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# Sleep Quality, Stress, Caregiver Burden, and Quality Of Life in Maternal Caregivers of Young Children With Bronchopulmonary Dysplasia

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Little is known about the influence of sleep quality, stress, and caregiver burden on quality of life in maternal caregivers of young children with bronchopulmonary dysplasia (BPD). In 61 maternal caregivers (mean age 29.59 years) of young children with BPD (mean age 13.93 months), caregivers reported sleeping a mean of 5.8 hours, and significant correlations were found between sleep quality and depressive symptoms and stress, as well as an inverse correlation with quality of life. Sleep quality was found to be the most significant predictor of quality of life in maternal caregivers.

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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, and Dodge, 2002). The rates of BPD have decreased over the past 5 years due to advanced treatments, however the acuity and healthcare expenditures for these infants and children has increased, especially as infants with BPD are spending a longer time in the NICU and requiring more complex care at home (Stroustrup and Trasande, 2010). The National Heart, Lung, and Blood Institute (NHLBI) reported that nearly 1 in 3 infants born with very low birth weight (VLBW) (less than 1,500 grams) will be diagnosed with BPD (National Heart Lung Blood Institute, 2009). Gracey and colleagues reported that an estimated 7,200 new cases of BPD will be diagnosed each year, and the majority of these cases are the

result of healthcare treatments (e.g., ventilation, requiring oxygen) or lung immaturity.

Upon hospital discharge, many of these infants will have multiple co-morbidities and are sent home with complex health care treatment regimens. The primary caregiver, usually the mother, is ultimately responsible for providing the health care treatments, monitoring the child and the child's equipment, and general physical care of the child while at home (Sawyer et al., 2011). However, mothers may have received little to no preparation prior to the child's discharge. Thus, the consequences of providing relentless care on the mother are possibly far-reaching, influencing several aspects of her quality of life, and influencing the family (Singer, Salvator, and Gua, 1999). Caregivers of chronically ill children often report poor sleep quality, and stress and burden may be high, leading, possibly, to overall poor quality of life (QOL) (Klassen et al., 2008; Meltzer and Mindell, 2006). However, little is known about how sleep, caregiver burden, and stress may influence quality of life in maternal caregivers of young children with BPD.

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## Review of the Literature

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). Although the definition of BPD has undergone several changes throughout the years (Gracey et al., 2002), most health providers now use the definition proposed by the NIH, National Institute of Child Health and Human Development, the NHLBI, and the Office of Rare Diseases (Jobe and Bancalari, 2001). This definition encompasses mild, moderate, and severe BPD, classified mainly by the child's need for oxygen after she or he has been sent home or after birth, and helps to guide treatment decisions. The more severe forms of BPD require greater oxygen while at home and possibly CPAP (Jobe and 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, and Burchinal, 2001; Singer et al., 2010). Maternal caregivers of young children with BPD may be at risk for increased levels of stress, caregiver burden, depressive symptoms, and poor sleep due to maintaining their child's health and managing this complex care. This combination of elevated stress and caregiver burden, elevated depressive symptoms, combined with poor sleep quality, may result in decreased levels of QOL, as demonstrated in other caregivers of children with a chronic illness or condition (Cummings et al., 2010; Klassen et al., 2008; Singer et al., 2010). Caregivers of children with BPD have reported increased levels of stress and anxiety, especially pre-discharge when the child required in-home oxygen therapy (Zanardo and Freato, 2001). Zanardo and Freato found that anxiety was at its highest before discharge, and in the immediate period after bringing the child home, but would decrease as the child's condition improved, or the need for in-home oxygen therapy ended, as caregivers became more comfortable providing treatments.

Singer et al. (2010) found that mothers of children born very low birth weight and diagnosed with BPD, reported higher levels of stress and parenting stress than mothers of term infants, especially during the first 3 years of life. However, by school age, levels of stress were equal, as mothers of term children reported increasing stress levels. This may be due to the onset of adolescence, a typically stressful period of development for both parent and child (Singer et al. (2010)).

Little is known about caregiver burden in maternal caregivers of young children with BPD. However, elevated stress and anxiety have been positively associated with higher levels of caregiver burden in parental caregivers of children requiring home enteral nutrition (Calderon et al.,

2010). Similarly, in parental caregivers of young children with cancer, decreased caregiver strain was found to be related to increased health-related QOL (Klassen et al., 2011). In fact, caregivers' strain was found to be one of the most important determinants of the parent's QOL, as well as parental health (e.g., lower caregiving demands were associated with elevated caregiver health scores) (Klassen et al., 2011). These findings suggest that caregiver burden and stress influence overall QOL in caregivers.

Sleep quality has not been assessed in maternal caregivers of young children with BPD. However, maternal caregivers of young children with BPD may be at risk for poor sleep for a number of reasons, including elevated feelings of anxiety (Zanardo and Freato, 2001), equipment alarms at night, needing to change formula bags, medications or treatments to be given at night, along with child awakenings (Deakins, 2009; Singer, Yamashita, Lilien, Collin, and Baley, 1997). Previous literature on children with chronic illnesses and conditions has found that caregivers often report poor sleep quality and restricted sleep duration (sleeping between 4–6 hours per night) (Cottrell and Khan, 2005; Meltzer, Boroughs, and Downes, 2010; Meltzer and Mindell, 2006). Poor sleep quality has also been associated with increased feelings of stress and elevated anxiety in maternal caregivers of young children with developmental disabilities (Gallagher, Philips, and Carroll, 2010). 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, stress, caregiver burden, and QOL in caregivers of young children with BPD (Monaghan, Hilliard, Cogen, and Streisand, 2009; Zanardo and Freato, 2001).

## Framework

Lazarus and Folkman's theory of stress, appraisal, and coping was used as the framework for this study. 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 (a challenge having a more positive connotation) (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 et al., 2005). Sleep quality and caregiver burden may act as

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