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Maternal Stress, Sleep, and Well-being in Mothers of Middle Age Children with Developmental Disabilities

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This dissertation, MATERNAL STRESS, SLEEP, AND WELL-BEING IN MOTHERS OF MIDDLE AGE CHILDREN WITH DEVELOPMENTAL DISABILITIES, by Jiwon Lee was prepared under the direction of the candidate's dissertation committee. It was accepted by the committee members in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing in the Byrdine F. Lewis School of Nursing and Health Professions, Georgia State University.

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ABSTRACT

MATERNAL STRESS, SLEEP, AND WELL-BEING IN MOTHERS OF MIDDLE AGE CHILDREN WITH DEVELOPMENTAL DISABILITIES

by

JIWON LEE

Problem: Mothers of children with developmental disabilities (DDs) experience high levels of stress due to their children with DDs' life-long care needs. The high levels of stress results in impaired sleep as well as poor well-being, and impaired sleep has been related to both high levels of stress and depressive symptoms among mothers raising children with DDs. Mothers' sleep may be an important mediator in linking maternal stress to health-related well-being. The purpose of this study was to examine the mediating effect of mothers' sleep between maternal stress and well-being after controlling for child behavior problems in a community sample of mothers of middle age children (ages 6-12) with DDs. This study used the integrated model, which proposes both the individual differences to the stress response and the cumulative effects of stress on health.

Methods: A cross-sectional, correlational design was used. Forty mothers of middle age children with DDs ($M = 8.8 \pm 2.2$ years) from various community settings volunteered and completed a set of questionnaires and a 5-day sleep diary. Instruments measured parenting stress, caregiving burden, perceived sleep quality, child behavior problems, depressive symptoms, and physical as well as mental well-being. A series of regression analyses were used to test the mediation.

Results: Mothers were in early 40's ($M = 42.1 \pm 5.3$ years), married (75%), White (70%), well-educated (88% with college degree), and with a high income (73% were \$75,000 or greater). Children were mostly boys (74%) and diagnosed with autism, Down syndrome, or cerebral palsy. Although the mothers' physical well-being scores fell around the U.S. norm scores, their mental well-being scores were almost 1 SD below the general population. Mothers also reported on average poor sleep quality (PSQI > 5 , $M = 7.9 \pm 4.8$), high parenting stress, moderate to severe caregiving burden, and high levels of depressive symptoms (CES-D > 16 , 53%). Mothers' perceived sleep quality only mediated in the relationship between caregiving burden and depressive symptoms.

Conclusions: The study results call for close monitoring of mothers' sleep and provide a direction for interventions designed to improve sleep and well-being in mothers of children with DDs.

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MATERNAL STRESS, SLEEP, AND WELL-BEING IN MOTHERS OF MIDDLE
AGE CHILDREN WITH DEVELOPMENTAL DISABILITIES

by

JIWON LEE

A DISSERTATION

Presented in Partial Fulfillment of Requirements for the Degree of Doctor of Philosophy
in Nursing in the Byrdine F. Lewis School of Nursing and Health Professions
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LIST OF ABBREVIATIONS

AFOs	Ankle Foot Orthotics
ASD	Autism Spectrum Disorders
BP	Blood Pressure
BP	Body Pain
BMI	Body Mass Index
CES-D	Center for Epidemiological Studies Depression Scale
CP	Cerebral Palsy
DAS	Dyadic Adjustment Scale
DC	Difficult Child
DDs	Developmental Disabilities
DHEA-S	Dehydroepiandrosterone Sulphate
DS	Daytime Sleepiness
GH	General Health
HDL	High Density Lipoprotein
HPA	Hypothalamic Pituitary Adrenal
ICU	Intensive Care Unit
IDs	Intellectual Disabilities
IRB	Institutional Review Board
MCS	Mental Component Summary
MH	Mental Health
NHIS	National Health Interview Surveys
NREM	Non Rapid Eye Movement

ONS	Oncology Nursing Society
OR	Odds Ratio
PCDI	Parent Child Dysfunctional Interaction
PCS	Physical Component Summary
PD	Parent Distress
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
PF	Physical Functioning
PI	Principal Investigator
PSI	Parenting Stress Index
PSI-SF	Parenting Stress Index Short Form
PSS	Perceived Stress Scale
PSQI	Pittsburgh Sleep Quality Index
RE	Role Emotional
RP	Role Physical
SBP	Systolic Blood Pressure
SCN	Suprachiasmatic nucleus
SD	Standard Deviation
SDQ	Strengths and Difficulties Questionnaires
SE	Sleep Efficiency
SEP	Socioeconomic Position
SES	Socioeconomic Status
SF	Social Function

SF-36v2	Short Form 36 Version 2
SOP	Sleep Onset Latency
SPSS	Statistic Package For Social Science
TST	Total Sleep Time
VIF	Variance Inflation Factor
VT	Vitality
WASO	Wake After Sleep Onset
ZBI	Zarit Burden Interview

CHAPTER I

INTRODUCTION

Empirical evidence shows mothers of children with developmental disabilities (DDs) - a group of severe chronic mental and/or physical conditions that have resulted in substantial limitations in physical, cognitive, speech or language, psychological, and/or self-care (Developmental Disabilities Assistance and Bill of Right Act of 2000) - experience higher levels of psychological stress than mothers of typically developing children (Estes et al., 2009; Montes & Halterman, 2007; Seltzer et al., 2010) as well as fathers of children with DDs (Gerstein, Crnic, Blacher, & Baker, 2009; Oelofsen & Richardson, 2006). According to the recent report from the National Health Interview Surveys (NHIS) using data collected between 1997 and 2008, one in six or 15% of U.S. children ages 3 to 17 years have DDs, and there was a 17% increase in prevalence (12.84% to 15.04%) over a 12-year study period (Boyle et al., 2011). Children with DDs are more likely to have profound limitations in activities of daily living as well as complex medical conditions that require a high level of caregiving responsibilities (Boulet, Boyle, & Schieve, 2009; Raina et al., 2004). In addition, many children with DDs have behavior problems that greatly influence their mothers' daily parenting stress (Estes et al., 2009; Papaeliou et al., 2012; Seltzer et al., 2010). In most families of children with DDs, mothers are the primary caregivers and face everyday challenges that are associated with caregiving as well as managing their children's healthcare needs. Thus, high levels of stress in mothers of children with DDs are understandable.

The high levels of maternal stress have been linked to poor psychological and physical well-being in mothers of children with DDs. For example, higher levels of parenting stress were associated with greater depressive symptoms in mothers of children with autism spectrum disorders (ASD) (Weitlauf et al., 2014) and in mothers of adolescents with DDs (Mitchell & Hauser-Cram, 2008). Higher levels of parenting stress were also significantly associated with a blunted cortisol pattern in mothers of children with DDs, implying a hypothalamic-pituitary-adrenal (HPA) axis hypoactivity due to chronic stress (Dykens & Lambert, 2013). Similarly, when children with DDs have behavioral problems, their mothers experience higher levels of parenting stress, which is associated with a poorer perception of mothers' physical health (Eisenhower et al., 2009).

In general, exposure to prolonged or chronic psychological stress, such as maternal stress, has been shown to result in poor health and well-being. Psychological stress occurs when an individual's perceives transactional relationship between the individual and his or her environment as demanding or exceeding his or her resources and jeopardizing his or her well-being (Lazarus & Folkman, 1984). When vulnerable individuals perceive environmental challenges that they are unable to overcome or adapt to, the body activates neural, endocrine, and immune systems (McEwen, 1998). Although these bodily systems promote adaptation to the stressful challenges in the short term, this response may result in pathophysiologic responses that influence the development of physical disease over the long term (Karatsoreos & McEwen, 2013). Behavioral changes, such as impaired sleep, also often occur as adaptations or coping mechanisms to stress responses (Cohen, Janicki-Deverts, & Miller, 2007). However, these behavioral changes may disrupt the bodies' natural restorative effects, and these

disruptions may affect health and well-being. Thus, examining these behavioral changes is important for evaluating possible areas of intervention.

Although studies examining sleep in mothers of children with DDs are limited, findings indicate that mothers of children with DDs experience impaired sleep. Impaired sleep can be categorized as either sleep deprivation resulting from an inadequate amount of sleep or sleep disruption resulting from fragmented sleep during the night (Lee, 2003). In a recent study of mothers with school-aged children who have DDs, nearly half (49%) of the mothers reported that child care interrupted their sleep most nights (Bourke-Taylor, Howie, Law, & Pallant, 2011). Another study of mothers with children who have Smith-Magenis Syndrome, a genetic disorder featuring intellectual disability and behavior problems, reported that mothers awoke five nights a week to care for their children (Foster, Kozachek, Stern, & Elsea, 2010). In addition, their sleep duration at night was only an average of 6.40 hours (Foster et al., 2010), which is much shorter than the recommended duration of 7 to 8 hours per night for healthy adults (Colten & Altevogt, 2006). Similarly, Gallagher, Phillips, and Carroll (2010) conducted a study of 67 parents (79% mothers) with children who have DDs, and 30 parents (71% mothers) with typically developing children as a control group to examine the psychological predictors of poor sleep quality in parents caring for children with DDs. Parents of children with DDs reported significantly poorer sleep quality than parents of typically developing children. In fact, 72% of the parental caregivers were categorized as “poor sleepers,” indicated by a global score greater than 5 on the Pittsburgh Sleep Quality Index (PSQI), compared to 22% of the control group. Clearly, mothers of children with DDs experience significantly impaired sleep, which requires a further examination.

While the underlying mechanisms linking maternal stress, sleep, and well-being have yet to be clarified, sleep may be an important mediator between maternal stress and well-being in mothers of children with DDs. Impaired sleep has been positively associated with maternal stress (Chu & Richdale, 2009; Gallagher et al., 2010; Ikeda et al., 2011) and negatively associated with psychological well-being (Bourke-Taylor et al., 2013; Chu & Richdale, 2009; Wayte, McCaughey, Holley, Annaz, & Hill, 2012) in mothers of children with DDs. Given that increasing evidence shows mothers of children with DDs also experience poor physical well-being (Dykens & Lambert, 2013; Gallagher, Phillips, Drayson, & Carroll, 2009; Gallagher & Whiteley, 2012; Seltzer et al., 2010, 2011), examining the mediating role of sleep between maternal stress and well-being, both psychological and physical, will be the next logical step for better understanding the relationship between stress, sleep, and well-being in this population. Thus, the proposed study will address these relationships.

When examining the relationship between stress, sleep, and well-being in mothers of children with DDs, child behavior problems and socioeconomic position (SEP) will be controlled as covariates in this study. Child behavior problems and SEP have been identified as risk factors on maternal stress and well-being in mothers of children with DDs, yet studies are limited once these risk factors are considered. Child behavior problems have been identified as a significant contributor to maternal stress (Lee, 2013; Seltzer et al., 2009), psychological distress (Estes et al., 2009), and poor immune response (Gallagher et al., 2009) in mothers (or parents) of children with DDs. In addition, child behavior problems are significantly associated with maternal stress regardless of the child's diagnosis or cognitive/functional status (Baker et al., 2003;

Herring et al., 2006; Neece, Green, & Baker, 2012). Socioeconomic position is also known to be an influential factor on maternal well-being in mothers of children with DDs (Eisenhower & Blacher, 2006; Emerson et al., 2006). Given the significantly positive association between SEP and health (Marmot & Wilkinson, 2005) such a relationship may also be present in mothers of children with DDs.

The role of maternal characteristics (spousal relationship quality and employment status) on maternal stress and well-being also will be explored. Studies have shown that spousal relationship quality (Gerstein et al., 2009; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Weitlauf et al., 2014) and employment status (Bourke-Taylor et al., 2011; Olsson & Hwang, 2008) are influential to maternal well-being and the adaptation of stress among mothers of children with DDs. Given the variability of adaptation of maternal stress in mothers of children with DDs (Lee, 2013), further examination of these maternal characteristics is necessary. Information about the impact of these maternal characteristics on stress and well-being would not only help in identifying which mothers are more at-risk for high levels of maternal stress and adverse well-being, but also provide in designing more effective interventions targeting the variables that are most related to maternal stress and well-being.

Purpose of the Study

The purpose of the study is to examine the mediating effect of mothers' sleep between maternal stress and well-being after controlling for child behavior problems and SEP in a community sample of mothers of middle age children (ages 6-12) with DDs. In addition, the effect of maternal characteristics (spousal relationship quality and employment status) on maternal stress and well-being will be explored.

Specific Aims and Hypotheses of the Study

The specific aims are:

1. To examine the mediating effect of mothers' sleep on the relationship between maternal stress and well-being after controlling for child behavior problems and SEP as covariates in a community sample of mothers of middle age (ages 6-12) children with DDs.
2. To explore the effects of maternal characteristics (spousal relationship quality and employment status) on maternal stress and well-being in a community sample of mothers of middle age children with DDs.

The hypotheses are:

After controlling for child behavior problems and SEP:

Hypothesis 1a: Mothers' sleep (perceived sleep quality) will mediate the relationship between maternal stress (parenting stress and caregiving burden) and depressive symptoms.

Hypothesis 1b: Mothers' sleep (perceived sleep quality) will mediate the relationship between maternal stress (parenting stress and caregiving burden) and physical well-being.

Hypothesis 2a: Mothers who have better relationship quality with their partners will report lower levels of maternal stress (parenting stress and caregiving burden) and better well-being (depressive symptoms and physical well-being).

Hypothesis 2b: Working mothers (either part-time or full-time) of children with DDs will show lower levels of maternal stress (parenting stress and caregiving stress) and better well-being (depressive symptoms and physical well-being) than non-working mothers of children with DDs.

Research questions are:

Research Question 1: What other characteristics of sleep (total sleep time, sleep latency, wake after sleep onset (WASO), daytime sleepiness, sleep efficiency, and daytime sleepiness) will be associated with maternal stress and well-being?

Research Question 2: What are the common types of child behavior problems that children with DDs exhibit?

Research Question 3: What types of child behavior problems will be associated with high levels of maternal stress and poor well-being?

Theoretical Framework

The theoretical framework for this study is derived from the transactional model of stress and coping (Lazarus & Folkman, 1984) and the theory of allostasis and allostatic Load (McEwen, 1998; McEwen & Stellar, 1993; Sterling & Eyer, 1988). The proposed model (Figure 1) has integrated the strengths of two models and expanded the extant limitations to serve as a more comprehensive conceptual model. Although these two models have been widely applied to the study of examining the stress-health relationship, each model has certain strengths and limitations. For example, the transactional model of stress and coping does not consider physiological response to stress, whereas the theory of allostasis and allostatic load's focus is the cumulative effects of chronic stress across the physiological response systems. The theory of allostasis and allostatic load permits examining the chronic and cumulative stress effects well-being and to explore behavioral changes, such as sleep, in the relationship between maternal stress and well-being in mothers of children with DDs. On the other hand, the transactional model of stress and coping allows measuring how each mother perceives and adopts parenting and caregiving

stress differently by examining influencing factors (e.g., spousal relationship quality and employment status) on maternal stress and well-being.

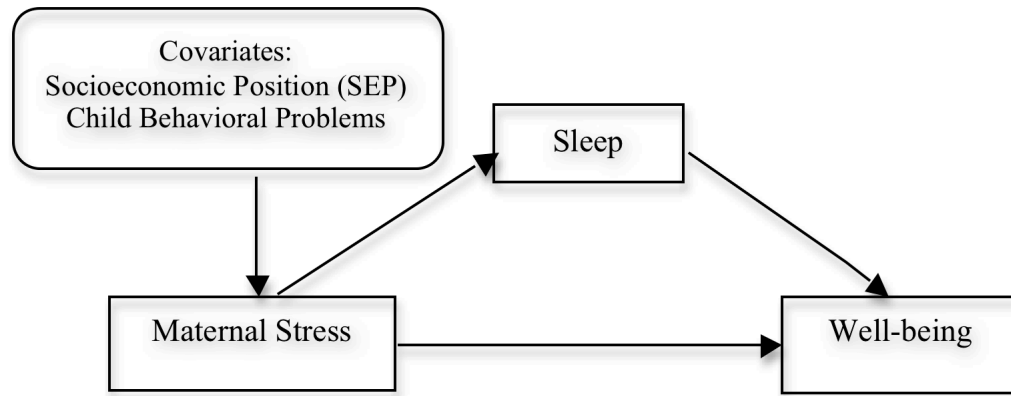


Figure 1. Integrated theoretical framework: Lazarus & Folkman, 1984; McEwen, 1998

Transactional Model of Stress and Coping

The transactional model of stress and coping is the psychological approach emphasizing the importance of how individuals perceive and evaluate stress differently based on their appraisals of the stress and available coping resources to reduce or overcome the stressful situation. The stressful experiences are considered as person-environment interactions, in which both external stressors and available psychological, socioeconomic, and cultural resources influence on the person's appraisal of the stressor (Lazarus & Folkman, 1984).

In this study, **maternal stress** will be defined as a perceived psychological distress experienced by mothers due to parenting and caregiving of children with DDs and measured by both parenting stress and caregiving burden. Although most children with DDs require life-long caregiving responsibilities, studies in mothers of children with

DDs are mainly focused on parenting stress alone (Lee, 2013), and little is known about stress associated with caregiving aspect. Both measures of maternal stress will allow for determining if it is caregiving or parenting or a combined effect from both contribute most to negative well-being in mothers of children with DDs.

Allostasis and Allostatic Load

The theory of allostasis and allostatic load (McEwen, 1998; McEwen & Stellar, 1993; Sterling & Eyer, 1988) emphasizes the chronic and cumulative stress impact on health. The term stress refers to the threatening “events” that can elicit physiological and behavioral responses besides the normal life cycle effects (McEwen & Wingfield, 2003). Physiologically, the HPA axis and the autonomic nervous system respond to stressful events and release stress hormones, such as glucocorticoids and catecholamines. These stress hormones have protective effects in the short run, but it produces damaging effects on the body in the long run. Behaviorally, stressed individuals can produce either protective or damaging effects on the body by choosing either the health-promoting (e.g., good diet, exercise, or self-protection) or health-damaging behaviors (e.g., smoking, alcohol consumption, poor diet, and sedentary lifestyle) (McEwen, 1998). In this study, behavioral changes will be examined by measuring mothers’ sleep. **Sleep** is defined as active, cyclic, and reversible behavioral state of perceptual disengagement from the environment (Carskadon & Dement, 2005). Given the significant association between maternal stress and sleep (Gallagher, Phillips, & Carroll, 2010; Ikeda et al., 2011) as well as between sleep and well-being (Bourke-Taylor et al., 2013) in mothers of children with DDs, sleep may be an important mediator between stress and well-being in this population. While the mediating role of sleep on the stress-health relationship has been

tested in mothers of low birth weight infants (Lee & Hsu, 2012) and non-routine adult caregivers of diverse health conditions (Phillips et al., 2009), there is no study testing the mediating role of sleep between stress and well-being in mothers of children with DDs.

The theory of allostasis and allostatic load also supports individual differences in coping with challenges. Diverse factors, such as individuals' physical condition, genetic predisposition, early-life experiences, and socioeconomic status, play a major role in risk for stress-related health outcomes (McEwen, 2000; McEwen & Seeman, 1999). Given the significant impact of child behavior problems and SEP on stress and well-being in mothers of children with DDs (Baker et al., 2003; Eisenhower & Blacher, 2006; Emerson et al., 2006; Gallagher et al., 2009; Herring et al., 2006; Lee, 2013; Neece et al., 2012; Seltzer et al., 2010), these two variables will be controlled as covariates in this study.

Allostasis is defined as the process of adaptation to changing environments or stressful challenges in order to achieve stability (McEwen, 2000). The allostatic system allows a greater variability within physiological parameters, indicating a healthy adaptive mechanism to environmental challenge (Carlson & Chamberlain, 2005). The primary mediators of allostasis are stress hormones, such as hormones of the HPA axis, catecholamines, and cytokines. These hormones have protective effects in the short run, yet they can have damaging effects over a long period of time (McEwen, 1998).

An allostatic state is defined as altered and sustained states of the primary mediators that integrate physiology and associated behaviors in response to changing environments and challenges (McEwen & Wingfield, 2003). The allostatic state results in an imbalance of the primary mediators, reflecting excessive production of some and inadequate production of others. Examples of allostatic states are chronic hypertension; a

flattened cortisol rhythm in major depression or chronic sleep deprivation; and chronic elevation of inflammatory cytokines (McEwen, 2005).

Allostatic load refers to the excessive damaging (“wear and tear”) effect on the body and brain due to chronic and repeated activation of allostasis (McEwen, 1998; McEwen & Stellar, 1993). Excessive damage on physiological systems accumulates from either an overactive or ineffectively managed allostatic response to change. The health outcomes of allostatic load can be described in terms of primary mediators and secondary outcomes (McEwen & Seeman, 1999; Seeman et al., 1997). A group of stress hormones, such as cortisol, epinephrine, norepinephrine, and dehydroepiandrosterone sulphate (DHEA-S), are released as part of allostasis, and these hormones are called as primary mediators. Primary effects lead in turn to secondary outcomes, such as an elevated blood pressure and a low high-density lipoprotein (HDL) cholesterol level. Finally, tertiary outcomes are the actual disease or disorders that arise from allostatic load.

Assumptions

The followings are assumptions inherent in the transactional model of stress and coping:

- A transactional relationship between the individual and his or her environment is constantly changing.
- A transactional relationship is mediated by individuals’ cognitive appraisal.
- The stress perception by each individual is more important than an external stressor.

The followings are assumptions inherent in the allostasis and allostatic load:

- Brain plays a significant role in interpretation of a stressful event and eliciting physiological and behavioral responses to the stress.
- Individuals' physical conditions, genetic predisposition, early-life experiences, and socioeconomic status all play an important role in risk for stress-related health outcomes.
- Psychological distress, such as worry, anxiety, and cognitive preparation for a coming event, could trigger the activation of stress hormone.

CHAPTER II

REVIEW OF THE LITERATURE

Children with Developmental Disabilities

Developmental disabilities, life-long conditions that usually originate in early childhood, are defined as a group of severe chronic mental and/or physical conditions that result in substantial limitations in at least three of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity of independent living, and economic self-sufficiency (Developmental Disabilities Assistance and Bill of Right Act of 2000). It is estimated that about 15% of U.S. children, or 10 million children aged 3-17 years old experience DDs, and the number of children with DDs has significantly increased in the past 15 years (from 12.84% in 1997-1999 to 15.04% in 2006-2008) (Boyle et al., 2011). Examples of DDs include intellectual disabilities (IDs); neuromuscular disorders such as cerebral palsy, blindness, deafness, epilepsy, and autism; genetic disorders such as Down syndrome and Fragile X syndrome; and other developmental delays (Boulet, Boyle, & Schieve, 2009; Developmental Disabilities Assistance and Bill of Right Act of 2000; McCallion & Nickle, 2008).

Developmental disabilities significantly affect children's health and health care utilization. Children with DDs are 4 to 32 times more likely than children without DDs to have (1) greater limitations in their ability to walk, run, or play; (2) more needs for special equipment and home health care; and (3) higher long-term (> 3 months) use of prescription medication (Boulet et al., 2009). In addition, 41% of children with DDs

have multiple disabilities (Boulet et al., 2009). Furthermore, children with DDs have greater health care use than children without DDs. For example, compared with children without DDs, children with DDs are 2 to 8 times more likely to have used various health care services and to have had a high number of total annual health care visits (Boulet et al., 2009).

Stress in Mothers of Children with DDs

Within the context of families with children who have DDs, raising children with DDs are often described in terms of stress. Stress is a multi-dimensional construct and can be defined in various ways. For example, stress can be defined as “a cause of human distress and dysfunction” in ordinary life (Lazarus, 1993), a psychological stress response to the transactional relationship between a person and his or her environment (Lazarus & Folkman, 1984), or a physiological stress response to a stressor (Selye, 1976). Across the literature of families with children who have DDs, stress has been described in terms of psychological distress and examined in terms of daily hassles associated with parenting (Gerstein et al., 2009), parenting stress (Papaeliou et al., 2012; Weitlauf et al., 2014), stress having a child with DDs (Corrice & Glidden, 2009; Estes et al., 2009), the family impact of having a child with DDs (Azad, Blacher, & Marcoulides, 2013; Baker et al., 2003), and caregiving burden (Gallagher, Phillips, Oliver, & Carroll, 2008).

Given the multi-dimensional nature of stress in the context of families with children who have DDs, stress in this study will be measured by both parenting stress and caregiving burden. Parenting stress is included because most available studies of families with children who have DDs focus on parenting stress experienced by parents in their role as parents (Lee, 2013). Children with DDs have multiple physical, intellectual, and

self-care limitations; thus it is reasonable to assume that raising children with DDs demands higher caregiving than the usual caregiving needed by typically developing children. Caregiving burden is a construct used to represent the stress experienced by caregivers when caring for adults or children who are unable to care for themselves. Caregiver burden can be affected by both objective components associated with the difficulty and/or time of the caregiving task and subjective components related to the perceived emotional and/or social stress that can arise the role of caregiving (Higginson, Gao, Jackson, Murray, & Harding, 2010). Within the studies of mothers with children who have DDs, caregiving burden in mothers of children with DDs has been primarily conceptualized as an emotional and social burden of the stress of caregiving (Gallagher et al., 2008). Integrating multiple perspectives of maternal stress may provide a more complete picture of the stress experienced by mothers of children with DDs.

Stress associated with parenting and caregiving may affect more mothers than fathers in families of children with DDs. Empirical evidence has shown that mothers of children with DDs experience more stress than fathers. For example, in a recent study of parents with children who had IDs, mothers' perceived daily parenting stress significantly increased across the preschool to early school-aged period, but fathers' perceived daily parenting stress was not only lower, but more stable over time (Gerstein et al., 2009). Another study found that mothers of children with DDs reported higher levels of parenting stress scores falling within the clinical range (84%) than fathers of children with DDs (67%) (Oelofsen & Richardson, 2006). Similarly, mothers of toddlers with pervasive developmental disorders (PDDs) or developmental delays without a PDD reported significantly higher parenting stress than fathers of children with PDDs or

developmental delays without a PDD (Herring et al., 2006). Usually, mothers are more likely to be the primary caregivers and face daily caregiving as well as parenting challenges of their children with DDs. Therefore, higher levels of stress in mothers of children with DDs than fathers of children with DDs are expected.

While the demands that mothers face can vary depending on the different stages of childhood, researchers have found high levels of maternal stress during the early childhood period. For example, Gerstein et al. (2009) described a significant increase in maternal stress, measured by daily parenting hassle, during early (from 36 months to 60 months) childhood of children with IDs. Guralnick, Hammond, Neville, and Connor (2008) also examined mothers' parenting stress, measured by parenting stress index (PSI), in mothers of children (ages 47 - 77 months) with DDs. The total child and parent domain PSI scores remained high during the two-year study period, and there were no meaningful differences neither for the parent domain PSI scores (124.63 at time 1, 122.59 at time 2, $p > .05$) nor the child domain PSI scores (123.84 at time 1, 119.62 at time 2, $p < .05$). Similarly, Most, Fidler, Laforce-Booth, and Kelly (2006) investigated changes of mothers' parenting stress, measured by PSI, in mothers of early childhood children (ages 12-15, 30, and 45 months) with Down syndrome and DDs of mixed etiologies. The authors of this study found that the stress trajectory differed during early childhood between these two groups, and maternal stress remained high for the mixed etiologies group or increased for the Down syndrome group throughout these early years.

Studies are limited and showed inconsistent results in mothers of middle age children with DDs. For example, Azad et al. (2013) examined the differences in maternal stress between early (ages 3-5) and middle (ages 6 - 13) childhood using a longitudinal

study of families of children with ($n = 94$) and without ($n = 125$) DDs. In their study, maternal stress remained high and stable without significant individual differences in early childhood but declined with significant individual variation in middle childhood for both mothers of children with DDs and mothers of typically developing children. On the other hand, Neece et al. (2012) found that maternal stress was significantly increased over time across the early and middle childhood (ages 3 - 9) for mothers of children with developmental delays ($n = 93$), while there was no significant difference in maternal stress among mothers of typically developing children ($n = 144$) after controlling for child behavior problems.

In summary, empirical evidence shows that mothers of children with DDs experience higher levels of stress than fathers of children with DDs. Although stress experienced by families of children with DDs contains diverse aspects of psychological distress, most studies mainly address parenting stress. Given that caring for children who have DDs involves significant and prolonged caregiving, an aspect of caregiving stress also needs to be examined. Therefore, maternal stress in the present study will be investigated by examining both parenting stress and caregiving burden to expand the current knowledge of stress experienced by mothers of middle age children with DDs.

Psychological Well-being in Mothers of Children with DDs

Although positive aspects of having children with DDs have been recognized (Weeks, Bryanton, Kozma, & Nilsson, 2008), the majority of research has shown poor psychological well-being or mental health in mothers of children with DDs. In a comprehensive systemic review, there was strong evidence that mothers of children with DDs experience poor psychological well-being (Lee, 2013). A population-based study of

364 American mothers of children (ages 4 - 17) with autism found that they were more likely to report poor or fair mental health than mothers in the general population after controlling for the child's social skills as well as the mothers' demographic variables (age, gender, race, Hispanic ethnicity, education, and family structure) (Montes & Halterman, 2007). A recent study of Australian mothers with school-aged children who have DDs also confirmed poor overall mental health (on the Short Form 36 version 2 (SF-36v2) score) more than two standard deviations below other Australian adults (Bourke-Taylor, Howie, Law, & Pallant, 2012). Another study of Australian mothers with children and adolescents (ages 5 - 19.5) who had IDs found that they exhibited higher levels of mental health problems (such as somatic symptoms, anxiety, social dysfunction, and depression) compared with Australian normative data when their children were young (the mean child age of 12.1 years), and mental health problems remained high when the children were late teens (the mean child age 19.5) (Gray et al., 2011). English mothers of children with rare genetic disorders also reported a much higher percentage (range 33.3 - 71.4%) at or above clinical cut-off for anxiety and depression than normative samples from United Kingdom (4 - 12%) (Griffith et al., 2011).

Among the diverse psychological well-being measures, depressive symptoms are the most commonly reported in research on mothers of children with DDs (Carter et al., 2009; Mitchell & Hauser-Cram, 2008; Smith et al., 2008; Woodman & Hauser-Cram, 2012). In general, mothers of children with DDs experience higher levels of depressive symptoms than mothers of typically developing children (Lee, 2013). A meta-analysis from 18 studies of depression in mothers of children with DDs reported that they were at

an elevated risk of depression compared to mothers of children without disabilities (Singer, 2006). In this meta-analysis, almost one-third (29%) of mothers of children with DDs fell on or above the clinical cut-off for high depressive symptoms compared to 19% of mothers of children without disabilities, indicating a 10% difference in prevalence of depression between the two groups.

While longitudinal studies examining the trajectories of depressive symptoms in mothers of children with DDs are limited, available research has shown that many mothers of children with DDs continue to experience depressive symptoms, and these depressive symptoms remain stable over time. For example, Smith et al. (2008) reported that there was no difference between mothers (mean age = 36.0 years) of toddlers with ASD (36%) and mothers (mean age = 44.7 years) of adolescents with ASD (37%) in their depressive symptoms (on the Center for Epidemiological Studies Depression Scale (CES-D) score ≥ 16). Seltzer et al. (2011) also examined depressive symptoms (CES-D) in 220 parents (112 fathers and 108 mothers) of individuals with IDs or DDs when the parents were in their early 50s or in their mid-60s and compared the CES-D with 1,230 parents (533 fathers and 509 mothers) without IDs or DDs. There was no difference in mothers' depressive symptoms between mothers of individuals with IDs or DDs and the control group when mothers were in their early 50s. However, mothers of children with IDs or DDs reported significantly higher levels of depressive symptoms than the comparison group when they were in their mid-60s ($F = 4.66, p < .001$).

In summary, consistent findings indicate that mothers of children with DDs experience poor psychological well-being. Depressive symptoms have been identified as an important variable of psychological well-being in this population. Available studies

confirm that depressive symptoms are present when mothers of children with DDs are young and remain high when these mothers age are in their later life. Therefore, the proposed study will include a measure of depressive symptoms to allow comparison across studies.

Physical Well-being in Mothers of Children with DDs

While research is limited, the impact of raising children with DDs on mothers' physical well-being has been investigated, and studies have found that mothers of children with DDs are at risk for poor physical health and well-being. For example, Dykens and Lambert (2013) observed a dysregulated pattern of cortisol activity in mothers of children with DDs. The authors reported that two-thirds (63%) of mothers in this study showed a blunted cortisol pattern, a profile of HPA axis hypoactivity, and 37% of mothers showed a steep cortisol pattern. Although the direction of a dysregulated pattern of cortisol activity (either increased or reduced) among individuals experiencing chronic stress is still debatable, a blunted cortisol pattern, in general, is considered to be a result of chronic stress. In this study, mothers with a blunted cortisol pattern had significantly higher levels of parenting stress scores and lower perceived health than mothers with a steep cortisol trajectory. Gallagher et al. (2009) reported a poor antibody response to pneumococcal vaccination in parents (mean age = 42.8 years) of children with DDs. A twofold increase in antibody titer from baseline to one-month follow-up was used as an indicator of a clinically protective antibody response. The study results showed 20% of parents ($n = 30$, 76% were mothers) of children with DDs failed to mount an adequate response compared to only 4% of parents of children with typical development ($n = 29$, 69% were mothers). At six months, almost half (48%) of the

parents of children with DDs did not meet the twofold criteria compared with 4% of the parents of children with typical development. Gallagher and Whiteley (2012) found elevated levels of blood pressure (BP) in parents of children with DDs. In their study, parents ($n = 31$, 84% mothers, mean age = 41.3 years) of children with DDs had significantly higher mean 24-hour, daytime, and nighttime systolic blood pressure (SBP) than parents ($n = 30$, 69% mothers, mean age = 40.1 years) of typically developing children, indicating elevated cardiovascular system vulnerability among parents of children with DDs.

For older mothers (> 50 years) of children with DDs, the deteriorating effect of caregiving on physical health and well-being appears more substantial. Seltzer et al. (2011) found that mothers of children with IDs or DDs had significantly higher body mass index (BMI) as well as more musculoskeletal and cardiovascular problems than mothers of children without IDs or DDs when they were in their early 50s and their mid-60s. Seltzer et al. (2010) compared the diurnal rhythms of cortisol between 86 mothers (mean age = 53.9 years) of adolescents and adult children with ASD and 171 mothers (mean age = 50.1 years) of similarly age-matched unaffected children. The results of this study demonstrated that mothers of children and adult children with ASD showed significantly lower levels of salivary cortisol throughout the day compared with mothers of the control group, indicating a possible HPA axis hypoactivity due to chronic stress.

While extensive research has confirmed the negative impact of raising children with DDs on mothers' psychological well-being, little is known about these impacts on mothers' physical well-being. Available research suggests that prolonged parenting and caregiving stress in these mothers may also negatively affect their physical health. Thus,

the proposed study will include an established, self-report measure of physical health as part of the overall health-related well-being.

Factors Associated with Maternal Stress and Well-being

Maternal characteristics.

Although chronic stress due to long-term caregiving and parenting may add additional strain and lead to poor psychological and physical well-being in mothers of children with DDs, some mothers of children with DDs are well-adjusted and show resilience than other mothers. This pattern may indicate that there are external factors that could influence the adaptation of mothers' role as a parent as well as a caregiver over time. A number of factors have been identified as possible predictors of maternal stress and well-being within research of mothers with children who have DDs. Within the maternal characteristics, marital status has been significantly associated with maternal well-being in mothers of children with DDs. For example, Eisenhower and Blacher (2006) reported that married mothers showed significantly better well-being (e.g., lower depression and higher self-rated physical health) than unmarried mothers in their study of mothers with adolescents or young children (mean age of 20) who had IDs. Among the married mothers, greater marital quality appears to be associated with lower maternal stress and better well-being in mothers of children with DDs. For example, Kersh et al. (2006) demonstrated that marital quality was significantly associated with parenting stress ($r = -.48, p < .001$) and depressive symptoms ($r = -.49, p < .001$), and it also explained 9.5% of the variance in parenting stress as well as 12.3% of the variance in depressive symptoms. Similarly, Weitlauf et al. (2014) reported that relationship satisfaction moderated the relationship ($\beta = -.28, p = .01$) between maternal stress and

depressive symptoms in mothers of children with ASD. Gerstein et al. (2009) found that mothers' perceived marital adjustment was negatively associated with mothers' daily parenting hassles, and the authors described marital quality as "a compensatory factor" on maternal stress in mothers of children with DDs. In this study, both mothers who are married and mothers who have a relationship with a significant other will be included, and their relationship will be referred as spousal relationship. The quality of the relationship also will be measured.

Mothers' involvement in paid work is another maternal characteristic that has been positively associated with maternal stress and well-being. For example, Olsson and Hwang (2008) showed a positive relationship between levels of participation in paid work (more working hours) and well-being (depressive symptoms) in Swedish mothers of children with IDs. Bourke-Taylor et al. (2011) also described that working mothers of children with DDs reported significantly better health-related quality of life than mothers who did not work on five of the eight subscales of the 36-Item Short-Form version 2 (SF-36v2), including overall mental health.

Mothers' involvement in paid work may have a positive effect on the maternal stress and well-being in mothers of children with DDs. For example, data from a limited number of qualitative studies described work as a "respite" and a "welcome distraction" (Freedman, Litchfield, & Warfield, 1995). Parish (2006) also found that work was important for working mothers of children with DDs both financially and emotionally, implying a psychological benefit of mothers' employment. In a study of Canadian mothers with children who have disabilities, mothers' employment was reported as providing an opportunity to expand their social life (Donovan, VanLeit, Crowe, & Keefe,

2005). Therefore, examining the impact of mothers' employment status on maternal stress and well-being in mothers of children with DDs may be another important maternal characteristic to understand the adaptation process in mothers of children with DDs.

Socioeconomic position.

Increased risk for high levels of maternal stress as well as poor well-being in mothers of children with DDs may be attributed to adverse socioeconomic circumstances in families of children with DDs. Families of children with DDs are more likely to live in poverty (Parish & Cloud, 2006) and to be socioeconomically disadvantaged (Emerson et al., 2006). In addition, families of children with DDs are more than likely to spend additional costs due to their children's specialized therapies, adaptive medical devices, and expenses associated with their children's ongoing medical care (Parish & Cloud, 2006). Furthermore, studies find that mothers of children with DDs have less opportunity to participate in paid work. For example, Parish, Seltzer, Greenberg, and Floyd (2004) reported that mothers of children with DDs were less likely to be employed compared to mothers of children without DDs when mothers were mid - 30's (46% vs. 64% $p < .05$), and they were more likely to be employed part-time (34% vs. 28%, $p < .01$) as well as less likely to have a full-time job compared to the comparison mothers (12% vs. 38%). Bourke-Taylor et al. (2011) also described that mothers of children with DDs were involved in less full-time (9%) and more part-time (45%) employment when compared to other working mothers with typically developing school-aged children (28% full-time and 38 % part-time), even though mothers of children with DDs in their study had higher education levels than the mothers of typically developing children. In addition, 82% of mothers reported wanting to work more often. Perhaps, limited opportunities of mothers'

involvement in paid work may make families of children with DDs more financially vulnerable.

In general, higher levels of SEP are associated with better health (Marmot & Wilkinson, 2005). Within families of children with DDs, such a relationship may also exist. For example, one study with a nationally representative sample of 514 British mothers of children (16 years of younger) with IDs ($N = 514$) showed SEP (indicators of (1) household income; (2) material and social hardship; (3) household occupational and work status; (4) maternal education; (5) debt and savings; (6) housing quality) was significantly responsible for the elevated risk for poor maternal well-being in mothers of children with DDs (Emerson et al., 2006). In this study, mothers of children with IDs described that they were significantly less happy, had lower self-esteem, and had low self-efficacy when compared with mothers of children without IDs. However, these differences were not significant after controlling for SEP. Eisenhower and Blacher (2006) also found that socioeconomic status (SES: maternal education and family income) mediated the relationship between maternal marital/working status and well-being (i.e., a positive relationship between marital/employment status and well-being was disappeared after controlling for SES) in their sample of Anglo and Latino mothers with adolescent and young adult children who have IDs. As such, the SEP is an important risk factor for mothers' well-being and will be controlled as a covariate when examining the relationship between maternal stress and well-being.

Child behavior problems.

Among the child characteristics, children's behavior problems have been consistently linked to maternal stress. In general, children with DDs are more likely to

have higher behavior problems than typically developing children (Eisenhower, Baker, & Blacher, 2005). A recent literature review of 28 articles examining maternal stress in mothers of children with DDs supported that higher levels of child behavior problems were associated with higher levels of maternal stress (Lee, 2013). Several researchers also have described that children's behavior problems were positively correlated with maternal stress regardless of their child's diagnosis or cognitive/functional status (Baker et al., 2003; Herring et al., 2006; Neece et al., 2012). One recent study found that a history of children's behavior problems moderated the relationship between children's daily behavior problems and mothers' morning cortisol rise in mothers of children with ASD (Seltzer et al., 2009). Similarly, children's pro-social behavior (Beck, Hastings, Daley, & Stevenson, 2004) and better social skills (Azad et al., 2013) have been negatively correlated with maternal stress.

In relation to maternal well-being, a study reported that children's problem behaviors were positively associated with psychological distress, measured by the brief symptom inventory, in mothers of pre-school aged children with ASD and DDs without autism (Estes et al., 2009). Child behavior problems also have been found to be a significant influencing factor on the difference in the antibody immune response between parents of children with (76% mothers) and without (69% mothers) DDs (Gallagher et al., 2009). Given that children's behavior problems have a significant influence on both maternal stress and health outcomes, child behavior problems also will be considered as a covariate in the proposed study.

Sleep in Mothers of Children with DDs

Sleep is as an active, cyclic, and reversible behavioral state of perceptual disengagement from the environment (Carskadon & Dement, 2005). According to the two-process model of sleep regulation (Achermann & Borbély, 2003; Borbély, 1982), both a circadian process (maintaining wakefulness) and a homeostatic process (promoting sleep) involve in the sleep-wake cycle, and each process controlled by separate mechanisms. The circadian process is responsible for maintaining wakefulness and controlled by the suprachiasmatic nucleus (SCN) in the anterior hypothalamus (Weaver, 1998). The SCN receives light input through a direct retinophthalmic tract from photosensitive retinal ganglion cells. Then, the SCN sends signals through direct and indirect projections in the brain and through coordinated trimming of the release of multiple peptides and hormones that circulate throughout the brain and the body to synchronize other oscillators in various tissues (McClung, 2011). The homeostatic process is responsible for promoting sleep and influenced by the individual's sleep-wake behaviors and the duration and quality of prior sleep. Interaction between the circadian process and the homeostatic process controls the sleep-wake cycle, and they are working against each other. For example, the homeostatic process is increased during the day and decreased during the sleep depending on the amount of non-rapid eye movement (NREM) sleep a person previously had (Diji & von Schantz, 2005). On the other hand, the circadian process is accumulated during the day, working against the homeostatic process and promoting wakefulness and alertness. When a person has an adequate amount of sleep at night, the homeostatic drive for sleep is reduced, and the circadian drive is thus increased (Colten & Altevogt, 2006).

Having undisturbed as well as an adequate amount of sleep has proven to be essential for both psychological and physical health in general population. Impaired sleep, such as inadequate amount of sleep or sleep disruption (Lee, 2003), not only contributes to increased stress and fatigue (Nie et al., 2011), but it also plays a role in disease development such as cardiovascular (Kato, Adachi, Koshino, & Somers, 2009) and metabolic diseases (Van Cauter et al., 2007). In addition, prolonged poor sleep quality has been associated with depressive symptoms (Edge, 2010) and decreased immune functions (Fondell et al., 2011; Motivala, 2011).

Although studies are limited within the United States, emerging evidence suggests that mothers of children with DDs increasingly experience impaired sleep and poor sleep quality. For example, a recent study of 152 Australian mothers with school-aged children who have DDs reported that about half (49%) of the study participants experienced sleep disruptions at night due to their children's caregiving responsibilities, and 11% of mothers who had reported sleep disruptions never slept through the night (Bourke-Taylor et al., 2013). Another recent study found that 40 % (16 out of 40) of British mothers with children who have cerebral palsy experienced poor sleep quality (PSQI > 5) (Wayte et al., 2012). Japanese mothers of children with DDs also reported that 34% of the participants had poor sleep quality using the global PSQI scores (Ikeda et al., 2011). One American study objectively measured mothers' sleep by using actigraphy, a wristwatch-like device to monitor rest-activity patterns, in mothers of children with ASD. They woke 37 minutes earlier and had an average of 51 minutes less sleep per night than mothers of typically developing children (Meltzer, 2008).

Maternal Stress and Sleep in Mothers of Children with DDs

While diverse environmental as well as intrinsic factors can influence maternal sleep, higher levels of maternal stress have been significantly associated with poor sleep quality in mothers of children with DDs. In a study of parents ($N = 53$, 79% mothers) with children who have DDs, parenting stress was found to be a significant predictor for parents' poor sleep quality after controlling for parents' BMI and gender (Gallagher et al., 2010). Higher levels of perceived caregiving burden were also significantly related to mothers' poor sleep quality ($r = .38, p < .01$) in mothers of children with DDs (Ikeda et al., 2011). Similarly, higher levels of global stress scores (measured by perceived stress scale: PSS) were significantly associated with poor sleep quality ($r = .36, p < .01$) in mothers with a low birth weight infant (Lee & Hsu, 2012).

Sleep and Well-being in Mothers of Children with DDs

Although studies are limited, poor sleep quality has been associated with poor psychological well-being in mothers of children with DDs. Bourke-Taylor et al. (2013) reported that Australian mothers of school-aged children with DDs had interrupted sleep at least once a week, and those mothers who had sleep disruptions reported that their mental health component of the SF-36v2 scores were more than two standard deviations (SD) below compared to the Australian norm based scores. Similarly, in a study of mothers with low birth weight infants, mothers' sleep disturbances were significantly associated with low mental health scores on the SF-36v2 (Lee & Kimble, 2009). While there is no study examining the relationship between sleep and physical well-being in mothers of children with DDs, a positive relationship may also exist given that impaired

sleep has been associated with poor health outcomes in general population (Edge, 2010; Fondell et al., 2011; Kato et al., 2009; Van Cauter et al., 2007).

Mediating Effect of Maternal Sleep between Stress and Well-being

Although the underlying mechanisms linking maternal stress, impaired sleep, and well-being have not been clarified, studies from different populations found a mediating role of sleep between stress and well-being. Lee and Hsu (2012) reported the mediating role of mothers' sleep quality (PSQI) between maternal stress (PSS) and physical as well as mental health related quality of life (SF-36v2) in mothers with hospitalized low birth weight infants. Similarly, Meltzer and Mindell (2006) found that mothers' sleep quality (PSQI) mediated the effect of child health status on caregivers' depression and fatigue in mothers of children with and without chronic illnesses, implying mothers' sleep quality may provide an additional explanation for why mothers of children with chronic illnesses experience poor psychological health. The role of mothers caring for children with chronic illnesses may be similar to the role of mothers rearing for children with DDs because both mothers of children with DDs continue to provide caregiving beyond what is expected for mother of typically developing children.

Research has found that mothers of children with DDs experience high levels of stress due to parenting (Gerstein et al., 2009; Papaeliou et al., 2012; Weitlauf et al., 2014) and caregiving (Gallagher et al., 2008) of their children. Available data also strongly support that mothers of children with DDs encounter poor psychological (Bourke-Taylor et al., 2012; Gray et al., 2012; Montes & Halterman, 2007) as well as physical well-being (Dykens & Lambert, 2013; Gallagher et al., 2009; Seltzer et al., 2011). Indeed, mothers of children with DDs often have inadequate amount of sleep (Meltzer, 2008) and poor

sleep quality (Bourke-Taylor et al., 2013; Wayte et al., 2012) and mothers who have impaired sleep also experience high levels of stress (Gallagher et al., 2010; Ikeda et al., 2011) and poor psychological well-being (Estes et al., 2009; Mitchell & Hauser-Cram, 2008; Weitlauf et al., 2014). Given the existing relationship between maternal stress and sleep as well as between sleep and well-being in mothers of children with DDs, mothers' sleep quality may mediate the relationship between maternal stress and well-being in this population. If mothers' sleep explains the relationship between maternal stress and psychological and physical well-being, then it gives a direction for potential interventions designed to improve mothers' sleep and their well-being.

Summary

The proposed study will address several gaps in the current literature. First, although maternal stress is a multi-dimensional construct that contains diverse aspects of stress associated with rearing children with DDs, most studies have focused on parenting stress alone (Lee, 2013). Mothers of children with DDs face high caregiving responsibilities than mothers of typically developing children due to their children's physical, intellectual, and self-care limitations (Boulet et al., 2009; Raina et al., 2004). This study will extend the measures of maternal stress by examining both parenting stress and caregiving burden. Integrated measures of maternal stress will expand the current knowledge of maternal stress and provide better strategies for the future interventions to alleviate stress in mothers of children with DDs.

Second, this study will examine the mediating role of mothers' sleep in the relationship between maternal stress and psychological and physical well-being. While understanding the mediating role of mothers' sleep between maternal stress and well-

being is necessary for the development of future interventions to reduce impaired sleep in this population, the mediation of sleep between stress and well-being has not been tested in this population. In addition, a little is known about the relationship between sleep and physical health in mothers of children with DDs.

Third, the child behavior problems and SEP will be considered as covariates when examining the role of sleep in the relationship between maternal stress and well-being. Research of mothers with children who have DDs consistently has suggested child behavior problems as a risk factor for maternal stress (Baker et al., 2003; Herring et al., 2006; Lee, 2013; Neece et al., 2012) and well-being (Estes et al., 2009; Gallagher et al., 2009). Socioeconomic position is a well-known covariate for poor health, and studies have found that families of children with DDs are poorer and financially vulnerable than families of children without DDs (Parish & Cloud, 2006; Parish, Rose, Swaine, Dababnah, & Mayra, 2012). Little is known the relationship between sleep, stress, and well-being once these risk factors of mothers' well-being are considered. Controlling risk factors of child behavior problems and SEP when examining the relationship among stress, sleep, and well-being will be a rigorous approach.

Finally, maternal characteristics of relationship quality and employment status will be explored in relation to the maternal stress and well-being. Although mothers of children with DDs continue to experience high levels of stress, substantial variation exist in the nature and extent to which mothers report stress. Couples having children with DDs are more likely to experience poor relationship quality, and in turn, this may negatively affect to mothers' stress. Mothers of children with DDs are less likely to be involved in paid work (Bourke-Taylor et al., 2011), and available studies supports that

mothers' work may play an important role for their emotional well-being (Donovan et al., 2005; Parish, 2006). This study will evaluate the role of maternal characteristics on maternal stress and well-being, which could be potential moderators in the relationship between maternal stress and well-being.

The well-being of mothers of children with DDs is a major concern due to associated psychological and physical health problems. The proposed study will provide a better understanding of the role of mothers' sleep in the relationship between maternal stress and well-being as well as maternal characteristics that may have a significant influence on maternal stress and well-being.

CHAPTER III

METHODOLOGY

This chapter describes the research design of the proposed study and is organized as follows: study design, sample and setting, instruments, data collection procedures, data management plan, data analysis for specific aims, limitations, and protection of human subjects.

Design

A non-experimental, cross-sectional, correlational design was used to examine the mediating effect of mothers' sleep between maternal stress and psychological and physical well-being after controlling for child behavior problems and SEP in a community sample of mothers with middle childhood children (ages 6-12) who have DDs. The effects of maternal characteristics (marital status, spousal relationship quality, and employment status) on maternal stress and psychological and physical well-being were also explored. Data were collected using a set of self-report questionnaires and a sleep diary during the week.

Sample and Setting

The target population for this study was mothers of middle childhood children with DDs. A non-random sample of mothers who met the inclusion criteria was recruited from various pediatric specialty clinics, inclusive childcare facilities, and local support groups for families of children with DDs in metropolitan Atlanta. Because of the

low prevalence of children with DDs, referrals and a snowball sampling technique were used as well. The children with developmental disabilities were referred based on the federal definition found in 42 U.S. Code 15001. Inclusion criteria consisted of mothers who were 21 years of age or older and had middle childhood children (ages 6-12) with DDs who: (1) were self-identified mothers and primary caregivers of middle childhood children with DDs, including but not limited to intellectual disabilities, cerebral palsy, blindness, deafness, epilepsy, autism or ASD, genetic disorders such as Down syndrome and Fragile X syndrome, and other developmental delays; (2) were married or living with a significant other; and (3) had the ability to read, speak, and write English. Exclusion criteria consisted of mothers who: (1) were pregnant (due to changes of sleep patterns); (2) were a shift worker (changes of sleep patterns); (3) had a history of a sleep disorder; and (4) had been diagnosed with severe mental health conditions, such as schizophrenia or bipolar disorder.

Sample Size Calculation

G*Power (Faul, Erdfelder, Buchner, & Lang, 2009) was used to determine the sample size. Based on multiple regression and correlations analysis procedure with a power of .80, .15 effect size, and five independent variables at an alpha level of .05, the recommended sample size was 78 participants. Because there was no previous study to estimate the effect size, the investigator chose the medium effect size of 0.15 for multiple regression analysis (Cohen, 1988). Due to slow recruitment, a sample of 40 participants was included in the final analysis. Although the final sample size was small, mothers of children with DDs are in general considered to be a hard to reach population.

Recruitment of Sample

The study participants were recruited using multiple recruitment strategies. Flyers and brochures were distributed at various pediatric specialty clinics, inclusive childcare facilities, and local support groups for families of children with DDs. Referrals and a snowball sampling technique also were used to recruit the participants for the study.

The potential participants were asked to either contact the student principal investigator (PI) or provide their contact information to the student PI if they decide to volunteer. For those who gave the student PI permission to contact, the student PI contacted the potential participants by telephone or e-mail to provide additional information regarding the study. When the student PI contacted the potential participants, the student PI screened for the eligibility criteria and described the involvement of the participants in the study. Those mothers who were not eligible for the study were informed that they did not meet the eligibility criteria and were thanked. Once the potential participant decided to participate in the study, a meeting was arranged at a mutually convenient location.

Instruments

Several instruments were used to collect predictor variables, outcome variables, covariates, and maternal characteristics. Table 1 is the overview of the study instruments.

Maternal stress.

In this study, maternal stress was defined as a psychological distress experienced by mothers due to parenting and caregiving of children with DDs and was measured with two instruments. The first instrument was the **Parenting Stress Index-Short Form**

Table 1

Overview of Study Instruments

Variables	Instruments	Scoring	Interpretation
<u>Outcome Measures:</u> Psychological Well-being	Center for Epidemiologic Studies Depression Scale (CES-D)	20 items. Four subscales: Somatic symptoms (7 items), Depressed affect (4 items), Positive affect (4 items), and Interpersonal functioning (2 items). 4-point Likert scale: 0 (rarely or none of the time) to 3 (most or all of the time). Score Range: 0-60	Higher score indicating greater depressive symptoms. A total score of 16 or higher suggesting a risk for clinical depression.
Physical Well-being	Physical Component Summary (PCS) from the 36-Item Short-Form version 2 (SF-36v2)	21 items from PCS. Four subscales: Physical functioning (10 items), Role physical (4 items), Body Pain (2 items), and General health (5 items). Five-choice response scales. Score range: 0-100	Higher scores indicating better health. The PCS scores are the standardized scores with a mean score of 50 and a standard deviation of 10, which makes it possible to compare with other study results.

(Table 1 Continues)

(Table 1 Continued)

Variables	Instruments	Scoring	Interpretation
<u>Predictor Variables:</u>			
Maternal Stress	Parent Distress (PD) Subscales from Parenting Stress Index-Short Form (PSI-SF)	12 items from PD subscale. 5-point scale: 1 (strongly disagree) to 5 (strongly agree). Score range: 12-60	Higher scores indicating higher levels of parenting stress.
	Zarit Burden Interview (ZBI)	22 items. Two dimensions: personal strain (12 items) and role strain (6 items). 5-point ordinal scale: 0 (never) to 4 (nearly always). Score range: 0-88	Higher scores indicating greater caregiving burden.
Sleep	Pittsburgh Sleep Quality Index (PSQI)	19 items. 7 subscales: sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbances, use of sleeping medicine, daytime dysfunction. 4-point ordinal scale: 0 (no difficulty) to 3 (severe difficulty). Score range: 0-21	Global composite score greater than 5 indicating poor sleep quality.
Socioeconomic Composition	Household income during the last year		

(Table 1 Continues)

(Table 1 Continued)

Variables	Instruments	Scoring	Interpretation
<u>Maternal</u>			
<u>Characteristics:</u>			
Spousal Relationship Quality	Dyadic Adjustment Scale (DAS)	32 items. 4 subscales: consensus, cohesion, satisfaction, and affection. A Likert scale: Score range: 0-151	Higher scores indicating greater satisfaction of their relationships.

(PSI-SF). The PSI-SF is a 36-item questionnaire with three subscales measuring the stress people experience in their role as parents (Abidin, 1995). The PSI-SF is composed of three subscales: Parent Distress (PD), Parent-Child Dysfunctional Interaction (PCDI), and the Difficult Child (DC), and each subscale consists of 12 items. Although the PSI-SF has been administered to diverse parent populations including parents of children with DDs, it was not specifically designed for parents of children with DDs. In addition, studies examining the psychometric properties of the PSI-SF in parents of children with DDs failed to support the stability in the PCDI and DC subscales (Dardas & Ahamd, 2013; Zaidman-Zait et al., 2010). Therefore, only the 12 items of the PD subscale were used to measure parenting stress in this study.

The parent distress subscale of the PSI-SF measures parents' perception of distress due to the personal factors related to parenting, such as a lack of social support, depression, conflict with partner and from life restrictions due to the demands of child-rearing. The scale of each item ranges from 1 (strongly disagree) to 5 (strongly agree), and higher scores indicate higher levels of parenting stress. Raw scores above 33 are

considered to be clinically significant (Abidin, 1995). Abidin (1995) reported internal reliability coefficients (Cronbach's alpha) of .80 to .87 for the three subscales, .91 for the total parenting stress, and .84 for test-retest reliability. The construct validity of the PD subscale was well supported in parents of children with DDs (Dardas & Ahmad, 2013; Zaidman-Zait et al., 2011). Maternal stress was also measured by using an adapted version of the **Zarit Burden Interview (ZBI)** (Zarit, Orr, & Zarit, 1985). The ZBI consists of a 22-item questionnaire and was originally developed to measure strain associated with caregiving of persons of Alzheimer disease. Questions were modified by replacing "your relative" with "your child." Examples of items include "Do you feel that because of the time you spend with your child that you don't have enough time for yourself?"; "Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?"; and "Overall, how burdened do you feel in caring for your child? Responses are scored on a 5-point ordinal scale ranging from never (0) to nearly always (4). The range of possible ZBI scores is 0 to 88, with higher total scores reflecting greater caregiving burden.

The ZBI has been extensively used in caregiver research (Bachner & O'Rourke, 2007) and studies of mothers with children who have DDs (Gallagher et al., 2008; Gallagher et al., 2009). A meta-analysis study concluded that the 22-item ZBI is reliable across populations of caregivers (e.g., spouses, children, parents) (Bachner & O'Rourke, 2007). In addition, a high internal consistency ($\alpha = .94$) has been also shown in parents of children with DDs (Gallagher et al., 2008). The construct validity supported three dimensions in adult caregivers of dementia: negative social and personal consequence, psychological burden, and guilt (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005).

Sleep.

Mothers' sleep was measured by using the **Pittsburgh Sleep Quality Index (PSQI)** (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989) and a sleep diary for five days during the week. The PSQI is a 19-item self-rated measure of sleep quality and disturbances over the past month. The PSQI includes 18 items that measure 7 sleep components (sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbances, use of sleeping medicine, daytime dysfunction) on a 0 (no difficulty) to 3 (severe difficulty) scale. These component scores are summed into a global score ranging from 0 to 21. Global composite scores greater than five are considered to reflect poor sleep quality (Buysse et al., 1989).

Although polysomnography is still considered to be a gold standard for measuring sleep (Irwin, 2008), the PSQI has demonstrated good psychometric properties in diverse populations, including substantial correlations with polysomnography and sleep diary data (Backhaus, Junghanns, Broocks, Riemann, & Hohagen, 2002; Buysse et al., 1989). In addition, the PSQI is the most commonly used instrument in research of mothers with children who have DDs (Lee, 2013).

Although the PSQI is a highly recommended instrument measuring sleep parameters in sleep research (Berger et al., 2005), a single scale may not be adequate to evaluate some sleep variables. Therefore, additional sleep characteristics were obtained from a sleep diary, and they include total sleep time, sleep latency, awakenings, WASO, daytime napping, and sleep efficiency. These sleep characteristics are the recommended sleep parameters from the Oncology Nursing Society (ONS) State-of-the-Science Conference on Sleep/Wake Disturbance in People with Cancer and Their Caregivers in

2004 (Berger et al., 2005). Participants were asked to complete a sleep diary for five consecutive days during the week (from Monday to Friday). The weekdays are chosen because a weekend sleep schedule can be affected by various factors and can be different than the weekday sleep schedule. All calculations were averaged over the nights of collected data. The number of times and the length of time awakened during the night and reason for being awake were recorded. The number of daytime naps and the time for each nap were also calculated. These sleep characteristics are summarized in Table 2.

Table 2

Measures of Sleep Characteristics from 5-day Sleep Diary

Sleep Characteristics	Definition
Total Sleep Time	Number of minutes of sleep in bed
Sleep Latency	Number of minutes between getting into bed and falling asleep
WASO	Number of minutes awake after initial sleep onset
Daytime napping	Number of minutes of sleep during daytime naps
Sleep efficiency	Number of minutes of sleep divided by the number of minutes in bed

Note. WASO = Wake After Sleep Onset

Maternal well-being.

Maternal well-being was measured by two instruments. First, mothers' psychological well-being was measured by the **Center for Epidemiologic Studies Depression Scale (CES-D)** (Radloff, 1977). The CES-D is a 20-item self-report measure of depressive symptoms and contains four subscales: somatic symptoms (7 items), depressed affect (7 items), positive affect (4 items), and interpersonal functioning (2

items). Respondents indicate the frequency of occurrence during the past week of each symptom on a 4-point Likert scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time). Scores range from 0 to 60, with higher score indicating greater depressive symptomatology. A score of 16 or higher indicates a risk for clinical depression. A total score of the CES-D was used as a measure of psychological well-being for this study.

Since the original report by Radloff (1977) regarding its validation, the CES-D has been evaluated in diverse ethnic groups and has been translated for use in multiple languages (Opoliner, Blacker, Fitzmaurice, & Becker, 2013). The CES-D is also one of the most commonly used instruments measuring depressive symptoms in studies of mothers with children who have DDs (Lee, 2013).

Mothers' physical well-being was measured by the Physical Component Summary (PCS) from the **36-Item Short-Form version 2 (SF-36v2)** (Hawthorne, Osborne, Taylor, & Sansoni, 2007). The SF-36v2 is a self-reported questionnaire to assess subjective health status and health-related quality of life. Because the SF-36 is a generic measure of general health, it can be used to evaluate health outcomes across different diseases and treatments. This characteristic has made the use of the SF-36 increasingly popular, and it has become the most frequently used instrument to measure health-related quality of life across the clinical research (Garratt, Schmidt, Mackintosh, & Fitzpatrick, 2002). It yields eight domain scores that represent a person's health status in the areas of physical functioning (PF: 10 items), role physical (RP: ability to meet physical role demands, 4 items), body pain (BP: 2 items), vitality (VT: 4 items), general health (GH: 5 items), social function (SF: 2 items), role emotional (RE: ability to meet

emotional role demands, 3 items), and mental health (MH: 5 items). These eight domains can be aggregated into the Physical Component Summary (PCS) and the Mental Component Summary (MCS). The domains of PF, RP, BP, and GH consist of PCS, while the MH, RE, VT, and SF correlates highly with the MCS. All items are rated on Likert-type or frequency response scales, rating from three response categories for the PF items and to six categories for the BP items. The scores of the SF-36 range from 0 to 100, with higher scores indicating better health status. The scores also can be composed of two distinct summary scores, a physical and a mental, and these scores are standardized by using normative data from the 1998 US general population with a mean score of 50 and a standard deviation of 10 (Ware, Kosinski, & Dewey, 2000). Since the new version of the SF-36 (SF-36v2) was introduced in 1996, several studies have confirmed the psychometric properties of the SF-36v2 (ten Klooster et al., 2013; Lim, Seubsman, & Sleigh, 2008). In this study, the PSC was calculated and used to measure physical well-being.

Covariates.

Child behavior problems.

The **Strengths and Difficulties Questionnaires (SDQ)** - parent version - was used to measure child behavior problems (Goodman, 1997). The SDQ is a 25-item questionnaire that measures both psychosocial problems and strengths (pro-social behaviors) in children aged three to 16. The SDQ consists of five subscales: one scale for child pro-social behavior and four scales assessing problem behaviors including emotional symptoms, conduct disorder, hyperactivity, and peer relationships. The items are measured on a three-point Likert scale from 0 (not true) to 2 (certainly true), and the

sum of all the sub-scale scores except the pro-social sub-scale reflects total difficulties. The total difficulty scores range from 0 to 40, and higher scores indicate more behavior difficulties. The SDQ is a well-validated instrument and has been shown to be reliable with a Cronbach's α of .80 for internal consistency and .76 for test-retest reliability on total difficulty scores for the parent version (Stone, Otten, Engels, Vermulst, & Janssens, 2010). As for the validity, most studies support the five-factor structures of the SDQ and demonstrate good concurrent validity (Stone et al., 2010). The SDQ has been used as a predictor of both mental and physical health in families of children with DDs (Gallagher et al., 2009; Gallagher & Whiteley, 2012). The total difficulty scores were used as the measure of child behavior problems in this study.

Socioeconomic position.

The overall **household income** during the last year was used as a measure of SEP. Household income was the sum of income from all sources received by all members of the household. The sources included the followings: money received from jobs, unemployment benefits, public assistance, income from rental properties, child support, and other informal incomes.

Maternal characteristics.

Spousal relationship quality.

Spousal relationship quality was measured by the **Dyadic Adjustment Scale (DAS)**. The DAS is a 32-item self-administered questionnaire for evaluating the quality and adjustment of a couple's relationship (Spanier, 1976). The DAS contains four subscales: consensus (agreement on important matters), cohesion (the degree of closeness in the couple), satisfaction (the individual's satisfaction of their relationships), and

affection (the amount of physical demonstrations of affection). The DAS items are rated on a Likert scale, and the summative scores range from 0 to 151, with higher scores indicating greater satisfaction of their relationships. The total scores of the DAS were used for this study.

Spanier's original study (1976) supported the construct validity and internal consistency reliability of the total scores (Cronbach's $\alpha = .96$). Graham, Liu, & Jeziorski (2006) also conducted a meta-analysis and found an average of .92 for the reliability of the total score. The DAS has been used in research of families with children who have DDs and has shown adequate reliability (Kersh et al., 2006; Weitlauf et al., 2013).

Data Collection Procedures

The approval for this study was obtained from the Institutional Review Board (IRB) at Georgia State University. The meetings with study participants were held in a quiet and comfortable setting, such as a home or private conference room in a public library. The student PI collected all the data, and it took about 45 minutes to an hour. Informed consent documents were provided, reviewed with participants, and signed. The participant was encouraged to ask any questions that she had regarding the research project and the consent. The student PI insured that each participant understood the purpose of the study, her role in the research project, confidentiality, and voluntary withdrawal at any time during the project. A copy of the signed informed consent form was given to each participant. Mothers' and their child's demographic information as well as a set of questionnaire were collected during this meeting. The mothers' demographic form contained mothers' and her partners' demographic information, such as mothers'/ their partners' age, race/ethnicity, marital status, occupation, employment

status, educational background, religion, and mothers' health history. A child's health history was obtained as a part of child characteristic information (age, gender, type of development disabilities, diagnoses, and any technology used).

When the study participants completed all the questionnaires, the student PI gave a \$10 gift card for a local store to the participant as a token of appreciation for their time. The participant was asked to sign the paperwork when she received a gift card. At the end of the meeting, the participant was asked to complete a 5-day sleep diary and send it back to the student PI when they completed it by using a pre-addressed, stamped envelope.

Data Management Plan

Once each participant completed the questionnaires, the PI checked them for missing data and obtained additional information from the participants. The PI created a codebook based on the scoring instructions provided by the authors' of the instruments and entered the questionnaires data into the computer data file using the Statistic Package for Social Science (SPSS) version 22.0 for Mac (Chicago, IL). All data were analyzed using SPSS 22.0. Scores of all study variables were computed according to the codebook. All analyses were performed using two-tailed tests and setting statistical significance at $p < .05$.

An internal consistency coefficient for each instrument was calculated as appropriate. Frequencies and percentages were calculated for the categorical data. Descriptive statistics were used to describe the continuous variables. Each study variable was checked for outliers, missing data, and distribution by performing frequency distribution, residual scatter plots, and descriptive statistics. Descriptive statistics,

including measures of central tendency and dispersion, were reported for each study variable. Bivariate correlations using Pearson correlation coefficients were used to identify the relationship between study variables. Prior to performing inferential data analyses, study variables were examined for outliers, influential observations, and assumption violations of regression analyses (linearity, normality, and homoscedasticity). If the data deviated from a normal distribution, appropriate transformations were conducted or non-parametric procedures were performed.

Data Analysis for Specific Aims

The first specific aim with hypothesis 1a and 1b were examined by a series of regression analyses suggested by Baron and Kenny (1986). If the mediating effect of mothers' sleep in the relationship between maternal stress and well-being is supported, following statistical conditions must be met: (1) both measures of maternal stress (parenting stress and caregiving burden) must be significantly related to mothers' well-being; (depressive symptoms and physical well-being), and (2) both measures of maternal stress (parenting stress and caregiving burden) must be significantly related to mothers' perceived sleep. When these preconditions were met, the mediating relationship was tested by regressing mothers' well-being on mothers' sleep and maternal stress. If a mediating relationship was present, the relationship between maternal stress and well-being must reduce or non-significant from the first regression described above. The covariates of child behavior problems, a priori from the literature, were entered as a block first into each regression equation. The analysis was run separately for each independent (parenting stress and caregiving burden) and dependent variable (depressive symptoms and physical well-being). Therefore, the same process was repeated for each independent

and dependent variable (Figure 2).

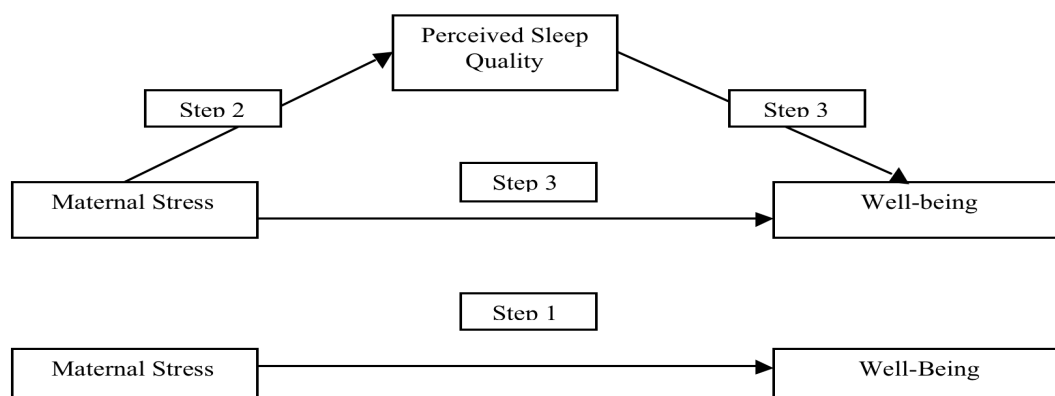


Figure 2. Mediation model of perceived sleep quality in the relationship between maternal stress and well-being

Hypothesis 2a was examined by using Pearson product moment correlations. A series of bivariate correlations were computed for the relationships between relationship quality and maternal stress (parenting stress and caregiving burden) as well as between relationship quality and mothers' well-being (depressive symptoms and physical well-being). Negative, significant correlations for the relationship between relationship quality and maternal stress (parenting stress and caregiving burden) supported the hypothesis. Negative, significant correlations for the relationship between relationship quality and depressive symptoms as well as positive, significant correlations for the relationship between relationship quality and physical well-being supported the hypothesis.

Hypothesis 2b was tested by using the independent two-sample t-test. The mean scores of the maternal stress (the PSI and ZBI) and well-being (the CES-D and PCS SF-36v2) were compared between working mothers and non-working mothers of children

with DDs. The significant differences of the stress and well-being scores between working and non-working mothers' supported the hypothesis.

To answer Research Question 1, descriptive statistics were evaluated from the sleep diary and the sleep disturbance component from the PSQI. Bivariate correlations were performed for the relationships between sleep characteristics (total sleep time, sleep latency, WASO, daytime sleepiness, sleep efficiency, and sleep disturbance) and maternal stress (parenting stress, and caregiving burden) and between sleep characteristics and well-being measures (depressive symptoms and physical well-being).

To answer Research Question 2, descriptive statistics were examined from the five subscales of the SDQ.

To answer Research Question 3, bivariate correlations were performed for the relationships between four subcomponents (problems behaviors) of the SDQ and maternal stress (parenting stress and caregiving burden) and between four subcomponents (problems behaviors) of the SDQ and well-being measures (depressive symptoms and physical well-being).

Limitations

Several limitations to the study were present. The use of a non-random sample may allow the introduction of confounding extraneous variables, which could mask the true nature of the relationships under examination. This may potentially limit the generalizability of the findings to other samples. Threats to validity were present. Study participants may want to portray their best attitudes and health practices knowing that they were being observed and measured. Nonetheless, this study can be used as a

springboard for future studies that may employ larger random samples. This would increase generalizability and possibly lead to intervention studies.

Protection of Human Subjects

Protection of human subjects was assured by obtaining an appropriate approval from Georgia State University IRB. The student PI thoroughly explained the purpose, the overall procedure of the study, and the potential risks and benefits of participating in the study to the potential participants. Any questions the potential participant has were answered prior to obtaining written informed consent. No data were collected before obtaining the informed consent. All participants received a copy of the signed consent. All participants were told that their participation was voluntary, and they can withdraw from the study at any time.

There was no more risks to the mothers of this study other than those they encounter in everyday life. However, participants may experience emotional distress while answering the PSI-SF, the ZBI, and the CES-D questionnaires. If necessary, the PI contacted the faculty advisor, and a referral was provided for counseling. However, if counseling was needed, the participant was informed that any expenses incurred were her own responsibility.

Confidentiality of the data was assured by the following procedures. Only the student PI and faculty advisor reviewed the data collection. The personal information was coded by using individual identification codes. All computer databases were password protected. The demographic information was labeled with the identification code and kept in a separate file from the informed consent forms and the original coding

information. All records were kept in a locked cabinet in the student PI's home office.

The student PI was the only individual with access to the coding information.

CHAPTER IV

RESULTS

This chapter first presents the findings of this correlational study examining the mediating effect of sleep between stress and well-being and the effect of maternal characteristics (spousal relationship quality and employment status) on stress and well-being in mothers of children with DDs. Then, this report provides a description of mothers as well as their children with DDs' characteristics, the findings of hypotheses, and research questions.

Screening and Response Rate

From September 12, 2014 to February 25, 2015, 46 mothers of children with DDs volunteered and were screened for eligibility criteria. The final sample included 40 mothers of middle childhood children with DDs. Figure 3 provides details of screening and response rates.

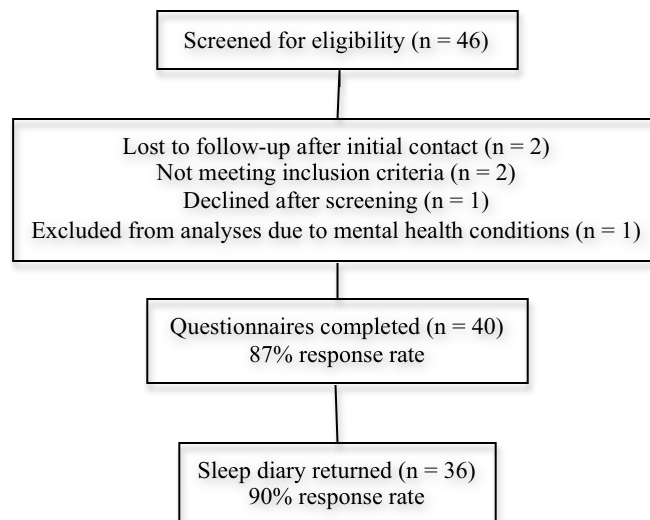


Figure 3. Screening and response rate

Mother's Characteristics

The mothers' demographic data are presented in Table 3. The majority of mothers were early middle-aged, with ages ranging from 32 to 55 years, married, and White. Most mothers (83%) had at least a college degree. About half of the mothers were working either full-time (32.4%) or part-time (23.5%). More than half (56.4%) of the mothers reported their annual household gross income to be greater than \$100,000 for the last year. More than half (52.5%) of the mothers reported that they had some medical conditions, the two most commonly reported medical conditions being depression (48%) and thyroid disease (29%). The vast majority (95%) were biological mothers of their disabled children. Of the mothers participating in the study, four reported having two children with DDs; three of them had children within middle childhood for a total of 43 children with DDs. However, 40 children with DDs were included in the analyses to avoid violating the assumption of independent observations. Of those families who had more than one child with DDs, one child was randomly selected and included in the final analyses.

Table 3

Mother Characteristics (N = 40)

Characteristics	<i>M</i>	<i>(SD)</i>	<i>n</i>	<i>(%)</i>
Age (years)	42.05	(5.25)		
Race/Ethnicity				
Caucasian/White			28	(70.0%)
African American/Black			8	(20.0%)
Others			4	(10.0)

(Table 3 Continues)

(Table 3 Continued)

Characteristics	<i>M</i>	<i>(SD)</i>	<i>n</i>	<i>(%)</i>
Marital Status				
Married			30	(75%)
Divorced/Separated/Single			7	(17.5%)
Living with a partner			3	(7.5%)
Highest Level of Education				
Some College			5	(12.5%)
Bachelor's Degree			18	(45.0%)
Master's Degree			14	(35.0%)
PhD or Professional Degree			3	(7.5%)
Employment Status				
Full-time			15	(37.5%)
Part-time (fewer than 35 hours per week)			10	(25.0%)
Not working			15	(37.5%)
Annual Household Income				
Less than \$49,999			6	(15.0%)
\$50,000 to \$74,999			5	(12.5%)
\$75,000 to \$99,999			6	(15.0%)
\$100,000 to \$149,999			13	(32.5%)
\$150,000 or more			10	(25.0%)

Child's Characteristics

Table 4 presents demographic characteristics of the children with DDs. As mentioned above, a total of 43 children with DDs were included in the study, but only 40 were used in the analysis. The majority of the children were White and boys. The three most frequently reported medical diagnoses were autism, Down syndrome, and cerebral palsy (CP). The vast majority of children (90.7%) had more than one medical diagnosis, ranging from 1 to 7, and 93% received at least one therapy session per week, ranging from 1 to 7. About 47% ($n = 20$) used special equipment (excluding ordinary

eyeglasses); 33.0 % ($n = 14$) used augmentative communication devices, 23.3% ($n = 10$) wore orthotics, such as Ankle Foot Orthotics (AFOs), and 16.3% ($n = 7$) used seating devices. Mothers of children with DDs reported they spent an average of 2 hours and 27 minutes per day to help with their children's daily living skills; the vast majority (90.7%) of the children reported having speech and language delay, and high caregiving needs due to lack of skills in personal care (e.g., bathing, dressing, and toileting). Almost three-quarters of the mothers (72.1%) in this study reported that their children had sleep problems, and the children woke up, on average, 1.23 ($SD = .84$) times per night.

Table 4

Child Characteristics (N = 43)

Characteristics	<i>M</i>	<i>(SD)</i>	<i>n</i>	<i>(%)</i>
Age (years)	8.79	(2.22)		
Gender				
Boy			32	(74.4%)
Girl			11	(25.6%)
Primary Diagnoses				
Autism Spectrum Disorder (ASD)			22	(51.2%)
Autism			15	(68.2%)
PDD-NOS			5	(22.7%)
Asperger Syndrome			2	(9.1%)
Genetic Disorder			10	(23.3%)
Down Syndrome			8	(88.9%)
Cerebral Palsy (CP)			5	(11.6%)
Other DDs			6	(14.0%)

(Table 4 Continues)

(Table 4 Continued)

Characteristics	<i>M</i>	<i>(SD)</i>	<i>n</i>	<i>(%)</i>
Number of additional diagnoses	2.09	(1.41)		
Number of therapies/specialized services per week	2.56	(1.20)		
Child's Challenging Behavior Scale (SDQ) (0-40)	17.14	(7.32)		
Daily Living Skills (min/day)	147.02	(121.60)		
Dress Self			23	(56.1%)
Bathe Self			11	(26.8%)
Feed Self			36	(87.8%)
Walk Self (including with assistance)			39	(95.1%)
Toilet Self			31	(75.6%)
Communication				
Speech and Language Delay or Disorder			39	(90.7%)
Use Communication Device			8	(19.5%)

Note. PDD-NOS = Pervasive Developmental Disorder – Not Otherwise Specified;

SDQ = Strengths and Difficulties Questionnaires

Descriptive Statistics for Major Study Variables

Prior to testing the hypotheses, descriptive statistics were performed to check each study variable's distribution, outliers, and missing data. Normality was assessed for the five main variables (parenting stress, caregiving burden, perceived sleep quality, depressive symptoms, and physical well-being) as well as two covariates (income and child behavior problems) by examining skewness, kurtosis, histograms, and a goodness of fit test (Shapiro-Wilk test). Screening indicated that parenting stress, caregiving burden, depressive symptoms, and child behavior problems variables were normally

distributed. However, the perceived sleep quality, physical well-being, spousal relationship quality, and income variables were negatively skewed. A logarithmic transformation and a square root transformation were conducted on these variables, but normal distribution was achieved only for the perceived sleep quality variable. Previous studies have used different cut-off scores, ranging from 92 to 107 to distinguish between distressed and non-distressed couples (Graham, Liu, & Jeziorski, 2006). Therefore, the median score of 100 (between 92 and 107) was used to dichotomize where 0 = poor dyadic adjustment (below 100 of the total DAS score) ($n = 7$, 21.2%) and 1 = better dyadic adjustment (greater than 100 of the total DAS score) ($n = 26$, 78.8%). Physical well-being was also dichotomized by a median split of the sample where 0 = below 54.7 (the sample median score of the PCS) and 1 = 54.7 or greater.

Prior to conducting the mediation analysis, assumptions of linear regression were assessed. First, the assumption of linearity was evaluated by examining bivariate scatter plots for each independent variable (parenting stress, caregiving burden, and perceived sleep quality) with the dependent variables (depressive symptoms and physical well-being) to examine the linear relationship between the dependent and independent variables. The normality of residual assumption was evaluated by examining the distribution of the residual values on the normal Q-Q plots. Homoscedasticity was evaluated by examining the residual plots of the standardized residuals by the regression standardized predicted value. Multicollinearity was examined by checking the tolerance and variance inflation factor (VIF). There was no violation of assumptions.

Table 5 shows descriptive statistics for all instruments representing theoretical concepts. All instruments had acceptable Cronbach's alpha coefficients ($> .70$).

Table 5

Descriptive Statistics and Cronbach's Alpha for Major Study Variables (N = 40)

Variables	<i>M</i>	<i>(SD)</i>	<i>Observed Range</i>	<i>Possible Range</i>	<i>Cronbach's Alpha</i>
<u>Well-being (SF-36v2)</u>				0 - 100	.92
Physical Component Summary (PCS)	50.90	(10.25)	22.1-66.1		
Mental Component Summary (MCS)	42.65	(9.05)	21.5-56.0		
Depressive Symptoms (CESD)	16.05	(9.57)	2 - 39	0 - 60	.90
^a Perceived Sleep Quality (PSQI)	7.90	(4.68)	1 - 19	0 - 21	.78
<u>Maternal Stress</u>					
Parenting Stress (PD subscale from the PSI/SF)	34.73	(7.26)	18 - 52	12 - 60	.71
Caregiving Burden (ZBI)	44.43	(13.41)	11 - 66	0 - 88	.90
^b Spousal Relationship Quality (DAS)	108.15	(18.96)	40 - 145	0 - 151	.95
Child Behavior Problems (SDQ)	17.14	(7.32)	0 - 33	0 - 40	.74

Note. ^a*n* = 39. ^b*n* = 32. SF-36v2 = 36-Item Short Form Health Survey Version 2; CESD = Center for Epidemiologic Studies Depression Scale; PSQI = Pittsburg Sleep Quality Index; PD = Parental Distress; PSI/SF = Parenting Stress Index Short Form; ZBI = Zarit Burden Interview; DAS = Dyadic Adjustment Scale; SDQ = Strengths and Difficulties Questionnaires.

Mothers' physical and psychological well-being.

Mothers of children with DDs reported having physical well-being scores (PCS) that fell around the U.S. general population norms (Ware et al., 2007). Although mothers' mean PCS score was around the population mean, three out of four subscales on

the PCS were below the U.S. population mean: 51.49 ($SD = 7.94$) for Physical Functioning (PF), 48.25 ($SD = 10.72$) for Role Physical (RP), 49.77 ($SD = 10.78$) for Bodily Pain (BP), and 46.41 ($SD = 12.26$) for General Health (GH).

In contrast, mothers in this sample experienced low psychological well-being. The mean MCS score was almost one standard deviation below the U.S. general population norms (Ware et al., 2007). All four subscales of the MCS also fell below the U.S. general norm score of 50: 41.63 ($SD = 8.87$) for Vitality (VT), 47.41 ($SD = 9.63$) for Social Functioning (SF), 44.42 ($SD = 10.70$) for Role-Emotional (RE), and 45.43 ($SD = 8.36$) for Mental Health (MH). In addition, more than half ($n = 21$, 52.5%) of the mothers in this study were at or above the CES-D cut-off score of 16, indicating high risk for depression.

Perceived sleep quality.

Table 6 shows the PSQI subscale scores of the study participants. Mothers reported, on average, they slept 6.2 hours per night, which indicates shorter total sleep time than the recommended 7 to 9 hours of sleep (Berger et al., 2005). The mean global PSQI scores ranged from 1 to 19, with a mean of 7.90 ($SD = 4.78$), which reflects generally poor sleep quality. Using the clinically significant cut-off score of 5, 61.5% ($n = 24$) of the mothers in this study reported poor sleep quality. About one-third ($n = 13$, 33%) of the mothers reported that they were waking up during the night at least once a week during the last month because their children with DDs woke them up or they had to take care of their children with DDs. Mothers' sleep latency (number of minutes between when someone lays down to bed and actually goes to sleep) was slightly higher than the recommended latency (less than 20 minutes), and the sleep efficiency (the number of

minutes of sleep divided by the total number of minutes in bed, multiplied by 100) fell within the normal range (Berger et al., 2005).

Table 6

Descriptive Statistics for Pittsburgh Sleep Quality Index (PSQI) Subscale Scores

(*N* = 40)

Component Scores (0 = better - 3 = worse)	<i>M</i>	<i>SD</i>
1. Subjective Sleep Quality ^a	1.49	(0.77)
2. Sleep Latency	1.40	(1.03)
3. Hours of Actual Sleep	1.13	(0.97)
4. Sleep Efficiency	.53	(0.91)
5. Sleep Disturbances	1.57	(0.59)
6. Use of Sleep Medications ^a	.74	(1.16)
7. Daytime Dysfunction ^a	1.03	(0.90)
Global Sleep Quality ^a (1-21)	7.90	(4.68)
Minutes to Fall Asleep	27.73	(28.01)
Sleep Efficiency in Percent	88.91	(16.09)

Note. ^a*n* = 39

Maternal stress.

Mothers in this study on average reported that they experienced high levels of maternal stress. The average PD subscale score on the PSI/SF was high, and more than two-thirds of the mothers (*n* = 27, 67.5%) scored at or above the 85th percentile, suggesting ‘clinically significant’ parenting stress (Abidin, 1995). The mean caregiving burden score on the ZBI was also high. More than half of the mothers (*n* = 23, 53.5%) scored between 41 and 60, indicating the moderate to severe caregiving burden range,

and 30 % ($n = 12$) were fell into the mild to moderate caregiving burden range (21 – 40) (Zarit, Todd, & Zarit, 1987).

Spousal relationship quality.

The average spousal relationship quality (DAS) score was 108.15 ($n = 33$, $SD = 18.96$), and only seven mothers (21.2%) in this study scored below the cut-off score of 100, indicating ‘distressed’ couples. The four subscale scores also suggested well-adjusted relationship quality in this sample: Dyadic Consensus (possible range: 0 - 65) ($M = 47.73$, $SD = 6.94$), Dyadic Cohesion (possible range: 0 - 24) ($M = 14.64$, $SD = 2.56$), Dyadic Satisfaction (possible range: 0 - 50) ($M = 37.73$, $SD = 7.63$), and Affectional Expression (possible range: 0-12) ($M = 8.06$, $SD = 2.56$).

Child behavior problems

On average, children with DDs in this study scored high for behavior problems. The mean total SDQ score was 17.14 ($SD = 7.32$). More than half ($n = 24$, 55.8%) of the children in this study fell into the ‘abnormal’ category, and 14% ($n = 6$) were in the ‘borderline’ category (Goodman, Renfrew, & Mullick, 2000). Children in this sample also fell into the ‘abnormal’ category for the hyperactivity ($M = 7.05$, $SD = 2.63$) and peer problem ($M = 4.63$, $SD = 2.60$) subscales.

Relationships among Major Study Variables

Bivariate correlations were calculated to describe the relationship between major study variables and presented in Table 7. Pearson’s product moment correlation coefficients (r) were calculated for normally distributed variables, and Spearman’s rho correlation coefficients (r_s) were calculated for the physical well-being, income, and DAS variables due to their non-normal distribution. For the income variable, data

Table 7

Relationships among Major Study Variables

	1 ^a	2	3	4 ^b	5	6	7 ^a	8	9	10 ^a
1. PCS										
2. MCS	.17									
3. CES-D	.50**	-.69**								
4. PSQI ^b	-.45**	-.48**	.73**							
5. PD	-.33*	-.39*	.59**	.38*						
6. ZBI	-.36*	-.43**	.60**	.52**	.69**					
7. Income ^a	.04	.12	-.19	-.15	-.12	-.15				
8. SDQ	-.14	-.43**	.43**	.30	.37*	.61**	.23			
9. ES	.29	.04	-.17	-.28	-.08	-.17	.09	-.04		
10. DAS ^a	.16	.33	-.28	-.16	-.49**	-.28	.43*	-.28	-.19	

Note. * $p < .05$, ** $p < .01$, ^aSpearman's rho reported; ^bNatural log transformed data were used; PCS=Physical Component

Summary; MCS=Mental Component Summary; CES-D= Center for Epidemiologic Studies Depression Scale;

PSQI=Pittsburgh Sleep Quality Index; PD=Parental Distress from the Parenting Stress Index Short Form (PSI/SF); ZBI=Zarit

Caregiver Burden Interview; SDQ=Strength and Difficulties Questionnaire; ES=Employment Status; DAS=Dyadic

Adjustment Scale

transformation did not improve the distribution, and none of the major study variables showed a significant relationship with the income variable. Therefore, the income variable was not included as a covariate in hypothesis testing.

Consistent with previous research, higher depressive symptoms, an indicator of psychological well-being, were significantly related to more parenting stress, greater caregiving burden, poor perceived sleep quality, and more child behavior problems. A similar trend was observed in physical well-being; better physical well-being was significantly associated with fewer depressive symptoms, better perceived sleep quality, less parenting stress, and less caregiving burden. As expected, higher levels of child behavior problems were significantly correlated with greater mothers' depressive symptoms, higher parenting stress, and more caregiving burden. Among maternal characteristics, better spousal relationship quality was associated with less parenting stress and higher income. However, no significant association was found between mothers' working status and any of the major study variables.

Hypothesis Testing

Specific Aim 1: *To examine the mediating effect of mothers' sleep on the relationship between maternal stress and well-being after controlling for child behavior problems and SEP as covariates.*

Hypothesis 1a: *Mothers' sleep (perceived sleep quality) will mediate the relationship between maternal stress (parenting stress and caregiving burden) and depressive symptoms.*

A series of multiple regression analyses by Baron and Kenny (1986) were used to test whether perceived sleep quality mediated the association between maternal stress and

depressive symptoms. Before proceeding to test mediation, the following preconditions must be met: (a) in the first regression equation (Model 1), the predictor variable must be significantly related to the outcome variable, and (b) in the second regression equation (Model 2), the predictor variable must be significantly related to the mediator variable. To demonstrate mediation, the relationship between the predictor and the outcome in the third equation (final model), where both the predictor and the mediator variables are present, must be reduced to non-significant from the first regression equation (Baron & Kenny, 1986; Frazier, Tix, & Barron, 2004). As mentioned above, only the child behavior problems (SDQ) variable was included as a covariate and entered as a block in this analysis. The variables of maternal stress, parenting stress and caregiving burden, were run separately in each analysis. The results of hierarchical linear regressions with parenting stress are presented in Table 8. In Model 1, parenting stress, controlling for child behavior problems, were significantly associated with depressive symptoms ($B = .66, t(38) = 3.69, p < .01$). In Model 2, however, parenting stress, controlling for child behavior problems, was not significantly associated with the log transformed sleep quality ($B = .01, t(38) = 1.92, p = .06$). Therefore, no further analyses were performed.

Table 8

Summary of Regression Analysis for Testing Mediating Effect of Perceived Sleep Quality (PSQI) on the Relationship Between Parenting Stress (PD) and Depressive Symptoms (CES-D) (N = 39)

	<i>B</i>	<i>SE</i>	β	<i>t</i>	<i>p</i>
<u>Model 1: PD → CES-D</u>					
Child Behavior Problems	.34	.19	.23	1.79	.08
Parenting Stress	.66	.18	.50	.69	.00

(Table 8 Continues)

(Table 8 Continued)

	<i>B</i>	<i>SE</i>	β	<i>t</i>	<i>p</i>
Model <i>F</i>	12.52***				
<i>R</i> ²	.40				
ΔR^2	.22**				
<hr/>					
<u>Model 2 : PD → PSQI^a</u>					
Child Behavior Problems	.01	.01	.18	1.13	.26
Parenting Stress	.01	.01	.31	1.92	.06
Model <i>F</i>	3.76 *				
<i>R</i> ²	.17				
ΔR^2	.09				
<hr/>					
<u>Final Model :</u>					
PD& PSQI ^a → CES-D				Not Performed	

* $p < .05$. ** $p < .01$. *** $p < .001$.

Note. ^aNatural log transformed data were used. CES-D=Center for Epidemiologic Studies Depression Scale; SDQ=Strength and Difficulties Questionnaires; PD=Parental Distress subscale from the Parenting Stress Index-Short Form (PSI/SF); PSQI=Pittsburgh Sleep Quality Index

The results of testing the mediating effect of sleep quality on the relationship between caregiving burden and depressive symptoms are presented in Table 9. In Model 1, caregiving burden, controlling for child behavior problems, was positively associated with depressive symptoms ($B = .39, t(38) = 3.28, p < .01$). In Model 2, caregiving burden, controlling for child behavior problems, was positively associated with the log transformed sleep quality ($B = .01, t(38) = 3.01, p < .01$). In the final model, sleep quality was significantly associated with depressive symptoms ($B = .18.81, t(38) = 4.57, p < .001$). In addition, the unstandardized beta coefficient of the caregiving burden was

greatly reduced and became non-significant ($B = .17, t(38) = 1.57, p = .13$) than the beta coefficient of the caregiving burden in Model 1. Therefore, perceived sleep quality mediated in the relation between caregiving burden and depressive symptoms in this sample, and the hypothesis 1a with caregiving burden was partially supported (Figure 4).

Table 9

Summary of Regression Analysis for Testing Mediating Effect of Perceived Sleep Quality (PSQI) on the Relationship Between Caregiving Burden (ZBI) and Depressive Symptoms (CES-D) (N = 39)

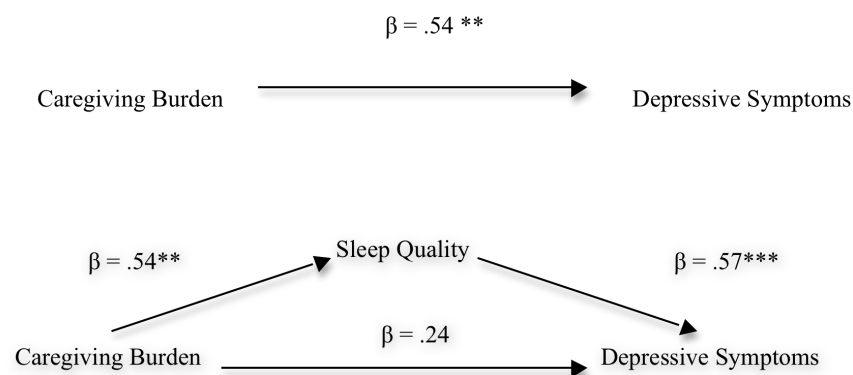
	<i>B</i>	<i>SE</i>	β	<i>t</i>	<i>P</i>
<u>Model 1: ZBI → CES-D</u>					
Child Behavior Problems	.13	.23	.10	.58	.57
Caregiving Burden	.39	.12	.54	3.28	.00
Model <i>F</i>	10.79***				
<i>R</i> ²	.37				
ΔR	.18**				
<u>Model 2: ZBI → PSQI^a</u>					
Child Behavior Problems	-.00	.01	-.03	-.19	.85
Caregiving Burden	.01	.00	.54	3.01	.01
Model <i>F</i>	6.72**				
<i>R</i> ²	.27				
ΔR ²	.18**				
<u>Final Model: ZBI & PSQI^a → CES-D</u>					
Child Behavior Problems	.15	.19	.11	.84	.41
Caregiving Burden	.17	.11	.24	1.57	.13
Sleep Quality ^a	18.81	4.12	.57	4.57	.00
Model <i>F</i>	17.78***				
<i>R</i> ²	.60				
ΔR ²	.42***				

(Table 9 Continues)

(Table 9 Continued)

* $p < .05$. ** $p < .01$. *** $p < .001$.

Note. ^aNatural log transformed data were used. ZBI=Zarit Caregiver Burden Interview; CES-D= Center for Epidemiologic Studies Depression Scale; SDQ=Strength and Difficulties Questionnaires; PSQI=Pittsburgh Sleep Quality Index



Controlling for child behavior problems

* $p < .05$. ** $p < .01$. *** $p < .001$.

Figure 4. Mediation model of perceived sleep quality in the relationship between caregiving burden and depressive symptoms.

Hypothesis 1b: *Mothers' sleep (perceived sleep quality) will mediate the relationship between maternal stress (parenting stress and caregiving burden) and physical well-being (physical component summary from the Short-Form 36 version 2).*

Because the outcome variable of physical well-being was dichotomized, logistic regression was conducted to test hypothesis 1b. Although the Baron and Kenny's (1986) steps were used to test the mediation, the coefficients were transformed according to MacKinnon and Dwyer's (1993) recommendation because the coefficients were not comparable across equations. In logistic regression, the coefficients in the mediation analyses are in different scales because the error variances are fixed to each dichotomous

outcome variable. To make the coefficients comparable across equations, each coefficient was multiplied by the standard deviation of the predictor variable and divided by the standard deviation of the outcome variable. As mentioned previously, only the child behavior problems variable (SDQ) was included as a covariate and entered as a block.

The results of the mediating effect of sleep quality on the relationship between parenting stress and physical well-being are presented in Table 10. In Model 1, parenting stress, controlling for child behavior problems, was a significant contributor to predict physical well-being ($B = -.11$, Wald $\chi^2 = 3.72$, $p = .05$). In Model 2, the PSQI variable was dichotomized where 0 = good sleep quality (global PSQI ≤ 5) and 1 = poor sleep quality (global PSQI > 5) because the outcome variable should be categorical in logistic regression. The test results showed that parenting stress was not significantly associated with sleep quality ($B = .12$, Wald $\chi^2 = 3.37$, $p = .07$) in model 2. Therefore, no further analyses were performed.

Table 10

Summary of Logistic Regression Analysis for Testing Mediating Effect of Sleep Quality (PSQI) on the Relationship Between Parenting Stress (PD) and Physical Well-being (PCS) (N = 40)

	B	SE	β	χ^2	p	OR	95% CI
<u>Model 1: PD \rightarrow PCS</u>							
Child Behavior Problems	-.02	.05		.15	.70	.98	(.88, 1.09)
Parenting Stress	-.11	.06	-.41	3.72	.05	.89	(.80, 1.00)

(Table 10 Continues)

(Table 10 Continued)

	<i>B</i>	<i>SE</i>	β	χ^2	<i>p</i>	OR	95% CI
Model χ^2	49.51*						
<u>Model 2: PD → PSQI</u>							
Child Behavior Problems	.03	.05		.25	.61	1.03	(.93, 1.14)
Parenting Stress	.12	.06	.05	3.37	.07	1.12	(.99, 1.27)
Model χ^2	46.14*						
<u>Final Model:</u>							
PD & PSQI → PCS	Not performed						

**p* < .05

Note. PD=Parental Distress subscale from the Parenting Stress Index-Short Form

(PSI/SF); PCS=Physical Component Summary from the Short-Form 36 version 2 (SF-

36v2); PSQI=Pittsburgh Sleep Quality Index; SDQ=Strength and Difficulties

Questionnaire

The results of the mediating effect of sleep quality on the relationship between caregiving burden and physical well-being are presented in Table 11. In Model 1, caregiving burden was a significant contributor to predict physical well-being ($B = -.10$, Wald $\chi^2 = 5.85$, $p = .02$). In Model 2, caregiving burden was a significant contributor to predict sleep quality ($B = .10$, Wald $\chi^2 = 5.83$, $p = .02$). In Model 3, however, sleep quality was not a significant contributor to predict physical well-being ($B = -.88$, Wald $\chi^2 = 1.20$, $p = .27$). In addition, testing for mediation by using the Sobel test showed sleep quality did not mediate this association, $z = -1.65$, $p = .10$. Therefore, the hypothesis 1b was not supported.

Table 11

Summary of Logistic Regression Analysis for Testing Mediating Effect of Sleep Quality (PSQI) on the Relationship Between Caregiving Burden (ZBI) and Physical Well-Being (PCS) (N = 39)

	B	SE	β	χ^2	<i>p</i>	OR	95% CI
Model 1: ZBI → PCS							
Child Behavior Problems	.05	.07		.60	.44	1.05	(.93, 1.20)
Caregiving Burden	-.10	.04	-.59	5.85	.02	.91	(.84, .98)
Model χ^2	46.21**						
Model 2: ZBI → PSQI							
Child Behavior Problems	-.05	.07		.53	.47	.95	(.83, 1.09)
Caregiving Burden	.10	.04	.09	5.83	.02	1.11	(1.02, 1.21)
Model χ^2	42.44**						
Final Model:							
ZBI & PSQI → PCS							
Child Behavior Problems	.04	.07		.40	.53	1.04	(.91, 1.19)
Caregiving Burden	-.08	.04	-.40	3.53	.06	.92	(.85, 1.00)
Sleep Quality	-.88	.80	-.43	1.20	.27	.41	(.09, 2.00)
Model χ^2	44.52*						

p* < .05. *p* < .01.

Note. ZBI=Zarit Caregiver Burden Interview; PCS=Physical Component Summary from the Short-Form 36 version 2 (SF-36v2); SDQ=Strength and Difficulties Questionnaires; PSQI=Pittsburgh Sleep Quality Index

Hypothesis 2a: *Mothers who have a better relationship quality with their partners will report lower levels of maternal stress (parenting stress and caregiving burden) and better well-being (depressive symptoms and physical well-being).*

As shown in Table 7, higher parenting stress was significantly associated with poor spousal relationship quality ($r = -.413, p < .05$). However, no significant association was found between caregiving burden and spousal relationship quality. Neither depressive symptoms nor physical well-being was associated with spousal relationship quality in this sample. Therefore, hypothesis 2a was partially supported.

Hypothesis 2b: *Working mothers (either part-time or full-time) of children with DDs will show lower levels of maternal stress (parenting stress and caregiving burden) and better well-being (depressive symptoms and physical well-being) than non-working mothers of children with DDs.*

Independent samples t-tests were performed to examine difference in parenting stress, caregiving burden, and depressive symptoms between working and non-working mothers of children with DDs (Table 12). Because the physical well-being variable was not normally distributed, a Chi-Square test was performed to compare the physical well-being scores between these two groups. Working mothers reported significantly higher mean physical well-being scores (PCS) than non-working mothers ($\chi^2(1, 40) = 5.23, p = .05$). However, no statistical differences were noted in the other variables (parenting stress, caregiving burden, and depressive symptoms). Therefore, hypothesis 2b was partially supported.

Table 12

Comparison of Maternal Stress and Well-Being for Working and Non-Working Mothers (N=40)

(Table 12 Continues)

(Table 12 Continued)

Variable	Working ^a M (SD)	Not Working ^b M (SD)	t statistics/ χ^2
Maternal Stress			
Parenting Stress	33.64 (6.30)	36.53 (7.70)	1.23
Caregiving Burden	41.52 (14.12)	49.27 (10.92)	1.82
Well-Being			
Depressive Symptoms	14.28 (8.64)	19.00 (10.59)	1.54
Physical Well-being	53.25 (8.79)	46.97 (11.56)	5.23* ^c

Note. * $p < .05$. ^a $n = 25$. ^b $n = 15$. ^cChi-Square Test

Research Questions

Research Question 1: *What other characteristics of sleep (total sleep time, sleep latency, wake after sleep onset (WASO), daytime sleepiness, sleep efficiency, and daytime sleepiness) will be associated with maternal stress and well-being?*

The 5-day sleep diary was analyzed to answer research question 1, and the means and standard deviations for the sleep parameters from the 5-day sleep diary are presented in Table 13. Mothers, on average, slept 7.19 hours, ranged from 5.64 to 9.27 hours. Although the mean total sleep time (TST) was within the recommended 7 to 9 hours of sleep (Berger et al., 2005), about 39% ($n = 14$) reported that they slept less than 7 hours. Mothers in this study took 23.13 minutes to fall asleep, indicating slightly increased sleep latency. Mothers reported that they woke up on average 2.2 times per night for various reasons (e.g., partner's sleep disturbance, other children's caregiving needs, using the restroom, or stress), and about 30% of mothers' sleep disruption was because of their children with DDs. More than half (52.9%) of the mothers who had sleep disruptions reported their children with DDs woke them up at least once a week. About 39% of the mothers reported they took a nap during the day at least once a week. They reported

better sleep efficiency in the sleep diary than the PSQI sleep efficiency rate ($M = 86.64\%$, $SD = 13.86$).

Table 13

Sleep Parameters from 5-Day Sleep Diary (N = 36)

Sleep Parameter	<i>M</i>	<i>SD</i>
TST (min)	431.12	(53.95)
Latency (min)	23.13	(55.54)
Awakening during Sleep	2.20	(1.67)
Awakening due to Child	0.57	(0.69)
WASO (min)	40.22	(47.60)
Nap during the Day (min) ^a	75.79	(60.32)
Quality of Perceived Sleep (1-4)	2.54	(0.50)
Sleep Efficiency (%)	90.31	(6.95)

Note. ^an = 14. TST=Total Sleep Time While in Bed; WASO=Wake After Sleep Onset;

Quality of Perceived Sleep ranged poor (1) to very good (4)

Table 14 summarizes the correlations between maternal stress, well-being, and sleep parameters from the 5-day sleep diary. Higher parenting stress was associated with greater naptime in minutes, whereas none of the sleep parameters were significantly associated with caregiving burden. Greater depressive symptoms were related with greater daytime sleepiness, whereas better physical well-being was related with greater total sleep time and less naptime in minutes.

Table 14

Correlations among Maternal Stress, Well-Being, and Sleep Parameters from 5-Day Sleep Diary (N = 36)

	DS	TST	SOL	Awake	Awake Child	WASO	NAP ^a	SE
PD	.49	-.55	-.13	-.07	.37	.29	.75**	-.04
ZBI	.39	-.33	.51	-.16	-.10	-.23	.36	.12
CES-D	.71*	-.35	.17	-.05	.36	.23	.58	-.15
PCS ^a	-.30	.63*	-.34	.56	-.13	-.34	-.78**	-.14

Note. * $p < .05$. ** $p < .01$. ^aSpearman's rho reported. DS = Daytime Sleepiness;

PD=Parental Distress from the Parenting Stress Index Short Form (PSI/SF); ZBI=Zarit

Caregiver Burden Interview; CES-D= Center for Epidemiologic Studies Depression

Scale; PCS=Physical Component Summary; TST = Total Sleep Time; SOL = Sleep

Onset Latency; WASO = Wake After Sleep Onset; SE = Sleep Efficiency

Research Question 2: *What are the common types of child behavior problems that children with DDs exhibit?*

The most commonly reported behavior problems were hyperactivity, and on average it was in the 'abnormal' range. Children with DDs in this sample also scored the 'borderline' range for the peer problems and prosocial behaviors. Emotional and conduct problems were within the normal range (Table 15).

Table 15

Summary of Strengths and Difficulties Questionnaires (SDQ)(N = 43)

Subscales	<i>M</i>	<i>(SD)</i>
Hyperactivity	7.05	(2.63)
Peer Problems	4.63	(2.60)
Prosocial Scale	5.60	(3.22)
Emotional Problems	3.00	(2.79)
Conduct Problems	2.47	(2.98)

Note. Each subscale ranges 0 to 10

Research Question 3: *What types of child behavior problems will be associated with high levels of maternal stress and poor well-being?*

Table 16 presents the correlations among maternal stress, well-being, and subscale scores of the SDQ. Higher parenting stress was associated with higher child hyperactivity, whereas higher caregiving burden was associated with lower child prosocial behaviors, higher child emotional problems, higher child conduct problems, and higher child hyperactivity. Greater depressive symptoms in mothers of children with DDs were related to greater child emotional problems and higher child hyperactivity. None of the child behavior problems subscales was significantly associated with mothers' physical well-being scores.

Table 16

*Relationships among Maternal Stress, Well-Being, and Child Behavior Problems**(N = 40)*

	Prosocial Behavior	Emotional Problems	Conduct Problems	Hyperactivity	Peer Problems
PD	-.06	.26	.27	.33*	.19
ZBI	-.32*	.44**	.49**	.53**	.29
CES-D	-.00	.35*	.29	.34*	.24
PCS ^a	-.15	-.30	.06	-.04	-.19

Note. * $p < .05$. ** $p < .01$. ^aSpearman's rho reported. PD=Parental Distress from the Parenting Stress Index Short Form (PSI/SF); ZBI=Zarit Caregiver Burden Interview; CES-D=Center for Epidemiologic Studies Depression Scale; PCS=Physical Component

Summary

This chapter summarizes the results of a cross-sectional, correlational study to test the mediating effect of mothers' sleep between maternal stress and well-being and to examine the effects of maternal characteristics (spousal relationship quality and employment status) on maternal stress and well-being in a community sample of mothers with middle age children (ages 6-12) who have DDs. A description of participants' characteristics, findings from the questionnaires and results of hypothesis testing as well as research questions were reported.

CHAPTER V

DISCUSSION AND CONCLUSIONS

Chapter V presents a discussion of the study results described in Chapter IV in reference to the hypotheses made at the beginning of the study. This chapter ends with a discussion of the study limitations, strengths of the study, implications for practice and theory building, and future research.

The results of this study add to a body of research reporting the relationships among stress, sleep, and depressive symptoms in mothers of middle age children with DDs. To our knowledge, this study was the first to test the mediating role of sleep quality between the relationship of stress and depressive symptoms among mothers raising a child with DDs. Moreover, this study extends prior work by documenting that high levels of stress and depressive symptoms are present in mothers of middle age children with DDs. Given the challenges in raising children with DDs, in particular the high caregiving demands and the children's sleep problems, it is not surprising that mothers experience high levels of stress and poor sleep quality. Taken together, these findings highlight the need to address both maternal stress and depressive symptoms while at the same time recognizing that many mothers also suffer from inadequate sleep.

Mediating Effect of Sleep between Maternal Stress and Well-Being

The hypothesis about the mediating effect of mothers' perceived sleep quality between maternal stress (parenting stress and caregiving burden) and depressive

symptoms controlling for child behavior problems was partially supported. Although both parenting stress and caregiving burden were significantly associated with depressive symptoms, perceived sleep quality was the only mediator between caregiving burden and depressive symptoms. As stated earlier, we believe this is the first study that has tested the mediating role of sleep in relationship to the stress-health pathway as suggested by the allostasis and allostatic load (McEwen & Stellar, 1993) within the context of mothers of children with DDs. Although it is not clear in general why sleep quality did not mediate the relationship between parenting stress and depressive symptoms in this sample, it may be that caregiving burden better reflects the challenges that mothers of children with DDs face. The results of this study differ from an earlier study with mothers of low-birth-weight preterm infants (Lee & Hsu, 2012). In their study, maternal stress was measured by both global stress and situational stress that was associated with having a low-birth-weight preterm infant hospitalized in an Intensive Care Unit (ICU). Mothers' perceived sleep quality mediated only in the relationship between global stress and mental well-being. Further research may be needed to better understand the contribution of different stressors to mother's psychological well-being among mothers caring middle age children with DDs.

In contrast, mothers' perceived sleep quality did not mediate the relationship between maternal stress (parenting stress and caregiving burden) and physical well-being. The reason for this finding could be due to the mothers' overall good physical health. In this study, mothers on average reported their physical health slightly above the mean U.S. general population PCS score ($M = 49.22$, $SD = 15.13$) (Maglante, Hays, & Kaplan, 2012). Within the theory of allostasis and allostatic load (McEwen, 1998; McEwen &

Stellar, 1993), chronic exposure and/or inadequate adaptation to stress can cause wear and tear on physiological systems that can lead to chronic health conditions, such as type II diabetes or Alzheimer's disease. Previous research has found that the manifestation of poor health and functional abilities in parents of children with DDs takes decades to develop and is more evident in their early years of old age (Seltzer et al., 2011). Given the mean mothers' age in this study was in their early 40's and the average length of caregiving was estimated to be less than 9 years (based on the mean child age), adverse physical changes due to mother's parenting and caregiving stress may be not evident in mothers of middle childhood children. For example, although the impact of both measures of maternal stress on physical well-being were statistically significant in this study, stress effect on physical well-being was relatively small (PSI: OR = .91, 95 % CI (.84, .98) (ZBI: OR = .89, 95% CI (.80, 1.00), indicating it may not be clinically significant. Furthermore, the majority of study participants in this study were White mothers with high socioeconomic positions, which may serve as a buffer for adverse physical health and well-being (Seeman, Epel, Gruenewald, Karlamangla, & McEwen, 2010). Due to the cross-sectional design of this study, the changes of maternal stress and long-term effects of maternal stress on health cannot be observed, which may also explain the lack of association of maternal stress to physical well-being as well.

Evaluation of Maternal Stress, Sleep, and Well-being

Maternal stress.

Consistent with previous studies (Neece et al., 2012; Woodman, Mawdsley, & Hauser-Cram, 2014), mothers of middle childhood children with DDs in the present study experienced a high level of maternal stress. More than two-thirds of the mothers in this

sample reported clinically significant parenting stress. In addition, mothers on average reported they experienced moderate to severe caregiving burden, which was similar to earlier work (Gallagher et al., 2008). One possible reason for this result may be due to the ongoing caregiving demands for middle age children with DDs. As typically developing children grow, they progress in their cognitive, adaptive, and social skills, which results in them becoming more independent and self-sufficient in many activities of daily living. However, mothers of children with DDs often need to continue to help with their children with daily living activities due to their impairment in self-care, adaptive skills, and communication as well as other medical conditions that require specific caregiving activities. For example, mothers in this study spent more than two hours a day helping their children with daily living skills or supervising their children's behaviors. On average, children with DDs had two additional medical diagnoses in addition to their primary diagnosis. Even at this age, children also had at least two therapy visits per week that required mothers to spend extra hours for their care.

Another possible explanation for high maternal stress may be related to the child's behavior problems. Previous studies consistently indicated that the child's behavior problems are positively associated with maternal stress (Lee, 2013) and a transactional relationship exists between parenting stress and child's behavior problems during middle childhood (Neece et al., 2012; Woodman, Mawdsley, & Hauser-Cram, 2015), suggesting the significant impact of the child's behavior problems on maternal stress in mothers of children with DDs. However, we controlled child behavior problems as a covariate in the regression model in the current study. Previous findings from longitudinal studies showed that the trajectories of child's behavior problems decreased across early and

middle childhood (Azad et al., 2013; Neece et al., 2012). Due to cross-sectional design, the changing patterns of child behavior problems were not observed; the results from this study indicated that middle childhood children with DDs still exhibited a high level of behavior problems. Child behavior problems were more strongly related to caregiving burden than parenting stress, although both were statistically significant. Because children with DDs are more likely to have high levels of behavior problems (Eisenhower et al., 2005), which requires spending significant time for the direct care and supervision of children, this effect may be more reflective of caregiver burden than general parenting stress. Regardless of the difference between parenting stress and caregiving burden, findings of this study demonstrate the importance of providing continuous support to reduce maternal stress during the middle childhood.

Mothers' sleep.

In line with previous research (Bourke-Taylor et al., 2013; Gallagher et al., 2010) mothers in this study reported inadequate sleep and poor sleep quality using a well-established questionnaire (PSQI) that give instructions to reflect on sleep over the past month. In this study, the mean PSQI score was above the cut-off score for poor sleep quality. Although there were differences in total sleep time between the PSQI and 5-day sleep diary, mothers' nocturnal total sleep time from the PSQI averaged about 6.2 hours, which was comparable to the mothers who were nursing for a newborn at home (Kendall-Tackett, Cong, & Hale, 2011). From the diary, mothers slept an average of 7.2 hours per night, which was closer to the recommended total sleep time. Mothers in the present study also reported slightly longer sleep onset latency than the recommended sleep onset latency time (adult latency normally is less than 20 minutes) from both the PSQI and

their 5-day sleep diary measures. Noticeably, mothers' nighttime sleep was interrupted on average 2.2 times per night, and approximately one-third of their sleep interruptions were due to their children with DDs' nighttime waking, which was comparable with an earlier study with school-aged children with DDs (Bourke-Taylor et al., 2013). More than two-thirds of mothers (72.1%) in the current study reported that their child with DDs had sleep problems, and majority of these children who had sleep problems (70%) had nighttime waking problems.

Findings from the present study suggest a close monitoring of children's sleep problems among nurses and other health care professionals who provide care for middle age children with DDs. While typically developing children often have sleep problems during the early childhood, their sleep problems tend to decrease over time. However, sleep problems often continue until middle childhood to early adolescence in children with DDs (Sivertsen, Posserud, Gillberg, Lundervold, & Hysing, 2012). In general, sleep problems are common among children with DDs than typically developing children (Anders, Losif, Schwichtenberg, Tang, & Goodlin-Jones, 2012). In addition, children with DDs are more likely to have shorter sleep duration and frequent nighttime waking than typically developing children (Humphreys et al., 2013), which require increased mothers' caregiving responsibility at night. Research has shown that children's sleep problems were significantly associated with mothers' sleep problems, which in turn may contribute to mothers' poor psychological well-being (Chu & Richdale, 2009; Wayte et al., 2012). Children's sleep quality was also a significant predictor of mothers' depressive symptoms in mothers of children with ASD (Meltzer, 2011).

Given the significant association between children's sleep and mothers' sleep as

well as the impact of mothers' sleep on their psychological well-being, better sleep and well-being in mothers of children with DDs may be achieved by improving children's sleep problems through effective interventions. Current research supports the improvement of child's sleep with behavioral interventions and interventions related to pharmacological treatment among children with ASD (Cortesi, Giannotti, Ivanenko, & Johnson, 2010; Vriend, Corkum, Moon, & Smith, 2011). Future studies need to focus on factors associated with children's sleep problems as well as evaluating effective strategies to manage children's sleep problems.

Mothers' well-being.

Consistent with previous studies (Bourke-Taylor et al., 2012; Gallagher & Hannigan, 2013), mothers of children with DDs reported poor mental health and increased risk of depression. In this study, mothers' mental well-being scores were compatible with a report from Australian mothers who have school-age children with DDs, which reported two standard deviations below other Australians in the MCS score (Bourke-Taylor et al., 2012). In contrast, mothers' physical well-being scores were in general around the average or slightly below the U.S. norm scores. Relatively good physical well-being among early middle age mothers of children with DDs has been also reported previously (Bourke-Taylor et al., 2012). It is not clear why caregiving burden has a significant impact on mothers' psychological well-being, but not for physical well-being among mothers of middle age children with DDs. Nevertheless, it is well established that depression is commonly concurrent with and increases the risk for development of chronic medical conditions, such as diabetes and cardiovascular disease (Gunn et al., 2012; Moussavi et al., 2007; Prince et al., 2007). Since mothers in this

study had high levels of depressive symptoms, they are likely at risk of developing physical health problems. More research is needed to examine the long-term effect of life-long caregiving on physical health in this population.

The Effect of Maternal Characteristics on Stress and Well-being

The present study explored whether spousal relationship quality was associated with stress and well-being of mothers of middle age children with DDs. Of these mothers who were married or with a significant partner, better relationship quality was associated with less parenting stress, but not with caregiving burden, depressive symptoms or physical well-being. Previous work has found that relationship quality may buffer the deleterious effect of parenting stress on mothers' depressive symptoms in mothers of young children with autism (Weitlauf et al., 2014). This may be that spousal relationship quality helps with general stress associated with raising children, such as parenting stress, but if the mother is in the primary caregiving role, it may not affect the caregiving burden. Also spousal relationship quality may buffer milder depressive symptoms but may not be able to buffer when the mothers have high depressive symptoms. More severe depressive symptoms may require pharmacological therapy or counseling for treatment.

Regarding the mothers' involvement in paid work, working mothers reported significantly better physical well-being than non-working mothers in this study. However, there was no significant difference in parenting stress, caregiving burden, and depressive symptoms between working and non-working mothers. The results of the present study differ from previous studies (Bourke-Taylor et al., 2011; Olsson & Hwang, 2006), which showed a positive relationship between mothers' work participation and

psychological well-being in mothers of children with IDs. One explanation for the lack of difference of stress and depressive symptoms between working and non-working mothers may be due to the small sample size. In fact, descriptively, working mothers reported on average lower levels of maternal stress and less depressive symptoms than non-working mothers, but the difference between these two groups did not reach statistical significance.

Although mothers' work participation in this sample was slightly higher than Australian mothers of children with DDs (Bourke-Taylor et al., 2011), it was lower than other working mothers in the U.S. According to the U.S. Department of Labor (2013), 74.7% of mothers with children 6-17 years of age were participating in the workforce. In the present study, the vast majority mothers had higher education levels (87.5% had a bachelor's degree or higher), but only 37.5% worked full-time and 25% worked part-time. Given that findings from previous studies have supported significantly better psychological well-being and lower stress levels among working mothers of children with DDs (Bourke-Taylor et al., 2011; Olssen & Hwang, 2006), more studies are warranted with a larger sample size to investigate the direction of the relationship between mother's participation in paid work and health. Future studies also need to address barriers to participate paid work in this population.

Limitations of the Study

There are several limitations that need to be considered in evaluating the findings of this study. The first limitation is due to the cross-sectional study design. Therefore, causal effects cannot be determined, and only temporal relationships between the variables can be established. Future studies using longitudinal prospective designs would

address changes over time. In addition, although this study provided important information regarding the relationships between stress, sleep, and well-being, it is likely that these relationships are complex. A more sophisticated statistical approach (e.g., structural equation modeling) with a larger sample size could be used to test the interrelationships and pathways among the variables in future studies.

The second limitation is related to the representativeness of the sample. Sampling bias may exist because the mothers in this study volunteered to participate; the mothers who responded to the recruitment may have had higher levels of stress, poorer sleep quality and well-being, and greater interest in the study. Therefore, mothers were not necessarily representative of the wider population of the mother of middle age children with DDs. Generalization of the current findings is also limited because the sample was relatively small and homogeneous with respect to ethnicity and socioeconomic status. The study needs to be replicated with a larger random sample, which may increase the chance to include more ethnically and socioeconomically diverse samples. The sample predominantly consisted of married mothers; it cannot be assumed that results would be similar if the sample is mainly single mothers of middle age children with DDs.

Lastly, there were several limitations related to the study instruments. All measures were based on mothers' self-report, which could contribute to shared variance. Stressed mothers and those with high levels of depressive symptoms may have perceived their child's behavior problems more negatively. Although the problem of shared variance may be minimized because mothers in this study completed all the questionnaires together, this problem could have been avoided by the use of an independent report, such as a teacher report of child behavior problems. Similarly, it is

possible that depressed mothers were also more sensitive to their sleep problems. This study was limited by having only subjective measures of sleep. Although the use of subjective measures was suitable for evaluating individual perceptions of sleep quality, the inclusion of an objective sleep measure (e.g., actigraphy) would have strengthened the study. Future studies should also include objective measures of sleep, which would allow for an unbiased, accurate examination of the sleep parameters, since there were the differences in reported sleep parameters (e.g., total sleep time) in this study. Depressive symptoms were measured using a screening instrument. Diagnostic clinical interviews may be more accurate in determining the level of clinical depression in these mothers. Regardless the high levels of these depressive symptoms are a concern. The current study also examined physical well-being by using a self-report measure of health. This measure was appropriate for the current study's focus on mothers' perceived health, but limited as it is unknown the proportion of mothers with clinical depression. Future studies need the inclusion of objective measures of health, such as biomarkers of allostatic load, which demonstrated as significant predictors for developing cardiovascular, metabolic, and immune diseases (Juster, McEwen, & Lupien, 2010). Evaluation of these objective measures of allostatic load may expand the understanding of how chronic stress related to caregiving increases allostatic load and elevates risk not only for depression but also for the development of other chronic health conditions in this population.

Strengths of the Study

Despite its limitations, this study had several strengths. First, the present study was the first study to show the mediating role of perceived sleep quality in the

relationship between caregiving burden and depressive symptoms controlling for child behavior problems within a context of mothers raising children with DDs. Second, this study extended previous knowledge of maternal stress in mothers of middle age children with DDs by examining both parenting stress and caregiving burden, where as most studies have focused on parenting stress alone. Given raising middle age children with DDs requires significant caregiving responsibilities due to their child's self-care limitations and behavior problems, inclusion of both measures of stress has extended the current information of maternal stress in this population. Lastly, this study examined not only mothers' psychological well-being, but also mothers' perceptions of their physical health. Previous studies have mostly focused on documenting poor psychological well-being of mothers raising children with DDs. By examining both aspects of well-being, this study extended the knowledge about mothers' physical well-being and provided a better understanding of the impact of prolonged caregiving on mothers' well-being as a whole.

Implications for Theory Building

Consistent with the prediction of the theory of allostasis and allostatic load, findings from this study demonstrated that caregiving burden contributed to perceived sleep quality and depressive symptoms. While this study did not allow for following mothers over time, mothers' stress experiences were more likely to be the cumulative effect of daily caregiving of their children with DDs, given that these mothers caring for their children almost a decade. According to the theory of allostasis and allostatic loads, exposure to chronic stress can precipitate depression by structural changes in size and function of the brain. Individuals with major depression have shown structural changes,

such as atrophy of the hippocampus and hyperactivity of the amygdala, in areas of the brain that are involved in anxiety, memory, and decision-making (McEwen, 2004). Individuals with impaired sleep also are known to produce an allostatic overload that can cause structural remodeling in the hippocampus, amygdala, and prefrontal cortex (McEwen, 2006).

The theory of allostasis and allostatic load holds promise in examining the cumulative stress in mothers of children with DDs. In future studies, longitudinal studies are needed to identify what factors alleviate and buffer the chronic stress these mothers experience. Since a large portion of these mothers already had additional health problems, these high levels of stress, depressive symptoms, and poor sleep quality would indicate they are at risk for future health problems. As the mothers' poor sleep quality was significantly associated with their depressive symptoms, improving the mothers' sleep may result in a positive impact on their psychological well-being.

Implications for Practice

The findings of this study have a number of implications for practice. First, the mothers' mean depressive symptom scores in this study fell above the clinically significant risk for depression, yet self-reported treatment rates for depression were low (about 20% were currently on medications), suggesting many mothers of this study were not being treated for their depression. In the United States, a lifetime prevalence of depression in the general population is estimated to be 16.2%, and 6.6% depression rate for a 12-month prevalence (Kessler et al., 2003). Although caution is required to interpret the results of the present study due to a non-random and small sample size, mothers of children with DDs seemed to have an increased risk to developing depression

than the general population. Gallagher and Hannigan (2014) reported a low treatment rate of depression in Irish mothers of children with DDs and explained mothers often prioritized the care of their children with DDs over their own health care needs. Because the initial assessment and treatment of depression often started in the primary care settings (Shim, Baltrus, Ye, & Rust, 2011), it is important for primary care clinicians to be aware of a high risk for depression as well as under-treatment of depression among the mothers of children with DDs. Also, it is equally important to raise awareness regarding a high risk for depression among families of children with DDs.

Second, the results of this study confirmed that raising middle age children with DDs is associated with high levels of caregiving burden and provide insight for designing interventions to alleviate these mothers' caregiving burden. Plant and Sanders (2007) found perceived difficulty of caregiving tasks and the presence of children's behavior problems during caregiving were significant predictors for mothers' caregiving stress in mothers of preschool age children with DDs. The authors indicated that the key to designing effective interventions were to use cognitive behavioral techniques to promote positive appraisals of the caregiving roles and developing strategies to reduce behavior problems. A routine evaluation of caregiving needs for middle age children with DDs may also be useful to understand what specific caregiving tasks are difficult and require help. Given the negative effect of caregiving burden on psychological well-being in this population, health care providers need to recognize the need for more services, including in-home supports and respite care for these mothers.

Last, the results of this study suggest that assessment of children's sleep during the pediatric routine visits with middle age children with DDs may be the first step for

necessary interventions to promote health and well-being of mothers as well as their children with DDs. As mothers' sleep quality significantly mediated the relationship between caregiving burden and depressive symptoms in the present study, improving mothers' sleep may result in a positive impact on mothers' depressive symptoms. Since the findings from this study showed about one third of mother's interrupted sleep were due to their children's night waking and sleep problems, a positive impact on mothers' sleep and psychological well-being may be achieved by alleviating child's sleep problems through provision of an appropriate intervention of the child's sleep difficulty. The benefits of relieving child's sleep problems may have positive impact for both the mothers and children in this population.

Future Research

The findings of this study suggest several directions for future research. First, this study should be replicated using a larger, more representative sample of mothers of children with DDs. Little is known about the mediating effect of sleep in the stress-health relationship among low-income non-White mothers of middle age children with DDs, since the present sample was predominantly Caucasians with high socioeconomic status. In general, ethnic minorities and socioeconomically disadvantaged individuals are known to be at high risk for allostatic load and may have a stronger impact of stress on their health outcomes, causing various health problems (Geronimus, Hicken, Keene, & Bound, 2006).

Second, future research should include both subjective and objective measures of sleep to maximize the understanding of sleep in this population. Although previous studies have shown subjective sleep quality was not related to objective sleep-wake

patterns (Lee & Hsu, 2012), using multiple measures of sleep are recommended to reduce reporter bias when most major variables of the study rely on self-report and allow evaluation of the different constructs of sleep (Meltzer, 2008). For example, sleep quantity can be best estimated by objective measures of sleep, such as actigraphy, whereas sleep quality can be obtained by subjectively. Actigraphy measures the circadian rhythms, which are an important indicator for the sleep-wake cycle (Decker, 2012). Evaluation of the circadian rhythm activities may explain why and how perceived sleep quality mediate the relationship between stress and health in this population (Germain & Kupfer, 2008).

Lastly, the findings of this study highlight the need for research examining other behavioral pathways, such as health behaviors, that account for the physical health of mothers raising children with DDs. Chronic and accumulative maternal stress in this population may lead to decreased physical activity, poor diet, or unmet health care needs that impact for future development of health problems. Given mothers of middle age children already exhibit poor sleep quality and are at risk for depression, which are the well-known risk factors for chronic illnesses, understanding behavioral pathway of the stress-health relationship will provide valuable information for designing future intervention to improve mothers overall health and well-being.

Conclusion

Findings of this cross-sectional, descriptive study confirmed mothers of middle age children with DDs experienced high levels of parenting stress, caregiving burden, and depressive symptoms. Mothers' sleep quality mediated the relationship between caregiving burden and depressive symptoms after controlling for child behavior

problems; indicating mothers' perceived sleep quality is an important factor to consider in reducing the harmful and cumulative effect of stress on health in this population. Improvement of mothers' sleep may buffer the impact of caregiving burden on depressive symptoms. Furthermore, it would appear that the children's sleep problems may influence mothers' sleep continuity and sleep quality in mothers caring for middle age children with DDs. Future studies need to include evaluation of the sleep problems among middle age children with DDs as well as their impact on mother's sleep and health. Although mothers' perceived physical well-being was near the norm, their physical health is still concern because high levels of stress, impaired sleep, and depression are risk factors for developing chronic illness. Addressing these issues will allow us to advocate more research and policy development to aid the health and well-being of the mothers who often provide life-long caregiving for their children with DDs.

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APPENDIX A
Informed Consent

Georgia State University
Byrdine F. Lewis School of Nursing and Health Professions
Informed Consent

Title: Maternal stress, sleep, and well-being in mothers of children with developmental disabilities

Principal Investigator (PI): Patricia C. Clark, PhD, RN, FAHA, FAAN

Student Principal Investigator (PI): Jiwon Lee, RN, BSN, MPH, PhD(c)

I. Purpose:

You are being invited to participate in a research study. The purpose of this study is to learn about stress and sleep among mothers of children with developmental disabilities. We also want to know how these mothers' stress and sleep may affect their feelings and physical health. A total of 78 mothers will be asked to be in this study. If you are willing to take part in the study, you will be asked to answer a set of questions and finish a 5-day sleep diary. It will take about 1 hour 50 minutes to answer all the questions and a sleep diary.

II. Procedures:

If you agree to participate, the following will happen:

1. You and the student PI will meet one time. You will be asked to answer questions about your stress, your sleep, your feelings, and your health. Some questions will be about your relationship with your spouse (or a significant other). There will be some questions about your child's behavior problems. You will also be asked some general questions about you and your child. It will take about 1 hour to fill out the forms.
2. The meeting will be held at a quiet and comfortable place, such as a home or a meeting room in a public library.
3. The student PI will collect all the questions.
4. At the end of the meeting, you will be asked to fill out a 5-day sleep diary from Monday morning to Friday morning. We think it will take about 10 minutes a day.
5. When you finish your sleep diary, we ask you to send it back to the student PI by mail. Please use the pre-addressed, stamped envelope we give you.
6. When you finish answering all the questions at the meeting, you will receive a \$10 Target gift card as a token of appreciation for your time.
7. You may stop at any time during this study.

III. Risks:

In this study, you will not have any more risks than you would have in a normal day of life. However, it is possible that you may feel sad or upset while you are answering some questions. If your answers show that you may benefit from further evaluation, we will let you know. If you like, the student PI can also contact Dr. Clark who is the principal investigator for this study and ask her to contact you. If you become distressed, we will give you a list for counseling or you can call the Georgia State University Psychology Clinic at 404-413-6229. However, if counseling is needed, any expenses will be your own responsibility.

GSU IRB NUMBER: H14634 ¹
APPROVED IRB APPROVAL DATE: 10/30/2014
 IRB EXPIRATION DATE: 08/21/2015

IV. Benefits:

Taking part in this study may not benefit you personally. The findings from this study will help us to understand what it is like to be a mother raising a child with a developmental disability.

V. Voluntary Participation and Withdrawal:

Taking part in this study is voluntary. You have right to refuse to be in this study. If you decide to be in the study and later change your mind, you have the right to drop out at any time. Whatever you decide, you will not lose any benefits to which you are otherwise entitled. If you decide to drop out of the study, any information that has been collected will be used in the related study unless you ask us not to use the information.

VI. Confidentiality:

We will keep your records private to the extent allowed by law. Dr. Patricia Clark and Jiwon Lee are the only persons who will have access to the information you provide. Information may also be shared with those who make sure the study is done correctly (Georgia State University Institutional Review Board (IRB) and the Office for Human Research Protection [OHRP]). Health care professionals who gave you the information about this study will not be told whether or not you are in the study. We will use a study number rather than your name on study records. Your information will be kept in a locked cabinet as well as on password- and firewall-protected computers. Your name and other facts that might point to you will not show when we present this study or publish its results. The findings will be summarized and reported in group form. You will not be identified personally.

VII. Contact Persons:

Call Jiwon Lee at 404-599-0715 or email at orony75@gmail.com, if you have any questions about this study. You can also contact Dr. Patricia Clark at 404-413-1180 or pclark@gsu.edu. If you have questions or concerns about your rights as a participant in this study, you may contact Susan Vogtner in the Office of Research Integrity at 404-413-3513 or svogtner1@gsu.edu.

VIII. Copy of Consent Form to Subject:

We will give you a copy of this consent form to keep.

If you are willing to volunteer for this study, please sign below.

Participant

Date

Principal Investigator or Researcher Obtaining Consent

Date

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