnosed with BPD will require complex healthcare treatments in the home setting. In the majority of cases the mother is the one who assumes primary responsibility for the child’s care, and she often has little to no formal health care training and may have several other stressors in her life (Meltzer & Mindell, 2006; Ojmyr-Joelsson, Nisell, Frenckner, Rydelius, & Christensson, 2009). The complexity of the child’s care needs may lead to increased levels of caregiver strain and burden, perceived stress, and lowered sleep quality (Brannan, Heflinger, & Bickman, 1997; Happe & Berger, 2002). All of these factors in combination may influence the caregiver’s overall QOL (Arafa et al., 2008). However, little is known about the relationships among these variables, or how they may influence each other, especially sleep quality (Meltzer & Moore, 2008).

Poor sleep quality and disrupted sleep patterns have been reported in caregivers of adult family members with cancer and dementia, and have been found to be related to increased levels of depression, anxiety, and stress, as well as poor QOL (P. A. Carter,
2002; Happe & Berger, 2002; Rittman et al., 2009). Likewise, poor quality of sleep, disrupted sleep, and sleep deprivation have also been linked to diabetes, obesity, increased blood pressure, poor memory consolidation, and fatigue in adults (Knutson et al., 2009; McEwan, 2006). Few studies have focused on sleep in caregivers of children with a chronic illness (Meltzer et al., 2010; Meltzer & Mindell, 2006).

Sleep has been found to be related to QOL in the general adult population (Schubert et al., 2002). In a sample of 2,800 community-dwelling healthy adults, participants were asked to what extent they experienced difficulty getting to sleep, waking up at night, and having trouble getting back to sleep, (which the authors named “insomnia traits”), and then were asked about their QOL. Those participants who reported one or more “insomnia trait” showed significantly poorer QOL in every domain assessed (Schubert et al., 2002). Similarly, in a sample of 5,816 healthy adults from six different cities, subjective sleep symptoms (trouble falling asleep, disrupted sleep, and daytime fatigue) significantly predicted poor QOL, as well as sleep disordered breathing (Baldwin et al., 2001). Therefore, while it has been well established in the general adult population that sleep is a significant aspect of QOL, little is known about how sleep influences QOL in maternal caregivers of young children with a chronic condition, a vulnerable population. Parental caregivers of children with a chronic illness have reported poor sleep quality and disrupted sleep patterns, as well as increased levels of fatigue (Cottrell & Khan, 2005; Meltzer, 2008; Meltzer & Mindell, 2006). Parental caregivers have also reported increased levels of depressive symptoms and stress related to poor sleep quality and disrupted sleep patterns (Gallagher et al., 2010; Meltzer, 2008; Meltzer & Mindell, 2006). Poor sleep quality has been shown to negatively influence a parental
caregiver’s overall QOL; however, there are only a few studies that have examined sleep quality as it relates to QOL in caregiver’s of chronically ill children (Chien et al., 2003; Monaghan, Hilliard, Cogen, & Streisand, 2009). No studies have been published, to date, on sleep quality, stress, caregiver burden, and QOL in maternal caregivers of children with BPD (Meltzer & Moore, 2008).

Sleep needs may vary by age of the caregivers. BPD commonly occurs in infants born prematurely who must undergo treatment in the NICU (Deakins, 2009). Statistically, for percent of live births, mothers less than 20 years of age (14.5%), and over 40 years of age (17.1%) account for the most preterm births, therefore making adolescent mothers and older mothers at higher risk for having a child diagnosed with BPD (March of Dimes, 2007). Sleep needs differ between these two age groups, with adolescents requiring more sleep (around 9 hours) and having a circadian rhythm programmed to fall asleep later, and wake up later in the morning than adults. Studies have reported that adults need approximately 8 hours of sleep per night; they may have circadian rhythms that cause them to fall asleep earlier, but wake up earlier, and may have increased complaints of insomnia and disrupted sleep (Carskadon & Acebo, 2002; Kripke et al., 2005; Moore & Meltzer, 2008). Adolescents may have the same issues, but for different reasons (school start time, technology use and social media, school, work, and social demands). Circadian rhythm may shift in a person’s late teens, when researchers have found that there is a significant delay in sleep onset (longer intrinsic phase) that promotes later sleep onset, and a tendency to more “eveningness” or becoming a “night owl” (Kripke et al., 2005). A tendency towards eveningness reaches its maximum in the late adolescent period (19-22 years of age), after which, researchers
have suggested a slight shift toward morningness, although younger adults (19-25 years) still report a subjective preference for later wake times when compared to older adults (50-70 years) (Duffy & Czeisler, 2002; Roenneberg et al., 2004).

Caregiver burden is defined as the, “demands, responsibilities, difficulties, and negative consequences of caring for relatives with special needs” (Brannan et al., 1997, p. 212). Maternal caregiver burden has also been linked to QOL in maternal caregivers of children with cancer (Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008). Parental caregivers of children with cancer who reported increased levels of burden related to their child’s care also reported increased levels of stress, and poorer QOL than caregivers who reported lower levels of strain (Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008). Also, in caregivers of children with cancer, higher levels of caregiver burden were also related to reports of poorer sleep quality, more disrupted sleep, and higher levels of stress (Wright, 2010). Higher levels of stress and burden were also found to be positively associated in parental caregivers of children with cerebral palsy (Raina, O'Donnell, et al., 2005).

Parental caregivers’ perceived psychological stress influences QOL and has been linked with burden to influence overall QOL in caregivers of children with a brain tumor and with autism spectrum disorders (Chien et al., 2003; Khanna et al., 2010). The perception of stress may differ by caregiver gender. In caregivers of young children with an imperforate anus, mothers assumed more of the responsibility for the child, and they reported higher levels of stress than did fathers, but both mother and father reported increased stress (Ojmyr-Joelsson et al., 2009).
Stress refers to the person and environmental interaction that is appraised as a threat, reaching beyond the person’s ability to adapt (Lazarus & Folkman, 1984). Increased levels of stress in caregivers have been linked with decreased QOL, as well as increased caregiver burden in caregivers of children with cancer (Khanna et al., 2010). Increased stress has also been linked with poor sleep quality in caregivers of children with a brain tumor; however, there are few studies exploring this relationship in caregivers of children with a chronic condition (Chien et al., 2003). Even fewer studies have explored any links between all three factors, including stress, caregiver burden, sleep quality, and their influence on QOL of the maternal caregiver of a child with a chronic illness or condition (Cooper, Robertson, & Livingston, 2003). Perceived psychological stress and burden may also be increased by the maternal caregiver’s perception of her child’s illness or severity of the illness (Altiere & von Kluge, 2009; Bristol, 1987). In caregivers of children with autism spectrum disorders, the mother’s perception of her child’s diagnosis influenced how she perceived her own stress (Altiere & von Kluge, 2009). Other factors, such as race, age, marital status, education, and depressive symptoms may also influence not only QOL, but also sleep quality, caregiver burden, and stress in caregivers.

Depressive symptoms, education, and marital status have been shown to influence QOL in maternal caregivers of young children with a heart condition, and with cancer (Arafa et al., 2008; Aslan, Sanisoglu, Akyol, & Yetkin, 2009; Horowitz, 1993). Depression has been shown to influence both sleep quality and QOL in caregivers of both adult family members and children (P. A. Carter, 2003; Cottrell & Khan, 2005), however, the relationship is complex, with depression being considered both a possible predicator
of poor sleep and a result of poor sleep (Rittman et al., 2009). Likewise, sleep-deprived caregivers of adults who have suffered a stroke reported increased levels of depression and increased levels of strain and burden (Rittman et al., 2009). Increased levels of both depression and anxiety were reported in caregivers of children with a chronic condition who reported poor QOL (Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994).

Marital status was found to influence stress, depressive symptoms, and QOL (Khanna et al., 2010). Married maternal caregivers of children with a chronic illness reported lower levels of stress and increased QOL as compared to their single counterparts (Kenneson & Bobo, 2010). In contrast, lack of support from a spouse was found to increase stress in married maternal caregivers of children who were fed enterally (Pederson et al., 2004). Increased stress and anxiety were reported in unmarried caregivers of young children with cerebral palsy, and were found to influence coping style negatively (Raina, O'Donnel, et al., 2005).

Lower educational attainment was found to negatively influence burden and stress in caregivers of young children requiring enteral nutrition, as well as caregivers of children with cerebral palsy (Calderon et al., 2010). Lower socioeconomic status and fewer years of education were found in parental caregivers who reported decreased support and increased stress (Voorman, Dallmeijer, Van Eck, Schuengel, & Becher, 2009). Lower socioeconomic status, lower educational attainment, and having other children in the household were also found to correlate with higher levels of burden and lower reported QOL in caregivers of children (Hatzmann, Heymans, Ferrer-i-Carbonell, van Praag, & Grootenhuis, 2008; Khanna et al., 2010). Fewer years of parental education, lack of respite care, and frequent awakenings at night were found to be related
to poorer quality of sleep in caregivers of chronically ill children on a ventilator (Meltzer & Mindell, 2006).

While there is emerging research in sleep of caregivers of children with a chronic illness, there are significant gaps in what is known, and more studies are needed. Meltzer et al. (2008) identified several gaps in the literature, including the lack of objective measures used with caregivers of young children with a chronic illness or condition, the need to use established, reliable sleep measures, and to broaden the populations to include different diagnoses. Sleep quality and its influence on stress, caregiver burden, and QOL is still being explored to determine the extent of sleep deprivation in caregivers of young children with a chronic condition and how it may influence other factors in their lives (Meltzer & Moore, 2008). An understanding of sleep and how it interacts with different variables (such as caregiver burden and stress), especially QOL, would provide empirical knowledge to aid health care providers support and intervene with caregivers in a meaningful way to positively influence their well-being and their child’s well-being (Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008).

Statement of the Problem

Adequate sleep is important for physical and mental well-being and overall QOL (Berger et al., 2009). Poor sleep has the potential to influence psychological and physiologic facets of a caregiver’s life (P. A. Carter, 2002). Maternal caregivers of young children with BPD face many stressors and challenges in obtaining adequate duration and
quality of sleep, which may influence their overall QOL (Chien et al., 2003; Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008). As the primary caregiver, home care responsibilities may include monitoring the child’s condition, managing multiple and often complex medication regimens, monitoring the child’s oxygenation levels, and other respiratory treatments, and different feeding schedules or formulas, as well as coordinating clinic appointments with different complex health care teams (nurses, physicians, specialists, physical and occupational therapists, respiratory therapists, nutritionists, social workers, pharmacists, and nurse practitioners) (Deakins, 2009; Holditch-Davis et al., 2001; Nievas & Chernick, 2002). The mother may also be required to maintain a job and manage home responsibilities, care for other children or family members in the home, and care for her own health (Raina, O'Donnell, et al., 2005; Sullivan-Bolyai, Sadler, Knafl, & Gilliss, 2004).

Maternal caregiving of children with BPD sets up a delicate balancing act between the needs and QOL of the child and family, and the needs and QOL of the mother, where the mother’s own needs may not take priority (Koshti-Richman, 2009). However, the challenge is that because the mother is the primary caregiver of the young child with BPD, and if her needs are going unmet while her QOL is decreased, then the care of the child and family may suffer (Arafa et al., 2008; Aslan et al., 2009).

Sleep quality is one factor that may influence overall QOL in either a positive or negative manner, depending on reported quality of sleep, in caregivers of children with a chronic illness (Chien et al., 2003). Stress and burden from the myriad of responsibilities and tasks associated with caring for a young child with BPD may also influence QOL (Mitchell, 1996). However, little is known about the relationship between sleep quality
and stress, caregiver burden, and QOL in caregivers of young children with a chronic illness or, especially with BPD (Monaghan et al., 2009; Zanardo & Freato, 2001).

Statement of the Purpose

The three-fold purpose of this study was to: a) describe sleep quality, stress, caregiver burden, and QOL in maternal caregivers of young children with BPD; b) determine relationships between sleep quality, stress, caregiver burden, and QOL, as well as the confounding variables of depressive symptoms, education, marital status, race, and age; and c) determine the influence of sleep quality, stress and caregiver burden on QOL in maternal caregivers of young children with BPD.

Specific Aims

1. Describe sleep quality, caregiver burden, stress, depressive symptoms, and QOL in maternal caregivers of young children with BPD.
2. Determine relationships between sleep quality, caregiver burden, stress, and QOL in maternal caregivers of children with BPD.
3. Examine the influences of QOL on age, depressive symptoms, education, marital status, sleep quality, caregiver burden, and stress.
4. Determine if stress mediates the relationship between sleep quality and caregiver burden and QOL in maternal caregivers of young children with BPD.
Hypotheses

1. Sleep quality and caregiver burden will account for more variability and have the greatest influence on QOL, when controlling for depressive symptoms, education, marital status, age, and race.

2. Stress will mediate the relationship between sleep quality and caregiver burden in maternal caregivers of young children with BPD.

Significance of the Problem

Quality of life is an important concept for health care professionals and researchers to examine as it encompasses not just the physical aspect of the maternal caregiver’s life, but also the emotional, environmental, socioeconomic, and interpersonal aspects that can have such a large impact on the maternal caregivers’ every daily life (Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008). With nearly 7,200 new cases of BPD diagnosed each year, and most of these children being discharged home from the hospital to be cared for by the mother, examining a maternal caregiver’s overall QOL, and the most significant influences on QOL, may help to inform researchers and health care professionals about how they can best support these mothers (Chien et al., 2003; Deakins, 2009). Supporting maternal caregivers is important as they are usually the ones primarily responsible for the dependent child’s care and well-being (Pelchat, Lefebvre, & Perreault, 2003). For example, previous researchers have reported that ensuring the maternal caregiver has high quality of life aids in maintaining the
mother’s own health and the requirements of everyday living, while also caring for her child with cerebral palsy (Brehaut et al., 2004; Raina, O'Donnel, et al., 2005).

While QOL has received more attention in the literature on caregivers of chronically ill children, influences on QOL, such as stress and sleep quality, have not been explored as much (Chien et al., 2003; Gallagher et al., 2010). Sleep quality has been shown to significantly influence QOL, yet has not been examined in maternal caregivers of young children with BPD. Sleep may be an important concept in maternal caregivers, as it influences several aspects of the maternal caregiver’s life, including physical and emotional health, memory, and fatigue (Meltzer & Mindell, 2006). Likewise, sleep quality has also been shown to influence stress and caregiver burden, but all three have never been explored together in studies of maternal caregivers of young children with BPD.

Theoretical Framework

Lazarus and Folkman’s (1984) Transactional Theory of Stress, Coping, and Adaptation served as the theoretical framework of this study (Lazarus & Folkman, 1984). Maternal caregiving is a complex psychosocial process that changes and evolves with the caregiver and the demands she faces (P. A. Carter, 2003). Lazarus and Folkman’s (1984) theory, as shown in Figure one, focuses on the individual’s personal appraisal of any given situation. The appraisal of a situation will influence any future outcomes by determining what type of response the caregiver chooses.
The Transactional Theory of Stress, Coping, and Adaptation is a largely cognitive theory, and builds upon Selye’s more physiologic view of stress. Lazarus and Folkman (1984) sought to add further insight into Selye’s General Adaptation Theory (1951) by developing the ideas of distress and eustress and refining them to fit into a more unique model. Stress within the theory is viewed as a highly subjective and individualized concept, as each person will have a different view, or different antecedents, of the stressor or the interaction with the environment (Lazarus, 2000). The response to stress is dependent on appraisal. Lazarus (2000) makes the distinction between appraising (the process) and appraisal (the outcome), putting more emphasis on the latter, as it is a set of cognitive processes. There are two sub-concepts for appraisal: primary appraisal, and secondary appraisal.

Primary appraisal is a personal judgment of whether or not what is happening is important or will influence a person’s values, goals, beliefs about self and world, and the
situation, and if so, in what way (Lazarus, 2000; Lazarus & Folkman, 1984). In primary appraisal, the individual is concerned mostly with what is at stake and how important it is. If there is nothing at stake, or the transaction between the person and environment is not relevant, then the process may stop at primary appraisal (Lazarus & Folkman, 1984). However, primary appraisal never operates independently of secondary appraisal. Lazarus (2000) describes secondary appraisal as the individual deciding how to deal with the situation. If the transaction is viewed as important or relevant to the individual, then secondary appraisal and coping processes are begun (Lazarus & Folkman, 1984).

Secondary appraisal focuses on what can be done if the person feels the interaction with the environment is stressful, and essentially, what coping mechanisms are available and which one is the best (Lazarus & Folkman, 1984). There are three general outcomes of appraisal, which include perceiving the situation as a challenge, as a harm or loss, or as a threat. A challenge is similar to Selye’s (1951) idea of eustress, in that it has more positive connotations. A harm or loss is damage or loss that has occurred in the past; a threat is the possibility of damage or loss in the future (Lazarus, 2000). Lazarus (2000) has made it clear that threat and challenge can occur at the same time; but usually, one is more dominant than the other, which largely depends on the person’s perceptions and previous expectations or antecedents. There are several antecedents to appraisal that may influence outcomes, which have been divided into two basic categories: personal variables (values, commitments and beliefs, existential sense of control, age, gender, and genetics) and environmental (situational demands, constraints, and resources) (Lazarus, 1999). Reappraisal occurs when the person receives more information about the situation that may change their initial appraisal from threat to
challenge or from challenge to threat, and it usually happens with, or after, secondary appraisal and coping (Lazarus, 2000). Immediate effects of appraisal include physiologic changes, positive or negative feelings, and quality of the encounter outcome. Long term effects include somatic health and illness, morale (well-being), and social functioning (Lazarus & Folkman, 1984).

In relation to Lazarus and Folkman’s (1984) theory, sleep quality and caregiver burden have been shown to influence stress in maternal caregivers, and may act as antecedents to the maternal caregiver’s appraisal of the situation (Fletcher et al., 2008; Gallagher et al., 2010). Sleep quality may influence how the maternal caregiver perceives her interaction with her environment and how she perceives her child’s needs or care. Poor sleep quality may influence the maternal caregiver to report increased stress; and therefore, view her interaction with the environment as a threat, rather than a challenge (P. A. Carter, 2003, 2006; Gallagher et al., 2010; Meltzer, 2008). In the same way, the caregiver’s burden may also influence how the mother perceives her interaction with her environment, and as with sleep quality, may influence the maternal caregiver to report increased stress (Brehaut et al., 2004; Raina, O'Donnel, et al., 2005).

Sleep quality and caregiver burden may act as antecedents to appraisal to influence stress, while QOL is considered an outcome (Arafa et al., 2008; Lazarus & Folkman, 1984). Sleep quality and caregiver burden may also influence how the maternal caregiver views her overall environment. Maternal caregiver race, age, depressive symptoms, marital status, and educational attainment are also considered personal variables, and were considered covariates in this study. Individual person variables may also influence appraisal of the situation, and act as antecedents to influence the person-to-
environment interaction (Lazarus, 1993). Individually, sleep quality has been shown to significantly influence outcomes in maternal caregivers of chronically ill children, and poor sleep quality was found to be related to poor QOL (Chien et al., 2003). Caregiver burden has been shown to influence QOL in maternal caregivers of chronically ill children with a heart transplant and children with cancer, with mothers who report higher levels of burden also reporting poorer QOL, and increased stress (Arafa et al., 2008; Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008). However, few studies have examined the concepts of sleep quality, stress, or caregiver burden within a theoretical framework, and no studies have examined these concepts in mothers of young children with BPD. Because little is known about the interaction between sleep quality, caregiver burden, and stress in maternal caregivers of young children with BPD, studies examining these relationships need to be conducted (Gallagher et al., 2010; Meltzer & Moore, 2008; Singer et al., 2010). This study sought to examine relationships within a framework; therefore, parts of the Transactional Theory of Stress, Coping and Adaptation were used. Environmental characteristics (such as resources or support systems), appraisal, and coping were not assessed in this study, but may be useful for future studies. However, testing an entire framework may be beyond the scope of this study. Figure 2 displays the conceptual framework for this study.
Definition of Terms

The concepts used in this study include sleep quality, caregiver burden, stress, and quality of life (QOL). Each concept has a conceptual and operational definition to be held constant throughout this study. The definitions are based on theory, research, and the operationalization of each concept.

Sleep Quality

Sleep quality was defined using conceptual and operational definitions, based on the instrument to be used. Buysse et al. (1989) describe sleep quality as quantitative aspects, such as sleep duration, sleep latency, number of arousals, as well as subjective aspects, such as reported “depth” or “restfulness” of sleep. Sleep quality relies heavily on
the person’s perception and satisfaction of their sleep (Harvey, Stinson, Whitaker, Moskovitz, & Virk, 2008).

Operationally, sleep quality was defined in this study using the Pittsburgh Sleep Quality Index (PSQI) (Buysse et al., 1989). The instrument was originally designed to be used with clinical populations as a simple and valid assessment of both sleep quality and disturbances that might affect sleep quality (Carpenter & Andrykowski, 1998). The instrument was designed and originally used with elders; however, due to its wide use in a variety of populations and ages, it is still relevant for this population of maternal caregivers. The PSQI consists of 19 items that produce a global sleep quality score, and 7 subscales: sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbance, use of sleeping medications, and daytime dysfunction (Buysse et al., 1991).

**Caregiver Burden**

Caregiver burden was conceptually defined as the “demands, responsibilities, difficulties, and negative consequences of caring for relatives with special needs” (Brannan et al., 1997, p. 212). Montgomery, Gonyeah, and Hooyman (1985) build upon this definition by including three different dimensions to burden: relationship, stress, and objective burden (Montgomery, Gonyeah, & Hooyman, 1985; Savundranayagam, Montgomery, & Kosloski, 2010). Relationship and stress burden were further differentiated into subjective burden, defined as the participant’s attitudes toward or emotional reactions to caregiving, while objective burden embodied the extent of disruptions or changes in the various aspects of the caregiver’s life (Montgomery et al., 1985).
Operationally, burden was measured using the Montgomery-Borgatta Caregiver Burden Scale-Revised (Savundranayagam et al., 2010). The instrument consists of 22 items with a 5-point Likert-scale style, with answers ranging from “not at all” to “a great deal,” (Savundranayagam et al., 2010). The instrument has a relationship, objective, and stress subscale, as well as a separate uplifts scale (Savundranayagam et al., 2010). While this scale has been used in caregivers of adult family members, it has not been used in caregivers of children with a chronic condition.

**Stress**

Stress was conceptually defined based on the Transactional Theory of Stress, Coping, and Adaptation (Lazarus & Folkman, 1984). Within this model, stress is defined as the person-to-environment interaction that is appraised as a threat, reaching beyond a person’s ability to adapt (Lazarus & Folkman, 1984). For this study, stress refers to perceived psychological stress; physiological changes will not be examined.

Operationally, stress was measured using the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983). Cohen et al. (1983) based the measure on Lazarus and Folkman’s (1984) theory and conceptualization of stress, designing it to be a general measure to be used in a variety of populations. The instrument consists of ten 5-point Likert-style questions, with answers ranging from 0= never to 4= very often (Cohen et al., 1983).
Quality of Life

Quality of life was conceptually defined using the World Health Organization’s (WHO) (1998) definition. A task force on mental health convened by the WHO (1998) described QOL as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment (p.44).

The definition was developed to be wide-ranging, and to focus not merely on physical health, but to emphasize the holistic nature of the concept (World Health Organization, 1998).

Operationally, QOL was measured using the WHO’s Quality of Life Brief Scale (WHO QOL-BREF) (World Health Organization, 1998). The instrument consists of 26 Likert-style questions on a 5-point scale ranging from 1= very good to 5= very poor (World Health Organization, 1998). There are four different domains and a general score, including physical, psychological, social relationships, and environmental QOL.

Depressive Symptoms

Conceptually, depressive symptoms were defined based on Radloff’s (1977) work and the Center for Epidemiologic Studies Depression Scale (CESD). The four factors contained in this definition include: 1) Depressed affect (blues, depression, lonely, cry/sad), 2) Positive affect (good, hopeful, happy, enjoy), 3) Somatic activity (bothered, appetite, effort, get going), and 4) Interpersonal (unfriendly, dislike).
Operationally, depressive symptoms were defined according to Radloff’s (1977) CESD scale. The measure was designed for use in a general population of healthy adults. It uses a 4-point Likert scale and measures current level of depressive symptoms, including depressed mood, feelings of guilt, worthlessness, loss of appetite, sleep disturbance, and psychomotor retardation, and also includes four reverse scored items (Radloff, 1977). The scale arranges ranges from 1 (rarely or none of the time) up to 4 (most or all of the time), and a higher score indicates a higher incidence of depressive symptoms (Radloff, 1977).

Assumptions

The assumptions for this study included:

1) Caregiving for a child with BPD with complex healthcare needs takes extra time, and may place a burden on the maternal caregiver (Calderon et al., 2010).
2) Caregiving for a child may be perceived as stressful (Stewart et al., 1994).
3) Caring for a child with BPD influences the maternal caregiver’s sleep (Singer et al., 1997).
4) The person-to-environment interaction has an influence on how stress is perceived and its outcomes (Lazarus and Folkman, 1984).
5) Participants in the study will answer questionnaires truthfully.
CHAPTER TWO

REVIEW OF THE LITERATURE

Quality of life in maternal caregivers, measures not just the absence of physical maladies, but also seeks to address the entirety of a caregiver’s life, including physical health, social health, relationships, and physical environment (World Health Organization, 1998). Examining influences on QOL in caregivers is important; treatments could be tailored to meet the needs of caregivers, to ensure they are not at increased risk for poor outcomes, such as poor health or burnout (World Health Organization, 1998). Sleep quality, caregiver burden, and stress have all been identified as possibly influencing QOL in maternal caregivers of young children with chronic conditions (Calderon et al., 2010; Chien et al., 2003). However, there remain gaps in the research (Meltzer & Mindell, 2006).

Sleep Quality

Sleep quality is a broad term that can refer to a number of different aspects of sleep (Carpenter & Andrykowski, 1998). Research in healthy adults (Unruh et al., 2008),
and adults with insomnia (Harvey et al., 2008), reported sleep quality was the most often related to the subjective, reported experience of “depth” and “satisfaction” of sleep.

Sleep in Healthy Women

Sleep in healthy women is influenced by a number of internal and external factors, including physical and psychological stress, sex hormones, depression, and age (Paul, Turek, & Kryger, 2008; Shaver, 2002). Compared to men, women differ in quality and quantity of their sleep, and often report more age-related sleep difficulties (Paul et al., 2008; Shaver, 2002; Vitiello, Larsen, & Moe, 2004).

Reproductive hormones play an influential role the lives of women (Kalleinen, Polo, Himanen, & Polo-Kantola, 2008; Moline, Broch, & Zak, 2004). However, findings are inconsistent related to hormonal effects on sleep in women. For example, during the premenstrual phase, some women experience longer sleep latency and lower sleep efficiency (Lamarche, Driver, Wiebe, Crawford, & De Konick, 2007; Shaver, 2002). That is, women during the premenstrual phase may take longer to fall asleep and spend less time sleeping while in bed compared to other women. Differences or changes in sleeping pattern associated with menstruation may be more related to symptoms (tender breasts, cramping), rather than the actual onset of menstruation (Baker & Driver, 2004; Shaver, 2002). For most women, the cycling of hormones during menstruation do not influence sleep in a major way, though some report significant excessive sleep (hypersomnia) or insufficient sleep (insomnia) during the premenstrual phase, and poor quality of sleep (Baker & Driver, 2004; Shaver, 2002).
Research using surveys of women with premenstrual syndrome (PMS) and premenstrual dysorphic disorder (PMDD) suggests that subjective sleep disturbances, including unpleasant dreams, nighttime awakenings, and decreased sleep quality are associated with the late luteal phase of the menstrual cycle (Moline et al., 2004; Shaver, 2002). However, objective data from polysomnograms in this population are limited; and suggest that there are not major differences in sleep architecture for women with PMDD or PMS and a control group (Baker et al., 2007).

Sleep during pregnancy is influenced by several factors, including the growth of the fetus, physical symptoms of pregnancy, and hormonal changes (Suzuki et al., 2003). Although pregnant women experienced onset of less restful, lighter, and more easily disturbed sleep at 11-12 weeks of gestation (K. A. Lee et al., 2000), pregnancy-related sleep loss has been reported to peak during the third trimester (Gallo & Lee, 2008; K. A. Lee et al., 2000).

Menopausal women often report decreased sleep. Insomnia is common in perimenopausal and postmenopausal women, along with hot flashes, mood disorders, and sleep-disordered breathing (Phillips et al., 2008; Pien, Sammel, Freeman, Lin, & DeBlasis, 2008). While postmenopausal women reported feeling less satisfied with their sleep, polysomnography (sleep studies) indicated that they experience better sleep (longer total sleep time and increased slow wave sleep) compared to premenopausal women (Vitiello et al., 2004). Hormone replacement therapy has not been shown to consistently improve subjective sleep quality in women (Moline et al., 2003; Sowers et al., 2004; Vitiello et al., 2004; Young et al., 2003).
Married women, or women with a consistent partner, may report better sleep than those with an inconsistent partner (Troxel et al., 2010). Troxel et al. (2010) found that those with a long-term co-habitating partner reported better sleep quality and had better sleep as measured by polysomnography and actigraphy. However, some researchers have found that while partnered women may have better sleep, depression and depressive symptoms or bereavement in single women may be an important covariate (Booth, Rustenbach, & McHale, 2008). Women who have recently divorced, gone through a traumatic divorce, or lost a loved one to death may show increased depressive symptoms, and their sleep may therefore be influenced by their mental state (Cheek, Shaver, & Lentz, 2004).

Sleep and Race and Socioeconomic Status

In the United States, differences have been noted in the sleep of African Americans and Caucasian adults (Jean-Louis, Magai, et al., 2008). Time spent in sleep stages, sleep latency, and the number of awakenings during the night all differ when comparing Caucasians and African Americans. More time is spent by African Americans in stage 1 and stage 2 sleep (light sleep) and less time in stage 4 sleep (deep sleep) (Hall et al., 2009; Mezick et al., 2008; Rao et al., 1999; Redline et al., 2004). African Americans also spend less total time asleep, take longer to fall asleep, and have more time awake after sleep onset, than do Caucasians. However, there do not appear to be major differences in the amount of Rapid Eye Movement (REM) sleep when racial groups are compared (Hall et al., 2009; Kripke et al., 2004; Mezick et al., 2008). Subjective measures of sleep also differ between racial groups. Although African
Americans report poorer sleep quality than Caucasians (Hall et al., 2009; Mezick et al., 2008), they often under-report sleep symptoms and difficulties (e.g. snoring) when compared to Caucasians (Jean-Louis, Magai, et al., 2008; Jean-Louis et al., 2007; Mezick et al., 2008).

Socioeconomic status and health behaviors have been thought to influence the sleep differences observed in African Americans and Caucasians. Sleep differences were noted between races after controlling for both socioeconomic status (Hall et al., 2009; Mezick et al., 2008) and health behaviors (Mezick et al, 2008). Kravitz et al. (2008) studied sleep disturbances and the transition into menopause in a multi-ethnic sample of women; and found that Caucasians had the hardest time falling asleep when compared to Hispanics, Asians, and African Americans. They also found that for women going through the menopausal transition, there were no significant differences among the different ethnic groups based on time to fall asleep (Kravitz et al., 2008).

Racial disparities are also evident in sleep disorders. Sleep apnea is more prevalent in African Americans, compared to Caucasians. Jean-Louis et al. (2008) reported that African Americans may under-utilize sleep services and under-report symptoms. In the same study, African American participants who were referred for a sleep evaluation often followed through with their appointments (Jean-Louis, von Gizycki, et al., 2008). The authors speculate that African Americans may be more likely to consider sleep problem symptoms, such as excessive nighttime snoring, as normal. Therefore, they may be less likely to report symptoms such as snoring to a physician or to seek help for sleep problems (Jean-Louis, von Gizycki, et al., 2008).
Insomnia prevalence differs among racial groups. A study of insomnia symptoms in a multi-ethnic sample of women was conducted to gather data on sleep and behavioral variables (Jean-Louis, Magai, et al., 2008). The study found that African Americans reported higher rates of insomnia than did English-speaking from the Caribbean Islands (71% and 47% respectively), and were actually more similar to European Americans and Eastern Europeans (70% and 77% respectively) (Jean-Louis, Magai, et al., 2008). These results suggest that there may be inter-ethnic, and possibly cultural, differences that influence symptoms and reporting (Jean-Louis, Magai, et al., 2008). These findings are supported by Kravitz et al. (2008) in that differences were found among ethnicities for falling asleep and staying asleep. However, in a study, conducted with African American and Caucasian women in New York City, the prevalence of insomnia in African American women was less than in Caucasian women (Jean-Louis et al., 2007). The authors suggest this could be due to differences in coping techniques, with African American women using a more positive self-regulating framework than Caucasian women (Jean-Louis et al., 2007). Kravitz et al. found in their study of midlife women, that African American women had less difficulty than Caucasian women when falling asleep, and reported fewer sleep complaints (Kravitz et al., 2003).

**Gender, Aging, and Sleep**

Both men and women report differences in quality and quantity of sleep associated with aging (Kripke et al., 2005). Most sleep disorders become more apparent with aging, and some may become more severe (Unruh et al., 2008).

Gender differences are evident in both reported sleep quality and objective sleep measures. In a sample of 75 healthy elders (ages 60-80), women experienced deeper
sleep, greater sleep efficiency, and increased total sleep time, compared to men (Unruh et al., 2008). In another sample of elders from the Sleep Heart Health Study, women \((n=30)\) experienced better physiologic sleep than men, though they reported poorer subjective sleep (Driscoll et al., 2008). In a study of gender and estrogen effects on sleep, scores on the Pittsburgh Sleep Quality Scale (PSQI) and polysomnographic data were compared for men and women (Vitiello et al., 2004). Again, the polysomnography data from the women demonstrated better quality sleep, with greater total sleep time, sleep efficiency, and Rapid Eye Movement (REM) onset when compared to men (Vitiello et al., 2004).

Sleep differences are most pronounced as men and women age, with few differences in polysomnographic data in the 20-29 year age range. More pronounced differences begin in the 30-39 year age range, and continue into later years (Ehlers & Kupfer, 1997). Vitiello et al. (2004) suggest that subjective scoring for sleep may show gender differences, and that measures of subjective sleep used in their study may not accurately reflect how women assess their sleep quality. Studies have also found that, regardless of gender, healthy older adults (age 30 years and over) display a decline in slow wave sleep and decreased daytime sleep propensity, as opposed to younger adults (age 20-29 years) (Dijk, Groeger, Stanley, & Deacon, 2010).

Differences are also apparent in sleep disorders between men and women. Obstructive sleep apnea (OSA) is more common in men than in women, though both genders share common risk factors, including obesity, neck circumference, and smoking (Hiestand, Britz, Goldman, & Phillips, 2006; Paul et al., 2008). There are also gender differences in OSA-related depression, daytime sleepiness, and severity (Basta, Lin, Pejovic, Sarrigiani, & Bixler, 2008). Basta et al. (2008) found that a lack of regular
exercise, depression, and severity of apnea are significant predictors of daytime sleepiness in men with OSA, while in women with OSA, lack of regular exercise did not predict daytime sleepiness.

In a recent study of cardiovascular risk and sleep, researchers found that snoring was more prevalent in men, than in women. In the same study, a sleep duration of four hours or less was significantly related to increased mortality from coronary heart disease for women, and non-cardiovascular, non-cancer and all-cause mortality for both men and women (Ikehara et al., 2009). In another recent study using data from the National Health and Nutrition Examination Survey (NHANES I), extended sleep duration was not related directly to mortality, but instead, was a consequence of medical conditions or aging (Gangwisch et al., 2008). Short sleep duration was related to increased incidence of hypertension, diabetes, and obesity. All of these conditions were linked to increased mortality and were associated with aging (Gangwisch et al., 2008).

As men and women age, sleep changes begin to occur. Elderly men and women often report spending less time in bed, and shortened time asleep (Unruh et al., 2008). When an aging population was compared to a younger population, the elderly participants took longer to fall asleep and spent more time awake (Vitiello et al., 2004). Kripke et al. (2005) suggested that shortened time in bed and asleep were related to circadian changes and changes in melatonin secretion. However, in their sample of elderly participants (n=62), no significant variance in the elders’ circadian rhythms was found when compared to younger controls (20-46 years of age). The authors suggested that sleep disturbances and mood changes in elders are not related to circadian changes (Kripke et al., 2005). Several studies noted sleep quality differences by gender in an
aging population. Women experienced better sleep on objective measures (polysomnography and actigraphy), but reported more sleep disturbances and poorer quality of sleep overall (Driscoll et al., 2008; Unruh et al., 2008; Vitiello et al., 2004).

Sleep and Adolescents

Adolescence is a time of developmental change, growth, and maturation both physically and emotionally (Rew, 2005). Just as changes are occurring to the adolescent’s outer appearance, changes are also occurring within the adolescent, especially as cognition becomes increasingly more complex and the central nervous system of the adolescent undergoes major structural development that influences the how and when sleep occurs (Carskadon et al., 1980). An adolescent’s circadian rhythm changes, so that they fall asleep later, and wake up later, and require at least 9 hours of sleep (Dahl, 2002).

Adolescent sleep architecture undergoes a change during puberty (Carskadon et al., 1980). While there is a decrease in the duration and depth of non-REM sleep in school-age children, it is much more apparent in adolescents (Fredriksen, Rhodes, Reddy, & Way, 2004). There is a shift, during puberty, to lighter sleep (stages 1 and 2) and less deep sleep (stages 3 and 4) and REM sleep (Dahl, 2002). Sleepiness also increases during puberty, even when the total amount of sleep is held constant, suggesting that sleep needs increase during puberty (Carskadon & Acebo, 2002).

Researchers have described the sleep-pattern changes that occur during adolescence, as teens going from a “lark-like” pattern, to an increasingly “owl-like” pattern, with an ideal sleep-schedule consisting of falling asleep close to midnight, and
waking up sometime around mid-day (Carskadon & Acebo, 2002). This sets up an interesting juxtaposition between adolescent sleep needs, actual sleep schedule, and daytime needs.

It has been reported that adolescents get roughly 7.5 hours of sleep each night, which falls short of the 9 hours they require (Gangwisch et al., 2010). Various reasons have been proposed for this discrepancy, including the early start times of school, the variety of extra-curricular activities many adolescents are involved in, and technology (gaming, online social networking, television) (Dworak, Schierl, Bruns, & Struder, 2007; Gangwisch et al., 2010). The early start time of schools has, especially been related to poor sleep, as researchers have found a relationship between early start time, poor adolescent sleep, and increased daytime sleepiness (Carskadon & Acebo, 2002; Dahl, 2002). Carskadon and Acebo (2002) have argued that the early start time of school is against the adolescent’s circadian rhythm, and only leads to higher incidence of sleep propensity, sleepiness, irregular sleep schedules, and increased daytime fatigue, as well as the tendency to fall asleep during school. Poor sleep in adolescents may lead to poor psychosocial outcomes, such as depression and increased anxiety (Dahl, 2002; Gangwisch et al., 2010).

Sleep in Caregivers of Adults

The majority of research in the sleep of caregivers has been conducted with caregivers of adult family members (Aslan et al., 2009). Sleep disturbances are commonly reported by caregivers, regardless of their family member’s diagnoses (Rittman et al., 2009). Sleep loss in caregivers may stem from physical wellbeing of both
the patient and caregiver; and the caregiver’s emotional reactions (P. A. Carter, 2002; McCurry, Logsdon, Teri, & Vitiello, 2007). Caregivers report poorer sleep than non-caregivers of the same age, as well as increased levels of fatigue, depression, and anxiety (P. A. Carter, 2003; Rowe, McCrae, Campbell, Pe Benito, & Cheng, 2008). Sleep quality and sleep latency are strongly positively correlated with caregiver depressive symptoms and QOL over time (P. A. Carter, 2006).

In caregivers who experience decreased sleep, 95% reported experiencing increased anger, frustration, irritability, and feelings of depression ($n = 47$) (Carter, 2002). Sleep and depression varied from week to week in another study of caregivers ($n=30$) over a 10-week period (P. A. Carter, 2006). Depression and sleep quality improved with behavioral interventions that focused on setting relaxation and sleep goals and basic sleep hygiene principles (P. A. Carter, 2006).

Sleep disruption is a major influence on sleep quality in caregivers (Creese, Bedard, Brazil, & Chambers, 2008). Often, a caregiver’s schedule is focused around the responsibilities and needs of the person for whom she provides care. This may lead to sleep disturbances during the night, earlier wake times, and later bedtimes (D. Lee, Morgan, & Lindesay, 2007; McCurry et al., 2007). Caregivers of patients with Alzheimer’s disease (Creese et al., 2008), Parkinson’s disease (Happe & Berger, 2002), and prostate cancer (Rittman et al., 2009) all reported sleep disruption, decreased sleep quality, and depression. Caregivers of men with prostate cancer also reported clinically relevant anxiety and sleep quality that was influenced by illness severity of their family member (Rittman et al., 2009). Respite care was associated with improved sleep and increased time in bed for caregivers who typically slept with a dependent family member.
However, once the respite periods ended, the same caregivers reported declines in sleep quality as they resumed bed-sharing with their family members (D. Lee et al., 2007).

Sleep in Caregivers of Chronically Ill Children

Mothers of children with a chronic health condition are often identified as the primary caregivers of the child at home (Krulik et al., 1999). Caregiving is a continuous, 24-hour commitment for most mothers. Respite care may be hard to obtain and unreliable (Meltzer et al., 2010; Ratliffe, Harrigan, Haley, Tse, & Olson, 2002). Caregivers of children with a chronic illness or condition have reported inadequate or poor quality sleep (Gallagher et al., 2010; Harrigan, Ratliffe, Patrinos, & Tse, 2002; Meltzer & Mindell, 2006). However, there are few studies that examine sleep in maternal caregivers of children with a chronic illness or condition, as it is an emerging area of research (Meltzer & Moore, 2008).

Parents of ventilator-dependent children experienced much earlier wake times, frequent nighttime sleep disruptions, and overall poorer sleep quality compared to parents of children with cystic fibrosis and healthy controls (Meltzer & Mindell, 2006). Equipment alarms, and frequent night time awakening to check on the child were cited as possible reasons for sleep disruption in parents of ventilator dependent children (Meltzer & Mindell, 2006; Meltzer & Moore, 2008).

Sleep problems are also evident in caregivers of children who are chronically ill, but not technology-dependent. Earlier awakening and poor sleep quality were more prevalent in parents of children with autism spectrum disorders, compared to parents of typically developing children (Meltzer, 2008). Parental caregivers of children diagnosed
with epilepsy reported frequent nighttime awakenings as well, with an average of four hours of reported sleep during the night (Cottrell & Khan, 2005). These parents also reported elevated levels of stress and anxiety (Cottrell & Khan, 2005).

Similarly, in parents of children with physical disabilities compared to parents of typically developing children, parental caregivers (n=178) woke up more often, and had fewer hours of sleep per night (6.5 hours for caregivers, compared to 7.2 hours for the non-caregivers) (Wright, Tancredi, Yundt, & Larin, 2006). The child’s own sleep issues (frequent nighttime awakenings, pain) were cited as common reasons for the caregiver to be up at night, and caregivers also reported having trouble getting back to sleep once awake (Wright et al., 2006). In caregivers of children receiving treatment for cancer, parental caregivers reported fragmented sleep, with significantly fewer hours on the weekend when compared with parents of healthy children (Wright, 2010). Parental caregivers were also more likely to report difficulty falling asleep, and having their sleep influenced by their child (especially if the child was on steroids), as well as reported stress (Wright, 2010).

In parental caregivers of children with developmental disabilities, decreased sleep quality was found to be related to increased reports of stress (Gallagher et al., 2010). In 67 parents of children with a developmental disability, and 42 parents of typically developing children, parents reported on their child’s problem behaviors, as well as their own sleep quality, stress, and social support. The researchers controlled for the parents’ Body Mass Index (BMI), socioeconomic status, smoking, alcohol consumption, exercise patterns, medications, and caffeinated beverage intake (Gallagher et al., 2010). The authors found that, even when controlling for BMI, stress and sleep quality were still
related, with poor sleep quality being related to increased reports of stress in parental caregivers, and that parents of children with a developmental disability were more likely to meet the criteria for “poor sleeper” based on the PSQI (global score greater than or equal to 5) (Gallagher et al., 2010). Gallagher et al. (2010) conducted one of the first studies to examine stress and sleep quality in caregivers of children with a developmental disability.

Increased parental anxiety, burden, and depression are also linked to sleep disturbances (Cottrell & Khan, 2005; Gallagher et al., 2010; Meltzer & Mindell, 2006; Monaghan et al., 2009). Parents of ventilator-dependent children reported increased anxiety related to their child’s health and the technology necessary for care (Meltzer & Mindell, 2006; Meltzer & Moore, 2008). Parents described nighttime episodes of wakefulness not only to provide care for their child, but also due to increased stress related to their child’s diagnosis and future (Meltzer & Mindell, 2006). The severity of a child’s disease and symptoms has been suggested to decrease parental caregiver’s sleep quality and may be related to depression (Cottrell & Khan, 2005; Meltzer & Moore, 2008; Monaghan et al., 2009). Over time, chronic sleep deprivation or restriction may exacerbate the stress of caregiving and lead to increased feelings of depression in some caregivers (Meltzer, 2008).

When respite care or home care was available, parental caregivers still reported poor quality of sleep (Boroughs & Daugherty, 2009). Caregivers of children on a ventilator reported having most of their scheduled respite hours during the day (Meltzer et al., 2010). For parental caregivers who reported poor sleep, even with respite care at night, caregivers reported increased anxiety for their child’s care, not feeling comfortable
with the respite worker in the home unsupervised, and being awakened by the care
worker to answer questions or help with care (Green, Meaux, Huett, & Ainley, 2009;
McIntosh & Runciman, 2008). Trust for the respite worker was important to parental
caregivers in feeling comfortable enough to sleep while the respite worker was present
(Olsen & Maslin-Prothero, 2001).

Sleep, Caregivers, and Quality of Life

Quality of life may be an important aspect of a caregiver’s overall well-being
(White, Lauzon, Yaffe, & Wood-Dauphinee, 2004). While QOL has been examined in
caregivers (White et al., 2004), and sleep quality has been examined (Chang, Tsai,
Chang, & Chao-Jung, 2007), the relationship between the two has not received as much
attention (Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008). Recently,
more researchers have started to examine the relationship that sleep quality has on QOL
in caregivers of both adult and child family members, though gaps still exist (Chang et
al., 2007; Chien et al., 2003). This may be an important relationship, as sleep quality has
been found to be a significant predictor of poor QOL in caregivers of adults and children
(Chang et al., 2007; Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008).

Chang et al. (2007) examined sleep quality and QOL in caregivers (n=61) of adult
family members with breast cancer. In one of the first studies to focus mainly on the
concepts of sleep quality and QOL in caregivers, the researchers found that 88.5% of the
caregivers reported poor sleep, which correlated strongly with poor QOL (Chang et al.,
2007). They also found that poor sleep correlated with several domains of QOL, not just
physical, but also psychological and environmental (Chang et al., 2007).
In caregivers of adults waiting for a lung transplant, caregivers reported increased levels of burden, and stress, as well as poor sleep and decreased QOL (Claar et al., 2005). Poor sleep was found to influence the physical domain of QOL in these caregivers, more than the psychological or social (Claar et al., 2005). Interestingly, age was also found to influence QOL, with older caregivers reporting poorer QOL (Claar et al., 2005).

In parents of children with cancer, caregivers reported poorer QOL than parents of healthy children (Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008). While Klassen et al. (2008) discuss several influences on the caregiver’s QOL, including exercise and diet, sleep was reported as one of the strongest predictors of QOL in all domains (Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008). Also, in support of Claar et al.’ (2005) findings of older caregivers reporting poorer QOL, younger caregivers reported better QOL and sleep, compared to older caregivers (Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008).

In parental caregivers of children with brain tumors, Chien et al. (2003) found that the child’s treatment stage was associated with QOL, with caregivers of children no longer receiving treatment, in remission for at least 5 years, reporting higher levels of QOL, and also, the caregiver’s education status. Those caregivers who reported higher levels of education, and socioeconomic status, also reported higher levels of QOL (Chien et al., 2003). Sleep quality was also found to be decreased in caregivers who reported poor QOL (Chien et al., 2003). Sleep quality and QOL have been found to be related in caregivers of adult family members, as well as caregivers of children (Chien et al., 2003; White et al., 2004).
Gaps in the literature exist for sleep quality in maternal caregivers of young children with chronic illnesses or conditions. No studies were found that addressed the concepts of sleep quality, burden, stress, and QOL, together, in caregivers of adults or children. Few studies were found where the researchers examined QOL and sleep quality in caregivers of adult family members, but no studies were found for caregivers of children.

Caregiver Burden

Caregiver burden, as a concept, is incredibly broad and encompasses a number of aspects of a caregiver’s (to adults and children) life (Calderon et al., 2010; Pearlin, Mullan, Semple, & Skaff, 1990). In some cases, the role of caregiver can overtake previous roles held by the caregiver, including son or daughter, husband or wife, and mother or father (Pearlin et al., 1990). When caregiving activities become the pervasive impetus in a relationship between family members, either adult or child, lines are sometimes blurred between what is caregiving, and what is not (Stewart et al., 1994). In the case of maternal caregivers, a major question for some mothers is what is the difference between caregiving and parenting or the maternal role, and, similarly, what is burden (Department of Health and Human Services, 1998; May, 1997).

Maternal Role and Parenting

Mothers who must become caregivers to support a chronically ill child face several challenges. Not only must they go through the process of becoming a mother, but also, of defining and internalizing the role of a caregiver (Miles, Holditch-Davis,
Burchinal, & Deborah, 1999). This can be a complicated process, and aspects of the child’s care can influence maternal role outcomes, such as extended separations if the child is in the NICU, altered communication, and altered feeding routines (Cho, Holditch-Davis, & Miles, 2008).

Maternal role attainment was described by Rubin (1967) as a process leading to a woman’s achievement of maternal role identity. It involves moving from a known, current reality to an unknown, new reality (mother with a child) (Mercer, 2005). Rubin describes it as a process, involving several steps that begin during pregnancy as taking-in, mimicry, role-play, fantasy, introjection-projection-rejection, and identity (Rubin, 1967a). The woman “takes in” the maternal role continuously, even before pregnancy, though the core of the process begins with mimicry (Rubin, 1967a). Mimicry is the adoption by the woman of simple behavioral manifestations, such as dress, speech affects, and gestures that are recognized as pertaining to the role of mother, and is an active process that includes phases (Rubin, 1967b). The phases of mimicry included child-bearing, child birth, and child-rearing, though emphasis may be placed during different phases (Rubin, 1967b).

Role play extends beyond mimicry, in that it pertains to the actual actions, rather than the outward manifestations or affectations (Rubin, 1967a). Rubin (1967) describes it as answering the question of what a person of this position does in any given situation. In many cases, a woman will seek out a referent to observe, either their own mother, a friend with a young child, or a neighbor (Rubin, 1967a). This phase does not end with the birth of one child, as a woman about to have her second child will again, role-play as the

Mercer posited that the period before pregnancy was a time of psychosocial preparation for the role, then, at birth, the mother moved to the formal stage of motherhood (Mercer, 1981). In the formal stage of motherhood, the woman begins the care-taking tasks and acts on the information she has collected. As her comfort level increases, she will rely less and less on the advice of others and more and more on her own instincts. The stage of personal or maternal identity is characterized by the mother’s sense of, “harmony, confidence, satisfaction in the maternal role, and attachment to her infant” (Mercer, 2005, p. 649). Variables that have been found to influence maternal role attainment include socioeconomic status, perception of the birth experience, early mother-infant separations, social stress, social support, self-concept, and perception of the infant (Mercer, 1981, 1985; Mercer & Walker, 2006). Researchers have also found several characteristics of the maternal role, including maternal presence, engagement, physical presence, competence, and identity, that are frequently used throughout the literature to describe and measure the process (Miles, Holditch-Davis, Burchinal, & Brunssen, 2011).

Much of the research on maternal role attainment has been conducted with mothers of healthy infants, and has not extended significantly beyond the immediate post-partum phase (Mercer & Walker, 2006). Of the variables that may influence maternal role attainment, the mother’s perceived self-esteem (self-confidence and competence in the role), and mastery of the role were found to influence it the most (Mercer, 1981, 2005). Likewise, infant characteristics and responses have been found to influence the mother’s maternal role attainment, with more alert infants being related to
feelings of higher competence, and lower parental stress (Holditch-Davis et al., 2011). Maternal depressive symptoms and anxiety show an inverse relationship with maternal role attainment, and research also suggests that the mother’s image of herself as a mother reflects on her image of her child (Cho et al., 2008; Holditch-Davis et al., 2011; Miles, Burchinal, Holditch-Davis, Brunssen, & Wilson, 2002). Age of the mother has also been shown to influence maternal role attainment, but in varying ways and to varying degrees.

Having a medically fragile infant or child with a chronic illness can complicate the maternal (and parental) role (Miles et al., 2011). Recent research in maternal role attainment in mothers of medically fragile children has found mothers with more illness related stress, being unmarried, and with less education may be at the most risk for low maternal role attainment. In the same way, maternal role influenced the quality of parenting for their medically fragile infants (Holditch-Davis et al., 2011; Miles et al., 2011).

Researchers have found that the foundation for maternal role attainment is established by 4-6 months after the birth of the child (Mercer & Walker, 2006). However, the process may be interrupted or prolonged in mothers of medically fragile children (Miles et al., 1999). Mercer’s (1995) second stage, especially, may be inhibited, if the mother is separated from her child by lengthy stays in NICU (Miles et al., 1999). The second stage, which is characterized by the mother now taking on the bulk of the care for the child, may be complicated by separation from the child, and by sharing of this role with a nurse who may bear the primary responsibility for the child in the NICU (Kirk, 2001). For the mother and family, questions may arise on what is the parenting role, and what is the caregiving role (Kirk, Glendinning, & Gallery, 2005).
Parenting has been described as a social, continuously negotiated relationship between parent and child, characterized by physical care, love, security, material provision, protection, and encouragement of a child’s development provided by the mother, father or guardian (Coleman & Karraker, 2000; Horowitz, 1993). Caregiving has been described more generally, as meeting the physical and emotional needs of a dependent patient (Reinhard, Given, Huhtala, & Bemis, 2008). Both roles require caring for a dependent person, and there is overlap, however, caregiving can be a role taken on in a professional capacity, while parenting is a more informal role. The overlap is sometimes critical in the relationship between mothers (and parents), and health care professionals, especially nurses (Kirk et al., 2005; Ratliffe et al., 2002). The mother and the nurse may have to negotiate and communicate what is expected and what kind of responsibilities the mother can and is willing to assume. Kirk et al. (2005) have found that some mothers may feel “forced” to assume a responsibility for their child’s care they may not be ready for, and that there is an assumption of what the mother can and cannot do.

**Caregiver Burden, Stress, and Quality of Life**

The distinction between what the mother feels she can and cannot do is related to the mother’s perception of her situation (Kirk et al., 2005). It is also related heavily to her feelings of stress, and especially burden (Kirk, 2001). Burden has been defined as “demands, responsibilities, difficulties, and negative consequences of caring for relatives with special needs” (Brannan et al., 1997, p. 212). Stress has been defined as the person to environment interaction that is perceived as reaching beyond the individual’s resources
and abilities (Lazarus & Folkman, 1984). While each is a distinct concept that measures separate things, they are often found to be in relationship to one another, especially in caregivers of both adults and children (Happe & Berger, 2002). Burden has been found to be related to sleep quality, stress, and overall QOL in caregivers of both adults and children (Calderon et al., 2010; Krulik et al., 1999).

Increased burden has been linked to increased stress and anxiety in parental caregivers of young children requiring home enteral nutrition (Calderon et al., 2010). Calderon et al. (2010) examined stress, anxiety, and burden in 56 parental caregivers of young children requiring enteral nutrition while at home, and found that burden influenced the caregiver’s feelings of anxiety and stress, with increased reports of burden relating to increased reports of stress and anxiety. The researchers also found that there was no relationship between burden and the child’s diagnosis, and no significant relationship was found between maternal age, socioeconomic status, and caregiver burden (Calderon et al., 2010). The study also confirmed the hypothesis that stress mediates the relationship between feelings of burden and anxiety (Calderon et al., 2010). Also, although not a focus of the study, caregivers who reported increased stress and burden also reported having poor sleep (Calderon et al., 2010). Increased burden and stress was also found in parental caregivers of young children after a traumatic brain injury (Aitken et al., 2009).

Aitken et al. (2009) examined burden, stress, and QOL in parental caregivers of young children after a traumatic brain injury. The authors found that increased burden led to increased levels of stress and poor QOL in caregivers, both maternal and paternal (Aitken et al., 2009). Unmet healthcare needs and the severity of the child’s disability
were also related to poor QOL and increased reports of stress and burden in caregivers (Aitken et al., 2009).

Muller-Godeffroy et al. (2009) examined burden in 117 caregivers of children with type 1 diabetes mellitus. The authors found that, previous to the use of an insulin pump, parental caregivers reported increased levels of stress and anxiety, as well as burden related to their child’s condition (Muller-Godeffroy, Treichel, & Wagner, 2009). After the child received an insulin pump, parents reported decreased burden, stress, and the child reported increased QOL (Muller-Godeffroy et al., 2009). Not only do physical conditions, such as traumatic brain injury or the need for enteral nutrition, cause increased burden and stress in caregivers, but they also show an increase in developmental conditions, such as autism and Tourette’s Disorder (Cooper et al., 2003; Khanna et al., 2010).

In parental caregivers of children with Tourette’s Disorder compared to those with asthma, Cooper et al. (2003) found that increased burden was found to be positively related to increased depression and stress. Parents of children with Tourette’s Disorder reported higher levels of burden and stress than parents of children with asthma. In families where both the mother and the father were interviewed, the fathers reported lower burden than mothers, and lower stress in both the asthma and Tourette’s groups (Cooper et al., 2003). This finding was supported by Calderon et al. (2010) in parental caregivers of children with home enteral nutrition, with mothers reporting greater burden scores. In contrast however, lower socioeconomic status in caregiver’s of children with Tourette’s and asthma showed increased levels of burden and depression, while no significant relationship between socioeconomic status or education could be found in
parental caregivers of children requiring home enteral nutrition (Calderon et al., 2010; Cooper et al., 2003).

Burden and stress were also found to be related in caregivers of young children with autism spectrum disorders (Khanna et al., 2010). Khanna et al. (2010) examined burden, stress, and QOL in parental caregivers of children with autism spectrum disorders. In one of the few studies to examine burden, stress, and QOL, the authors found that increased burden led to decreased QOL, and increased levels of stress (Khanna et al., 2010). Along with burden and increased stress, the child’s behavior, and social support also emerged as significant predictors of QOL in the caregivers (Khanna et al., 2010).

Caregivers of young children commonly reported increased burden and increased stress (Calderon et al., 2010). Poor sleep quality has been found to exacerbate feelings of stress and burden, as well as to predict increased stress and burden (Gallagher et al., 2010). However, little is known about the relationship between sleep quality, stress, burden, and QOL in caregivers, especially caregivers of chronically ill children (Khanna et al., 2010).

Stress

Stress, in this study, refers to perceived psychological stress by the maternal caregiver. It is defined as the caregiver’s perception of the person to environment interaction as reaching beyond their resources (Lazarus & Folkman, 1984). Unlike burden, stress does not pertain, specifically, to the child’s illness or care, but to the
perception (appraisal) of the maternal caregiver’s environment (Lazarus & Folkman, 1984).

Stress interacts with both burden and sleep quality in caregivers of young children with a chronic illness or disability (Calderon et al., 2010; Gallagher et al., 2010). Burden has been found to be increased with stress in parents of children requiring enteral nutrition; and poor sleep and increased stress have been positively correlated in caregivers of young children with developmental disabilities (Calderon et al., 2010; Gallagher et al., 2010). Education, depressive symptoms, gender, race, and age have all been found to possibly influence stress, as well.

*Education*

Streisand et al. (2005), in their study of parental caregivers of children with diabetes, found that decreased socioeconomic status was associated with fewer years of education in caregivers, and also predictive of increased stress (Streisand, Swift, Wickmark, Chen, & Holmes, 2005). Lower socioeconomic status was also indicative of increased reports of burden, as well as stress related to the child’s illness severity (Streisand et al., 2005). Fewer years of education was also related to increased stress and burden in maternal caregivers of medically fragile children being cared for in the home (Miles et al., 2002).

Similarly, Miles et al. (1999) found that fewer years of education were related to increased stress in mothers of medically fragile children. Caucasian mothers attained higher levels of education than African American mothers, and increased stress and fewer years of education were related to higher levels of burden (Miles et al., 1999). Miles et
al. (1999) postulated that the increase may be related to “information overload” or mothers having difficulty organizing all of the information they receive, and so feeling overwhelmed by their child’s care.

Level of education was also tangentially found to influence stress in mothers of technology dependent children (Thyen et al., 1999). A higher education level (high school or beyond) was found to relate to having a job outside the home, especially for the mother. Having a job outside the home was found to decrease stress levels. Employment status was also related to depressive symptoms, with unemployed mothers reporting increased levels of depressive symptoms (Thyen et al., 1999). In mothers of children with irritable bowel syndrome, higher levels of stress were found to be related to fewer years of education and lower socioeconomic status (Guilfoyle, Denson, Baldassano, & Hommel, 2011).

Depression

Thyen et al. (1999) found that mothers of children dependent on technology reported higher levels of depressive symptoms (as well as physical symptoms), and those of reported increased depressive symptoms, also reported higher levels of stress. Also, mothers of technology dependent children, overall, reported higher levels of stress and depression that mothers of typically developing children (Thyen et al., 1999). Increased levels of stress and depressive symptoms were also found in 116 mothers of chronically ill children (Canning, Harris, & Kelleher, 1996). Increased levels of depressive symptoms were related to increased levels of stress, as well as burden in mothers of
chronically ill children, especially when mothers rated their child’s illness to be “very severe” (Canning et al., 1996).

Miles et al. (1999) found increased levels of stress related to depressive symptoms in their study of mothers of medically fragile children. Increased depressive symptoms were also related to lower socioeconomic status and fewer years of education. Overall, mothers who reported higher levels of distress, had lower socioeconomic status, reported higher levels of depressive symptoms, and had attained fewer years of education (Miles et al., 1999).

Brehaut et al., in their study of caregivers of children with cerebral palsy, found that increased stress was related to increased levels of “emotional complaints” as well as depressive symptoms (Brehaut et al., 2004). Caregivers also reported poorer physical health, with a higher incidence of “stress” related maladies, such as ulcers and migraines, than parents of typically developing children (Brehaut et al., 2004). In caregivers of children with irritable bowel syndrome, reports of increased depressive symptoms were found to influence levels of stress (Guilfoyle et al., 2011).

**Age and Gender**

Stress has been found to be different in men and women (Benn & McColl, 2004). Men tend to use more active forms of coping, while women use more passive forms of coping, and stressors also tend to differ. Fathers cite finances and employment as major stressors, such as not being able to “provide” for their family, while mothers can sometimes feel more anxiety over their child’s future and illness severity (Hastings et al., 2005).
Lee et al. (2005) found that mothers reported greater satisfaction with their child’s care when fathers were involved and they felt less stress overall. Similarly, fathers reported lower levels of stress when involved in the care of the child (T.-Y. Lee, Miles, & Holditch-Davis, 2005). Also, fathers reported participating more in care when married to the mother of the child (T.-Y. Lee et al., 2005).

Age may also impact how a caregiver perceives stress. In caregivers of young children with irritable bowel syndrome, younger caregivers reported increased stress compared to older caregivers (Guilfoyle et al., 2011). Older caregivers also reported more resources (finances and support), and the authors suspected this may have influenced the caregivers’ perceptions on stress (Guilfoyle et al., 2011).

In a study of “young” (under 45 years of age) and “old” (45 years of age and older) caregivers of adult family members, young caregivers reported higher levels of stress than old caregivers (J. H. Carter, Lyons, Stewart, Achbold, & Scobec, 2010). Young caregivers also reported increased levels of burden, and resisted the “caregiver” label. Carter et al. (2010) also found that young caregivers had a harder time seeing the “silver lining” in their caregiving duties, and that reports of mutuality between the caregiver and the dependent family member were lower for young caregivers, than old caregivers. Increased levels of burden in young caregivers may have also been related to feelings of less time for himself or herself (J. H. Carter et al., 2010).

Gender and age may influence how caregivers perceive and respond to stress when caring for a loved one (Guilfoyle et al., 2011). Mothers report different stressors as being the most influential, when compared to fathers (Streisand et al., 2005). Older and younger caregivers may view the caregiving role differently, and respond to the
responsibilities differently. Younger caregivers may view caregiving as more stressful and report higher burden scores. This could be related to available resources and experience (J. H. Carter et al., 2010; Streisand et al., 2005).

Race and Marital Status

Marital status and race may also interact and influence stress along with education, depression, age, and gender. Miles et al. (2002), in their study of caregivers of medically fragile children, found that there were actually few differences between the stress levels of African American caregivers and Caucasian caregivers. However, investigators found that African American maternal caregivers reported significantly higher levels of stress related to their environment. African American caregivers reported higher stress related the sights and sounds of having a baby in the NICU, as well as handling and using the various pieces of equipment required for their child’s care (Miles et al., 2002).

Streisand et al. (2005), however, found that “non-Caucasian” mothers reported higher levels of stress than Caucasian mothers; however, they postulated that this could be due to resources. Also, single caregivers with other children in the home reported higher levels of stress than older, married caregivers (Streisand et al., 2005). Lower socioeconomic status was also related to increased stress in single-parent caregivers, both Caucasian and African American (Streisand et al., 2005).

Lee et al. (2005) found that married couples reported lower levels of stress when caring for their child in the home. Further, fathers reported more satisfaction, and less stress, when they participated in their child’s care, and married mothers reported higher
levels of mutual satisfaction when the father participated than unmarried mothers and fathers (T.-Y. Lee et al., 2005). Married couples also reported lower initial stress than unmarried couples and higher satisfaction (T.-Y. Lee et al., 2005).

Montagnino and Mauricio (2004) in their study of caregivers to technology-dependent children found that caregivers reported increased stress when compared to non-caregiver parents (Montagnino & Mauricio, 2004). However, maternal caregivers of technology-dependent children reported lower levels of stress when married. The authors speculated this may be related to feeling more supported at home. Caregivers also reported feeling “overwhelmed” with responsibilities, the authors highlighted the need for respite care, especially for those mothers without a spouse or other support system (Montagnino & Mauricio, 2004).

Research Gaps

There are several gaps in the literature. The first major gap exists in caregivers of young children with a chronic condition of illness. The majority of research on sleep in caregivers has been conducted in caregivers of adult family members (Meltzer & Moore, 2008). Also, few studies have used objective measures, such as actigraphs or polysomnography in caregivers of young children with a chronic illness or condition (Meltzer, 2008). To date, there is only one study that examines sleep quality and stress in caregivers of young children with developmental disabilities (Gallagher et al., 2010), and there are no studies that describe or examine sleep or sleep quality, stress, caregiver burden, and QOL, combined, in caregivers of young children with BPD.
No studies have examined sleep quality and caregiver burden and QOL in caregivers of young children with a chronic illness or condition. Methodologically, there are no available instruments to measure general caregiver burden in caregivers of young children with a chronic condition or illness, and no measures exist specifically for the BPD population. There are few studies that examine caregiver burden, stress, and QOL in caregivers of young children with a chronic condition or illness, and of those studies, few use minority populations or differentiate between maternal caregivers or both maternal and paternal caregivers (Aitken et al., 2009; Calderon et al., 2010).

Overall, this study seeks to bridge these gaps by being one of the first studies to examine sleep quality, stress, caregiver burden, and QOL in maternal caregivers of young children with BPD.

Summary

Maternal caregivers assume the responsibility of caring for their young child with a chronic illness. While facing the challenges and responsibilities of this new role, several aspects of their lives are influenced, including their sleep, caregiver burden, stress, and overall QOL (Klassen et al., 2010; Meltzer & Mindell, 2006). For many maternal caregivers, these areas are also influenced by other variables, such as age, race, education status, marital status, and depressive symptoms (Meltzer, 2008; Miles et al., 1999; Rittman et al., 2009). While more studies are being conducted in maternal caregivers of children with a chronic illness, several gaps still exist.

Little is known about how sleep influences caregivers (female or male) of young children with a chronic illness or condition (Meltzer & Moore, 2008). The few studies
that have been conducted, have shown that caregivers are reporting deprived sleep, and disrupted sleep for a variety of reasons addressed in this chapter, as well as relationships between sleep and daytime functioning, stress, and QOL (Gallagher et al., 2010; Meltzer & Mindell, 2006; Xiang, Luk, & Lai, 2009). While previous research indicates that sleep quality, stress, and caregiver burden may all be significantly related to QOL in caregivers (Chien et al., 2003; Gallagher et al., 2010), few studies have combined these variables in caregivers to children with a chronic illness. To date, no studies have examined sleep in caregivers of chronically ill children and caregiver burden, stress, and QOL combined.
CHAPTER THREE

METHODS

Determining the influences on QOL in caregivers of children with chronic illnesses, such as BPD, may provide knowledge upon which interventions may be developed and then tested (Taylor, Gibson, & Franck, 2008). This study examined maternal caregivers’ perceived sleep quality, caregiver burden, and stress and the relationship to QOL, as well as the covariates of age, race, education status, marital status, and depressive symptoms. The methods used in the study are described in this chapter and include study design, sample and setting, instrumentation, data collection procedures, and plans for data analysis.

Design

A non-experimental, descriptive, correlational, cross-sectional design was used to describe sleep quality, caregiver burden, stress, and QOL in maternal caregivers of young children with BPD. A correlational, cross-sectional examination among study variables, including sleep quality, caregiver burden, stress, and QOL was undertaken, because little research has been done to examine such relationships in maternal caregivers of young children with a chronic illnesses or conditions (Meltzer & Mindell, 2006). The limited amount of research in the area of sleep in caregivers of children with a chronic illness has
used descriptive, non-experimental methods, so building upon previous work would allow for more appropriate comparisons (Polit & Beck, 2008). Non-experimental, cross-sectional, descriptive research designs can be used to develop the literature and evidence base, so that more rigorous designs can be used in later studies (Burns & Grove, 2009). However, there are limitations to using a cross-sectional design, including a lack of generalizability, and these types of designs do not determine cause and effect (Burns & Grove, 2009).

Sample and Setting

A nonprobability, convenience sample of 61 maternal caregivers of young children with BPD was recruited for this study. Grandmothers were included if they identified as the primary caregiver. This type of sampling technique is one of the most commonly used techniques in research to ensure an adequate number of participants is reached, however, it does carry an increased risk for bias due to self-selection (Burns & Grove, 2009). Convenience sampling is useful in correlational studies conducted in new areas of research (Polit & Beck, 2008). However, using nonprobability and convenience sampling limits the generalizability of the study findings due to the possibility of selection bias.

Inclusion criteria for the sample consisted of self-identified maternal caregivers who were at least 16 years of age; spoke, understood, and could write in English; and had a child: 1) diagnosed with mild or moderate BPD; 2) between the ages of 4 months and 3 years, and 3) was living at home for at least 2 months. In order to be referred to the clinic used for this study, the child had to meet certain requirements, including the need for
oxygen via nasal cannula while at home and requiring diuretics (e.g. lasix or aldactone). Maternal caregivers for this study were defined as the female caregiver who acknowledged herself as the primary family caregiver responsible for the child’s daily physical health care needs. Exclusion criteria for the maternal caregiver included: 1) unable to read or write English, and 2) diagnosed by a physician with a sleep disorder (obstructive sleep apnea, insomnia, restless leg syndrome). Exclusion criteria for the child included requiring a tracheotomy or ventilator.

The setting for this study was a regional children’s hospital ambulatory care clinic located in an urban, Southeastern U.S. city. The clinic serves mainly children with BPD and is held on the same day each week. The children are scheduled for clinic appointments every 3-6 months. An interdisciplinary team consisting of a social worker, physician, nurse, nurse practitioner, nutritionist, and respiratory therapist are present at each clinic visit. The clinic sees approximately 6 to 9 patients each week, with a total number of approximately 166 patients followed in the clinic.

Power Analysis

Multiple linear regression was used to test the study hypotheses, therefore, the sample size was based on these statistical methods. The effect size was determined based on the dependent variable of interest, QOL, and was measured using the WHO QOL-BREF scale (World Health Organization, 1998). QOL in parental caregivers of children with attention-deficit-hyperactivity disorder (n= 77) was examined by Xiang, Luk, and Lai (2009) using multiple linear regression to determine influences of demographic characteristics (age, child gender, parental education) on parental QOL (WHO QOL-
From the Xiang, Luk and Lai (2009) study, the reported F statistic was \( F(4, 71) = 6.99 \) for modeling physical QOL. The principal investigator of this study calculated an \( F^2 \) measure resulting in an effect size of .3938. For this study, there were a total of 9 predictors (sleep quality, caregiver burden, stress, QOL, marital status, depression, race, age, and education status). Using an alpha set at .05, a power of 90, and the calculated effect size of .3938, the total estimated sample size needed was 60 maternal caregivers.

**Instrumentation**

All variables were assessed using self-report questionnaires (Table 1). The variables included sleep quality, stress, and caregiver burden, and QOL. Sleep quality was assessed using the Pittsburgh Sleep Quality Index (PSQI) (Buysse et al., 1989). Stress was assessed using the Perceived Stress Scale (Cohen et al., 1983). Burden was assessed using the Montgomery-Borgatta Caregiver Burden Scale-Revised (Montgomery et al., 1985). QOL, the dependent variable, was assessed using the WHO QOL-BREF (World Health Organization, 1998). The investigator developed a demographic questionnaire to collect demographic data about the child with BPD and maternal caregiver, including age, marital status, ethnicity, socioeconomic status, education, and depression.

**Sleep Quality**

The PSQI was chosen as a measure of subjective sleep quality. It is a self-report, 19 item, 4-point scale, with responses ranging from “not during the past month,” to “three
or more times a week.” The instrument measures sleep disturbances in adults, and provides a global score, as well as seven subscale scores (sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbances, sleep medications, and daytime dysfunction) that range in score from 0-3, with higher scores indicating a greater disturbance (Buysse et al., 1989; Meltzer & Mindell, 2006). The instrument was originally designed for use in older adults, however, it has been widely used and validated on a number of diverse populations (Mezick et al., 2008). Items are summed for a total score, with a score greater than five indicating severe sleep difficulties (Buysse et al., 1989).

The PSQI has been validated against polysomnography (the gold standard for assessing sleep) in adults. Concurrent validity was established for the PSQI measure, with t-tests, and no significant differences were found for the majority of the measure’s subscales; with the exception of sleep duration. Sleep duration was overestimated when compared to polysomnography (Buysse et al., 1989; P. A. Carter, 2002). Reliability has been assessed in a variety of adult populations, with studies reporting Cronbach’s alphas ranging from 0.81 to 0.83 for global and subscales (Buysse et al., 1991; Buysse et al., 1989). Carter (2002) reported a Cronbach’s alpha of 0.81 for her study of caregivers to adult family members with cancer. Aslan et al. (2009) reported a Cronbach’s alpha of 0.82 in a study of caregivers of children with cancer. The instrument has a Flesch-Kinkaid reading level of 5.4, as determined by the principal investigator using the Microsoft Word 2008 readability function.
Stress

The Perceived Stress Scale assesses a participant’s global perception of stress and was designed within the context of Lazarus and Folkman’s (1984) conceptual model of stress appraisal (Golden-Kreutz, Frierson, & Anderson, 2004). It is a 10-question, self-report, Likert scale, with six of the items being negative (i.e., “In the last month, how often have you felt nervous and stressed?”) and the four remaining questions being reverse scored, and more positive (i.e, “In the last month how often have you felt things were going your way?”) (Cohen et al., 1983). Scores range from 0 (never) to 4 (very often), with higher scores indicating greater stress (Cohen et al., 1983).

Cohen et al. (1983) established concurrent validity via a sample of healthy, community dwelling adults in a smoking cessation group. The Perceived Stress Measure was found to be highly correlated with the life-events scale (Cohen et al., 1983). Reliability of the Perceived Stress Measure was reported as a Cronbach’s alpha of 0.86 in a population of healthy adults (Cohen et al., 1983). The Perceived Stress Measure has been used in caregivers of children with peanut and nut allergies, with a reported Cronbach’s alpha of 0.84 (King, Knibb, & Hourihane, 2009). The instrument has a Flesch Kinkaid reading level of 3.7, as determined by the principal investigator using the Microsoft Word 2008 readability function.

Caregiver Burden

The Montgomery-Borgatta Caregiver Burden Scale-Revised was used to assess caregiver burden in this study (Savundranayagam et al., 2010). The measure has four different subscales: subjective burden (scores range from 6-30), relationship burden
(scores range from 5-25), and objective burden (scores range from 6-30), as well as an Uplifts (scores range from 5-25) portion and consists of 22 items (Savundranayagam et al., 2010). Item responses use a 5-point Likert type scale, with the responses ranging from “not at all” to “a great deal.” The scale, developed by Montgomery and Borgatta, was based on previous caregiver literature, and adapted from Zarit et al.’s (1980) Zarit Burden Scale. Content validity was established based on previous literature and a panel of experts (Savundranayagam et al., 2010). Construct validity was examined in relation to activities of daily living items and the caregiver’s characteristics (such as age and gender) (Montgomery et al., 1985). Cronbach’s alpha was reported by Savundranayagam et al. (2010) for each subscale: for the subjective burden subscale (0.90), for the relationship burden subscale (0.89), and for the objective burden subscale (0.93), and for Uplifts (0.90). The instrument has not been used in caregivers of children with a chronic illness. The instrument has a Flesch Kinkaid reading level of 4.2, as determined by the Microsoft Word 2008 readability function.

Quality of Life

QOL was assessed using the WHO QOL-BREF (World Health Organization, 1998). It is a 26 item tool, on a 5-point Likert scale, with responses ranging from “Never” to “Always.” This instrument is a general measure of QOL used internationally, and it has been validated in adult populations (World Health Organization, 1998). The instrument consists of four domains, physical (scores range from 7-35), psychological (scores range from 6-30), social relationships (scores range from 3-15), and environmental domains (scores range from 8-40). Cronbach’s alphas for the four domains
included 0.84 for physical, 0.77 for psychological, 0.69 for social relationships, and 0.80 for environmental, as measured in healthy adults (World Health Organization, 1998). The WHO QOL-BREF has shown discriminant validity with the longer, more in-depth questionnaire, the WHO QOL-100, which measures the same domains, but in a similar Likert-style 100-item format. The instrument was able to discern between healthy and ill participants in all domains (World Health Organization, 1998). The instrument has been used in parental caregivers of children with peanut and nut allergies, with reported Cronbach’s alphas of 0.80 and 0.82 (Cummings et al., 2010; King et al., 2009), and maternal caregivers of children with cancer (Chien et al., 2003). The instrument has a Flesch Kinkaid reading level of 3.4, as determined by the principal investigator using the Microsoft Word 2008 readability function.

**Depressive Symptoms**

The Center for Epidemiological Studies Depression Scale (CES-D) was used to assess depressive symptoms in maternal caregivers. The CES-D is a measure of depression that was designed to be used in a general population of healthy adults (Radloff, 1977). It is a 20-item, 4-point Likert measure that assesses current levels of depressive symptoms, including depressed mood, feelings of guilt, worthlessness, loss of appetite, sleep disturbance, and psychomotor retardation (Radloff, 1977). The scale ranges from 1 (rarely or none of the time) to 4 (most or all of the time), and a higher score indicates greater incidence of depressive symptoms. A score greater than or equal
to 16 has been found to be highly correlated with a clinical diagnosis of depression (Radloff, 1977).

Test-retest reliability for the CES-D was reported at two-weeks $r=0.51$, and 8-weeks $r=0.59$, and Cronbach’s alpha of 0.85 in caregivers to cancer patients, and 0.86 in caregivers to children with chronic conditions (P. A. Carter, 2003; Meltzer & Mindell, 2006). The measure has demonstrated high validity, and high correlation with other depression scales, as well as the ability to discriminate between depressed and non-depressed samples (Weissman, Sholomskas, Pottenger, Prusoff, & Locke, 1977). The instrument has a Flesch Kinkaid reading level of 2 as determined by the principal investigator using the Microsoft Word readability function. The observed Cronbach’s alpha for this instrument for this study was .777, slightly lower than the recommended .80 by Polit and Beck (2008).

**Demographic Questionnaire**

The principal investigator developed the demographic questionnaire. The questionnaire had 6- items to determine the maternal caregiver’s age, marital status (married or single), socioeconomic status (categorical), education (categorical), ethnicity (categorical), and the child’s age. The demographic questionnaire has a Flesch Kinkaid reading level of 4.3, using the Microsoft Word readability function.
Table 1

*Instrumentation*

<table>
<thead>
<tr>
<th>Instrument Name and Reading Level</th>
<th># of Items</th>
<th>Reliability</th>
<th>Validity</th>
</tr>
</thead>
</table>
| Pittsburgh Sleep Quality Index (PSQI) 5.4 | 19 | • Caregivers of adults with cancer (Carter, 2002): Cronbach’s alpha 0.81  
• Caregivers of children with cancer (Aslan, Sanisoglu, Akyol, & Yetkin, 2009): Cronbach’s alpha 0.82 | • Validated against Polysomnography using t-tests, highly correlated, only significant difference was in estimated time asleep (Buysse et al., 1989) |
| Perceived Stress Scale 3.7 | 10 | • Healthy adults: Cronbach’s alpha 0.86 (Cohen et al., 1983)  
• Caregivers of children with a peanut or nut allergy: Cronbach’s alpha 0.84 (King, Knibb, & Hourihan, 2009). | • Concurrent validity- Highly correlated with life-events scale (Cohen et al., 1983) |
| Montgomery-Borgatta Caregiver Burden Scale-Revised 4.2 | 21 | • Subjective burden subscale: 0.90  
• Relationship burden subscale: 0.89  
• Objective burden subscale: 0.93  
• Uplifts: 0.90 (Savundranayagam et al., 2010) | • Content validity with a panel of experts and literature review. Construct validity with ADL Short Form (Montgomery et al., 1985) |
| World Health Organization Quality of Life Scale-Brief (WHO QOL-BREF) 3.4 | 26 | • Parental caregivers of young children with peanut and nut allergies: Cronbach’s alpha of .80-.86 (Cummings et al., 2010) | • Discriminate validity established with longer WHO Quality of Life-100 question form (measures same domains), able to discriminate between healthy and ill persons (World Health Organization, 1998) |
| Center for Epidemiologic Studies Depression Scale (CES-D) 2 | 20 | • Healthy adults: test-retest reliability at two-weeks: r=0.51, and 8-week r=0.59 (Radloff, 1977)  
• Caregivers of children with chronic conditions: Cronbach’s alpha of 0.86 (Meltzer & Mindell, 2006) | • Discriminate validity: Established with depressed and non-depressed participants (Weissman, Sholomskas, Pottenger, Prusoff, & Locke, 1977). |
Protection of Human Subjects

To ensure protection of human subjects, the research proposal for this dissertation was submitted to the Institutional Review Board (IRB) at the University of Alabama at Birmingham, as well as submitted to the Children’s Hospital System and clinic medical director for review. A letter of support from the medical director of the clinic was submitted along with the IRB protocol materials. All protocol, informed consents, and questionnaires were submitted for approval prior to initiating data collection.

Collected data did not include the name of the participant, and did not ask for a geographic location. All data were reported as a group aggregate, with no participant individually identified. Data were entered into a password protected database on an IRB-approved encrypted flash drive (IronKey), with hard copies kept separately from the database. Hard copies were secured in a locked drawer in a locked faculty office at the UAB School of Nursing. Informed consent was obtained before the participant was entered into the study, and the participant was able to withdraw or stop the study at any time. Questionnaires were administered while the participant was in the individual clinic room. The staff and clinical medical director of the clinic supported these procedures for ensuring participant confidentiality during the informed consent and data collection processes.

Data Collection

The principal investigator collected all data at the specialty ambulatory clinic for children with BPD at the Children’s Hospital. A meeting was held with clinic nurses and staff prior to initiation of data collection to inform them of the study purpose, procedures,
and inclusion/exclusion criteria. All clinic nurses and staff expressed willingness to assist with identifying potential study participants. Clinic nurses approached maternal caregivers about their interest in participating in the study and their willingness to be included. This allowed for the maternal caregiver to express her willingness to be approached about participation in the study, as well as to have the clinic nurse conduct initial screening. Once the participant agreed to participate, the principal investigator ensured that sample inclusion and exclusion criteria were met, and completed the consent process prior to collecting data.

The maternal caregiver recruitment and informed consent process took place during the child’s regularly scheduled clinic visits. During the informed consent process, the principal investigator explained the study purpose and study procedures to the maternal caregiver. Maternal caregivers who agreed to participate after the discussion with the primary investigator were asked to sign the consent form. Once signed, all data collection was conducted in a manner that ensured confidentiality (no identifying information on data forms). The child remained in the room for data collection. If the maternal caregiver declined to participate, the clinic visit continued as scheduled.

Data were collected by self-report questionnaire. Limited education and low literacy may be present within this population; therefore, the principal investigator read the questionnaires to the participant. If the study participant requested to complete the questionnaires without assistance, the principal investigator remained in the room to be available for any questions. The questionnaires were administered in a specific order, starting first with the demographic questionnaire, followed by the Center for Epidemiological Studies Depression Scale (CES-D), then the PSQI, the Montgomery-
Borgatta Caregiver Burden Scale-Revised, the Perceived Stress Scale, and finally the WHO QOL-BREF. The order was determined to allow for longer questionnaires to be followed by relatively shorter questionnaires. All questionnaires were composed at a 6th grade or lower reading level via the Flesch Kinkaid reading level tool on Microsoft Word 2008. Upon completion of the study measures, the study participant was given a $5 gift certificate.

Data Management

Prior to the completion of each interview, the principal investigator reviewed each questionnaire to ensure completion of all the measures and to prevent missing data. If unanswered items were identified, the principal investigator would repeat these items for the participant. If the participant refused to answer a question, it was recorded as such. If the participant changed her answer, the principal investigator asked the participant to initial any changes.

All forms, including personal and identifiable information were kept in a locked file by the principal investigator. An encrypted, password-protected, IRB-approved flash drive (IronKey) maintained all computerized data. These confidential measures provided security for all documents within the study. All data collected, including completed questionnaires and signed consent forms, were transported to the School of Nursing at the end of each day, to be placed in a locked cabinet in a locked, faculty office (Dr. Anne Turner-Henson).
Data Coding and Entry

The principal investigator served as the single coder for this study. A codebook was developed based on questionnaires and demographic information. For questionnaires with subscales (PSQI, WHO QOL-BREF, Montgomery-Borgatta Caregiver Burden Scale-Revised) items were entered to indicate their subscale. For example, the environmental subscale of the WHO QOL-BREF was entered under “environ.” All responses were self-marked by the maternal caregiver and were identified by number (i.e., 1= strongly agree, 5= strongly disagree, depending on the Likert scale).

The principle investigator entered data into the Statistical Package for the Social Sciences (SPSS) 18.0 program as the forms were completed. Upon completion of data collection, the data were re-entered and compared to ensure accuracy of the data entry.

Data Analysis

Data were analyzed using SPSS 18.0 software and procedures. The level of significance was set at an alpha of .05, for two-tailed tests. A statistician from the principal investigator’s PhD dissertation committee reviewed all data for accurate data analyses and calculations. Any question that the maternal caregiver refused to answer was coded as 888. Descriptive statistics were run on demographic questions to include measures of central tendencies (mean, range) for such data as child and maternal caregiver’s age. Frequencies were run to examine the sample and evaluate the descriptive data. A Pearson’s correlational table with appropriate correlation or association measures was created to evaluate relationships between independent variables (sleep quality,
caregiver burden, stress, depression, education, marital status, and race) and with the dependent variable (caregiver QOL). Multiple linear regression was run to determine which variables best explain variability in QOL in maternal caregivers of young children with BPD. Also, a mediation model was tested to determine if stress mediates the relationship between sleep quality and caregiver burden, and QOL.

Data Analysis Description and Plan for Hypotheses

Hypothesis 1: Sleep quality and caregiver burden will account for more variability and have the greatest influence on QOL, when controlling for depressive symptoms, education, marital status, age, and race.

In order to determine the accuracy of Hypothesis 1, the primary investigator developed Specific Aim 1: Describe sleep quality, burden, stress, and QOL in maternal caregivers of young children with BPD. This description was enumerated so that tables display percentages and frequencies for the variables of race, age, education, depressive symptoms and marital status. Central tendency measures were reported for sleep quality, caregiver burden, stress, and QOL, as well as confounding variables (race, age, depressive symptoms, education, and marital status). Specific Aim 2 was developed to examine QOL under the influences of age, race, depressive symptoms, marital status, education, sleep quality, caregiver burden, and stress. To measure these influences, multiple linear regression was run to determine the variables with the greatest influence on overall QOL.
Hypothesis 2: Stress will mediate the relationship between sleep quality and stress in maternal caregivers of young children with BPD.

Specific Aim 3 was developed to determine if stress mediates the relationship between sleep quality and caregiver burden and QOL in maternal caregivers of young children with BPD. This assessment utilized Baron and Kenny’s (1986) four step method of mediation. First, the primary investigator used simple linear regression, to determine whether sleep quality and burden were significant in relation to QOL. Second, sleep quality and burden were compared with stress to look for a significant relationship. Third, the mediating variable, stress, was evaluated for any significant relationship with QOL. Fourth, stress and caregiver burden and sleep quality were evaluated to determine if the combination was significant as well.

Limitations

This study contains several limitations within the scope of its generalizability and with regard to its data collection. The study was cross-sectional, and therefore, it only captures the caregiver at one point in time (Polit & Beck, 2008). The study was self-report, and therefore, may be subject to participant bias and honesty (Polit & Beck, 2008). The study used a convenience sample, which also may have led to self-selection bias (Polit & Beck, 2008). The study used several questionnaires, for a total of 98 questions all together, and may have contributed to participant questionnaire fatigue and burden (Polit & Beck, 2008).
CHAPTER FOUR

FINDINGS

The findings of this study are presented in this chapter. Sample characteristics are described for the study population of maternal caregivers (age, race, education, marital status, and those living in the home), as well as the child (age, months since discharge to the home). Descriptive statistics (including frequencies, means, ranges, standard deviations) are presented. Paired relationships between variables were determined using Pearson’s product moment correlations, and correlation matrices are included. Reliability information is also presented for instruments used for measuring independent and dependent variables in this study.

This study was designed to examine relationships between sleep quality, stress, caregiver burden, and QOL in maternal caregivers of young children with BPD, as well as influences of these variables on QOL. Sleep quality, stress, and caregiver burden (objective) were the independent variables, with QOL as the main outcome variable for this study, using covariates of age, race, education status, depressive symptoms, and marital status. A mediation model was tested to determine if stress mediated the relationship between sleep quality and caregiver burden, and QOL. The study variables were measured using self-report scales completed by the maternal caregiver. Covariates
that provided demographic and educational information about the child and home characteristics were also collected.

Reliability

Reliability coefficients using Cronbach’s alpha were calculated to assess the internal consistency of the study instruments used in the collection of data. The Cronbach’s alpha reliability coefficient for the CESD for this study was .777, slightly lower than the recommended level of greater than .80 by Polit and Beck (2008). The Cronbach’s alpha reliability coefficients were determined for: the WHO QOL-BREF to be .888, and reliability coefficients for the PSQI was .835, and .722 for the Perceived Stress Scale, which was slightly lower than the recommended level. Finally, the Cronbach’s alpha for the Montgomery-Borgatta Caregiver Burden Scale- Revised for objective burden subscale was .880.

Specific Aims

Specific Aim 1: Describe sleep quality, burden, stress, and QOL in maternal caregivers of young children with BPD.

Demographic

A convenience sample of 61 maternal caregivers (oversampled by one) of young children (ages 4 months- 3 years) was recruited from a pediatric pulmonary clinic in a southeastern United States children’s hospital. A total of 64 maternal caregivers were
screened over a 6 month period (each met inclusion criteria), and 61 consented to participate in the study, yielding a response rate of 95%. No maternal caregivers reported having a sleep disorder, or taking medications (prescribed or over the counter) to sleep.

Demographic variables collected on the sample included the maternal caregivers’ age, race, marital status, and educational attainment (some high school, high school graduate, some college, college graduate degree, graduate school) (see Table 2). The relationship to child (mother, grandmother, aunt) also was collected as a demographic variable, because other female family members could be included if they self-identified as the primary female caregiver for the child. Child demographic variables included child’s date of birth, child’s age, and how long the child had been living at home (see Table 3). The other variable included identification of others (father of child, grandparents, aunts or uncles, and siblings) living in the home (see Table 4).

All maternal caregivers recruited for this study had a child between the ages of four months to three years who had moderate BPD, and did not require a tracheotomy or ventilator. The children in this study had a mean age of 13.93 months, with a range of four months to three years. The child had been living in the home for a mean of 8.7 months, with a range of two months to three years.

The maternal caregiver as defined for the purposes of this study was the individual who self-identified as the primary caregiver for the child. Mothers comprised the majority of the caregivers in this study (96.7%), with grandmothers being the only other primary caregiver (3.3%). The mean age of maternal caregivers was 29.59 years, with a range of 17-50 years. For mothers, 54.1% (n=33) were 28 years or younger, and 41% of the sample was between the ages of 21-25 years (n=25). Over one third the
sample of mothers (39.3%, n=24) had attended at least one year of college; however, 37.7% (n=23) of the sample had graduated from high school or attended at least one year of high school.

In the home, 52.5% (n=32) maternal caregivers reported having the child’s father living with them, and 18.1% (n=11) maternal grandmothers were reported as living in the home. Two maternal grandfathers (3.3%) lived in the home with the child and one paternal grandmother lived in the home (1.6%). For all sixty-one caregivers included in the final sample, the mother lived with the child, even in the two cases where the grandmother identified as primary caregiver. 41% (n=25) of maternal caregivers reported having no other children living in the home, while 59% (n=36) maternal caregivers reported at least one other sibling for the child with BPD in the home, with a range of one up to seven other children in the home.
Table 2

Demographic Characteristics of the Sample (N=61)

<table>
<thead>
<tr>
<th>MATERNAL CAREGIVER CHARACTERISTICS</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>41</td>
<td>67.2</td>
</tr>
<tr>
<td>Caucasian</td>
<td>20</td>
<td>32.8</td>
</tr>
<tr>
<td>Education status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some high school</td>
<td>7</td>
<td>11.5</td>
</tr>
<tr>
<td>High school graduate</td>
<td>16</td>
<td>26.2</td>
</tr>
<tr>
<td>Some college</td>
<td>24</td>
<td>39.3</td>
</tr>
<tr>
<td>College graduate-Associates Degree</td>
<td>2</td>
<td>3.3</td>
</tr>
<tr>
<td>College graduate-Bachelors Degree</td>
<td>5</td>
<td>8.2</td>
</tr>
<tr>
<td>Masters/Graduate Degree</td>
<td>7</td>
<td>11.5</td>
</tr>
<tr>
<td>Relationship Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>23</td>
<td>37.7</td>
</tr>
<tr>
<td>Single- never married</td>
<td>34</td>
<td>55.7</td>
</tr>
<tr>
<td>Divorced</td>
<td>2</td>
<td>3.3</td>
</tr>
<tr>
<td>Separated</td>
<td>2</td>
<td>3.3</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>29.59</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>17-50</td>
<td></td>
</tr>
</tbody>
</table>


Table 3

*Child Characteristics*

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (months)</td>
<td>13.93</td>
<td>4-36</td>
</tr>
<tr>
<td>Time at home (months)</td>
<td>8.79</td>
<td>2-36</td>
</tr>
</tbody>
</table>

Table 4

*Home Characteristics*

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Those living in the home with mother and child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father of child</td>
<td>32</td>
<td>52.5</td>
</tr>
<tr>
<td>Maternal Grandmother of child</td>
<td>12</td>
<td>18.1</td>
</tr>
<tr>
<td>Maternal Grandfather of child</td>
<td>2</td>
<td>3.3</td>
</tr>
<tr>
<td>Paternal grandmother of child</td>
<td>1</td>
<td>1.6</td>
</tr>
<tr>
<td>Aunt of child</td>
<td>2</td>
<td>3.3</td>
</tr>
<tr>
<td>Number of Siblings in the home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>25</td>
<td>41</td>
</tr>
<tr>
<td>1</td>
<td>17</td>
<td>27.9</td>
</tr>
<tr>
<td>2</td>
<td>12</td>
<td>19.7</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>8.2</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>1.6</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>1.6</td>
</tr>
</tbody>
</table>
Descriptive Statistics for Independent and Dependent Variables

The independent variables for this study included sleep quality, stress, and caregiver burden. The variables were measured using self-report measures, completed by the maternal caregiver. The independent variable measures used in the study included the Pittsburgh Sleep Quality Index (PSQI) (Buysse et al., 1989), the Perceived Stress Scale (Cohen et al., 1983), and the Montgomery-Borgatta Caregiver Burden Scale-Revised (Savundranayagam et al., 2010). The PSQI global sleep quality score was used in this study to measure overall sleep quality, and the Montgomery-Borgatta Caregiver Burden Scale-Revised objective subscale was used to measure caregiver burden. A higher score on the caregiver burden scale indicated a higher incidence of caregiver burden, likewise a higher score on the stress scale also indicated higher stress, and a higher score on the PSQI indicated poorer sleep. The dependent variable for this study was QOL, and was measured using the WHO QOL-BREF scale (World Health Organization, 1998). Depressive symptoms were measured as a covariate using the Center for Epidemiological Studies Depression Scale (CESD), with a higher score indicating a higher incidence of depressive symptoms (Radloff, 1977).

As shown in Table 5, the PSQI global scores ranged from zero to seventeen, with a mean of 7.62 (standard deviation of 3.72). The Perceived Stress Scale scores ranged from 2 to 26, with a mean of 18.34 (standard deviation of 4.73), and the Montgomery-Borgatta Caregiver Burden Scale-Revised objective subscale scores ranged from 7 to 29, with a mean of 17.41 and standard deviation of 5.99. The WHO QOL-BREF scores also ranged from 7 to 29, with a mean of 17.41. The CESD scores ranged from zero to sixty, with a mean of 10.53 (standard deviation of 8.06).
Descriptive statistics were assessed for the subscales for each of the measures (7 for the PSQI, 4 for the WHO QOL BREF scale, and 4 for the Montgomery-Borgatta Caregiver Burden Scale-Revised), as described in Tables 6, 7, and 8. There were no subscales for the Perceived Stress Scale or for the CESD, which have been described previously in this chapter, and are listed below in Table 5.

Table 5

Descriptive Statistics of Independent and Dependent Variables

<table>
<thead>
<tr>
<th></th>
<th>Sleep Quality</th>
<th>Stress</th>
<th>Caregiver Burden</th>
<th>Depressive Symptoms</th>
<th>Quality of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Possible Score Range</td>
<td>0-21</td>
<td>0-40</td>
<td>5-30</td>
<td>0-60</td>
<td>26-130</td>
</tr>
<tr>
<td>Mean</td>
<td>7.62</td>
<td>18.34</td>
<td>17.41</td>
<td>10.53</td>
<td>90.4</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>3.72</td>
<td>4.73</td>
<td>5.99</td>
<td>8.06</td>
<td>10.74</td>
</tr>
<tr>
<td>Range of Scores</td>
<td>0-17</td>
<td>2-26</td>
<td>7-29</td>
<td>0-32</td>
<td>66-119</td>
</tr>
</tbody>
</table>

Sleep

The PSQI was used to measure sleep quality in maternal caregivers, and has seven subscales that measure: subjective sleep quality (subscale 1), sleep latency (subscale 2), sleep duration (subscale 3), sleep efficiency (subscale 4), sleep disturbances (subscale 5), the use of sleep medications (subscale 6), and daytime dysfunction (subscale 7), as well a global sleep measure of overall sleep quality (Buysse et al., 1989). Maternal caregivers reported sleeping a mean of 5.8 hours a night (range of 1 to 10 hours a night with standard deviation of 1.7). The majority (68.8%, n=42) of caregivers reported 6 or fewer hours of sleep, with 42.6% (n=26) reporting less than 5 hours, and 21.3% (n=13) reported 4 or less hours of sleep a night. Thirty-one (50.8%) maternal caregivers reported their overall sleep quality as fairly good, ten (16.4%) reported their overall sleep quality as very good, nineteen (31.1%) reported it as fairly bad, and one (1.6%) reported it as very
bad. maternal caregivers reported taking a mean of 37.8 minutes to fall asleep (range of 1 minute to 4 hours, standard deviation of 41.0686 minutes). The majority of maternal caregivers (78.7%, n=48) reported a global sleep score of 5 or above, indicating clinically disturbed sleep (Buysse et al., 1989).

Table 6 displays descriptive statistics for the seven PSQI subscales. The mean score for subjective sleep quality (first PSQI subscale) was 1.08, with a standard deviation of .800, and a range of 1-3. The mean score for sleep latency, the second subscale of the PSQI, was 1.36, with a standard deviation of 1.103, and a range of 1-3. Sleep duration, the third subscale for the PSQI, had a mean score of 1.48, standard deviation of 1.112, and range of 1-3. The mean scores of the sleep efficiency (subscale 4) and sleep disturbances (subscale 5) subscales were 1.40 and 1.28, respectively, and had standard deviations of 1.112 and 1.256, with a range of 1-3 for both. Mean scores for use of sleep medications (subscale 6) and daytime dysfunction (subscale 7) subscales were .57 and .53, with standard deviations of .819 and .754, both with a range of 0-2.

Table 6

Descriptive Statistics for PSQI Sub Scales

<table>
<thead>
<tr>
<th>Possible Score Range</th>
<th>PSQI 1</th>
<th>PSQI 2</th>
<th>PSQI 3</th>
<th>PSQI 4</th>
<th>PSQI 5</th>
<th>PSQI 6</th>
<th>PSQI 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>1.08</td>
<td>1.36</td>
<td>1.48</td>
<td>1.40</td>
<td>1.28</td>
<td>.57</td>
<td>.53</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>.800</td>
<td>1.103</td>
<td>1.112</td>
<td>1.256</td>
<td>.643</td>
<td>.819</td>
<td>.754</td>
</tr>
<tr>
<td>Range in Study</td>
<td>1-3</td>
<td>1-3</td>
<td>1-3</td>
<td>1-3</td>
<td>1-3</td>
<td>1-3</td>
<td>0-2</td>
</tr>
</tbody>
</table>

Note: PSQI 1-subjective sleep quality; PSQI 2- sleep latency; PSQI 3- sleep duration; PSQI 4-sleep efficiency; PSQI 5- sleep disturbances; PSQI 6- use of sleep medications; PSQI 7- daytime dysfunction
**Caregiver Burden**

The subscales for the Montgomery-Borgatta Caregiver Burden Scale-Revised are displayed in Table 7. The mean score for the Uplifts subscale was 23.74, with a standard deviation of 4.35, and a range of 7-30. The mean score for the subjective burden subscale was 11.84, with a standard deviation of 4.76, and a range of scores for this sample of 5-22. The Relationship burden subscale had a mean score of 8.33, a standard deviation of 3.65, and a range of possible scores for this sample of 5-21.

<table>
<thead>
<tr>
<th>Table 7</th>
</tr>
</thead>
</table>

**Descriptive Statistics for Montgomery-Borgatta Caregiver Burden Scale-Revised Sub Scales**

<table>
<thead>
<tr>
<th></th>
<th>Uplifts</th>
<th>Subjective</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Possible Score Range</td>
<td>6-30</td>
<td>5-25</td>
<td>5-25</td>
</tr>
<tr>
<td>Mean</td>
<td>23.74</td>
<td>11.84</td>
<td>8.33</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>4.35</td>
<td>4.76</td>
<td>3.65</td>
</tr>
<tr>
<td>Range of Study Scores</td>
<td>7-30</td>
<td>5-22</td>
<td>5-21</td>
</tr>
</tbody>
</table>

The subscales for the WHO QOL BREF scale are displayed in Table 8. The mean score for the physical domain was 22.90 (standard deviation of 3.20, range of 15-33), and for the psychological domain the mean score was 22.99 (standard deviation of 2.26, range of 16-27). The mean score for the social relationships domain was 11.92 (standard deviation of 2.20, range of 6-15), and for the environmental domain it was 31.72, with a standard deviation of 4.64, and a range of 19-40.
Specific Aim 2: Determine relationships among sleep quality, caregiver burden, stress, and QOL in maternal caregivers of young children with BPD.

Correlations Among All Variables in Study

Pearson’s Product-Moment Correlations were computed to assess relationships among the continuous study variables, and a Bonferroni correction was used due to the number of comparisons done (alpha set at .05 divided by 10 comparisons yielded a corrected alpha of .005 with Bonferroni correction). Table 9 reports the Pearson Correlation values, with asterisks indicating significance at the .05 and .005 level.

The length of time the child had been in the home was positively and significantly correlated with the age of the child \((r = .890, p = .000)\), that is older children had been living in the home longer than younger children. Maternal depressive symptoms were also moderately correlated with the length of time the child had been in the home \((r = .405, p = .001)\), suggesting that the longer a child had been living at home with the maternal caregiver, the higher her incidence of depressive symptoms. The length of time the child had been home was also weakly, inversely, and significantly correlated \((r = -.389, p = .002)\) with the maternal caregiver’s years of education, suggesting that

<table>
<thead>
<tr>
<th></th>
<th>Physical Domain</th>
<th>Psychological Domain</th>
<th>Social Relationships</th>
<th>Environmental Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Possible Score Range</td>
<td>7-35</td>
<td>6-30</td>
<td>3-15</td>
<td>8-40</td>
</tr>
<tr>
<td>Mean</td>
<td>22.90</td>
<td>22.99</td>
<td>11.92</td>
<td>31.72</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>3.20</td>
<td>2.26</td>
<td>2.20</td>
<td>4.64</td>
</tr>
<tr>
<td>Range of Study Scores</td>
<td>15-33</td>
<td>16-27</td>
<td>6-15</td>
<td>19-40</td>
</tr>
</tbody>
</table>
maternal caregivers reporting fewer years of education had been living with their child at home longer. However, the time the child had been living at home with the maternal caregivers was not significantly correlated with other major study variables, including sleep quality, caregiver burden, or stress. The age of the child in months was negatively correlated with the years of education the maternal caregivers had completed ($r = -0.369$, $p = 0.003$), indicating that the more years of education a maternal caregiver completed, the younger her child. Depressive symptoms were positively correlated with global sleep quality scores ($r = 0.529$, $p = 0.000$), suggesting that elevated depressive symptoms in maternal caregivers may be related to maternal report of poor sleep quality.

Table 9

*Pearson’s Correlation Matrix of the Study Variables*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Cg age</th>
<th>Child’s Age</th>
<th>Sibling</th>
<th>Time Home</th>
<th>Dep Symp</th>
<th>Yrs Ed</th>
<th>Stress</th>
<th>Sleep Quality</th>
<th>Cg Burden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cg age</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child’s age</td>
<td>0.52</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>0.164</td>
<td>0.051</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time home</td>
<td>-0.015</td>
<td>0.890**</td>
<td>0.075</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive Symptoms</td>
<td>-0.146*</td>
<td>0.297*</td>
<td>0.175</td>
<td>0.405**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years Ed</td>
<td>0.079</td>
<td>-0.389**</td>
<td>-0.188</td>
<td>-0.337</td>
<td>-0.030</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>0.016</td>
<td>-0.077</td>
<td>-0.360*</td>
<td>0.003*</td>
<td>0.092</td>
<td>0.317*</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep</td>
<td>0.055</td>
<td>0.228</td>
<td>0.143</td>
<td>0.277</td>
<td>0.529**</td>
<td>0.049</td>
<td>0.284*</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Quality</td>
<td>-0.170</td>
<td>-0.079</td>
<td>-0.235</td>
<td>-0.051</td>
<td>0.087</td>
<td>0.236</td>
<td>0.326*</td>
<td>0.233</td>
<td>-</td>
</tr>
<tr>
<td>Cg Burden</td>
<td>0.079</td>
<td>-0.185</td>
<td>-0.169</td>
<td>-0.144</td>
<td>0.061</td>
<td>0.214</td>
<td>0.101*</td>
<td>-0.292*</td>
<td>0.133</td>
</tr>
</tbody>
</table>

Note: $N = 61$ for all correlations. *$p \leq 0.05$, **$p \leq 0.005$ (Bonferroni corrected alpha). Cg= Maternal, QOL= quality of life, Dep symp= depressive symptoms, siblings= number of siblings in the home, Yrs ed= years of maternal education

Relationships were examined between variables using Pearson’s Product-Moment correlations. Table 10 displays the Pearson’s ($r$ value) correlations between the main study variables (alpha set at .05).
Stress and sleep quality were found to be significantly correlated ($r = .284, p = .027$), indicating that maternal caregiver report of increased stress scores was weakly correlated with increased global sleep quality. A higher global score on the PSQI indicates higher levels of disordered sleep (5 or above is considered clinically significant). Maternal caregivers who reported high levels of stress, also reported poorer sleep quality, or had higher scores indicating higher levels of disordered sleep.

Stress and caregiver burden were also found to be weakly, but significantly correlated ($r = .326, p = .010$), indicating that higher levels of stress, were related to higher levels of caregiver burden in the maternal caregiver. Finally, sleep quality and QOL were found to have an inverse relationship and to be weakly, but significantly correlated ($r = -292, p = .022$). A negative correlation indicates that higher levels of QOL were related to lower scores for disordered sleep, possibly suggesting that better sleep may be related to higher QOL in maternal caregivers.
Multiple Linear Regression

Specific Aim 3: Examine the influences on QOL of age, depressive symptoms, education, marital status, child’s age, time in the home, ethnicity, sleep quality, caregiver burden, and stress.

Using forced entry multiple linear regression, with a sample size of 61, the overall model is presented in Table 11, with all independent and dependent variables included. Table 12 shows the part and partial correlations for the overall model. Table 13 describes the order variables were entered. To determine the best model, changes in R squared were assessed using three steps (Blackwell, 2008), as shown in Table 14. The independent variables of sleep quality, stress, and caregiver burden were entered first, then the covariate of depressive symptoms was entered in step two, then the other demographic covariates were entered (maternal caregiver’s age, education level, relationship status, and race) for step three. The categorical covariates of education level (high school or greater and less than high school), relationship status (married or single), and race (black or white) were collapsed and entered as binary variables.
Table 11

*Overall Model Using All Study Variables (N=61)*

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized Coefficients</th>
<th>Standard Coefficient</th>
<th>t</th>
<th>p</th>
<th>Collinearity Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
<td>Tolerance</td>
</tr>
<tr>
<td>(Constant)</td>
<td>3.099</td>
<td>.478</td>
<td></td>
<td>6.487</td>
<td>.000</td>
</tr>
<tr>
<td>Stress</td>
<td>.017</td>
<td>.011</td>
<td>.206</td>
<td>1.538</td>
<td>.131</td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>-.059</td>
<td>.016</td>
<td>-.542</td>
<td>-3.757</td>
<td>.000*</td>
</tr>
<tr>
<td>Objective Burden</td>
<td>.011</td>
<td>.008</td>
<td>.174</td>
<td>1.327</td>
<td>.191</td>
</tr>
<tr>
<td>Dep. Symp.</td>
<td>.019</td>
<td>.007</td>
<td>.384</td>
<td>2.635</td>
<td>.011*</td>
</tr>
<tr>
<td>Cg Age (yrs)</td>
<td>.013</td>
<td>.007</td>
<td>.252</td>
<td>1.864</td>
<td>.068</td>
</tr>
<tr>
<td>Education</td>
<td>-.284</td>
<td>.156</td>
<td>-.222</td>
<td>-1.818</td>
<td>.075</td>
</tr>
<tr>
<td>Married or not</td>
<td>.304</td>
<td>.129</td>
<td>.380</td>
<td>2.358</td>
<td>.052</td>
</tr>
<tr>
<td>Dad at home</td>
<td>.054</td>
<td>.074</td>
<td>.095</td>
<td>.723</td>
<td>.473</td>
</tr>
<tr>
<td>BPD mother's first</td>
<td>-.018</td>
<td>.105</td>
<td>-.023</td>
<td>-.174</td>
<td>.863</td>
</tr>
<tr>
<td>Race</td>
<td>-.126</td>
<td>.126</td>
<td>-.154</td>
<td>-.993</td>
<td>.325</td>
</tr>
</tbody>
</table>

a. Dependent Variable: Average of WHO totals

Note: *p<.05
In examining standard coefficients (as seen in Table 12) and the partial and multiple partial (part) coefficients, sleep quality ($t=-3.757; p=.000; \text{Beta}=-.542; \text{partial}=-.473, \text{part}=-.427$), emerges as the variable with the greatest influence on QOL in the overall model. Depressive symptoms ($t=2.635; p=.011; \text{Beta}=.384; \text{partial}=.352 \text{ part}=.299$), was also a significant predictor of QOL and after sleep quality, was found to be exerting the greatest influence on QOL.
Table 13

Sequence of Variables Entered into Multiple Linear Regression Model

<table>
<thead>
<tr>
<th>Variables Entered&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
</tbody>
</table>

Note: <sup>a</sup> represents Dependent Variable: Quality of Life; <sup>b</sup> represents all requested variables entered.

The model summary below (Table 14) shows that model 2 (the independent variables, plus depressive symptoms, a covariate) may be the best model for predicting QOL in maternal caregivers of young children with BPD, based on the significant F change. While the increase is not large, model two has a significant F change of .025, which is less than model 1 or 3. The adjusted R square for model two is .166, indicating that 16.6% of the variance in QOL is explained by the major independent variables and depressive symptoms. Model three contains all of the variables, as displayed in the overall model.
Table 14

Multiple Linear Regression Model Summary

<table>
<thead>
<tr>
<th>Model</th>
<th>R</th>
<th>R Square</th>
<th>Adjusted R Square</th>
<th>Std. Error of Estimate</th>
<th>Change Statistics</th>
<th>F</th>
<th>df1</th>
<th>df2</th>
<th>Sig. F</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>.384</td>
<td>.147</td>
<td>.103</td>
<td>.365561</td>
<td>.147</td>
<td>3.284</td>
<td>3</td>
<td>57</td>
<td>.027</td>
</tr>
<tr>
<td>2</td>
<td>.471</td>
<td>.222</td>
<td>.166</td>
<td>.352381</td>
<td>.074</td>
<td>5.343</td>
<td>1</td>
<td>56</td>
<td>.025</td>
</tr>
<tr>
<td>3</td>
<td>.574</td>
<td>.330</td>
<td>.227</td>
<td>.339298</td>
<td>.108</td>
<td>2.101</td>
<td>4</td>
<td>52</td>
<td>.094</td>
</tr>
</tbody>
</table>

Note: a represents Predictors: (Constant), PSS global score, PSQI global score, Objective Burden;
b represents Predictors: (Constant), PSS global score, PSQI global score, Objective Burden, CESD final score; c represents Predictors: (Constant), stress, sleep quality, burden, depressive symptoms, maternal caregiver’s relationship status, number of years of reported education, maternal caregiver’s age (yrs), maternal caregiver’s race

The results of forced entry multiple linear regression, using model two, are shown in Table 15 along with collinearity statistics. Based on model two, sleep quality and depressive symptoms are the only significant predictors of QOL in this sample of maternal caregivers of young children with BPD (p-values of .000 and .025, respectively). Sleep quality is the only independent variable from the study to show a significant predictive relationship with QOL.

In examining the standardized regression coefficients, sleep quality (Beta= -.552) and depressive symptoms (Beta= .322) had the strongest influence on the outcome variable of QOL. No major problems for the model were found based on multicollinearity statistics. Based on Polit and Beck (2008), desirable tolerance levels are close to 1, with values closer to 0.1 suggesting multicollinearity may be a threat. For the variance inflation factor (VIF), levels below 10 indicate that there is little multicollinearity among the variables.
Table 15

*Multiple Linear Regression Using Model 2*

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
<th>T</th>
<th>P</th>
<th>Collinearity Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
<td>Tolerance</td>
</tr>
<tr>
<td>Constant</td>
<td>3.593</td>
<td>.203</td>
<td>17.720</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Cg Burden</td>
<td>.011</td>
<td>.008</td>
<td>.178</td>
<td></td>
<td>1.411</td>
</tr>
<tr>
<td>Sleep</td>
<td>-.057</td>
<td>.015</td>
<td>-.552</td>
<td>-3.777</td>
<td>.000*</td>
</tr>
<tr>
<td>Quality</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>.014</td>
<td>.010</td>
<td>.170</td>
<td></td>
<td>1.326</td>
</tr>
<tr>
<td>Depressive</td>
<td>.015</td>
<td>.007</td>
<td>.322</td>
<td></td>
<td>2.312</td>
</tr>
<tr>
<td>Symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: *p-value ≤ .05

Mediation

Specific Aim 4: Determine if stress mediates the relationship between sleep quality and burden and QOL in maternal caregivers of young children with BPD.

Mediation was measured using Baron and Kenny’s (1986) four-step method, with an alpha set at .05. In the first step, shown in Tables 16 and 17, sleep quality and caregiver burden were examined as predictors of QOL, with simple regression conducted separately for both variables to predict QOL.
Table 16

Sleep Quality as Predictor of QOL

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standardized Coefficients (Beta)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>6.428</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>.292</td>
<td>-2.345</td>
<td>.022*</td>
</tr>
</tbody>
</table>

Note:*p<.05

Table 17

Caregiver Burden as Predictor of Quality of Life

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standardized Coefficients (Beta)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>23.688</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>.133</td>
<td>2.029</td>
<td>.308</td>
</tr>
</tbody>
</table>

Note:*p<.05

Step 2 assessed stress as the outcome variable. As shown in Tables 18 and 19, simple linear regression was used, with sleep quality as a predictor of stress, and caregiver burden as a predictor of stress (the mediator variable being tested).

Table 18

Sleep Quality as Predictor of Stress

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standardized coefficients (beta)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>11.593</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>.284</td>
<td>2.275</td>
<td>.027*</td>
</tr>
</tbody>
</table>

Note:*p<.05
Table 19

*Caregiver Burden as Predictor of Stress*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standardized coefficients (beta)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>13.685</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>.326</td>
<td>.264</td>
<td>.010*</td>
</tr>
</tbody>
</table>

*Note: *p<.05

Table 20

*Stress as Predictor of Quality of Life*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standardized coefficients (beta)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>18.111</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>.101</td>
<td>.779</td>
<td>.439</td>
</tr>
</tbody>
</table>

*Note: *p<.05

Then, in step 3, shown in Table 20, simple linear regression was run, to determine if stress, the mediating variable, significantly predicted QOL. And finally, in step 4, shown in Tables 21 and 22, sleep quality and stress were placed in the same model to predict QOL, then caregiver burden and stress were placed in the same model to see if either showed any significant prediction of QOL.

Table 21

*Sleep Quality and Stress as Predictors of Quality of Life*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standardized coefficients (beta)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>19.160</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>.200</td>
<td>1.558</td>
<td>.125</td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>-.349</td>
<td>-2.717</td>
<td>.009*</td>
</tr>
</tbody>
</table>

*Note: *p<.05
Table 22

*Caregiver Burden and Stress as Predictors of Quality of Life*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standardized coefficients (beta)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>16.235</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>.064</td>
<td>.469</td>
<td>.064</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>.122</td>
<td>.613</td>
<td>.412</td>
</tr>
</tbody>
</table>

*Note: *p* <.05

Based on Baron and Kenny’s (1986) steps, stress was not a mediating variable for sleep quality and caregiver burden to QOL with an alpha set at .05. Caregiver burden was found to be a significant (*t*=.2644, *p*=.010) predictor of stress, but not QOL. Sleep quality was found to be significant as a predictor of QOL (*t*=-2.345, *p*=.022), and stress (*t*=2.275, *p*=.027). And finally, stress was not found to be a significant predictor of QOL (*t*=.779, *p*=.439). In order for stress to be a mediating variable, caregiver burden and sleep quality must have a significant relationship with QOL. Likewise, caregiver burden and sleep quality must also have a significant relationship with stress. Stress, must also have a significant relationship with QOL, the overall outcome variable. Thus, the steps and requirements for mediation were not satisfied.

**Hypotheses**

1. Sleep quality and caregiver burden will account for more variability and have the greatest influence on QOL, when controlling for depression, education, marital status, age, and race.
This hypothesis was not supported. Only sleep quality showed a significant relationship with QOL using multiple linear regression. Forced entry multiple linear regression was used to determine the variables with the greatest influence on QOL. As previously stated, sleep quality had the greatest influence ($p \leq .000$), but caregiver burden was not found to be a significant predictor of QOL ($p \leq .191$). Depressive symptoms, a covariate, however, were shown to be a significant predictor of QOL ($p \leq .011$).

2. Stress will mediate the relationship between sleep quality and stress in maternal caregivers of young children with BPD

This hypothesis was not supported. The requirements for stress to be a mediating variable, using a series of simple linear regression models, were not supported. Therefore, stress did not mediate the relationship between sleep quality and caregiver burden, and QOL in maternal caregivers of young children with BPD. Baron and Kenny’s (1986) four-step method was used, with an alpha set at .05. For step one, while sleep quality did significantly predict QOL ($p \leq .022$), caregiver burden did not ($p \leq .308$). In step two sleep quality did predict stress ($p \leq .027$), and so did caregiver burden ($p \leq .010$); however, all steps must show significant relationships, so, the process could have been stopped after step one, however, further steps were run. For step three, stress was not shown to be a significant predictor of QOL ($p \leq .439$), and in step four, sleep quality was the only other variable, when compared with stress, to significantly predict QOL ($p \leq .009$).
Exploratory Analyses

Exploratory analyses were run excluding certain participants based upon age, as well as examining relationships among variables and the subscales. The grandmothers ($n=2$) and teenage mother ($n=1$) were excluded based on age and scatterplot results. The grandmothers (both over the age of 45) were excluded based on sleep considerations. Circadian rhythms and sleep change as a person ages (Heller, Caldwell, & Factor, 2007). Older women have increased reports of insomnia and restless leg syndrome, as well as a shift to “morningness” indicating they get tired earlier in the evening, and wake up earlier in the morning (Duffy & Czeisler, 2002). Adolescents, however, into their mid-twenties, tend to stay up later, and wake up later. Thus, their sleep patterns and perceived sleep quality may differ for intrinsic reasons, rather than being related to stress or caregiver burden. The 17-year-old in the study sample was excluded due to possible differences in developmental level and caregiving differences of an adolescent mother, as well as circadian differences (Culp, Culp, & Osofsky, 1991; Duffy & Czeisler, 2002) as compared to adult women. Based on the scatterplot (appendix A) of the standardized residuals and predicted values for QOL, one grandmother and the adolescent mother were found to be outliers, further supporting their exclusion.

All further analyses reported have a total sample of 59 participants, for an age range of 20-40 years for the maternal caregiver, and an alpha set at .05. The power analysis originally run, and discussed in chapter three, was based on multiple linear regression, and called for at least 60 maternal caregivers. Since three participants have
been excluded, and the sample has been reduced to 59 participants, there has been a loss of statistical power.

Pearson’s Correlation was used to assess relationships between all major continuous variables, including study measures subscales (4 for the WHO QOL-BREF, 7 for the PSQI, and 4 for the Montgomery-Borgatta Caregiver Burden Scale- Revised). Multiple linear regression was used to determine the influences on QOL in maternal caregivers of sleep quality, stress, caregiver burden, and the covariates of depressive symptoms, age, race, marital status, and education status using a sample that excluded the two grandmothers and 17-year old participant. The categories of having the father present in the home (or not), and the child with BPD as the first and only child in the household (or not) were added. Models including the measures’ subscales were also tested to determine the influence of subscales on QOL.

Independent t-tests were run to compare means of the major variables (sleep quality, caregiver burden, QOL, stress, and depressive symptoms) based on categorical variables. The categorical variables were classified by the major covariates of race (Caucasian or African American), marital status (married or single), father of the child in the home (dad in the home or dad not present), education status (high school graduate and greater or less than high school graduate), child with BPD as the only child (child with BPD is first and only child or other siblings), maternal caregiver reports of sleep quality less than 5 or greater than or equal to 5 on the PSQI, and maternal caregiver’s age (less than 30 or greater than 30). Also included was whether or not the grandmother was present in the home.
Multiple Linear Regression

The same method of multiple linear regression and forced entry of variables was used to examine the influences on QOL of the study variables. In the first step, sleep quality, caregiver burden, and stress were entered. Then, in the second step, depressive symptoms were entered. Finally, in the last step, the descriptive variables were entered. Table 23 displays the model summary.

Table 23

<table>
<thead>
<tr>
<th>Model</th>
<th>R Square</th>
<th>R Square Change</th>
<th>Std. Error of Estimate</th>
<th>R Square Change</th>
<th>Change Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.415a</td>
<td>.415 - .172</td>
<td>.125</td>
<td>.33742</td>
<td>3.610</td>
</tr>
<tr>
<td>2</td>
<td>.467b</td>
<td>.467 - .218</td>
<td>.157</td>
<td>.33122</td>
<td>2.987</td>
</tr>
<tr>
<td>3</td>
<td>.624c</td>
<td>.624 - .389</td>
<td>.254</td>
<td>.31162</td>
<td>2.103</td>
</tr>
</tbody>
</table>

Note: a= Predictors: (Constant), Caregiver Burden, Sleep Quality, Stress; b= Predictors: (Constant), Caregiver Burden, Sleep Quality, Stress, Depressive Symptoms; c=Predictors: (Constant), Caregiver Burden, Sleep Quality, Stress, Depressive Symptoms, Education, Marital Status, Is the child with BPD mother's first and only child?, Dad living at home, Mother's Age (yrs), Mom's Ethnicity.

The adjusted R square for model three is .254, suggesting that the model accounts for roughly 25.4% of the variance in QOL in maternal caregivers of young children with BPD, the highest of all three models. Model 3, therefore, would explain the most variance in QOL of the models presented, and includes all of the independent variables and covariates.
Table 24

**Exploratory Multiple Linear Regression Model 3 with Collinearity Statistics and Including All Variables**

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized Coefficients</th>
<th>Stand Coefficients</th>
<th>t</th>
<th>p</th>
<th>Collinearity Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
<td>Tolerance</td>
</tr>
<tr>
<td>(Constant)</td>
<td>2.864</td>
<td>.464</td>
<td></td>
<td>6.176</td>
<td>.000</td>
</tr>
<tr>
<td>Stress</td>
<td>.018</td>
<td>.010</td>
<td>.250</td>
<td>1.822</td>
<td>.075</td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>-.058</td>
<td>.014</td>
<td>-.592</td>
<td>-3.985</td>
<td>.000</td>
</tr>
<tr>
<td>Cg Burden</td>
<td>.008</td>
<td>.008</td>
<td>.135</td>
<td>1.021</td>
<td>.313</td>
</tr>
<tr>
<td>Dep. Symp.</td>
<td>.018</td>
<td>.007</td>
<td>.398</td>
<td>2.588</td>
<td>.013</td>
</tr>
<tr>
<td>Cg’s age</td>
<td>.018</td>
<td>.008</td>
<td>.328</td>
<td>2.267</td>
<td>.028</td>
</tr>
<tr>
<td>Education</td>
<td>-.241</td>
<td>.152</td>
<td>-.192</td>
<td>-1.578</td>
<td>.121</td>
</tr>
<tr>
<td>Married or not</td>
<td>.271</td>
<td>.127</td>
<td>.367</td>
<td>2.132</td>
<td>.069</td>
</tr>
<tr>
<td>Dad living at home</td>
<td>.098</td>
<td>.072</td>
<td>.179</td>
<td>1.356</td>
<td>.182</td>
</tr>
<tr>
<td>or other BPD mother's</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>first and only child?</td>
<td>-.045</td>
<td>.106</td>
<td>-.061</td>
<td>-.422</td>
<td>.675</td>
</tr>
<tr>
<td>Race</td>
<td>-.064</td>
<td>.126</td>
<td>-.085</td>
<td>-.507</td>
<td>.614</td>
</tr>
</tbody>
</table>

*Note: a=Dependent Variable: Quality of Life. Dep symp- depressive symptoms, BPD-bronchopulmonary dysplasia, cg’s age- maternal caregiver’s age

Table 24 shows the coefficients for Model 3, including all of the variables. Sleep quality ($p \leq .000$), depressive symptoms ($p \leq .013$), and age ($p \leq .028$) are all significant predictors of QOL in maternal caregivers of young children with BPD. In examining the standardized coefficients, sleep quality had the most influence on QOL (Beta=-.592), with depressive symptoms (Beta=.398), and mother’s age (Beta=.328) also influencing QOL. The partial and semi-partial correlations (Table 25) also reflect sleep quality as having the greatest influence on QOL, with an inverse and moderate partial correlation of -.511 and a semi-partial correlation of -464. Depressive symptoms had the second largest
influence with a partial correlation of .360 and a semi-partial correlation of .301, followed by mother’s age, with a partial correlation of .320 and a semi-partial correlation of .264. Collinearity statistics, as previously discussed, do not indicate that multicollinearity was a problem. The reported tolerance scores are above 0.1 and none of the VIF scores approach 10 (Polit & Beck, 2009).

Table 25

*Multiple Linear Regression Model 3 with Partial Correlations and All Variables Included*

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized Coefficients</th>
<th>Stand. Coefficient</th>
<th>t</th>
<th>p</th>
<th>Correlations</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Constant)</td>
<td>2.864</td>
<td>.464</td>
<td>6.176</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>.018</td>
<td>.010</td>
<td>.250</td>
<td>1.822</td>
<td>.075</td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>-.058</td>
<td>.014</td>
<td>-.529</td>
<td>-3.985</td>
<td>.000</td>
</tr>
<tr>
<td>Cg Burden</td>
<td>.008</td>
<td>.008</td>
<td>.135</td>
<td>1.021</td>
<td>.313</td>
</tr>
<tr>
<td>Dep symp.</td>
<td>.018</td>
<td>.007</td>
<td>.398</td>
<td>2.588</td>
<td>.013</td>
</tr>
<tr>
<td>Cg’s Age (yrs)</td>
<td>.018</td>
<td>.008</td>
<td>.328</td>
<td>2.267</td>
<td>.028</td>
</tr>
<tr>
<td>Education</td>
<td>-.241</td>
<td>.152</td>
<td>-.192</td>
<td>-1.578</td>
<td>.121</td>
</tr>
<tr>
<td>Married or not</td>
<td>.271</td>
<td>.127</td>
<td>.367</td>
<td>2.132</td>
<td>.069</td>
</tr>
<tr>
<td>Dad living at home</td>
<td>.098</td>
<td>.072</td>
<td>.179</td>
<td>1.356</td>
<td>.182</td>
</tr>
<tr>
<td>BPD mother's first and only child?</td>
<td>-.045</td>
<td>.106</td>
<td>-.061</td>
<td>-.422</td>
<td>.675</td>
</tr>
<tr>
<td>Race</td>
<td>-.064</td>
<td>.126</td>
<td>-.085</td>
<td>-.507</td>
<td>.614</td>
</tr>
</tbody>
</table>

*Note:* “=Dependent Variable: Quality of Life. Dep symp- depressive symptoms, BPD-bronchopulmonary dysplasia, cg’s age- maternal caregiver’s age

In the exploratory analysis, when excluding the two grandmothers and one adolescent mother, one demographic variable, age, was found to be significant ($t=2.267$;
In the previous model for the total sample (n=61), age was not significant ($t=1.864$, $p=.068$).

**Independent t-Tests**

A series of independent $t$-tests was run to compare the mean scores of two groups for each of the variables (QOL, depressive symptoms, stress, and sleep quality, as well as depressive symptoms) based on demographic variables that were split into two categories (for example, race became African American and Caucasian). Tables were constructed (Tables 26-33) to display the total for each category, the mean, standard deviation, and $t$ and $p$-values.

Significant differences were found for stress (Table 32) when comparing the mean stress scale scores for mothers who reported the child with BPD as their first and only child, as compared to mothers who reported having other children ($t=2.216$, $p \leq .031$). Significant differences were also found for depressive symptoms ($t=4.833; p \leq .000$) and stress for maternal caregivers who reported a PSQI score of 5 or greater and those reporting a PSQI score of less than 5 (Table 30). Tables for all demographic variables are listed below with the mean, standard deviation, $p$-value and $t$ statistic indicated.

There was a significant difference in maternal caregiver’s depressive symptoms ($t= -2.161, p \leq .035$), sleep quality ($t=-2.053, p \leq .045$), and caregiver burden ($t= 1.999, p \leq .033$) if the child had been living in the home for a year or less (Table 34). If the child has been home for at least a year ($n= 20$), maternal caregivers reported a higher mean score on the CESD (14.00, standard deviation of 9.363), compared to those maternal caregivers with a child who had not been home for less than a year ($n=38$), who had a mean CESD score of 9.342 and standard deviation of 6.867. However, for sleep quality,
scores were lower for maternal caregivers who had been home for at least a year (mean 7.921, standard deviation 3.790) when compared to mothers who had not had the child at home with them for a year (mean 9.000, standard deviation 3.670). For caregiver burden, maternal caregivers who reported having the child at home with them for less than a year reported higher levels of caregiver burden (mean 12.894, standard deviation 5.097), than maternal caregivers who reported having the child at home for at least a year or more (mean 10.300, standard deviation 3.790).

In examining the subscales for the PSQI, Montgomery Borgatta Caregiver Burden Scale-Revised, and WHO QOL BREF, daytime dysfunction (subscale 7) of the PSQI was significantly higher for maternal caregivers who reported being married than those who reported being single ($t$=2.234, $p\leq.024$). Subscale 7 was also significantly higher (mean .612) for those who reported having the grandmother living in the home than those who did not ($t=3.173; p\leq .004$). Sleep duration (subscale 3) of the PSQI was also significantly higher (mean .174 for dad at home, and .950 for dad not at home) for those who reported having the father of the child living with them ($t=-2.609; p=0.012$). Likewise, habitual sleep efficiency (subscale 4) of the PSQI was significantly higher (mean .1.677 vs .9000) for those reporting the father living in the home as well ($t=-2.227, p\leq.031$). No other subscales were significantly different for the demographic variables.
### Table 26

**t-Test Comparisons of Major Variables Based on Grandmother of Child Living at Home**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Grandmother living with Mother and Child Mean (SD)</th>
<th>Grandmother not living with Mother and Child Mean (SD)</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Life</td>
<td>3.888 (.317)</td>
<td>3.779 (.363)</td>
<td>-.844</td>
<td>.402</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>8.000 (4.500)</td>
<td>11.489 (8.466)</td>
<td>1.200</td>
<td>.235</td>
</tr>
<tr>
<td>Stress</td>
<td>19.111 (4.044)</td>
<td>18.245 (4.994)</td>
<td>-.490</td>
<td>.626</td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>7.444 (3.283)</td>
<td>7.653 (3.934)</td>
<td>.149</td>
<td>.882</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>20.778 (4.500)</td>
<td>16.595 (8.465)</td>
<td>-1.757</td>
<td>.084</td>
</tr>
</tbody>
</table>

Note: *<.05

### Table 27

**t-Test Comparisons of Major Variables Based on Father of Child Living at Home**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Father living with Mother and Child Mean (SD)</th>
<th>Father not living with Mother and Child Mean (SD)</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Life</td>
<td>3.781 (.405)</td>
<td>3.780 (.282)</td>
<td>-.010</td>
<td>.992</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>11.000 (6.843)</td>
<td>11.952 (10.327)</td>
<td>.370</td>
<td>.693</td>
</tr>
<tr>
<td>Stress</td>
<td>19.100 (5.548)</td>
<td>17.333 (4.041)</td>
<td>-.125</td>
<td>.219</td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>8.433 (4.157)</td>
<td>6.619 (3.278)</td>
<td>-1.668</td>
<td>.102</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>19.800 (6.630)</td>
<td>15.904 (5.030)</td>
<td>-1.105</td>
<td>.275</td>
</tr>
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</table>

Note: *<.05
Table 28

*t-Test Comparisons of Major Variables Based on Maternal Caregiver’s Age*

<table>
<thead>
<tr>
<th></th>
<th>Maternal Caregiver less than 30 years of age</th>
<th>Maternal Caregiver 30 years or older</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n=33</td>
<td>n=25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of Life</td>
<td>3.77 (.381)</td>
<td>3.818 (.326)</td>
<td>-.419</td>
<td>.677</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>10.970 (7.355)</td>
<td>10.920 (9.046)</td>
<td>.023</td>
<td>.982</td>
</tr>
<tr>
<td>Stress</td>
<td>18.455 (5.093)</td>
<td>18.280 (4.578)</td>
<td>.135</td>
<td>.893</td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>7.272 (3.826)</td>
<td>8.080 (3.829)</td>
<td>-.795</td>
<td>.430</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>17.970 (6.065)</td>
<td>17.000 (6.262)</td>
<td>.596</td>
<td>.554</td>
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</table>

Note: *<.05

Table 29

*t-Test Comparisons of Major Variables Based on Maternal Caregiver’s Marital Status*

<table>
<thead>
<tr>
<th></th>
<th>Single</th>
<th>Married</th>
<th>t</th>
<th>p-value</th>
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<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n=36</td>
<td>n=22</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of Life</td>
<td>3.842 (.051)</td>
<td>3.720 (.090)</td>
<td>-1.177</td>
<td>247</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>10.091 (6.568)</td>
<td>11.472 (8.885)</td>
<td>-.631</td>
<td>.531</td>
</tr>
<tr>
<td>Stress</td>
<td>19.818 (4.532)</td>
<td>17.500 (4.867)</td>
<td>1.806</td>
<td>.076</td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>8.182 (4.500)</td>
<td>7.278 (3.352)</td>
<td>.874</td>
<td>.386</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>17.028 (5.887)</td>
<td>18.409 (6.486)</td>
<td>.834</td>
<td>.408</td>
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</table>

Note: *<.05
Table 30

*t-Test Comparisons of Major Variables Based on Global PSQI Score*

<table>
<thead>
<tr>
<th></th>
<th>PSQI Global Score of 5 or Greater</th>
<th>Global PSQI Score Less Than 5</th>
<th>t</th>
<th>p value</th>
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<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n=45</td>
<td>n=13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of Life</td>
<td>3.756 (.630)</td>
<td>3.932 (.324)</td>
<td>-1.588</td>
<td>.118</td>
</tr>
<tr>
<td></td>
<td>45</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>12.578 (8.324)</td>
<td>5.307 (3.066)</td>
<td>4.833</td>
<td>.000*</td>
</tr>
<tr>
<td>Stress</td>
<td>19.089 (4.828)</td>
<td>15.923 (4.152)</td>
<td>2.143</td>
<td>.036*</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>18.044 (6.164)</td>
<td>15.846 (5.786)</td>
<td>1.147</td>
<td>.256</td>
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</table>

Note: *<.05

Table 31

*t-Test Comparisons of Major Variables Based on Maternal Caregiver’s Educational Attainment*

<table>
<thead>
<tr>
<th></th>
<th>High School Graduate or Greater</th>
<th>Did Not Graduate High School</th>
<th>t</th>
<th>p value</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n=53</td>
<td>n=5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of Life</td>
<td>3.819 (.352)</td>
<td>3.548 (.332)</td>
<td>1.659</td>
<td>.104</td>
</tr>
<tr>
<td></td>
<td>53</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>13.000 (9.434)</td>
<td>10.754 (7.985)</td>
<td>-.515</td>
<td>.630</td>
</tr>
<tr>
<td>Stress</td>
<td>18.396 (4.387)</td>
<td>18.200 (9.121)</td>
<td>.048</td>
<td>.964</td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>7.547 (3.891)</td>
<td>8.400 (3.131)</td>
<td>-.475</td>
<td>.637</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>17.735 (6.620)</td>
<td>15.600 (5.030)</td>
<td>.745</td>
<td>.459</td>
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</table>
Table 32

*t-Test Comparisons of Major Variables Based on Child with BPD Only Child in Home*

<table>
<thead>
<tr>
<th></th>
<th>Child with BPD is Only Child in Home</th>
<th>Other Children in the Home</th>
<th>t</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n=24</td>
<td>n=34</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of Life</td>
<td>3.821 (.350)</td>
<td>3.777 (.365)</td>
<td>.457</td>
<td>.649</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>10.083 (7.603)</td>
<td>8.411 (8.400)</td>
<td>-.684</td>
<td>.497</td>
</tr>
<tr>
<td>Stress</td>
<td>20.000 (4.032)</td>
<td>17.235 (5.082)</td>
<td>2.216</td>
<td>.031*</td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>7.667 (4.556)</td>
<td>7.588 (3.267)</td>
<td>.076</td>
<td>.939</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>18.417 (6.420)</td>
<td>16.941 (5.890)</td>
<td>.906</td>
<td>.369</td>
</tr>
</tbody>
</table>

Note: *<.05

Table 33

*t-Test Comparisons of Major Variables Based on Maternal Caregiver’s Race*

<table>
<thead>
<tr>
<th></th>
<th>Caucasian</th>
<th>African American</th>
<th>t</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n=19</td>
<td>n=39</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of Life</td>
<td>3.778 (.385)</td>
<td>3.804 (.346)</td>
<td>-.261</td>
<td>.795</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>8.421 (8.736)</td>
<td>12.180 (5.843)</td>
<td>-1.696</td>
<td>.095</td>
</tr>
<tr>
<td>Stress</td>
<td>19.790 (4.791)</td>
<td>17.692 (4.769)</td>
<td>1.569</td>
<td>.122</td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>7.526 (4.538)</td>
<td>7.667 (3.474)</td>
<td>-.119</td>
<td>.906</td>
</tr>
</tbody>
</table>

Note: *<.05
Table 34

*t-Test Comparisons of Major Variables Based Child Living at Home for 1 Year*

<table>
<thead>
<tr>
<th></th>
<th>Child Living at Home &lt; 1 years</th>
<th>Child Living at home &gt;1 year</th>
<th>t</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of Life</td>
<td>3.852 (.357)</td>
<td>3.687 (.337)</td>
<td>1.709</td>
<td>.093</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>9.342 (6.867)</td>
<td>14.000 (9.363)</td>
<td>-2.161</td>
<td>.035*</td>
</tr>
<tr>
<td>Stress</td>
<td>18.868 (4.992)</td>
<td>17.450 (4.501)</td>
<td>1.063</td>
<td>.292</td>
</tr>
<tr>
<td>Sleep Quality</td>
<td>6.897 (3.732)</td>
<td>9.000 (3.671)</td>
<td>1.276</td>
<td>.045*</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>18.269 (6.225)</td>
<td>16.150 (5.752)</td>
<td>1.709</td>
<td>.093</td>
</tr>
</tbody>
</table>

*P ≤ .05

Correlations

Pearson’s correlations were run to examine the bivariate relationships between subscales (7 for the PSQI, 4 for the WHO QOL-BREF, and 4 for the Montgomery-Borgatta Caregiver Burden Scale-Revised), with significance set at .05. Tables 35-40 display the results of the Pearson’s correlations in six different matrices so that subscales, and continuous variables are compared to each other.

Significant correlations were found between the subjective sleep quality (subscale 1) subscale of the Pittsburgh Sleep Quality Index (PSQI 1) and several other variables, as shown in the tables below. PSQI 1 showed moderate positively relationships with depressive symptoms ($r=.447$), objective caregiver burden ($r=.410$), and subjective caregiver burden ($r=.423$). PSQI subscale 1 showed moderate inverse relationships with the four domains of QOL (QOL1 is the physical domain, QOL2 is the psychological
domain, QOL3 is the social relationships domain, and QOL4 is the environmental domain): QOL1 ($r=-.415$), QOL2 ($r=-.350$), QOL3 ($r=-.407$), and QOL4 ($r=-.407$).

Sleep latency, the second subscale of the PSQI (PSQI 2) showed a positive, moderate significant correlation with depressive symptoms ($r=.518$).

The subjective caregiver burden subscale showed a weak, significant correlation with stress ($r=.372$), and the uplifts subscale (of the Montgomery-Borgatta Caregiver Burden Scale-Revised) had a moderate, positive correlation ($r=.403$) with the physical domain subscale (QOL1) of QOL. The environmental domain subscale of QOL (QOL4) had a significant, moderate, inverse relationship with maternal caregivers educational attainment ($r=-.420$), and with depressive symptoms ($r=-.453$).
Table 35

*Pearson’s Correlations Between Continuous Variables and Sleep Quality Subscales*

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Edu</th>
<th>How long</th>
<th>Dep</th>
<th>Stress</th>
<th>PSQI 1</th>
<th>PSQI 2</th>
<th>PSQI 3</th>
<th>PSQI 4</th>
<th>PSQI 5</th>
<th>PSQI 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-</td>
<td></td>
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<td></td>
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<tr>
<td>How Long</td>
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<td></td>
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<tr>
<td>Dep</td>
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<td>.234</td>
<td>.391*</td>
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<td>-.011</td>
<td>.090</td>
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<td>PSQI2</td>
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<td>.518*</td>
<td>.254</td>
<td>.361*</td>
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<td>PSQI3</td>
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<td>-.027</td>
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<td>.228</td>
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<td>-.093</td>
<td>.019</td>
<td>.047</td>
<td>.070</td>
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<td>.104</td>
<td>.210</td>
<td>.242</td>
<td>.474*</td>
<td>.333*</td>
<td>.063</td>
<td>.124</td>
<td>.522*</td>
<td>.266*</td>
</tr>
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</table>

*Note: p\leq.05*, p\leq.001**; PSQI- Pittsburgh Sleep Quality Index- subscales: 1= subjective sleep quality; 2= sleep latency; 3= sleep duration; 4= sleep efficiency; 5= sleep disturbances; 6= use of sleep medications; 7= daytime dysfunction; G= global sleep quality
Table 36

**Pearson’s Correlations Between Continuous Variables and QOL Subscales**

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Edu</th>
<th>How long home</th>
<th>Dep Symp</th>
<th>Stress</th>
<th>QOL1</th>
<th>QOL2</th>
<th>QOL3</th>
</tr>
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<tbody>
<tr>
<td>Age</td>
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<td></td>
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<td></td>
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<tr>
<td>How long</td>
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<td>.099</td>
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<td></td>
</tr>
<tr>
<td>Dep Symp</td>
<td>-.129</td>
<td>.234</td>
<td>.391*</td>
<td>-</td>
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<tr>
<td>Stress</td>
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<td>-.011</td>
<td>.090</td>
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<td>QOL2</td>
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<td>-.298</td>
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<td>-.370*</td>
<td>-.398*</td>
<td>.437*</td>
<td>-</td>
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<tr>
<td>QOL3</td>
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<td>-.050</td>
<td>-.440*</td>
<td>-.402*</td>
<td>-.101</td>
<td>.261*</td>
<td>.370*</td>
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<td>QOL4</td>
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<td>-.483*</td>
<td>-.453*</td>
<td>-.117</td>
<td>.468*</td>
<td>.475*</td>
<td>.537*</td>
</tr>
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*Note: p ≤ .05*, p ≤ .001**; QOL1 = physical domain of the WHO QOL BREF scale, QOL2 = psychological domain of the WHO QOL BREF scale, QOL3 = social relationship domain of the WHO QOL BREF scale, QOL4 = environmental domain of WHO QOL BREF scale.*
Table 37

Pearson’s Correlations Between Continuous Variables and Caregiver Burden Subscales

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Edu</th>
<th>How long home</th>
<th>Dep Symp</th>
<th>Stress</th>
<th>Burden R</th>
<th>Burden O</th>
<th>Burden S</th>
<th>Burden U</th>
</tr>
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<td>Age</td>
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<td></td>
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<td>Edu</td>
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<tr>
<td>How long</td>
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<tr>
<td>Stress</td>
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<td>.349</td>
<td>-.011</td>
<td>.090</td>
<td>-</td>
<td></td>
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</tr>
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<td>.352*</td>
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<td>.202</td>
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<td>.619</td>
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<tr>
<td>Burden S</td>
<td>.030</td>
<td>.223</td>
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<td>.041</td>
<td>.372**</td>
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<tr>
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Note: p ≤ .05*, p ≤ .001**; Burden O= Objective burden; Burden R= Relationship burden; Burden S= Subjective burden; Burden U= Uplifts
Table 38

Pearson’s Correlations Between Caregiver Burden and Sleep Quality Subscales

<table>
<thead>
<tr>
<th></th>
<th>Burden R</th>
<th>Burden O</th>
<th>Burden S</th>
<th>Burden U</th>
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<tr>
<td>Burden R</td>
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<td>Burden O</td>
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<td>-</td>
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<tr>
<td>Burden S</td>
<td>.097</td>
<td>.629**</td>
<td>-</td>
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<tr>
<td>Burden U</td>
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<td>.117</td>
<td>.186</td>
<td>-</td>
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<td>PSQI1</td>
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<td>.410**</td>
<td>.423**</td>
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<td>PSQI2</td>
<td>.307*</td>
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<td>-.016</td>
<td>-.203</td>
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<td>PSQI3</td>
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<td>.210</td>
<td>-.204</td>
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<tr>
<td>PSQI4</td>
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<td>.051</td>
<td>-.234</td>
</tr>
<tr>
<td>PSQI6</td>
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<td>-.132</td>
</tr>
<tr>
<td>PSQI7</td>
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<td>.251</td>
<td>.265*</td>
<td>-.026</td>
</tr>
<tr>
<td>PSQIG</td>
<td>.307*</td>
<td>.236</td>
<td>.292*</td>
<td>-.208</td>
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Note: \( p \leq .05 \), \( p \leq .001 \), PSQI- Pittsburgh Sleep Quality Index- 1= subjective sleep quality, 2= sleep latency; 3= sleep duration; 4= sleep efficiency; 5= sleep disturbances; 6= use of sleep medications; 7= daytime dysfunction; G= global sleep quality; Burden O= objective burden; Burden R= Relationship burden; Burden S= Subjective burden; Burden U= Uplifts
Table 39

Pearson’s Correlations between Sleep Quality and QOL subscales

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<th>PSQI3</th>
<th>PSQI4</th>
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<th>PSQI6</th>
<th>PSQI7</th>
<th>PSQIG</th>
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<td>PSQI2</td>
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<td>.154</td>
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<td>-.104</td>
<td>.496*</td>
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<tr>
<td>PSQI7</td>
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<td>.124</td>
<td>.522*</td>
<td>.266*</td>
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<td>.554**</td>
<td>.475**</td>
<td>.708**</td>
<td>.559**</td>
<td>.608*</td>
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<td>-.270*</td>
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<td>-.281*</td>
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<tr>
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<td>-.342**</td>
<td>-.355*</td>
<td>-.192</td>
<td>-.491**</td>
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Note: *p ≤ .05, **p ≤ .001, QOL1= physical domain of the WHO QOL BREF scale, QOL2= psychological domain of the WHO QOL BREF scale, QOL3= social relationship domain of the WHO QOL BREF scale, QOL4= environmental domain of WHO QOL BREF scale. PSQI- Pittsburgh Sleep Quality Index- 1= subjective sleep quality, 2= sleep latency; 3= sleep duration; 4= sleep efficiency; 5= sleep disturbances; 6= use of sleep medications; 7= daytime dysfunction; G= global sleep quality
Table 40.

Pearson’s Correlations between QOL and Caregiver Burden Subscales

<table>
<thead>
<tr>
<th></th>
<th>QOL1</th>
<th>QOL2</th>
<th>QOL3</th>
<th>QOL4</th>
<th>Burden R</th>
<th>Burden O</th>
<th>Burden S</th>
<th>Burden U</th>
</tr>
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<td></td>
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<td></td>
<td></td>
</tr>
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<td></td>
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<td></td>
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</tr>
<tr>
<td>QOL3</td>
<td>.261*</td>
<td>.370**</td>
<td>-</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>QOL4</td>
<td>.468**</td>
<td>.475**</td>
<td>536**</td>
<td>-</td>
<td></td>
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<tr>
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</tr>
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<td>-.039</td>
<td>.049</td>
<td></td>
<td></td>
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</tr>
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<td>.026</td>
<td>.220</td>
<td>.629*</td>
<td></td>
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</tr>
<tr>
<td>Burden U</td>
<td>.403**</td>
<td>.298*</td>
<td>.234</td>
<td>.318*</td>
<td>.011</td>
<td>.117</td>
<td>.189</td>
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Note: p ≤ .05*, p ≤ .001**, QOL1 = physical domain of the WHO QOL BREF scale, QOL2 = psychological domain of the WHO QOL BREF scale, QOL3 = social relationship domain of the WHO QOL BREF scale, QOL4 = environmental domain of WHO QOL BREF scale. Montgomery-Borgatta Caregiver Burden Scale-Revised: Burden O = objective burden; Burden R = Relationship burden; Burden S = Subjective burden; Burden U = Uplifts.
CHAPTER FIVE

DISCUSSION

While the number of new cases of BPD has decreased due to improved treatments that prolong pregnancy and medications (such as surfactant) to promote in utero lung development (Gracey et al., 2002, p. 4; Stroustrup & Trasande, 2010), the acuity and costs to treat BPD have increased (Stroustrup & Trasande, 2010). Many of these children are sent home from the NICU requiring complex care, usually provided by the maternal caregiver (Holditch-Davis et al., 2001).

Maternal caregivers of children with BPD may have little to no health care training, yet may be responsible for coordinating, executing, and assessing a complex healthcare regimen, including several medications throughout the day, managing equipment, monitoring her child and her child’s equipment, administering gastrostomy-tube feedings, specialized diets, and coordinating appointments with a variety of health care providers (Deakins, 2009). A maternal caregiver may spend so much time caring for her child, her own needs may go unmet or be sacrificed in the face of meeting other responsibilities (McAleese, Knapp, & Rhodes, 1993; Zanardo & Freato, 2001). While previous research has reported increased levels of stress and caregiver burden in these mothers (Singer et al., 2010), as well as poorer QOL, little is known about how sleep
quality may influence or interact with the variables of stress and caregiver burden, as well as maternal caregiver depressive symptoms in the maternal caregiver. Finding the right balance of caregiving and other responsibilities that lends a higher QOL is important for these maternal caregivers because it offers a way of assessing more than just the absence of illness, but provides a larger picture of their overall well-being (Arafa et al., 2008; Xiang et al., 2009). Examining the relationships between sleep quality, stress, caregiver burden, and QOL in maternal caregivers provides a better understanding of how these variables interact to influence each other and is necessary in order to develop future interventions.

In this study, the influence of sleep quality, stress, caregiver burden, depressive symptoms, and other covariates (age, race, education status, and marital status) on QOL of maternal caregivers of young children with BPD were studied. The main finding of this cross-sectional, descriptive, correlational study indicated that sleep quality was a significant predictor of quality of life in maternal caregivers, and that relationships were found between sleep quality, quality of life, and stress. Caregiver burden, however, was not a significant predictor of QOL, but was found to be positively correlated with stress. Stress was not found to mediate the relationship between sleep quality and caregiver burden with QOL. Furthermore, maternal caregivers in this study were sleep deprived, with many reporting 6 or less hours of sleep a night; comparatively, Meltzer et al. (2006) found that maternal caregivers of healthy children reported 7 hours of sleep per night.

In this chapter, the following sections are presented: major findings, procedures, purpose and research questions, summary of findings, and recommendations for future
In this study of maternal caregivers of young children with BPD, sleep quality and depressive symptoms were the significant predictors of quality of life. Multiple linear regression forced entry method was used with a sample of 61 maternal caregivers to evaluate influences on quality of life in maternal caregivers. In the overall model, and based on the standardized coefficients discussed in chapter four, sleep quality had the greatest influence on QOL ($t=-3.757; \text{Beta}= -.542; p \leq .000$), followed by depressive symptoms ($t= 2.635; \text{Beta}= .384; p \leq .011$). Sleep quality emerged as the only independent variable to significantly predict QOL in maternal caregivers of young children with BPD. Depressive symptoms, as a covariate, was also significant as a predictor of QOL.

Weak, but significant, correlations were found between sleep quality and stress ($r=.284$), stress and caregiver burden ($r=.326$), and an inverse correlation was found between sleep quality and QOL ($r=-.292$). Significant correlations were also found between the child’s age and time home ($r=.890$) and depressive symptoms ($r=.297$) as well as an inverse correlation with maternal caregiver’s years of education ($r=-.360$). Number of siblings was weakly and inversely correlated with stress ($r=-.360$). The length of time the child had been living at home was positively correlated with maternal caregiver depressive symptoms ($r=.405$) and stress ($r=.003$). Maternal caregiver depressive symptoms were moderately, positively correlated with sleep quality ($r=.529$).
Demographics

Few studies have examined sleep in maternal caregivers of young children with chronic illness or conditions. Caregivers in these studies have generally been non-minority, older (greater than 35 years), married, and had high levels of education (Gallagher et al., 2010; Meltzer & Mindell, 2006). In this study, the majority (67.2%) of the sample was minority (African American), younger (average age 29.54 years), and single, never married.

Meltzer et al. (2006) examined sleep in mothers of ventilator dependent children, with the sample having an average age of 37.9 years, 82% were married, 86% Caucasian, with an average of 14.7 years of education. In another study of sleep in caregivers of children with autism, the maternal caregivers average age was 37.9 years, 85% Caucasian, 60% married, with an average of 14.9 years of education (Meltzer, 2008). In a study of sleep in caregivers of children with developmental disabilities, the average age of the maternal caregivers was 42.6 years, 90% Caucasian, 81% married, and 73% reported “professional” as an occupational status (Gallagher et al., 2010).

Depressive Symptoms

Maternal caregivers of young children with a chronic illness report increased levels of depressive symptoms, which may be exacerbated by reporting increased stress and poor sleep quality (Meltzer, 2006). In this study, depressive symptoms was measured as a covariate using the Center for Epidemiological Studies Depression Scale (CESD) (Radloff, 1977). The scale can be used to determine clinically significant levels of depressive symptoms that may indicate a participant at greater risk for depression.
(Radloff, 1977). For this study, a cut-off score was determined to be 33, based on previous research that used a similar cut-off in maternal caregivers of young children with cystic fibrosis, children requiring a ventilator, and healthy children (Meltzer & Mindell, 2006). As described in chapter three, maternal caregivers who scored a 33 or above on the questionnaire were to be referred to the BPD clinic social worker for further follow-up. Based on the CESD scores for the maternal caregivers, no maternal caregiver in this study was referred to the social worker; however, one maternal caregiver scored close to the cut-off.

The mean CESD score for maternal caregivers of young children with BPD for this study was 10.53 (standard deviation of 8.06). This is slightly higher than a sample of healthy women (mean 9.06) (Makambi, Williams, Yalor, Rosenberg, & Adams-Campbell, 2009), and caregivers of healthy children who reported a mean score of 9.28 (standard deviation of 8.5) (Meltzer, 2008), but lower than a sample of maternal caregivers of children requiring a ventilator (mean 15.10, standard deviation of 9.5) (Meltzer & Mindell, 2006). These differences could be attributed to several factors, including the differences in acuity and health care needs of children requiring a ventilator and children with moderate BPD. While the literature has reported that maternal caregivers of both populations (child on ventilator and with BPD) report increased levels of stress and depressive symptoms (Kuster & Badr, 2006; McAleese et al., 1993), the differences in expected outcome may contribute to differences in depressive symptoms scores.

As children with BPD age, they may have fewer symptoms, be weaned off of oxygen and diuretics, and be able to eat by mouth, and “outgrow” their disease,
suggesting that the highly acute phase of maternal caregiving may lessen (Gracey et al., 2002). However, the same prognosis cannot be made for children requiring a ventilator, since maternal caregiving for these children may extend for several years (Carnevale, Alexander, Davis, Rennick, & Troini, 2006). Carnevale et al. (2006) have suggested that the unknown element of the child’s prognosis, as well as the length of expected care, and lack of home care or reliable respite care may contribute to elevated depressive symptoms scores, and burnout in caregivers of children requiring a ventilator.

In this sample of maternal caregivers, older children were more likely to have been living at home for a longer time \( (r = .890, p < .005) \). Time at home was positively correlated with depressive symptoms in maternal caregivers \( (r = .405, p < .005) \). This supports previous research that examined depressive symptoms in maternal caregivers of technology dependent children who required feeding pumps and oxygen saturation monitors, as well as ventilators, which found that mothers reported higher levels of depressive symptoms, the longer the child had been in the home (Boroughs & Daugherty, 2009; Heaton, Noyes, Sloper, & Shah, 2006). While the sample in this study did not require a ventilator and may have had lower acuity, the children did require oxygen while at home, which meant maternal caregivers were still responsible for monitoring, assessing, and tending to equipment and the child, similar to what a caregiver may do with a child on a ventilator (Jackson & Vessey, 1996).

The maternal caregiver’s self-reported depressive symptoms were negatively correlated with maternal age; that is, younger women reported higher levels of depressive symptoms. This is consistent with previous research in caregivers that older caregivers
may report higher levels of resources and support, which may influence their depressive symptoms and stress (Guilfoyle et al., 2011).

While the majority of the caregivers in this study reported having another person living in the home (32, or 52.5%, reported the father of the child, 12, or 18.1%, reported the maternal grandmother), the extent to which they provided care or support was not assessed. However, previous research in caregivers of young children with cystic fibrosis has found that social support, and having another adult in the home may help to decrease depressive symptoms in caregivers (Besier et al., 2011). Having the father present in the home was found to decrease stress in maternal caregivers of premature babies discharged from the NICU (Allen et al., 2004). Similar to the Allen et al. (2004) and Bessier et al. (2011) studies, maternal caregivers in this study were responsible for providing treatments, medications, and monitoring equipment required for their child. In future studies, it may be helpful to assess other caregivers in the home, and the extent that they help provide caregiving for the child with BPD.

It may be more likely that a younger caregiver is a first-time mother and may have difficulty in shifting her role, especially with a child with a chronic illness that requires care, and therefore, she may report higher levels of depressive symptoms (Holditch-Davis et al., 2011). Resources and social support were not assessed in this study, but should be included in future research, because they may provide a more accurate picture of the types of support the mother may have, not only from family, but also financial support (Guilfoyle et al., 2011). Respite care is also a resource that may be beneficial to maternal caregivers, and has been shown to increase sleep quality in caregivers of young children who require a ventilator (Meltzer et al., 2010). However, no
formal, trained respite care was available for the study sample of maternal caregivers, due to the lower acuity of the child’s illness and available resources in the state for trained, licensed respite care.

Postpartum depression may also influence depressive symptoms in maternal caregivers. Depression in women after the birth of a child is commonly referred to as postpartum depression (Clare & Yeh, 2012). While there is no specific diagnosis for postpartum depression (PPD) in the Diagnostic and Statistical Manual (DSM-IV), the “postpartum onset” modifier is used when a specific episode begins within the first four weeks of postpartum (Barbadoro et al., 2012; Clare & Yeh, 2012). The children in this study were at least four months of age, so the maternal caregivers may have been beyond the diagnostic window for development of PPD (Logsdon, Wisner, & Pinto-Foltz, 2006).

Postpartum depression was not screened in this sample, but could have possibly been a factor for some mothers. Logsdon, Wisner, and Pinto-Foltz (2006) found that increased stress and anxiety may increase feelings of postpartum depression, and increased stress has been found in maternal caregivers of young children with BPD (Singer et al., 1997). Research has found that elevated levels of stress or anxiety before the birth of the child, or prolonged separation from the child while in the hospital have also contributed to increased reported of postpartum depression in maternal caregivers (Righetti-Veltema, Conne-Perreard, Bousquet, & Manzano, 1998). Many children with BPD must spend time in the NICU, and are separated from their mothers for extended periods of time, possibly causing the mothers to be at higher risk for postpartum depression (Deakins, 2009).
Sleep

In this study, maternal caregivers reported, on average, 5.8 hours of sleep per night, which is similar to other studies of caregivers of children with a chronic illness or ventilator dependency (6.31 hours for caregivers of children on a ventilator, and 5.94 for caregivers of children with a chronic illness) (Cottrell & Khan, 2005; Meltzer & Mindell, 2006). Less than 6 hours of sleep per night is not recommended, because deficits in cognitive functioning (especially memory), and response times (reflexes) have been found in healthy, female participants sleeping 6 or less hours a night (Pilcher & Huffcutt, 1996; Stenuit & Kerkhofs, 2008).

In this study, the mean global sleep score for maternal caregivers of children with BPD was 7.6, which is reflective of elevated scores in previous studies with maternal caregivers of young children with developmental disabilities (mean of 9.9) (Gallagher et al., 2010) and of children on a ventilator (mean of 10.07) (Meltzer & Mindell, 2006). As seen in this study, maternal caregivers of children with BPD reported slightly better sleep, although the average was still above five, the reported PSQI scale cut-off for clinically disturbed sleep (Buysse et al., 1989). Interestingly, Meltzer and Mindell (2006) reported that caregivers of healthy children reported an average 7 hours of sleep a night, and a global sleep score of 5.94. This suggests that caring for a child with moderate BPD results in poorer sleep quality and disturbed sleep, however, these caregivers still are reporting higher quality of sleep than caregivers of children requiring a ventilator (Buysse et al., 1989). This may be due to a number of reasons.
While both populations (ventilator dependent and children with BPD) require equipment that sounds an alarm (feeding pumps, oxygen saturation monitors, apnea monitors) which could sound at night (Deakins, 2009), the child on a ventilator may have a higher acuity of care and a more unstable prognosis. These care needs may lead to more night disruptions (e.g., nighttime treatments, re-positioning the child if immobile, responding to nighttime alarms) (Meltzer & Mindell, 2006). Caregivers of children requiring a ventilator were older in the Meltzer and Mindell (2006) sample as compared to this study population, and may have been caring for their child longer. Older women may report poorer sleep quality than younger women, due to a higher incidence of insomnia and restless leg syndrome (Byles, Mishra, & Harris, 2005). Menopausal status was not measured in this sample, or the study of maternal caregivers of children requiring a ventilator (Meltzer & Mindell, 2006); however, previous research has reported that women currently going through menopause or who are post-menopausal will report poorer sleep quality than pre-menopausal women (Hachul et al., 2008).

Sleep in Healthy Women

In healthy women, the National Sleep Foundation’s Sleep in America Poll (2010) found that a sample of 151 African American women (between the ages of 25-60) reported getting at least 8.3 hours of sleep per night. From the same poll, a sample of 148 Caucasian women (between the ages of 25-60) reported 8.4 hours of sleep per night (National Sleep Foundation, 2010). Hall et al., (2009) found that for a sample of healthy women, the average global sleep score was 3.6, indicating better overall sleep than the caregivers in this sample. These differences could be explained by a number of reasons.
The Hall et al. (2009) study sample had an average age of 49, older than the sample for this study, and Hall et al. did not report the sample participants’ relationship status, although 41% of the sample was African American. This is somewhat contradictory, because older women, especially those who may be menopausal or post-menopausal (though menopausal status was not reported for this study or for Hall et al.,), often report poorer sleep than younger women, who are pre-menopausal (Byles et al., 2005).

However, in this case, the younger women who are caregivers reported poorer sleep than older women who are not caregivers. This difference suggests that caregiving does exert some influence on sleep quality.

Sleep Disruption

Maternal caregivers may report disrupted or short duration of sleep for a number of reasons, which may influence their overall sleep quality. Maternal sleep disruptions such as waking to tend to equipment alarms, worry of not hearing equipment alarms if they fall asleep, nighttime treatments or feeding schedule that requires the maternal caregiver to change a formula bag or disconnect a bolus of formula, or anxieties related to their child’s future or diagnosis all may cause the caregiver to wake at night (Aslan et al., 2009; Cottrell & Khan, 2005; Meltzer & Moore, 2008). Many of the maternal caregivers in this sample were single, never married, which may indicate limited means of support for help with caregiving duties, especially at night (Meltzer, 2008). Equipment alarms include oxygen saturation monitors, feeding pump alarms, or apnea monitor alarms (Jackson & Vessey, 1996). Having professional, in-home help is often not an option for these maternal caregivers, either because it is not available through the state, or because
their child does not meet the qualifications required for Medicaid to pay for trained caregivers, thus these maternal caregivers must manage on their own (Meltzer et al., 2010).

**Sleep Quality**

In this study of maternal caregivers of young children with BPD, sleep quality was significantly, weakly, inversely correlated with QOL ($r=-.292$, $p \leq .002$), but significantly, weakly, and positively correlated with stress ($r=.284$, $p \leq .027$), and significantly, moderately correlated with depressive symptoms ($r=.529$, $p \leq .000$). Sleep quality, stress, depressive symptoms, and QOL have all shown significant relationships in previous research of caregivers of children with a chronic illness or condition (Chien et al., 2003; Gallagher et al., 2010; Meltzer & Mindell, 2006). Depressive symptoms may be an especially complex relationship because studies of caregivers of chronically ill children and dependent adult family members have found depressive symptoms related to poor sleep quality (P. A. Carter, 2003; Meltzer & Mindell, 2006). In this study, depressive symptoms were measured to control for a confounding variable, but did show a significant relationship with sleep quality, and was significant in the model predicting QOL using multiple linear regression.

Depressive symptoms have been shown, previously, to be significantly correlated to QOL in caregivers (Cummings et al., 2010). Cummings et al. et al.,(2010) recruited a primarily Caucasian sample in the UK and the children were diagnosed with a nut allergy, and not a pulmonary illness. The children in Cummings et al., sample were older (school aged), while the children in this study were 4 months to 3 years of age. However,
in both samples, depressive symptoms were strong predictors of QOL in maternal caregivers, possibly suggesting that depressive symptoms are an important indicator of a caregiver’s overall well-being. Additionally, examining depressive symptoms in maternal caregivers is important in relation to QOL, regardless of a child’s age or diagnosis.

Marital status and education have also been found to be significantly correlated with sleep quality and QOL (Troxel et al., 2010); however, they were not found to be significant in this sample of maternal caregivers. Troxel et al. et al.(2010) found that women with a consistent partner slept better than single women; however, the average age of the women included in the study was 51.3 years, and only 38% of the sample was African American. Meltzer et al. (2006) found that caregivers of ventilator dependent children with a higher level of education had better sleep. However, as discussed previously, the average age (37.9 years) for Meltzer et al. (2006) study sample was higher than this sample (29.59 years) and was mostly Caucasian. In this sample, 67.2% of the sample of caregivers of children with BPD were African American, which may suggest cultural differences.

Of the independent variables measured, sleep quality was the only variable that showed a significant relationship with the outcome variable, QOL. As previously stated, this is reflective of previous research in this area that sleep quality is associated with QOL in maternal caregivers of children with cancer (Klassen et al., 2010) and children with brain tumors (Chien et al., 2003) and attention deficit hyperactive disorder (ADHD) (Xiang et al., 2009). Sleep quality and stress were significantly correlated, which also supports previous literature in this area. Caregivers of children with a developmental
disability showed increased stress and poorer sleep quality when compared to caregivers of healthy, typically developing children (Gallagher et al., 2010).

_Caregiver Burden_

Caregiver burden was assessed for this sample using the objective subscale of the Montgomery-Borgatta Caregiver Burden Scale-Revised (Savundranayagam et al., 2010). The instrument has not been used previously in studies of caregivers of young children with a chronic illness or condition; however, to date, there are no general caregiver burden scales for caregivers of young children with a chronic condition or illness. Therefore, a general measure was chosen that had been used in samples of adult caregivers to adult family members.

Recently, in one of the only published studies using the Montgomery-Borgatta Caregiver Burden Scale-Revised, a sample of 266 caregivers of adult family members were enrolled in a caregiver burden reduction intervention study (Montgomery, Kwak, Kosloski, & O'Connell Valuch, 2011). The baseline mean score for objective burden for the caregivers of adult family members was 21.54 (standard deviation of 6.35), higher than the average score of the maternal caregivers of this sample on the same subscale (17.41, 5.99 standard deviation) (Montgomery et al., 2011). This may be due to differences in the samples used.

The caregivers in Montgomery et al. (2011) study were older (mean age of 62.43 years), compared to the maternal caregivers (mean age of 29 years) in this study, and only 19.39% were African American. Montgomery et al. (2011) included both male and female caregivers, although the majority was female (79.7%). The study was an
intervention to decrease caregiver burden, and part of the inclusion criteria that Montgomery et al. (2011) used included asking if the caregiver would now, or in the near future, place their care recipient in a different kind of long-term care setting given their relative’s current condition. Therefore, caregivers with a desire to place their family member in a long-term care facility may have felt higher levels of burden, compared to those who felt they could care for their family member in the home, thus having a higher baseline score. While the populations may be different, these findings, reflect the elevated burden score of caregivers managing family members at home. The sample Montgomery et al. (2011) recruited did not have or was not using in-home nursing care, and is similar to maternal caregivers of young children with BPD, because the vast majority, if not all, of the care must be provided by a family member.

Several different factors may influence a caregiver’s reports of caregiver burden. Age may be one of those factors that influences how a caregiver may perceive and report their caregiving burden (Stewart et al., 1994). For older caregivers, concurrent comorbidities may be a major concern, with caregivers often having to manage their own chronic illnesses (diabetes, hypertension, heart disease), while also managing their dependent loved one’s care (Happe & Berger, 2002). Older caregivers may also find navigating and understanding complex health care delivery systems more time-consuming and stressful, which may limit the resources they have access to, because they may not be aware of resources or able to access them, which may influence their feelings of burden (Heller et al., 2007). As technology progresses, and children are being sent home with increasingly more complex and updated equipment (feeding pumps, apnea monitors, oxygen saturation monitors) that rely on caregivers having a familiarity with
technology and electronic interfaces, some older caregivers may face increased burden navigating and understanding the use of these machines (Leder, Grinstead, & Torres, 2007).

Adolescent mothers may face similar struggles as they attempt to care for a child with a chronic illness, although little has been reported on caregiver burden in adolescent mothers (Mercer & Walker, 2006). Maternal role attainment is a major milestone for adolescent mothers, and may be more complicated because adolescent mothers are still focused on their own developmental needs and defining their own identity (Mercer, 1985). Incorporating and internalizing the role of mother may take time, and is a process that may begin even before the child is born (Mercer, 2005; Rubin, 1967a). The stress and unpredictability of a child with a chronic illness may place an added strain or burden on the adolescent caregiver.

Interestingly, for grandparent caregivers and adolescent mothers, some stressors may be similar. Adolescent mothers who are primary caregivers may face challenges in fully realizing their maternal role identity, as it changes with the birth of a child that requires constant, complex home care, beyond what a typical child would require (DeVito, 2010). Role strain may be present as they balance the role of mother and adolescent, and attempt to reconcile the idea of a typical, healthy child to a child who will have chronic health care needs (Mercer, 2005; Miles et al., 1999). Similarly, grandparents who assume primary responsibility for a child with a chronic illness may also experience role strain, as they attempt to assume the role of “mother” again, as opposed to “grandmother,” and take full, continuous care of a child who may have needs different from children they raised in the past (Leder et al., 2007). Adolescent mothers
may feel added stress or role strain as they deal with prolonged separation from their child, as is likely with a child with a chronic illness like BPD, who may have had to spend several weeks to months in the NICU (Singer et al., 2010).

In this study, there was a significant positive correlation between stress and caregiver burden; that is, maternal caregivers’ reports of increased stress were associated with higher levels of caregiver burden. Few studies have examined stress and caregiver burden in chronically ill children. Calderon et al. (2010) found caregiver burden to be associated with increased levels of stress in caregivers of young children requiring enteral nutrition. While a different population from children with BPD in this study, the findings reflect how caregivers may feel in relation to caring for a child that requires care, but is not acute enough to warrant professional in-home help. Calderon et al. (2010) conducted their study in Spain, and the average age of the caregiver was 37.2 years. Both the father and mother could be included in the study, although 98% identified the mother as the primary caregiver, and 60% of the sample reported living with a partner (Calderon et al., 2010). Calderon et al. (2010) faced a similar challenge in choosing a burden measure, further complicated with finding a measure that was also translated to Spanish, and used a scale designed for caregivers of adult family members (the Zarit Burden Scale). The Zarit scale was not used in this study due to items focused specifically on caregiving for adults with dementia, rather than generic caregiving, thus the Zarit scale was considered inappropriate for this study.
Stress

Stress in this study was measured using the Perceived Stress Scale (PSS) (Cohen et al., 1983). In this study, maternal caregivers had a mean PSS score of 18.34 (standard deviation of 4.73). In a large, US national sample of 1,032 women, the mean PSS score was 16.14 (standard deviation of 7.56) (Cohen & Janicki-Deverts, in press, 2010). The mean age of the sample Cohen et al. (2010) reported on was 42.8, older than the current sample (29.54 years). Breaking down the PSS scores by race (including men and women), the average PSS score for African Americans was 15.68, lower than reported by maternal caregivers of young children with BPD. Because maternal caregivers in this sample reported higher stress than is found in a national sample, both in women, and by race, caregiving may negatively influence caregivers and elevate feelings of stress.

Stress scores were higher than the scores in this study for caregivers of young children with peanut allergies (King et al., 2009). The mean PSS score was 25.13 (standard deviation of 6.67) (King et al., 2009), much higher than this sample, and the normalized sample from the United States. King et al. (2009) recruited 46 families into their study, with the sample including both mothers and fathers. The mean age for the mothers was 42.39, and the children were between 8 and 12 years. No racial data was provided from the authors, and the study was conducted with families in the UK, a different sample than the one that was recruited for this study, which may account for some of the differences. The parent of a school-aged child with a peanut allergy may feel increased stress as their child starts individualized, autonomous food decisions at school, where the parent may not be able to monitor food choices, or to help if their child does have an allergic reaction. King et al. (2009) suggest that some parents may feel increased
stress due to hyper vigilance, because they have been able to control and monitor their
child’s food choices, but now are having to relinquish some of that control as the child is
at school. Singer et al. (1999), in their study of mothers of very low birth weight children
(including children with BPD), found that some mothers felt increased anxiety and hyper
vigilance of their child, the child’s monitoring equipment, and activities. This finding
suggests that both maternal caregivers of young children with BPD, and school-aged
children with a peanut-allergy reported elevated levels of stress on the PSS. Hyper
vigilance may be a common trait in both maternal caregivers of young children with
BPD, and mothers of children with a peanut allergy.

In this sample of maternal caregivers of young children with BPD, stress was
weakly but significantly correlated with burden ($r = .326; p \leq .05$) and sleep quality
($r = .284; p \leq .05$) but not QOL ($r = .133, p \leq .05$). The significant correlation with sleep
quality supports previous literature in caregivers of children with diabetes (Monaghan et
al., 2009) and caregivers of children with a developmental disability (Gallagher et al.,
2010). Gallagher et al. (2010) found that in caregivers of children with developmental
disabilities, there was a significant positive correlation between sleep quality and
increased stress ($r = .500, p \leq .001$). Gallagher et al. (2010) also found that stress was one
of the most significant predictors of poor sleep quality. Similarly, their finding was
supported in this study. Although stress did not mediate the relationship between sleep
quality and QOL, sleep quality was a significant predictor of stress ($t = 2.275 \ p \leq .027$) in
step two of Baron and Kenny’s (1986) mediation process. This may suggest that sleep
quality, which significantly predicted QOL and stress, is an important factor in a
caregiver’s overall well-being.
Monaghan et al. (2009) found that stress was increased in caregivers who reported poorer sleep, and was significantly associated with nighttime caregiving needs. Nighttime caregiving needs were not assessed in this sample of maternal caregivers of young children with BPD. Caregiver burden and stress were also significantly correlated, which also supports previous studies, as discussed in the caregiver burden portion of this chapter. Monaghan et al. (2009) finding of increased stress in caregivers who reported poorer sleep reflects similar findings in this study that mothers who reported elevated levels of stress, also reported poorer quality of sleep.

Nighttime caregiving duties were not assessed in this study, but research suggests that maternal caregivers of children with BPD may have nighttime disruptions due to caring for their child (Zanardo & Freato, 2001). In this study, children who had moderate BPD, requiring oxygen while at home, as well as medication and treatments, had the potential for needing care during the nighttime sleep hours. The child’s overnight “drip” gastrostomy tube feedings may require the caregiver to wake up during the night to change the bag of formula and restart the feeding. Apnea monitors and oxygen saturation monitors may sound an alarm during the night, causing the caregiver to respond to ensure the child’s safety (Jackson & Vessey, 1996). Nighttime medications may be ordered for the child that must be administered either late at night or early in the morning, causing the caregiver to waken administer the medication (Deakins, 2009).

In this sample, stress did not mediate sleep quality, caregiver burden, and QOL; and stress did not significantly predict QOL. Stress, as a mediating variable, has not been used in previous studies in combination with these variables. In contrast, Gallagher et al. (2010) reported that stress was the most significant predictor of poor sleep quality in
caregivers. This was one of the first studies to examine sleep quality and stress in caregivers of young children with a chronic condition, indicating that a significant relationship exists between these variables in caregivers, but Gallagher et al. (2010) did not examine QOL.

In caregivers of adults, stress was found to be a significant predictor of QOL in caregivers of breast cancer patients, in both the psychological and physical domains (Golden-Kreutz et al., 2005), although this was found in caregivers of adults and not children. However, this study does support the relationship between stress and QOL as significant in caregivers, as reflected in pediatric literature (Tsai et al., 2012). Tsai et al. (2012) found that caregivers and children who reported poorer QOL also reported higher levels of stress compared to healthy parents and children. This suggests that a significant relationship exists between QOL and stress; however, this was not reflected in this sample. Further studies are needed to examine maternal caregivers of children with BPD, to explore the relationships between stress and QOL. Sleep quality \( t = -3.757; p \leq .000 \) and depressive symptoms \( t = 2.635; p \leq .011 \) significantly predicted QOL in maternal caregivers of young children with BPD. A significant, positive correlation was found between child’s age and how long the child had been home \( r = -.890, p \leq .005 \). Significant inverse correlations were found between child’s age and depressive symptoms \( r = -.146; p \leq .005 \), and maternal caregiver’s years of education \( r = -.389, p \leq .005 \). Caregiver’s age and depressive symptoms were inversely, and weakly correlated \( r = -.146, p \leq .05 \).

Stress was found to be inversely and moderately correlated with the maternal caregiver having other children in the home \( r = -.360, p \leq .05 \). Stress was also found to be significantly and positively correlated with sleep quality \( r = .284, p \leq .05 \), caregiver
burden ($r=.326, p \leq .05$), the maternal caregiver’s years of education ($r=.317, p \leq .05$), and time the child had been living at home ($r=.003, p \leq .005$). Sleep quality was found to be moderately, significantly, and positively correlated with depressive symptoms ($r=.529, p \leq .005$), and inversely, but weakly, and significantly correlated to QOL ($r=-.292, p \leq .05$).

These findings suggest several conclusions about the study’s sample population. First, that sleep quality and depressive symptoms are important factors in a maternal caregiver’s life that may significantly influence her feelings of well-being. This finding is supported by previous literature, which shows that sleep quality and depressive symptoms are a significant predictor of QOL in maternal caregivers of young children with cancer (Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnell, et al., 2008). Sleep quality and depressive symptoms have a complex relationship, with some researchers in adult studies finding that sleep quality predicts depressive symptoms (P. A. Carter, 2002), and depressive symptoms predict poor sleep quality (Rittman et al., 2009). Both variables have a significant influence on a person’s overall affect (P. A. Carter, 2003; Schubert et al., 2002), which may influence how a person perceives her overall QOL.

Maternal caregivers who had older children, and were older, reported lower depressive symptoms, and lower educational attainment, according to reported correlations for this study. An inverse relationship between depressive symptoms and time at home and age of caregiver are somewhat contradictory to previous literature in caregivers of children with a chronic illness. Previous literature has found that the length of time a parent has been caregiving is positively correlated with higher depressive symptoms (Garro, Thurman, Kerwin, & Ducette, 2005). However, as children with BPD continue to grow and develop, some may outgrow their disease, and not require oxygen,
gastrostomy feedings, or monitoring, signaling an end to heightened caregiving duties by the maternal caregiver (Deakins, 2009). A lessening of caregiving duties may lead to decreased feelings of depressive symptoms, and so explain why caregivers with older children may report fewer depressive symptoms.

Maternal caregivers reporting increased stress were also likely to report decreased sleep quality, increased burden, higher educational attainment, and having the child in the home for a longer period of time. Reports of increased stress due to having the child home for a longer period of time may be related to the similar finding of increased stress being related to increased burden. While there are few studies examining stress and burden in caregivers of chronically ill children, Calderon et al. (2010) found that increased levels of stress were related to increased reports of burden, suggesting that the more parents view their child’s care as impacting their life, the higher their reports of stress. Having a child at home longer may lead to increased reports of stress as the maternal caregiver becomes inured to the care she is providing for the child on a constant basis (without the assistance of respite care), and realizes the chronic nature of her child’s condition and needs, and what her role is in responding to those needs on a constant, daily basis. While in some cases, having the child home longer may lead to a decrease in stress, as some caregivers with a child on a ventilator report, due to the establishment of a “new normal” or an equilibrium (Kuster & Badr, 2006). On the other hand, caregivers for whom the child is home longer may have increased feelings of stress, especially as the child goes through different developmental stages (starts to walk, starts to talk), and the caregiving needs change (Zanardo & Freato, 2001).
Correlations between increased stress and poor sleep have been found previously in studies of caregivers to children with epilepsy (Cottrell & Khan, 2005), and with developmental disabilities (Gallagher et al., 2010), reflecting the findings in this study that maternal caregivers who reported higher levels of stress, also reported poorer sleep quality. Maternal caregivers who reported poor sleep also reported increased depressive symptoms and lower QOL. These findings have been reported in previous research of children with cancer (Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnell, et al., 2008), children on a ventilator (Meltzer & Mindell, 2006), and children with asthma (Szabo, Mezei, Kovari, & Cserhati, 2010). These findings suggest that some aspect of caring for a child with a chronic illness or condition possibly influences caregiver’s feelings of well-being, including mood and affect. Although stress and caregiver burden were not significant predictors of QOL, they did show significant correlational relationships with the variables of depressive symptoms and sleep quality, two variables that did show significant relationship to QOL. If increased stress and increased burden have a positive relationship with stress and sleep quality, then interventions to alleviate caregiver burden or stress may help to improve depressive symptoms or sleep quality, thereby influencing overall QOL (Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008).

Exploratory Analyses

Forced entry multiple linear regression, independent t-tests, and Pearson’s correlations using subscales were run for exploratory analyses using a sample that
excluded the two grandmothers and one adolescent participant. The grandmothers were excluded due to differences in circadian rhythms (sleep characteristics such as, feeling tired earlier in the evening, waking earlier in the day when compared to younger adults), and the adolescent was excluded due to differences in developmental stage and caregiving of adolescent mothers (Culp et al., 1991; DeVito, 2010; Duffy & Czeisler, 2002; Kripke et al., 2005). When reviewing residual QOL scores (scatterplot, Appendix A), one grandmother and the adolescent were found to be outliers. The resulting sample size was 58 maternal caregivers, with an age range of 20-40 years. The power analysis for this study was based on multiple linear regression and called for 60 maternal caregivers. However, for the exploratory analyses statistical power was lost; although the sample is close to achieving power. The analyses were exploratory in nature, and provide support to inform future studies. The major findings from these analyses are briefly discussed in this section, as well as the subscales (PSQI, Montgomery-Borgatta Caregiver Burden Scale-Revised, and WHO QOL BREF).

Mean PSQI subscale score was found to be 1.08 for subjective sleep quality. The mean score for sleep latency was 1.36, and for sleep duration was 1.48. The mean sleep efficiency subscale score was 1.40, and the mean subscale score for sleep disturbances was 1.28, and the mean score for the sleep medications subscale was 0.57, and for the daytime dysfunction subscale was 0.53. The scores range from 0-3, with higher scores indicating higher levels of the concept being scored (Buysse et al., 1989). The scores for this sample were lower than scores for mothers of children requiring a ventilator (ranges from 1.45-2) (Meltzer et al., 2006).
The Montgomery-Borgatta Caregiver Burden-Revised is composed of 4 subscales. The objective subscale was used in this study to represent burden. The other subscales for the measure include subjective (range 6-30, mean for study 23.74) and relationship burden (range of scores 5-25, mean for study 11.84), as well as a subscale for uplifts (range of scores 5-25, mean for study 8.33). Higher scores indicate a higher level of caregiver burden (Savundranayagam et al., 2010). The WHO QOL BREF has four domains, the physical (score range 7-35, 22.90 average for study), psychological (scores range 6-30, mean 22.99 for study), social relationships (score range 3-15, mean 11.92 for study), and environmental (score range 8-40, mean 31.72 for study). Higher scores indicate higher QOL (World Health Organization, 1998). The scores for this study were lower than a US national average of healthy adults (ranges 12-35 for the four subscales) (World Health Organization, 1998).

The model including all variables in Table 23 (sleep quality, stress, caregiver burden, age, depressive symptoms, race, education status, dad living at home, marital status, and child with BPD only child in home) explained 25.4% of the variation in QOL in maternal caregivers of young children with BPD. After excluding the grandmothers and adolescent mother, age \( (t=2.267, p \leq .028) \) became a significant variable in the forced entry multiple linear regression, which is different from the original sample of 61 maternal caregivers, where age was not significant. Sleep quality \( (t=-3.985, p \leq .000) \) and depressive symptoms \( (t=2.588, p \leq .013) \) remained significant in the sample of 59 maternal caregivers. Previous research has found age to be significantly associated with QOL in maternal caregivers of young children after traumatic brain injury, with older caregivers reporting decreased levels of QOL (Aitken et al., 2009). Similar to caregivers
of young children with BPD, the caregivers of children after a traumatic brain injury must maintain and monitor their child’s medical equipment, as well their health.

Significant, moderate, positive Pearson’s correlations were found between subjective sleep quality (first subscale of the PSQI) and depressive symptoms \( r=.447, p\leq.05 \), objective burden \( r=.410, p\leq.05 \), and subjective burden \( r=.423, p\leq.05 \). Sleep latency, or how long it takes to fall asleep (second subscale of the PSQI) was also significantly, moderately, and positively correlated with depressive symptoms \( r=.518, p<.05 \). Significant inverse correlations were found between the first subscale of the PSQI (subjective sleep quality) and all four domains of the WHO QOL BREF measures: domain one, the physical domain \( r=-.415, p\leq.05 \); domain two, the psychological domain \( r=-.350, p\leq.05 \); domain three, the social relationships domain \( r=-.407, p\leq.05 \); and domain four the environmental domain \( r=-.415, p\leq.05 \). This suggests that poorer sleep quality was correlated with worse QOL, and higher levels of depressive symptoms in maternal caregivers of young children with BPD. These findings are similar to previous findings discussed in this chapter, as global sleep quality was significantly correlated with overall QOL \( r=-.292, p\leq.05 \), and depressive symptoms \( r=.529, p\leq.005 \) (Chien et al., 2003).

The subjective burden subscale of the Montgomery-Borgatta Caregiver Burden Scale was significantly, moderately, positively correlated with stress \( r=.518, p\leq.05 \). This is similar to previous findings of the objective burden subscale and stress \( r=.326, p\leq.05 \), suggesting and supporting previous findings that higher levels of stress are related to higher levels of caregiver burden in maternal caregivers of young children with BPD. The uplifts subscale of the Montgomery-Borgatta Caregiver Burden Scale was
significantly, positively, and moderately correlated with the first domain (physical) of the WHO QOL BREF scale ($r=.403, p\leq.05$). The fourth domain (environmental) of the WHO QOL BREF scale was moderately, inversely correlated with educational attainment ($r=-.420, p\leq.05$), and depressive symptoms ($r=-.453, p\leq.05$). This suggests that higher levels of QOL were related to lower levels of depressive symptoms, and educational attainment in maternal caregivers of young children with BPD. This is somewhat contradictory to previous research, which found that higher levels of educational attainment (high school graduate) were related to higher reported QOL in caregivers of young children with cancer (Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008).

For the independent $t$-tests for the main study variables, stress was significantly higher (mean stress score of 20.000) for maternal caregivers who only had a child with BPD in the home ($n=24$), compared to the stress (mean stress score of 17.235, $n=34$) of mothers who had other children in the home. Stress was also significantly different for those maternal caregivers who scored less than 5 on the global PSQI ($n=13$, mean stress score of 15.923), compared to those who scored 5 or greater on the global PSQI ($n=45$, average stress score of 19.098). Depressive symptoms were also different for those who scored less than 5 on the PSQI (mean CESD score of 5.307) and those who scored 5 or greater (average CESD score of 12.578). These findings suggest that sleep quality has a significant influence on depressive symptoms and stress in maternal caregivers of young children with BPD, with better sleep leading to better reported stress and fewer depressive symptoms. These findings support previous literature that found that found higher levels of depressive symptoms in poor sleepers (those who scored 5 or greater) in
maternal caregivers of young children on a ventilator, compared to maternal caregivers who reported greater than 5 on the PSQI (Meltzer & Mindell, 2006). While the samples were different, with children on a ventilator requiring more acute care, similarities do exist, as caregivers for both children on a ventilator and those with BPD require monitoring equipment that may sound an alarm at night, and gastrostomy tube feedings to be maintained, as well as medications.

Children with chronic conditions such as BPD often require complex caregiving in the home, having a great impact on the family, predominately the mother who is often the primary caregiver for the child (Holditch-Davis et al., 2011). Mothers most often provide healthcare treatments, monitoring, and general physical care of the child while at home (Singer et al., 2010). Often, maternal caregivers report poor sleep quality, and high stress and caregiver burden, leading, possibly, to overall poor QOL (Arafa et al., 2008; Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnel, et al., 2008; Meltzer, 2008). In this study, maternal caregivers reported poor sleep quality, high levels of stress, high caregiver burden and poor quality of life.

Theoretical Framework

The theoretical framework used for this study was Lazarus and Folkman’s (1984) Transactional Theory of Stress, Coping, and Appraisal. Maternal caregiving in this study was viewed as the complex psychosocial process that changes and evolves with the caregiver and the demands faced in daily care of the child (P.A. Carter, 2003). Lazarus and Folkman’s model focuses on the individual’s appraisal of any given situation.
In this study, sleep quality and caregiver burden were considered environmental and personal factors (causal antecedents). Stress was viewed as mediating process (appraisal), and the outcome variable was QOL, representing Lazarus and Folkman’s (1984) concept of “overall well-being” as an outcome of the model. The environment and personal factors may influence how a maternal caregiver may appraise her overall stress, which may influence how she perceives her overall QOL. Research questions were based on the model to assess how personal and environmental factors would influence both stress as a mediating variable, and QOL as the outcome variable.

Lazarus and Folkman (1984) highlight the cognitive nature of the model, as stress is very personalized, and based on the individual’s appraisal of what they perceive as stressful, or beyond their means to cope. Maternal caregiver cognitive functioning was not measured in this study, thus a limitation. However, sample inclusion criteria included all caregivers who were able to read, write, and understand English, and were able to complete the consent process. Questionnaires were read to maternal caregivers who requested it for convenience, but all maternal caregivers could read and understand instructions. Cognitive function may be assessed in future studies.

Variables from Lazarus and Folkman’s (1984) model components were selected for study. Future studies could include changes to the conceptual framework, based on the study results, as displayed in Figure 3. Revisions in the conceptual framework could include changing the mediating variable from stress to depressive symptoms, and adding more environmental variables as antecedents.
In this study, stress was not found to be a mediating variable, suggesting that other factors may be more influential in the relationship between sleep quality and caregiver burden and QOL. Depressive symptoms, in this sample, were significantly associated with sleep quality, and were found to be significant predictors of QOL in forced entry multiple linear regression models, while stress was not. Similarly depressive symptoms have been shown to have significant relationships with caregiver burden in parents of children with Tourette’s Disorder (Cooper et al., 2003), stress in caregivers of young children requiring technology (Aldwin, 2007), and sleep quality in maternal caregivers of children with epilepsy (Cottrell & Khan, 2005), as well as QOL in children with cancer (Klassen et al., 2010). Thus, depressive symptoms may act as a better mediator than stress for maternal caregivers.

Environmental characteristics as causal antecedents, as specified in the Lazarus and Folkman (1984) theory, include both situational demands and resources. In this
study, environmental factors were measured as caregiver burden and sleep quality, focusing on the situational demands of caring for a child with complex care needs and sleep quality as it influences the caregiver. Other influences, such as other caregivers in the home, social networks, and social support of the caregiver would fit with the resources portion of environment, and may need to be included in future studies.

Social support has been found to decrease maternal caregiver’s reports of stress (Butcher, Wind, & Bouma, 2008). However, social support was not measured in this study. Caregivers who report adequate levels of social support also report decreased levels of isolation and depressive symptoms (Bettle & Latimer, 2009; Canning et al., 1996). Having support in the home has also been shown to decrease maternal caregiver reports of stress (Aitken et al., 2009; Thyen et al., 1999). In this study, maternal caregivers reported other people living in the home; however, their contribution to the caregiving needs of the child was not assessed. In future studies, other family members’ or caregivers’ in-home support of the child may need to be assessed as part of the environmental resources of the primary caregiver.

Environmental factors include sleeping arrangement (child in the room, child co-sleeping with the mother, others sharing the bed). Bed sharing (or co-sleeping) is not recommended by the American Academy of Pediatrics (2011), due, to an increased risk for SIDS. However, updated recommendations go beyond that to discourage co-sleeping, not just due to the increased risk of SIDS, but all sleep-related infant deaths (Task Force on Sudden Infant Death Syndrome, 2011). In children with epilepsy, poorer sleep quality was found in parents who co-slept with their school-age child, than parents who slept in separate rooms (Cottrell & Khan, 2005). Parents of children with epilepsy also reported
changing their usual sleep routine due to the co-sleeping, which influenced their sleep quality, and increased their levels of stress (Cottrell & Khan, 2005). Parents of children with a chronic illness also reported poor sleep when co-sleeping due to increased stress. Some mothers of children on a ventilator reported feeling “less stressed” if their child was in the same room, but not necessarily the same bed (Kuster, Badr, Chang, Wuerker, & Benjamin, 2004; Sullivan-Bolyai et al., 2004).

Caregivers of adults with dementia reported poorer sleep if they slept in the same room and bed with the dependent loved one, due to increased nighttime awakenings (D. Lee et al., 2007). Sleep environment may be important for this sample of maternal caregivers as the incidence of bed sharing is common in African American urban households (Chianese, Ploof, Trovoto, & Chang, 2009), and may be a factor in the caregiver’s sleep quality.

Data Collection Procedures

The target population for this study included maternal caregivers of young children with BPD. The accessible population consisted of maternal caregivers visiting the specialty pediatric BPD clinic with their child diagnosed with BPD between September 2011 and February 2012. A total of 64 maternal caregivers were screened over six months and met inclusion criteria, and 61 consented to participate in the study for a response rate of 95%. The convenience sample reflected maternal caregivers, including mothers and grandmothers with a child between 4 months and 3 years of age with moderate BPD, not requiring a tracheotomy or ventilator, who had been home from the hospital at least two months. In order to be referred to the specialty BPD clinic, children
must have moderate BPD, require oxygen via nasal cannula, and require Lasix. No
maternal caregiver self-identified as having obstructive sleep apnea, restless leg
syndrome, or insomnia, or any other diagnosed sleep disorder. All maternal caregivers
recruited for the study were at least 17 years, and able to read and write English. Maternal
caregivers completed all study questionnaires on their depressive symptoms, sleep
quality, stress, caregiver burden, and QOL, as well as demographic information.

Sample recruitment and data collection were completed as described in chapter
three. Data were collected over a six month period by the principal investigator. The
principal investigator entered all data into the Statistical Package for the Social Sciences
(SPSS version 18.0) for data analysis. No missing data were reported. For data analysis,
the level of significance was set at .05, except for correlations, when a Bonferroni
correction was indicated due to the increased number of comparisons.

Descriptive statistics were used to summarize demographic and mother and child
characteristics of the sample. Frequencies and percentages were evaluated on
demographic variables and some sleep characteristics (hours per night, overall sleep
quality rating). Sleep quality, stress, caregiver burden, and QOL were scored and
assessed using measures of central tendency. Additionally, correlations were assessed
between all variables. Multiple regression forced entry methods were used to identify
independent variables that may predict the dependent variable of QOL.

Cronbach’s alpha was calculated to determine the internal consistency of the
instruments. Reliability coefficients ranged from .777 for the CESD to .888 for the PSQI.
Although the Montgomery-Borgatta Caregiver Burden Scale-revised has never been used
in this population, adequate internal consistency was demonstrated, with a Cronbach’s alpha of .880.

Methodological Considerations

The primary purpose of this study was to determine maternal caregiver perceptions, thus self-report questionnaires were appropriate for this study (Polit & Beck, 2008). However, other designs or data collection methodologies could have been used.

The use of a mixed methods approach with a qualitative component may have been helpful in eliciting further information from maternal caregivers and in supporting findings from questionnaires. Mixed methods research questions could address the attitudes of caregivers toward sleep, as well as measure their reported sleep quality.

Mixed methods uses multiple methods to assess a research question, and is best suited to questions that require “…real life contextual understandings, multi-level perspectives, and cultural influences…” as well as “employing rigorous quantitative research assessing magnitude and frequency of constructs,” (Creswell, Klassen, Clark, & Clegg-Smith, 2011, p. 4). In this way, assessing variables using quantitative questionnaires would help to support open-ended interviews that may result in common themes, or help to explain some of the quantitative information in a more meaningful way. For example, interviews could help to explain sleep schedules or concerns, or who lives at home and their relative contributions to caring for the child, or if there is someone at night who usually gets up to give the primary caregiver a “break” (Creswell et al., 2011; Wright, 2010).
Open-ended interviews with maternal caregivers of young children with BPD may elicit more information on caregiver burden, other caregivers in the home, who may help, and stress, as well as sleep quality. Because few studies have examined sleep quality, caregiver burden, stress, or QOL quality of life in maternal caregiver of young children with a chronic illness or condition, especially BPD, open-ended interviews may help to evoke information from caregivers not included in questionnaires or surveys (Creswell et al., 2011).

Furthermore, the use of objective measures, such as actigraphy or biomarkers (like cortisol as a biomarker for stress) could also be used with interviews, with the combination providing both quantitative and qualitative data. An actigraph and questionnaire would provide quantitative, objective measures of sleep, such as length of time asleep and sleep disruptions during the night. Interviews could be used to assess the caregiver’s experience with sleep, especially how caregiving may or may not influence the amount of sleep, or the reason why she feels she is or is not getting enough sleep. Open-ended interviews about family or social support may allow for the maternal caregiver to discuss other persons in the home who provide care, as well as other caregiver resources that serve to decrease caregiver burden and stress.

Implications for Practice

Maternal caregivers in this study reported poor sleep quality, reporting on average 5.8 hours a night sleeping, suggesting they may be chronically sleep deprived. Healthcare providers need to assess sleep habits of maternal caregivers. Assessments should include not only the hours of sleep, but sleep environments and other caregiving
and environmental factors that influence sleep quality. The importance of exercise, limiting caffeine intake before bed, establishing a bedtime routine, and limiting the sleeping environment to sleep (not watching television in bed) are important topics to discuss with maternal caregivers of young children with BPD. Clinicians may also want to assess the maternal caregiver’s usual sleeping patterns (naps during the day), as well as the child’s (does the child sleep regularly at night?) (Meltzer & Moore, 2008; Thorpy, 2003).

Education of maternal caregiver on healthy sleep habits, including sleep hygiene and assessing sleep needs in caregivers may be necessary. Sleep may not be seen as a priority to some caregivers. Maternal caregivers, specifically those who are young, as research suggests that young adults may be sleeping less due to social networking and the use of technology (Carskadon & Acebo, 2002). The average age of maternal caregivers for this study was under 30 years, thus focusing on the need for adequate hours of sleep (7-8 hours per night), a regular sleep schedule, limited caffeine intake, and regular exercise during the child’s clinic visits may be warranted (Thorpy, 2003). With adequate sleep quality, maternal caregivers will be more prepared to meet the caregiving demands of their child with BPD.

Maternal caregivers often provide relentless and intense care for their children that may occur during regular sleep hours (McCann, Bull, & Winzenberg, 2012). When possible, coordination of the child’s care (such as scheduling medications or breathing treatments) outside of normal sleeping hours so that it does not interfere with the maternal caregiver’s sleep may be helpful. Providers may need to assess the caregiver’s daily routines at home, including time for sleep and rest, so that health care treatments
can be scheduled when it is optimal for the child, as well as caregiver. If respite care is available and accessible for the caregivers, health care providers should discuss and educate parents who may not know it exists. Support resources, such as other caregivers in the home, friends, or family who can be called upon for support, should also be considered and discussed with healthcare providers to assist with the demands of caregiving.

Healthcare use for these children with BPD is complex, with many children being seen by a variety of individual health care providers and teams, often in different locations, with caregivers receiving conflicting plans of care or over-scheduling (McCann et al., 2012). Coordinating care and educating parents on the importance of efficient or bundled care may help them to organize their time and develop their own sleep schedule routine, as well as aid in the overall caregiver burden and stress they may perceive (Meltzer, 2008). Similar to other studies, this study has future implications for the need for respite care or supportive care for these caregivers, allowing for them to have time to sleep or nap, if uninterrupted nighttime sleep is impossible (Meltzer et al., 2010).

For caregiver burden and stress, clinical implications include the need for further education before the child with BPD is discharged. Ensuring that the maternal caregiver receives adequate training and education, and is aware of how to monitor the child’s condition may help her to feel a greater sense of empowerment, which may help to alleviate feelings of stress and caregiver burden (Nachshen & Minnes, 2005). Healthcare providers need to assess the caregiver burden of maternal caregivers, such as the amount of time that is being asked of caregivers, and the necessity of medication schedules (nighttime medications), breathing treatments, and monitoring equipment (Kirk et al.,
Teaching and assessment of available coping techniques and support systems may also help maternal caregivers to manage their stress (Churchill, Villareale, Monaghan, & Sharp, 2008). Focusing on available support systems, such as support groups, outreach networks, and hospital services may help caregivers who may not have in-home support from family or friends, or who may want contacts outside of their known circle (Sawyer et al., 2011).

Recommendations for Future Research

While the research examining sleep quality, stress, caregiver burden, and QOL in maternal caregivers of children with BPD is expanding, few studies have examined all of these variables in combination. The intensity of family caregiving has increased, as children are being sent home with complex health care needs that require almost constant monitoring and care from the maternal caregiver (Singer et al., 1999). While this study did identify sleep quality as a significant variable, examination of other variables, such as coping or social support, along with sleep quality may help identify other areas of a caregiver’s life that may be important factors in QOL. Further investigation of how sleep quality influences a caregiver’s QOL in different populations may also be important.

Building on the results of this study and the variable of sleep, adding objective measures (actigraphy or biomarkers, such as cortisol), may provide more detailed information on caregiver sleep. In this study, subjective, self-report measures of sleep quality were used, which may not be completely accurate, as caregivers may over or underestimate their sleep quality. Research has found that participants who are chronically sleep deprived may not accurately assess their sleep (Unruh et al., 2008), therefore objective measures may help to support a participants reported sleep quality.
Actigraphy has been used in studies of caregivers of adults (Rittman et al., 2009); however, few studies have used actigraphy with caregivers of young children (Meltzer & Moore, 2008). Actigraphy (highly correlated with polysomnography, the gold standard of sleep measurement) provides an objective measure of the maternal caregiver’s sleep, and can be used to support self-report. A sleep diary would also be necessary, in order to interpret the actigraphy results (when the caregiver actually went to bed, if the caregiver woke up to use the toilet, or to check on the child), as well as provide subjective information about sleep quality (Meltzer & Mindell, 2006). Meltzer (2008) assessed sleep using the PSQI and actigraphy, as well as a sleep diary, in caregivers of children with Autism spectrum disorders. Meltzer (2008) found that the PSQI and sleep diary scores were not significantly correlated with the actigraph, which, she explained, might be partly due to the fact that they measure different constructs. The PSQI and sleep diaries assesses sleep quality, and the actigraphy method is a more efficient measure of sleep duration and quantity (Meltzer, 2008). The use of both subjective and objective measures may provide strength in measuring sleep in caregivers in future studies.

Adding information about why the caregiver wakes during the night would prove helpful in tailoring interventions and understanding the true nature of the disrupted sleep. Once sleep has been adequately described in these caregivers of children with BPD, future studies could also examine child outcomes, such as hospitalizations or sick days and caregiver needs. Further expanding on sleep in maternal caregivers, simulation laboratories could be used, coupled with actigraphy and a sleep diary to determine if sleep deprivation or poor sleep ultimately influences the caregiver’s overall responses.
This may provide stronger evidence for the need for caregivers to get adequate sleep, and so, strengthen the need for greater support, such as respite care.

This study specifically focused on maternal caregivers of young children with BPD. Maternal caregivers are largely responsible for the child’s care (Stewart et al., 1994); however, some fathers may also be involved. For future studies, expanding the sample to include fathers or male (uncles, grandfathers, boyfriends, brothers) caregivers may be useful, because more and more fathers may be helping with the child’s care, as the economy shifts, and households may need a second income when possible (Ojmyr-Joelsson et al., 2009). The results of this study support that while many maternal caregivers reported their relationship status as single, never married, the father of the child was still, oftentimes, in the home. Further studies may seek to determine how much the father is involved in caregiving for the child if he is living in the home, but not married to the mother. For the variable of sleep, including fathers would bridge a gap, and help to determine if there are specific differences in the reported sleep of male versus female caregivers of a child with a chronic illness (Meltzer, 2008). This may help to determine if sleep quality is as important a variable in a male caregiver’s life, as in a female caregiver’s life.

To date, few studies have examined caregivers of young children with BPD, and no studies have examined the sleep of these maternal caregivers. While the incidence of BPD is decreasing (Stroustrup & Trasande, 2010), the acuity of infants with BPD remains high and children are being discharged earlier. BPD is primarily diagnosed in infants born prematurely, although with newer medications and treatments emerging to prolong pregnancy or to help support lung development (such as surfactant), the
incidence of BPD has slightly decreased for the past 10 years. However, researchers have noted that infants diagnosed with BPD are spending more time in NICUs, and treatment is more expensive and more complex than in years past (Stroustrup & Trasande, 2010). For example, Medicaid expenditures in Washington state in 1997, BPD costs were near $17,481,047 annually in reimbursements, second only to children with asthma (Ireys, Anderson, Shaffer, & Neff, 1997). However, today’s health expenditures have increased universally, as health care has become increasingly more complex in the home and in the hospital.

Continuing to examine caregivers of children with BPD to assess the needs of these caregivers is important, but also including other diagnoses may help identify the specific challenges of caregivers and differences or similarities in what may influence QOL (Mitchell, 1996). This study found that sleep quality (not stress or caregiver burden) was an important aspect of a caregiver’s QOL, as well as the relationship of sleep quality with stress. While this reflects previous literature which specifically examines the relationship between sleep quality and QOL for caregivers of children with different illnesses, such as cancer or ADHD (Chien et al., 2003; Xiang et al., 2009), further attention may need to be given to the relationships between sleep quality, stress, and caregiver burden, as well as QOL in other populations, such as children who require enteral nutrition, children on a ventilator, or children born prematurely (Calderon et al., 2010; Meltzer & Mindell, 2006). The use of different populations may allow for a larger sample size to be recruited.

In future studies, assessing social support and coping could lead to a better understanding of QOL in maternal caregivers (Tak & McCubbin, 2002). Social support
has been found to significantly influence feelings of stress and caregiver burden, but little
is known about the relationship between sleep quality and social support (Miles et al.,
1999; Smith, Smoll, & Ptacek, 1990). While stress was not found to be a significant
predictor of QOL, there was a significant relationship between sleep quality and
caregiver burden, suggesting that it may be an important variable in a caregiver’s life and
perceptions. Furthermore, if stress is significantly associated with sleep quality, and sleep
quality is significantly associated with QOL, influencing stress may help to influence
sleep quality. Thus, increased sleep quality may then lead to increased QOL. Future
studies may benefit from the inclusion of social support as a variable of interest in
caregivers of young children with BPD or a chronic illness.

Limitations

Several limitations should be noted for this study. The sampling method was a
convenience sample of maternal caregivers of young children with BPD, consisting of 61
maternal caregivers. A bias may be present, as maternal caregivers had to volunteer to be
in the study, so those who agreed to participate may be different from those who declined
(Polit & Beck, 2008).

While the use of sleep medications was used as an exclusion criterion, the
medication history (corticosteroids, beta blockers, antihistamines, and some
antidepressants, such as SSRIs) of the maternal caregiver was not assessed, and may have
had an impact on the maternal caregiver’s sleep (Clark, Flowers, Boots, & Shettar, 1995;
Redline et al., 2004). Other influences on sleep that were not assessed include the
maternal caregiver’s menopausal state, smoking status, alcohol use, and the sleeping environment (bed partner) (Rittman et al., 2009; Shaver, 2002). Women who are menopausal or post-menopausal report poorer sleep than women who are pre-menopausal, which suggests that a maternal caregiver’s menopausal status may influence her reported sleep quality (Bixler et al., 2009). Lack of data on these factors may provide an incomplete picture of sleep and sleep influences in maternal caregivers.

The variable caregiver burden was measured using the Montgomery-Borgatta Caregiver Burden Scale- Revised, which had never been used in caregivers of young children, and in fact, the revised version has only had limited use in caregivers of adults (Savundranayagam et al., 2010). However the internal consistency of the caregiver burden scale demonstrated high reliability. To date, there are no non-disease specific instruments available to measure caregiver burden in caregivers of children with a chronic illness or condition. Only the objective burden subscale was used for this study, as a total burden score was not indicated. Hence, the Montgomery-Borgatta Caregiver Burden Scale-Revised was used in this study in a non-standardized manner. A generalized measure specifically designed to assess caregiver burden in caregivers of young children has not yet been developed; however, the continued use of this measure in different populations may lend more reliability and validity data to support it.

The use of self-report measure is another limitation of this study. Self-report measures are frequently used in research to assess perceptions of a participant, such as maternal caregivers’ perceptions of their stress, caregiver burden, QOL, and sleep quality. However, self-report measures are subject to concerns with validity and reliability (Polit & Beck, 2008). The maternal caregiver’s sleep quality and hours of
sleep per night are all subject to her report and memory, as well as her stress, QOL, and caregiver burden. The findings may be influenced as self-report measures are very subjective and require the maternal caregiver to remember and report accurately.

Another limitation of the study may be in the accuracy of the data reported. Social desirability, a threat to external validity, may have also been a limitation. Some caregivers may not want to report feeling their child is a “burden” or may not want to seem as if having their child is a “stressor,” and so may not accurately reflect their feelings on a questionnaire (Polit & Beck, 2008). However, all maternal caregivers were told that their information will be kept confidential, and all data were anonymous. Accurately recalling how many hours of sleep per night may cause some caregivers to exaggerate or under-report. The study used several questionnaires, with a total of 98 questions that the maternal caregiver needed to answer, so questionnaire fatigue may have been a limitation, in that some caregivers may not have been as accurate with the final questionnaire the longer the questionnaires went on.

Health Policy Implications

The availability of respite care for maternal caregivers in many states is not always guaranteed. For children with BPD, respite care is almost non-existent, and many maternal caregivers must rely on their own resources, depending on the availability of family or friends to help to provide care (McNally, ben-Shlomo, & Newman, 1999). Maternal caregivers are oftentimes advised to limit the amount of time with strangers their child is exposed to, due to the risk of infection, (Deakins, 2009). Depending on her
own support network, this may lead the maternal caregiver to feel isolated as the lone participant in her child’s care.

The maternal caregivers in this study had elevated stress levels, as well as elevated caregiver burden, and reported only 5-6 hours of sleep per night. Respite care may be one resource that could help to alleviate feelings of stress, caregiver burden, and aid in the caregiver getting more sleep if nighttime disturbances are mostly associated with the child’s needs or care (McIntosh & Runciman, 2008; Meltzer et al., 2010). In one of the few studies to measure sleep and sleep quality in caregivers of young children with respite care, Meltzer et al. (2010) found that caregivers of children on a ventilator reported better sleep and longer duration of sleep if they had trained respite care, and mothers with regular nighttime respite care reported the best sleep. While children on a ventilator may require more care than a child with moderate BPD, certain aspects of caregiving are similar, including nighttime gastrostomy-tube feedings that may clog or sound an alarm, medications, pulse oximeter alarms, and apnea monitor alarms going off at night and during the day, as well as oxygen management (Deakins, 2009). However, respite care is not always available.

In Alabama, for children to be eligible for respite care through Medicaid, a screening process must be undertaken, and certain criteria must be met (child must require care beyond that which the caregiver could conceivably provide on his or her own for a certain number of hours) (Alabama Medicaid Agency, 2011). Primarily, skilled nursing care in Alabama is allocated for children requiring a ventilator. If the child is eligible for skilled nursing care at home, the hours are dependent on the needs of the child, and even then, can be truncated depending on the caregiver’s situation (Alabama
Medicaid Agency, 2011). For instance, in a two-parent home, nighttime respite hours may only cover a few hours, while a single parent with no other care providers in the home might be eligible for a full 8 hours. If a caregiver works, the respite hours only cover the number of hours devoted to working a shift, and one hour of transit time. Thus, after working a full day, a caregiver would then come home and assume full responsibility for the child, including during sleeping hours (Alabama Medicaid Agency, 2011). However, the availability of respite hours allows for the caregiver to maintain a job, but does not support sleep quality.

This study has shown that maternal caregivers of young children with moderate BPD report poor sleep quality, and sleep on average between 5-6 hours a night, as well as elevated stress and caregiver burden scores. Respite care, however, is not an option, as a child with moderate BPD, not requiring a ventilator or having a tracheotomy, does not meet eligibility criteria for respite care. Policy implications indicated in this study include support of broader respite care regulations that would allow for some respite hours for sleep for caregivers of young children with BPD, or other chronic illnesses, not just requiring a ventilator.

Conclusions

In this study, sleep quality was shown to be a significant influence on QOL, and was associated with stress in maternal caregivers of young children with BPD. Maternal caregivers reported, on average, 5-6 hours of sleep per night, suggesting they might be chronically sleep deprived. Being chronically sleep deprived may have a negative influence on the caregiver’s overall QOL, as well as their stress. Depressive symptoms
also showed a significant correlation with sleep quality, which suggests relationships between stress, sleep quality and depressive symptoms, and their influence on overall QOL. However, sleep quality was found to be the only variable that showed a significant relationship with QOL.

This study’s findings have implications for healthcare providers, in that healthcare providers should use these data when interacting with maternal caregivers, especially when nighttime care routines, such as medications or treatments can be scheduled for daytime instead.

Health care providers need to address sleep with maternal caregivers to highlight the importance of getting adequate sleep for the maternal caregiver. In some cases, sleep may be the most easily sacrificed aspect of the day for the maternal caregiver, but helping her to organize or plan for adequate hours of sleep may be a step in helping to improve overall QOL for these caregivers. Overall, adequate sleep and sleep quality is not only important for the caregiver’s overall QOL, but also for the child. This study is one of the first studies to examine the influence of the combination of sleep quality, stress, caregiver burden, and QOL in maternal caregivers of young children with BPD. For health care providers, these findings highlight the following: maternal caregivers of children with BPD are often not getting adequate hours of sleep per night, and this may influence their overall QOL; thus sleep is an important topic to address with these maternal caregivers.
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Figure 4. Scatterplot for Residual Scores for QOL
APPENDIX B

INSTITUTIONAL REVIEW BOARD APPROVAL AND INFORMED CONSENT

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on September 29, 2013. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator: FEELEY, CHRISTINE A.
Co-Investigator(s):
Protocol Number: X110804014
Protocol Title: *Sleep Quality, Stress, Caregiver Burden, and Quality of Life in Maternal Caregivers of Young Children with Bronchopulmonary Dysplasia (BPD)*

The IRB reviewed and approved the above named project on 8-26-11. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.
IRB Approval Date: 8-26-11
Date IRB Approval Issued: 8-26-11

Marilyn Doss, M.A.
Vice Chair of the Institutional Review Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.
MEMORANDUM

TO: Christine Feeley  
Principal Investigator

FROM: Leslie Cooper, CIP  
On behalf of IRB 01

DATE: August 24, 2011

RE: X110804014  
Sleep Quality, Stress, Caregiver Burden, and Quality of Life in Maternal Caregivers of Young Children with Bronchopulmonary Dysplasia (BPD)

The IRB 01 met on August 24, 2011 and approved the waiver of parental permission for the enrollment of 16- to 18-year-old mothers in this protocol.

Please note the following as related to this review:
• Dr. Anne Turner-Henson, who is an IRB member and your faculty advisor for this protocol, was not present at this meeting of the IRB.

LC/Jlg

Cc: Anne Turner-Henson, DSN, Faculty Advisor  
Cari Oliver, OIRB Assistant Director
Informed Consent

TITLE OF RESEARCH: Sleep Quality, Stress, Caregiver Burden, and Quality of Life in Maternal Caregivers of Young Children with Bronchopulmonary Dysplasia (BPD)

IRB PROTOCOL: X110804014

INVESTIGATOR: Christine Feeley

SPONSOR: University of Alabama at Birmingham

For Children/Minors (persons under 19 years of age) participating in this study, the term You addresses both the participant ("you") and the parent or legally authorized representative ("your child").

Explanation of Procedures

You are being asked to participate in this study because you are a maternal caregiver of a child who has been diagnosed with bronchopulmonary dysplasia (BPD). The purpose of this study is to examine factors that maternal caregivers face in taking care of children with bronchopulmonary dysplasia, BPD. This study is being conducted as part of my doctoral nursing studies at the University of Alabama at Birmingham. If you enter this study, you will be asked to complete 5 questionnaires about how you sleep, your perceptions about your life, stress, and providing care for your child. We will also look at your child’s medical record to find out how many days your child was in the NICU, birth day, and other hospital stays.

This study will take about 45-60' minutes.

Risks and Discomforts

The risks and discomforts associated with participating in this study are minimal. There may be some risk of disclosure and discomfort in answering questionnaires. We will refer you to the clinic social worker if you have any concerns from completing the questionnaires. You do not have to answer all the questions. You can stop at any time.

Benefits

You may not benefit directly from taking part in this study. However, this study may help us better understand what kinds of things influence mothers' quality of life, such as sleep, stress, and caring for children with bronchopulmonary dysplasia.

Alternatives

Your alternative is to not participate in this study.
show signs of clinical depression, we will refer you to a qualified health care professional for your protection.

Additionally, data that can identify you may be shared with the UAB Institutional Review Board (IRB) and others who make sure laws and rules are followed with research studies including the office of Human Research Protections (OHRP). The findings of the study may be published for scientific purposes. However, all data will be reported as group findings, and no specific names will be identified.

Since this study takes place at Children’s Hospital, your hospital, this consent document will be placed on the child’s file at that facility. The document will become part of your child’s medical record.

**Refusal or Withdrawal without Penalty**

Your taking part in this study is your choice. There will be no penalty if you decide not to be in the study. If you decide not to be in the study, you will not lose any benefits you are owed. You are free to withdraw from this research study at any time. Your choice to leave the study will not affect your relationship with this clinic.

**Cost of Participation**

There will be no cost to you from taking part in this study.

**Payment for Participation in Research**

You will receive a $5 gift card for your participation in this study.

**Questions**

If you have any questions, concerns, or complaints about the research or a research-related injury including available treatments, please contact Christine Feeley. Or, you may contact Ms Feeley’s research mentor, Dr. Anne Turner-Henson. They will be glad to answer any of your questions. Ms Feeley’s number is (205) 903-0239; Dr. Turner-Henson can be reached at (205) 934-7533.

If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact the Office of the Institutional Review Board for Human Use (OIRB) at (205) 934-3789 or 1-800-822-8816. If calling the toll-free number, press the option for “all other calls” or for an operator/attendant and ask for extension 4-3789. Regular hours for the OIRB are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday. You may also call this number in the event the research staff cannot be reached or you wish to talk to someone else.

**Legal Rights**

You are not waiving any of your legal rights by signing this informed consent document.
Signatures

Your signature below indicates that you agree to participate in this study. You will receive a copy of this signed document.

______________________________  __________________________
Signature of Participant        Date

______________________________  __________________________
Signature of Investigator or Person Obtaining Consent  Date

______________________________  __________________________
Signature of Witness         Date

Waiver of Assent

The assent of ______________________________ (name of child/minor) was waived because of:

Age ____X____  Maturity ________  Psychological state of the child ________

______________________________  __________________________
Signature of Parent or Guardian  Date

______________________________  __________________________
Signature of Investigator or Person Obtaining Consent  Date

______________________________  __________________________
Signature of Witness         Date
What is the purpose of this form? You are being asked to sign this form so that UAB may use and release your health information for research. Participation in research is your choice. If you choose to participate in the research, you must sign this form so that your health information may be used for the research.

Participant Name: ____________________  UAB IRB Protocol Number: X110804014

Research Protocol: Sleep Quality, Stress, Caregiver Burden, and Quality of Life in Maternal Caregivers of Young Children with Bronchopulmonary Dysplasia (BPD)

Principal Investigator: Christine Feeley

Sponsor: University of Alabama at Birmingham

What health information do the researchers want to use? Previous hospitalizations of your child, the child’s date of birth, and how long your child was in the NICU.

Why do the researchers want my health information? The researchers want to use your health information as part of the research study listed above and described to you in the Informed Consent document.

Who will disclose, use and/or receive my health information? The physicians, nurses and staff working on the research study (whether at UAB or someplace else); other operating units of UAB, HSF, UAB Highlands, The Children’s Hospital of Alabama, Callahan Eye Foundation Hospital and the Jefferson County Department of Public Health, as necessary for their operations; the IRB and its staff; the sponsor of the research and its employees; and outside regulatory agencies, such as the Food and Drug Administration.

How will my health information be protected once it is given to others? Your health information that is given to the study sponsor will remain private to the extent possible, even though the study sponsor is not required to follow the federal privacy laws. However, once your information is given to other organizations that are not required to follow federal privacy laws, we cannot assure that the information will remain protected.

How long will this Authorization last? Your authorization for the uses and disclosures described in this Authorization does not have an expiration date.
Can I cancel the Authorization? You may cancel this Authorization at any time by notifying the Director of the IRB, in writing, referencing the Research Protocol and IRB Protocol Number. If you cancel this Authorization, the study doctor and staff will not use any new health information for research. However, researchers may continue to use the health information that was provided before you cancelled your authorization.

Can I see my health information? You have a right to request to see your health information. However, to ensure truthfulness of the research, you will not be able to review the research information until after the research has been completed.

Signature of participant: _____________________________________________
Date: ____________
or participant's legally authorized representative: _______________________
Date: ____________
Printed Name of participant's representative: _____________________________
Relationship to the participant: ________________________________________
**APPENDIX C**

**MEASUREMENTS USED IN STUDY**

**Center for Epidemiologic Studies Depression Scale (CES-D), NIMH**

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

<table>
<thead>
<tr>
<th>Week</th>
<th>During the Past</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rarely or none of the time (less than 1 day)</td>
</tr>
<tr>
<td>1. I was bothered by things that usually don't bother me.</td>
<td>☐</td>
</tr>
<tr>
<td>2. I did not feel like eating; my appetite was poor.</td>
<td>☐</td>
</tr>
<tr>
<td>3. I felt that I could not shake off the blues even with help from my family or friends.</td>
<td>☐</td>
</tr>
<tr>
<td>4. I felt I was just as good as other people.</td>
<td>☐</td>
</tr>
<tr>
<td>5. I had trouble keeping my mind on what I was doing.</td>
<td>☐</td>
</tr>
<tr>
<td>6. I felt depressed.</td>
<td>☐</td>
</tr>
<tr>
<td>7. I felt that everything I did was an effort.</td>
<td>☐</td>
</tr>
<tr>
<td>8. I felt hopeful about the future.</td>
<td>☐</td>
</tr>
<tr>
<td>9. I thought my life had been a failure.</td>
<td>☐</td>
</tr>
<tr>
<td>10. I felt fearful.</td>
<td>☐</td>
</tr>
<tr>
<td>11. My sleep was restless.</td>
<td>☐</td>
</tr>
<tr>
<td>12. I was happy.</td>
<td>☐</td>
</tr>
<tr>
<td>13. I talked less than usual.</td>
<td>☐</td>
</tr>
<tr>
<td>15. People were unfriendly.</td>
<td>☐</td>
</tr>
<tr>
<td>16. I enjoyed life.</td>
<td>☐</td>
</tr>
<tr>
<td>17. I had crying spells.</td>
<td>☐</td>
</tr>
<tr>
<td>18. I felt sad.</td>
<td>☐</td>
</tr>
<tr>
<td>19. I felt that people dislike me.</td>
<td>☐</td>
</tr>
<tr>
<td>20. I could not get “going.”</td>
<td>☐</td>
</tr>
</tbody>
</table>

**SCORING:** zero for answers in the first column, 1 for answers in the second column, 2 for answers in the third column, 3 for answers in the fourth column. The scoring of positive items is reversed. Possible range of scores is zero to 60, with the higher scores indicating the presence of more symptomatology.
WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

<table>
<thead>
<tr>
<th></th>
<th>Very poor</th>
<th>Poor</th>
<th>Neither poor nor good</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How would you rate your quality of life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Very dissatisfied</th>
<th>Dissatisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. How satisfied are you with your health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

The following questions ask about how much you have experienced certain things in the last four weeks.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>A moderate amount</th>
<th>Very much</th>
<th>An extreme amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. To what extent do you feel that physical pain prevents you from doing what you need to do?</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>4. How much do you need any medical treatment to function in your daily life?</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5. How much do you enjoy life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. To what extent do you feel your life to be meaningful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>A moderate amount</th>
<th>Very much</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. How well are you able to concentrate?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. How safe do you feel in your daily life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. How healthy is your physical environment?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>Mostly</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.</td>
<td>Do you have enough energy for everyday life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11.</td>
<td>Are you able to accept your bodily appearance?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12.</td>
<td>Have you enough money to meet your needs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13.</td>
<td>How available to you is the information that you need in your day-to-day life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14.</td>
<td>To what extent do you have the opportunity for leisure activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Very poor</th>
<th>Poor</th>
<th>Neither poor nor good</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>15.</td>
<td>How well are you able to get around?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Very dissatisfied</th>
<th>Dissatisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.</td>
<td>How satisfied are you with your sleep?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17.</td>
<td>How satisfied are you with your ability to perform your daily living activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18.</td>
<td>How satisfied are you with your capacity for work?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19.</td>
<td>How satisfied are you with yourself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
20. How satisfied are you with your personal relationships?  1  2  3  4  5
21. How satisfied are you with your sex life? 1 2 3 4 5
22. How satisfied are you with the support you get from your friends? 1 2 3 4 5
23. How satisfied are you with the conditions of your living place? 1 2 3 4 5
24. How satisfied are you with your access to health services? 1 2 3 4 5
25. How satisfied are you with your transport? 1 2 3 4 5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Seldom</th>
<th>Quite often</th>
<th>Very often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Do you have any comments about the assessment?

[The following table should be completed after the interview is finished]

<table>
<thead>
<tr>
<th></th>
<th>Equations for computing domain scores</th>
<th>Raw score</th>
<th>Transformed scores*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>4-20</td>
<td>0-100</td>
</tr>
<tr>
<td>27. Domain 1</td>
<td>(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18</td>
<td>a. =</td>
<td>b:</td>
</tr>
<tr>
<td></td>
<td>□ + □ + □ + □ + □ + □ + □</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. Domain 2</td>
<td>Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)</td>
<td>a. =</td>
<td>b:</td>
</tr>
<tr>
<td></td>
<td>□ + □ + □ + □ + □ + □</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. Domain 3</td>
<td>Q20 + Q21 + Q22</td>
<td>a. =</td>
<td>b:</td>
</tr>
<tr>
<td></td>
<td>□ + □ + □</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. Domain 4</td>
<td>Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25</td>
<td>a. =</td>
<td>b:</td>
</tr>
<tr>
<td></td>
<td>□ + □ + □ + □ + □ + □ + □ + □</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* See Procedures Manual, pages 13-15
Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate by circling how often you felt or thought a certain way.

Name ___________________________________________________________ Date ________

Age _______ Gender (Circle): M F Other ________________________________

0 = Never 1 = Almost Never 2 = Sometimes 3 = Fairly Often 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly? .................................................... 0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life? .............................................................. 0 1 2 3 4

3. In the last month, how often have you felt nervous and "stressed"? .......... 0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems? ............................................................. 0 1 2 3 4

5. In the last month, how often have you felt that things were going your way? ............................................................................................... 0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do? .......................................................... 0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life? ................................................................. 0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things? . 0 1 2 3 4

9. In the last month, how often have you been angered because of things that were outside of your control? ................................................. 0 1 2 3 4

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them? .................... 0 1 2 3 4

Please feel free to use the Perceived Stress Scale for your research.

Mind Garden, Inc.
info@mindgarden.com
www.mindgarden.com

References
PITTSBURGH SLEEP QUALITY INDEX

INSTRUCTIONS:
The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions.

1. During the past month, what time have you usually gone to bed at night?
   
   BED TIME __________

2. During the past month, how long (in minutes) has it usually taken you to fall asleep each night?
   
   NUMBER OF MINUTES __________

3. During the past month, what time have you usually gotten up in the morning?
   
   GETTING UP TIME __________

4. During the past month, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spent in bed.)
   
   HOURS OF SLEEP PER NIGHT __________

For each of the remaining questions, check the one best response. Please answer all questions.

5. During the past month, how often have you had trouble sleeping because you . . .
   
   a) Cannot get to sleep within 30 minutes
      
      Not during the past month _______ Less than once a week _______ Once or twice a week _______ Three or more times a week _______

   b) Wake up in the middle of the night or early morning
      
      Not during the past month _______ Less than once a week _______ Once or twice a week _______ Three or more times a week _______

   c) Have to get up to use the bathroom
      
      Not during the past month _______ Less than once a week _______ Once or twice a week _______ Three or more times a week _______
d) Cannot breathe comfortably

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

e) Cough or snore loudly

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

f) Feel too cold

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

g) Feel too hot

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

h) Had bad dreams

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

i) Have pain

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

j) Other reason(s), please describe

How often during the past month have you had trouble sleeping because of this?

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

6. During the past month, how would you rate your sleep quality overall?

- Very good
- Fairly good
- Fairly bad
- Very bad
7. During the past month, how often have you taken medicine to help you sleep (prescribed or "over the counter")?

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

8. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

9. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?

- No problem at all
- Only a very slight problem
- Somewhat of a problem
- A very big problem

10. Do you have a bed partner or room mate?

- No bed partner or room mate
- Partner/room mate in other room
- Partner in same room, but not same bed
- Partner in same bed

If you have a room mate or bed partner, ask him/her how often in the past month you have had . . .

a) Loud snoring

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

b) Long pauses between breaths while asleep

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

c) Legs twitching or jerking while you sleep

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>
d) Episodes of disorientation or confusion during sleep

<table>
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</table>

e) Other restlessness while you sleep; please describe________________________________________________________

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Montgomery-Borgatta Caregiver Burden Scale - Revised

Have your caregiving responsibilities...

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>A lot</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) increased attempts by your relative to manipulate you?</td>
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<tr>
<td>(b) decreased time you have to yourself?</td>
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<td>(c) created a feeling of hopelessness?</td>
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<tr>
<td>(d) given your life more meaning?</td>
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<tr>
<td>(e) increased the number of unreasonable requests made by your relative?</td>
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<tr>
<td>(f) kept you from recreational activities?</td>
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<tr>
<td>(g) made you anxious?</td>
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<tr>
<td>(h) made you more satisfied with your relationship?</td>
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<tr>
<td>(i) caused you to feel that your relative makes demands over and above what he/she needs?</td>
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<tr>
<td>(j) caused your social life to suffer?</td>
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<tr>
<td>(k) depressed you?</td>
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<tr>
<td>(l) given you a sense of fulfillment?</td>
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<tr>
<td>(m) made you feel you were being taken advantage of by your relative?</td>
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<tr>
<td>(n) changed your routine?</td>
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<td>(o) made you anxious?</td>
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<td>(p) left you feeling good?</td>
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<tr>
<td>(q) caused conflict with your relative?</td>
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<td>(r) given you little time for friends and relatives?</td>
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<td>(s) caused you to worry?</td>
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<td>(t) made you enjoy being with your relative more?</td>
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<tr>
<td>(u) left you with almost no time to relax?</td>
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<tr>
<td>(v) made you cherish your time with your relative?</td>
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<td>(1)</td>
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<td>(4)</td>
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<td>(5)</td>
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</tbody>
</table>

Total

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Initial Information
Mom's name:____________________________________________________

Child's name: __________________________________________________

Child's Medical Record number: ___________________________

Mom Participant Number:   __  __ __ __ M

Child Participant Number: __ __ __ __  C

THIS PAGE ONLY, TO BE DETACHED
AND KEPT WITH CODEBOOK
Sleep Quality, Stress, Caregiver Burden, and Quality of Life in Maternal Caregivers of Young Children with Bronchopulmonary Dysplasia (BPD)

Participant number: _ _ _ M

Interview Form

Maternal Caregiver Date of the interview ___/____/________

Child’s date of birth ____ (month)/____ (day)/____ __ __ ____ (year)

Mother’s age________

Did you check for:

1. Are you the primary caregiver of your child and at least 16 years of age?
   ☐ Yes, continue with interview
   ☐ No, thank mother for her interest, but she does not qualify for the study

2. Is your child between 2 months and 3 years of age, and diagnosed with bronchopulmonary dysplasia (BPD)?
   ☐ Yes, continue with interview
   ☐ No, thank mother for her interest, but she does not qualify for the study

3. Have you ever been diagnosed with a sleep condition (e.g., obstructive sleep apnea, insomnia, or restless leg syndrome)? On any sleep medications?
   ☐ Yes, thank mother for her interest, but she does not qualify for the study
   ☐ No, continue with interview
4. Is your child on a ventilator or have a trach?
☐ Yes, thank mother for her interest, but she does not qualify for the study
☐ No, continue with interview

5. Does your child with BPD live at home, and have you been with your child at home for at least 2 months? (may need to check medical record)
☐ Yes, continue with interview
☐ No, thank mother for her interest, but she does not qualify for the study

Time interview started ________

Interviewer name__________________________
Hello. My name is Christine Feeley and I am a PhD student at the University of Alabama at Birmingham. I am conducting a study for my doctoral studies at UAB and I would like to talk with you.

My study focuses on assessing maternal caregivers of children ages 3 mo- 3 years with bronchopulmonary dysplasia, or BPD. I am interested in how you are sleeping, what your stress level is like, and what kind of caregiver burden you may be under, and ultimately, how all of this may impact your overall quality of life. In other words, I’m really interested in how having a young child with BPD may influence your overall life.

As part of this study, I will be reviewing your child’s medical record for previous hospitalizations, number of days in the hospital in the NICU, and birth date.

I am asking you to fill out some questionnaires about your background, your sleep, stress, burden, and quality of life. I will read the questions to you, unless you would like me not to. This will take you about 30 minutes to an hour.

Your participation would be greatly appreciated! Would you be willing to help?

**Maternal Caregiver Information**

What is your relationship to child (check all that may apply)

- Mother of child
- Grandmother of child
- Aunt of child
- Other (please specify) __________________________
How many years of education have you had?

☐ Some High School (# of years _____)

☐ High School graduate

☐ Some college (# of years ______)

☐ College graduate (Associate)

☐ College graduate (Bachelors)

☐ Graduate school (# of years _____)

Are you

Never married ☐ Divorced ☐ Separated ☐ Married ☐

What ethnic background best represents you?

☐ Caucasian, non-Hispanic ☐ African-American ☐ Hispanic ☐ Asian ☐ Other

Who lives in the home with the child? (check all that may apply)

Mother of the child ☐ Father of the child ☐

Maternal Grandmother of the child ☐ Maternal Grandfather of the child ☐

Paternal Grandmother of the child ☐ Paternal Grandfather of the child ☐
Aunt of the child ☐ Uncle of the child ☐

siblings (number and ages______________________________)

Child Characteristics

Other ☐

How long has the child been at home? _____days _____ weeks ____ months

When was the last time you and your child were in the hospital? ____________

I am going to look at your child’s medical record to get:

  - Length of Stay in the NICU __________
  - Last hospitalization __________
  - Number of days in the hospital __________

Time interview ended ________

Give the mother the packet of questionnaires.
Thank you so much for agreeing to participate in this study. There are five questionnaires that are included in this packet. Would you like me to read the questions to you?

☐ Did not request questions read

Okay, if you have any problems please let me know, I'll be right here. If you would like to stop at any time, that's fine, just let me know.

☐ Requested questions to be read to them

Okay, then, when you're ready, we'll begin. If you would like to stop at any time, please let me know.

Mother started to answer questionnaires @ ________ (list time)

Mother finished with questionnaires @ ________ (list time)

If there were interruptions (list times with approximate duration of interruption)

_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________

Clarification was requested by the mother on the (include question # and concern next to each questionnaire's name)

☐ CES-D:

☐ PSQI:

☐ Montgomery-Borgatta:

☐ PSS:
☐ WHO-QOL BREF