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by

Elizabeth Allain

August 2018

PERCEIVED DEVELOPMENTAL DELAYS
IN CHILDREN BORN PRETERM AND PARENTAL STRESS

A Dissertation Presented to the
Faculty of the College of Education
University of Houston

In Partial Fulfillment
of the Requirements for the Degree

Doctor of Philosophy

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Abstract

Background: Parents of children born preterm experience more parental stress than parents of typically developing children due to the increased likelihood of developmental delays occurring with prematurity. Parents' perceptions of their child's developmental performance are important because perceptions can increase parental stress which can impact parental actions concerning the child. **Purpose:** This study examined whether the perception of child developmental performance increased parental stress above actual developmental performance in children born preterm. Moreover, it explored whether actual and perceived developmental performance predicted the change in parental stress over time. Child birth weight and use of mechanical ventilation were also examined to determine which contributed to the prediction of parenting stress. **Methods:** Archival data from 22 parent-child dyads were extracted from a larger study in a high-risk infant clinic. Data included reports of parental stress, standard scores of child developmental performance, and reports of parent perceived child delay. Data regarding medical complications at birth were also included. **Results:** Bivariate analysis revealed a non-significant correlation between child birthweight and parental stress when children were 18-29 and 36-65 months. Use of mechanical ventilation at birth accounted for decreased amounts of the variance in parental stress as children aged. Multivariate analysis indicated that parental perception of child developmental delays significantly predicted more of the variance in parental stress when children were 36-65 months than actual child developmental performance. This prediction was not significant when children were 18-29 months. Actual and parent perceived developmental delay did not significantly predict the change in parental stress over time. **Conclusion:** Pediatric practitioners

should examine child and family functioning during pediatric medical visits, particularly during early childhood. It is valuable to consider a parent's perception of their child's disability, beyond an actual disability. Data regarding parent and family functioning will inform the provisions of interventions that target parental stress.

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Chapter I

Introduction

Stress is a condition characterized by symptoms of physical or emotional tension and is a reaction to a situation where a person feels threatened or anxious (CDC, 2015). Research suggests that chronic stress can lead to heart disease, diabetes, and other medical (Danielsson, et al., 2012) and psychological conditions (Alfonso, Frasch, & Flugge, 2005). Stress occurs when an individual identifies a perceived discrepancy between the demands of a situation and his/her resources or ability to cope with those demands (Quine & Pahl, 1991). It is this cognitive appraisal, or perception, that will impact stress (Beck, 2011; Honey, Morgan, & Bennet, 2003). Studies suggest the *perception* of the stressor is associated with distress in the individual, not the stressor, itself (Hedegaard, et al., 1996; Dole, et al., 2003; Lobel, et al., 1992).

Perceptions of a stressor's impact on mental health have been studied with individuals and families. Researchers have discovered that perceived levels of medical impairment and locus of control can impact individual well-being (Cott, Gignac, & Badley, 1999; Hirdes, 1993). Furthermore, in studies that incorporate parental perceptions, researchers suggest it is parental cognitions related to a child's disability that impact stress in parents, not the child's actual disability (Jones & Passey, 2004; Smith, Romski, Sevcik, Adamson, & Barker, 2014). Investigating predictors of parental stress is important because parent stress can impact parental actions regarding daily activities and medical decisions concerning the child (Mantymaa, Puura, Luoma, Salmelin, & Tamminen, 2006). These parental actions and decisions can, then, impact child outcomes

(e.g., socioemotional functioning, learning, and academics) (Crnic & Acevedo, 1995; Deater-Deckard, 2004).

Although parents may experience stress for a variety of reasons, parents who have children born preterm and/or born at Low Birth Weight (LBW) experience higher levels of stress because these children are often born with complex medical conditions and neurological deficits (Anderson & Doyle, 2008; Duerden, Taylor, & Miller, 2013; Taylor, 2010). These deficits can lead to developmental delays in language, motor, socioemotional, and/or cognitive functioning during infancy and early childhood, which are likely to further elevate stress in parents (Brummelte, Grunau, Synnes, Whitfield, & Petrie-Thomas, 2011; Grunau, et al., 2009; Robson, 1997; Singer et al., 1999).

Investigators have discovered that developmental delays among children born preterm, diagnosed by using norm-referenced, clinician-administered assessments, predict parental stress in longitudinal studies (Brummelte, Grunau, Synnes, Whitfield, & Petrie-Thomas, 2011; Singer, 1999; Grunau, et al., 2009; Robson, 1997; Singer et al., 1999). However, it is also important to investigate whether *perceived* developmental delays among children born preterm increases parental stress since previous studies suggest it is the perception of a stressor, not the stressor itself, that increases stress (Copper, et al., 1996; Dole, et al., 2003; Zhu, et al., 2010). Furthermore, researchers have not investigated whether the perception of a stressor (e.g., believing a child has a developmental delay) has a greater impact on parental stress among parents with children born preterm. Although neurodevelopmental difficulties (e.g., developmental delays) can become more apparent and impairing as the child born preterm ages (Anderson & Doyle, 2007; Maupin, 2012), no studies were found that investigated whether actual or

perceived developmental performance in children born preterm predicts the change in parental stress over time.

The purpose of this study was to investigate if perceived developmental skills in children born preterm predicted parental stress, as much or more than actual developmental skills when the children in the sample were, on average, 22 months during time one and 48 months during time two. In addition, another objective was to investigate whether actual and perceived developmental performance during toddlerhood in children born preterm predicted the change in parental stress from the time the child was a toddler to the time the child was in early childhood and whether child medical complications experienced at birth (e.g., child birth weight and use of mechanical ventilation) accounted for a significant portion of the variance in parental stress at time one (18-29 months) and time two (36-65 months). Therefore, the research questions for this study were as follows: a) Did parent perceived developmental delays in their child born preterm predict parental stress above and beyond actual developmental skills when the child was 18-29 and 36-65 months? b) Did actual developmental skills and perceived developmental delays when the children were toddlers predict the change in parental stress from the time the child born preterm was a toddler (18-29) to the time the child was in early childhood (36-65 months)? c) Did medical complications experienced by the child at birth (e.g., low birth weight and use of mechanical ventilation) contribute to the prediction of parenting stress?

Results indicated that parent perceived developmental delays in children born preterm significantly predicted parental stress above actual child developmental performance when children were 36-65 months, but not when children were 18-29

months. Contrary to expectations, actual developmental skills and perceived developmental delays did not significantly predict the change in parental stress from the time the child born preterm was a toddler to early childhood. Child birth weight was not significantly correlated with parental stress, and mechanical ventilation did not add significant variance to parental stress at either time point. Results suggest it is important to consider a parent's perception of their child's disability, beyond simply the presence of a disability, when examining child and family functioning during pediatric medical visits in early childhood. Medical practitioners should screen parents for stress associated with a child's development to identify those families in need of support. Interventions should focus on psycho-education of child development and evidence-based therapeutic strategies in reducing parental stress (e.g., cognitive behavioral therapy).

Chapter II

Literature Review

Stress is a condition categorized by symptoms of physical and/or emotional tension and is a reaction to a situation where a person feels threatened or anxious (CDC, 2015). Researchers suggest chronic stress can lead to a variety of physiological and psychological conditions (Alfonso, Frasch, & Flugge, 2005; Danielsson, et al., 2012). In 1979, Lazarus and Folkman developed the 'Transactional Model of Stress' in which stress is a process that involves continuous adjustments called *transactions* between person and environment. In this model, an individual becomes an 'active agent' who can influence the effect of a stressor through behavioral, cognitive, and emotional strategies. Stress results when the individual identifies a perceived discrepancy between the demands of a situation and his/her resources or ability to cope with those demands (Quine & Pahl, 1991). It is this transactional approach to understanding stress that is the most theoretically appropriate for this study, emphasizing the relationship between the person and how he/she perceives his/her environment.

Stress can occur within various social contexts and roles, such as within employment, familial, or parental roles (Conrad, 2011). It is documented that parents of children with medical or neurodevelopmental concerns have more parental stress than those of typically developing children (Cutrona & Troutman, 1986; Halpern & MacLean, 1997; Secco, Askin, & Yu, 2006; Warfield, Shonkoff, & Krauss, 2001). Parents' perceptions of their child's developmental skills are of importance because these appraisals can affect parental stress, which can impact parental actions regarding daily activities (e.g. how to discipline the child, when to put him/her to bed, how to feed the

child) and in decisions concerning the child's health (e.g. whether to seek medical or psychological help for the child) (Mantymaa, Puura, Luoma, Salmelin, & Tamminen, 2006). Parents who experience higher levels of stress are more likely to be harsher and more authoritarian in their parental practices. They are also less likely to provide the necessary stimulation that promotes their child's optimal cognitive and socioemotional development (Deater-Deckard, 2004). These adverse interactions can influence parental activities that impact child outcomes (e.g., socioemotional functioning, learning) (Crcic & Acevedo, 1995; Deater-Deckard, 2004).

Specifically, parents of children born preterm report greater levels of stress because these children are more likely to be born with medical complications and neurobehavioral disruptions that often lead to developmental delays (Brummelte, et al., 2011; Lowe, et al., 2014; Woodward, et al., 2005). A developmental delay is diagnosed based on multi-informant information (e.g., caregiver interviews, observations) along with norm-referenced, clinician-administered assessments that reveal either a cut-off score or standardized score that merits the diagnosis. In contrast, a *perceived* developmental delay is recognized when a caregiver who is familiar with the child reports a score or an item on a questionnaire that identifies concern regarding the development of the child. Although extant studies suggest that deficits in *actual* developmental performance among children born preterm increase parental stress, researchers have not investigated whether the *perception* of this stressor (e.g., believing your child has a developmental delay) has a greater impact on parental stress than an actual developmental delay in children born preterm. This is important because many researchers suggest it is the perception of the stressor, which can impact parental stress

(Deater-Deckard, 2009; Hedegaard, et al., 1996). Furthermore, although neurodevelopmental difficulties (e.g., developmental delays) can become more apparent and impairing as children who are born preterm age (Anderson & Doyle, 2007; Maupin, 2012), no studies were found that investigated whether actual developmental performance and parent perceived developmental delays in children born preterm predict the change in parental stress over time, and if medical complications experienced by the child at birth (e.g., low birth weight and use of mechanical ventilation) contribute to the prediction of parenting stress.

Impact of Stress on Wellbeing

Historically, the body's stress system had an adaptive value, used mostly to meet physical external threats (Danielsson, et al., 2012). External stimuli elicit a stress-related physiological response (Knight, Nguyen, & Bandettini, 2005). When experiencing stress, the brain signals the adrenal glands to produce stress hormones, which increases energy and mental concentration, while, blood pressure and blood sugar levels rise and pain sensitivity is reduced and the body's immune response is activated (Danielsson, et al., 2012). These biological reactions prepare an individual for a fight or flight response (Conrad, 2011). Once the stressful situation ends, biological functions shut down to allow the body to rest and recuperate (Conrad, 2011). However, dysfunction arises when the body's degenerative and regenerative functions become imbalanced and stress systems function over a long period of time, otherwise known as 'chronic stress' (Danielsson, et al., 2012). In addition to the biological effects, chronic stress can also lead to poorer mental performance (Zoladz, Park, & Diamond, 2011), anxiety (Pearson, Blanchard, &

Blanchard, 2011), and depression (Alfonso, Frasch, & Flugge, 2005; Fuchs & Flugge, 2011).

Perception of Stressful Stimulus Affects Wellbeing

Although chronic stress from a stimulus can produce debilitating physiological and psychological consequences in individuals, researchers suggest it is the perception of the stimulus, not the stimulus itself that can lead to stress and is related to adverse outcomes in individuals (Copper, et al., 1996; Dole, et al., 2003; Zhu, et al., 2010). For example, the literature reveals that perceived psychological functioning (e.g., self-esteem and social interactions) can impact well-being in persons (Cott, Gignac, & Badley, 1999; Hirdes, 1993). Cott, Gignac, and Bradley (1999) found that individuals with higher levels of perceived self-esteem measured by the Rosenberg Self-esteem Scale reported higher levels of perceived positive health (OR= 1.81) but those who reported low levels of self-esteem reported lower levels of perceived positive health (OR= 1.92), suggesting that perceptions of low self-esteem contributed significantly to poorer self-reported health. Similarly, Lunskey and Benson (2001) suggest the level of perceived social strain (e.g., “someone said bad things about you”) on the Inventory of Negative Social Interactions scale accounted for a significant portion of the variance in depressive symptoms on the Birleson Depressive Self-Rating Scale ($\beta = .23, p < .05$) and somatic complaints on a Somatic Complaints score ($\beta = .37, p < .001$) in 84 adults with mild ID. The results of these studies highlight the importance of assessing perceptions of stressors, rather than relying exclusively on observations, or actual stressors to assess wellbeing. Perceptions of child-stressors have also been studied among parents.

Parental Stress

Parenting can be a stressful endeavor and could lead to chronic stress in some parents. *Parental stress* is defined as a parent's perception, and feelings in response to that perception, that the demands that are associated with the role of being a parent exceed the resources available for dealing with those demands (Deater-Deckard, 2004). Feeling overwhelmed or incompetent in the parenting role is associated with parental stress (Gotlib & Goodman, 2002), which can disrupt family functioning (e.g., lead to marital discord) and impact children's development (Crnic & Acevedo, 1995). Since parental stress may have notable effects on familial functioning, these perceptions are important to understand, regardless of whether they are accurate (Mantymaa, et al., 2006). Moreover, parental stress can influence parental actions in activities of child care and discipline (Mantymaa, et al., 2006), whereby affecting child outcomes (e.g., socioemotional functioning, learning). Researchers suggest that even in low-risk populations (e.g., children without medical or emotional concerns), parental stress in the first years of a child's life is associated with specific child outcomes such as internalizing problems (Creasey & Jarvis, 1994). Parental stress during early childhood may manifest from multiple factors related to child development (Deater-Deckard, 2004; Mantymaa, et al., 2006).

Factors Influencing Parental Stress during a Child's First Years of Life

There are certain factors that can increase parental stress during a child's first years of life. However, it is the parental perceptions associated with these factors that will affect parent stress levels (Mantymaa, Puura, Luoma, Salmelin, & Tamminen, 2006; Smith, Ronski, Sevcik, Adamson, & Barker, 2014). Childrearing can be a very

challenging task that can produce stress in parents, particularly those who have high expectations of what is 'normal', which can produce self-doubt and increase stress due to this perceived discrepancy (Boekaerts, Pintrich, & Zeidner, 2000). Although all parents face added stress when raising children, some researchers suggest that certain factors are more likely to increase stress levels in parents (Deater-Deckard, 2004), such as child illness, temperament, and delays in development.

Childhood illness. Caring for a child with a chronic illness not only disrupts the daily lives of family members but threatens a foundational belief about life: that the parent can protect their child from harm and that their child will outlive them (Deater-Deckard, 2004). Compared to parents of healthy children, parents of children who are disabled or ill are more likely to experience parental stress (Lessenberry & Rehfeldt, 2004), which can impact the family system (Kazak, 1989). Parents must face the devastating news of their child's diagnosis, the associated medical risks, and in some cases, their child's potential for a shortened life expectancy (Cousino & Hazen, 2013). Many child illnesses require therapies and medical procedures that can place added financial and psychological stress on the family (Baker-Ericzén, Brookman-Frazer, & Stahmer, 2005; Frank, et al., 1991). A reason that it may be difficult to cope when a child is ill or disabled is that the parent may perceive him/herself as having little or no control over the symptoms or severity of the medical condition (Deater-Deckard, 2004).

Cousino and Hazen (2013) conducted a meta-analysis of thirteen studies that included children with asthma, cancer, cystic fibrosis, diabetes, epilepsy, juvenile rheumatoid arthritis, and sickle-cell disease and their caregivers. The authors found caregivers of children with chronic illness reported significantly greater 'total' parenting

stress on the Parenting Stress Index (PSI) and Pediatric Inventory for Parents (PIP) than caregivers of healthy children (Cohen's $d = .40$ [weighted mean effect size]; $p < .0001$). In all thirteen studies, greater parenting stress was associated with poorer psychological adjustment in caregivers with children who had chronic illness (effect sizes ranged from .12 to .52). In addition to childhood illnesses, researchers suggest parental stress is also more common among parents who have children with a difficult temperament (e.g., dysregulated behavior).

Child temperament. Several studies have investigated child temperament or “emotional regulation” and its influence on parental stress (Clark, Woodward, Horwood, & Moor, 2008; Evrard, et al., 2011; Spittle et al., 2009). Infants and children who are often in a fearful or angry mood, who react negatively to stimuli, and have poor self-control are more likely to have parents who report higher levels of stress (Osterg & Hagekull, 2000). For example, Treyvaud and colleagues (2010) investigated the mental health of mothers on the General Health Questionnaire (GHQ-28) and early socio-emotional development of children on the Infant and Toddler Social Emotional Assessment (ITSEA). The authors discovered that mothers with elevated levels of reported stress were more likely to have children classified as ‘at risk’ for dysregulated behavior ($OR = 2.51$ [$p < .05$]) on the ITSEA, suggesting that parental stress is associated with having a child with greater dysregulated behavior. In addition, to an illness or child temperament, having a child with a developmental delay can also place emotional burdens on parents’ due to the child’s lack of progress in age-appropriate abilities and skills.

Child Developmental Delays and Parental Stress

Developmental delays are identified when a child is not progressing in age-appropriate skills or has regressed in abilities. These problems may be found in various domains of functioning, ranging from cognitive (e.g., problem solving), language (receptive/expressive), physical (gross/fine motor), and socioemotional (e.g. interpersonal interactions) (Deater-Deckard, 2004). Many researchers have investigated child developmental delays and their impact on parental stress (Anthony, et al., 2005; Brummelte, et al., 2011; Gerstein, Crnic, Blacher, & Baker, 2009; Gray, Edwards, O’Callaghan, & Cuskelly, 2012; Joyner, Silver, & Stavinoha, 2009) and most suggest that parents of children with developmental delays experience more parental stress than parents of typically developing children (Cutrona & Troutman, 1986; Halpern & MacLean, 1997; Secco, Askin, & Yu, 2006; Warfield, Shonkoff, & Krauss, 2001). Developmental delays may not only adversely impact children at home, but also within the school setting and with peer interactions (Joyner, Silver, & Stavinoha, 2009; Payley, O’Connor, Frankel, & Marquardt, 2006). Children may have difficulty completing tasks, planning future actions, and managing unexpected events, all of which can emotionally and financially strain parents and increase stress (Baker, et al., 2003; Gotlib & Goodman, 2002).

Secco, Askin, and Yu (2006) investigated developmental delays of 61 ‘biologically vulnerable’ (e.g., children with spina bifida, autism, or fetal alcohol syndrome) toddlers when the children were two, three, and four years of age on the Bayley Scales of Infant Development (BSID) and parental stress on the Parenting Stress Index (PSI). The authors found that child cognitive level significantly predicted

parenting stress. Child cognitive development contributed the greatest variance (30%) to 'total' parenting stress at three and four years of age. This finding suggests that parenting stress is highest when the toddler has lower cognitive ability, as opposed to a language or motor delay, particularly as the child ages.

In a more recent study by Gerstein, Crnic, Blacher, and Baker (2009), the authors investigated reports of parenting stress on the PSI among 115 parents and child Intellectual Disability (ID) on the BSID during two time points: 8 and 18 months. Higher Mental Development Index (MDI) scores on the BSID predicted lower parenting stress at 18 months ($\beta = -.19, p < .05$), but not at 8 months, suggesting lower cognitive level did not predict parenting stress when the children were infants. However, cognitive ability significantly accounted for more of the variance when the children were toddlers, suggesting that parenting stress increased as the child aged. Other researchers have found similar results when investigating these variables among parents who have children with developmental delays (Blacher, Neece, & Paczkowski, 2005; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001).

Parental Cognitions and Stress

Although the previous studies suggest that parental stress is greater in parents who have children with developmental delays, other literature suggests it is the perception of the stressor that is associated with stress levels, not the stressor itself. Specifically, some researchers believe it is the cognitions associated with a child's disability that impact stress, not the actual disability (Beck, 2011; Deater-Deckard, 2009). It is important to study those cognitions because negative parental attitudes can have an adverse influence on the prognosis of the child with the disability (Gupta & Singhal, 2004). Researchers

have studied the role of parental cognitions and stress in relation to child characteristics in children with an Intellectual Disability, Down syndrome, and Cerebral Palsy (Hassall & McDonald, 2005; Jones & Passey, 2004). Hassall and McDonald (2005) investigated the effects of parental cognitions (e.g., locus of control) on parenting stress. The participants were 46 mothers of children with an ID who were recruited through six special schools in southeast England. The authors used the Parental Locus of Control Scale to assess locus of control and the PSI to assess parental stress. Parental locus of control accounted for 44% of the variance in 'total' parenting stress. These results suggest that it is the amount of perceived self-efficacy a parent has in managing behaviors associated with a child Intellectual Disability that will influence parental stress.

In a similar study, Jones and Passey (2004) investigated if child behavior problems (measured by a 'behaviors difficulty checklist') of children with Autism Spectrum Disorder, Down Syndrome, Attention-Deficit/Hyperactivity Disorder, or Cerebral Palsy and perceptions of locus of control on the Parental Locus of Control Scale (PLOC) predicted parental stress on the Family Stress and Support Questionnaire (FSSQ). Results indicated that the strongest predictor of parental stress was parental locus of control, beyond behavior problems in these children. Parents who believed their lives were not controlled by their child with a disability tended to show lower overall stress, despite how many child behavior problems they endorsed. Parental locus of control explained 32% of the variance in parental stress.

These studies suggest that parental cognitions of child behaviors can significantly impact stress, more than actual child behaviors. However, studies investigating whether parental cognitions, or perceptions, of child disabilities increase stress among parents

more than actual disabilities are scarce. The following section discusses a study that investigated perceptions of child language delays compared to actual delays in language and its impact on stress in a group of parents with children who had Down Syndrome or Learning Disabilities.

Perceived Child Disabilities and Parental Stress

Gupta and Singhal (2004) suggest that parents who believe their children have disabilities, or are not developmentally 'on-track', experience higher levels of stress. One research study investigated whether a parent's *perception* of child developmental language performance impacted parental stress above actual language performance. Smith, Ronski, Sevcik, Adamson, and Barker (2014) examined parent perceptions of language development among parents of children with Down Syndrome compared to perceptions of language development among parents of children with learning disabilities. The authors used the Sequenced Inventory of Communication Development-Revised as an *actual*, direct skills language measure and the Parent Perception of Language Development to assess *perceived* language development. They used the PSI-SF to assess parental stress. Results indicated that perceptions of language impairment predicted parental stress among parents with children diagnosed with a learning disability but not those with Down Syndrome (parent stress total score- $\beta=.23, p<.05$; child domain- $\beta= .33, p<.05$) even though there were not actual differences in expressive and receptive language impairment between the two groups. Parental perceptions of child disability differed between the two groups. Those parents who perceived their child had a delay in language had greater stress levels, even though there were no actual delays in language.

Children Born Preterm

Although all parents experience stress associated with raising children, parents of children born preterm and/or Low Birth Weight (LBW) are more likely to experience greater levels of stress than parents of children born full-term because these children are at higher risk of developing neurodevelopmental deficits. Preterm birth is the birth of an infant prior to 37 weeks gestational age (Goldenberg, et al., 2008). Researchers have divided preterm birth into four categories: (a) infants born late preterm, born between 32-37 weeks gestation; (b) infants born very preterm, born between 28-31 weeks gestation; (c) infants born extremely preterm, born between 26-27 weeks gestation; or (d) infants born micro-premature, born at less than 26 weeks (≤ 25) gestation (Prebic, 2012); however, cutoffs can vary by author (Goldenberg, et al., 2008). Low birth weight (LBW) is common among children born preterm (Goldenberg, et al., 2008). The World Health Organization (WHO) defines low birth weight as weight less than 2,500 grams (5.5 pounds) at birth. This definition is based on empirical observations that infants weighing less than 2,500 grams are approximately 20 times more likely to die than heavier babies and if these children survive, they have poor health outcomes (World Health Organization [WHO], 2004). Historically, there has been confusion regarding the concepts of 'preterm birth' and 'LBW' (Nosarti, Murray, & Hack, 2010). Although preterm birth and LBW are distinct in definition, when discussed in the literature, they are often interchanged.

Recent advances in medical care have contributed to greater numbers of children born preterm surviving (Aylward, 2002; Wolfe, 2002). In fact, the preterm birth rate has been steadily rising since 1981, from approximately seven percent, to almost thirteen

percent in 2006 (Martin, Osterman, & Sutton, 2010). The frequency and severity of neurodevelopmental delays and disabilities in children born preterm increases when the child is born at earlier gestational ages or LBW (Anderson & Doyle, 2003, 2008; Taylor, 2010). Parents who have children born at earlier gestational ages or LBW may experience more parental stress because these children are often born with greater neurodevelopmental impairments (Taylor, 2010).

Low Birth Weight

Research suggests LBW contributes to infant mortality and childhood morbidity (Hack & Fanaroff, 1999; Msall & Tremont, 2002; Vohr & Msall, 1997). About seven of ten children born low-birthweight are premature (March of Dimes, 2014). Children born with LBW are more likely to have neurological impairments that develop into neurodevelopmental deficits later. In a study conducted by Vohr and colleagues (2000) that investigated child morbidity among children born between 401-1000 grams, neurologic, developmental, neurosensory, and functional deficits increased with decreasing birth weight. Infants, born less than 500 grams were more likely to have abnormal head control (14%) and less secure sitting (29%). Fifty-seven percent of infants born at 401 to 500 grams, 64% of infants born at 501 to 700 grams, 66% to 72% of infants born at 701 to 900 grams, and 78% of infants born at 901 to 1000 grams walked fluently. However, only 64% of infants born at 401 to 500 grams had a pincer grasp, compared with 84% to 87% of infants in all other birth weight groups. Children born at LBW are also at greater risk for developing major neurodevelopmental impairments such as cerebral palsy, blindness, deafness, and severe cognitive developmental delays, particularly, those children born micropremature (i.e., birth weights <750 grams) (Hack & Fanaroff, 1999;

Msall & Tremont, 2002; Vohr & Msall, 1997). For example, in 2005, researchers from the National Institute of Child Health and Human Development-Neonatal Research Network (NICHD-NRN) (Laptook, O' Shea, Shankaran, & Bhaskar) investigated child outcomes of infants born with Extremely Low Birth Weight (ELBW) (< 1000 grams) at 18 to 22 months' corrected age (i.e., adjusted age) and found that MDI scores of less than <70 occurred in 25.3% of the children on the BSID. Others have found similar results (Wood, et al., 2000; Saigal, Stoskopf, Streiner, & Burrows, 2001).

Although some researchers have investigated associations between children born at LBW and parental stress (Singer, et al., 2007), no studies were found that investigated whether LBW predicts parental stress either when a child born preterm is a toddler and or during early childhood. Investigating this is important because others have found that birth weight status is associated with medical complications in children born at LBW (e.g., the lower the birthweight, the more likely the child will develop delays in development) (Laptook, et al., 2005; Vohr, 2000), which is likely to impact parental stress. This parental stress could increase as the child ages.

Children born preterm are also more likely to experience medical complications due to their younger gestational age and/or LBW (Hack & Fanaroff, 1999; Msall & Tremont, 2002; VanMarter, et al., 2002; Vohr & Msall, 1997). These children often need the use of medical equipment to enhance their survival rate, particularly in respiratory care (Brown & DiBlasi, 2011). One tool that is used in neonatal respiratory care is mechanical ventilation (Apisarnthanarak, Holzmann-Pazgal, Hamvas, Olsen, & Fraser, 2003).

Mechanical Ventilation

Neonatal mechanical ventilation has been considered a significant tool for managing respiratory distress syndrome (RDS) in children born preterm and/or LBW and continues to be regarded as an important factor in neonatal respiratory care (Apisarnthanarak, et al., 2003). Children born preterm and/or LBW often need to be placed on mechanical ventilation due to chronic lung diseases such as Bronchopulmonary dysplasia (BPD); however, it can result in medical complications such as ventilator-associated pneumonia or other infections (Van Marter, et al., 2002). Researchers suggest that children who are born with greater lung impairments and, thus, more likely to be placed under mechanical ventilation have a greater probability of having poor developmental outcomes (Schmidt, et al., 2003), which may increase parental stress.

Children born preterm are not only at an increased risk of experiencing illnesses and medical complications such as RDS, but have an increased risk of developing neurodevelopmental disabilities (Bhutta, et al., 2002) due to their LBW and potential medical complications at birth. These disabilities often lead to developmental delays and socio-emotional difficulties such as behavior problems (e.g., hyperactivity, impulsivity, aggression), all of which may contribute to academic and learning difficulties (Wood, et al., 2000; Bhutta, et al. 2002; Burnson, et al., 2013; Maupin, 2012), and are associated with increased levels of parental stress (Ratliffe, Harrigan, Tse, & Olson, 2002; Ray, 2002). Furthermore, these neurodevelopmental deficits become more apparent as the child ages (Anderson & Doyle, 2007; Maupin, 2012). Although initially believed that children born preterm catch up with their full-term peers, investigators have found contradictory results (Maupin, 2012).

Developmental Functioning of Children Born Preterm

Brain development in the third trimester and early neonatal period is rapid and extensive, therefore, infants born preterm are at high risk for neurological injury and disturbances in brain development (Volpe, 2009). Neuroimaging studies have revealed cortical and subcortical abnormalities in the brain of infants born preterm that persist through child development (Duerden, et al., 2013). Some of the main deficits found among children born preterm include delays in developmental functioning (Marlow, Wolke, & Bracewell, 2005; Isaacs, Lucas, & Chong, 2000; Ross, et., 1996; Vicari, et al., 2004; Bhutta et al., 2002).

Developmental Delays. It is well documented that children born preterm are more likely to have neurodevelopmental deficits at birth that affect typical development as the child ages. A multicenter cohort study conducted by Vohr, et al., (2000) found that of 1,151 children born preterm evaluated at 18 months of age, 25% had an abnormal neurologic examination, 37% had a BSID Mental Developmental Index (MDI) of less than 70, 29% had a Psychomotor Developmental Index (PDI) of less than 70, 9% had vision impairment, and 11% had hearing impairment. Moreover, neurologic, developmental, and neurosensory dysfunctions increased with decreasing birth weight (Vohr, et al., 2000). More recently, researchers have discovered children born preterm have specific delays in language, motor development, socioemotional development, and cognition. (Clark, Woodward, Horwood, & Moore, 2008; Haastert, De Vries, Helders, & Jongmans, 2006; Moore, et al., 2012; Schirmer, Portuguese, & Nunes, 2006; Wood, et al., 2001).

Language delays. Language delays are more common among children born preterm and/or LBW. In a study that assessed child language in a cohort of children born preterm at two years of age, children born extremely preterm (<28 weeks gestation) performed worse than those born very preterm (28–32 weeks gestation) (Cohen's $d=.40$; $p<.05$), and those children born very preterm performed worse than children born full term (38–41 weeks gestation) (Cohen's $d=.06$; $p<.05$) on vocabulary usage. Most importantly, these associations between gestational age at birth and language outcomes remained after controlling for socioeconomic status, maternal education, family stability, and number of family members (Foster-Cohen, Edgin, Champion, & Woodward, 2007). Others have found similar results (Lowe, et al., 2014; Schirmer, Portuguez, & Nunes, 2006). Schirmer, Portuguez, and Nunes (2006) assessed language in children born preterm at three years of age on the BSID and found children born preterm weighing less than 1,500 grams had significantly lower scores on the language scales of the BSID at age 36 months compared to children born full term (Cohen's $d=.25$, $p<.05$), suggesting an association between, not only gestational age, but LBW and language delay. Similarly, Lowe, et al. (2014) found significant differences between three to four-year-old children born preterm/LBW and children born full term on the Verbal Intellectual Quotient (VIQ) of the Wechsler Preschool and Primary Scale of Intelligence, 3rd edition (WPPSI-III) (Cohen's $d= .22$, $p<.05$). These differences remained significant even after adjusting for maternal education.

Motor delays. Many studies suggest that children born preterm and/or LBW develop delays in motor development. Different motor delays and/or motor disabilities are the most commonly detected problems among preterm children in the first years of

life (Bartlett, 1997; Jeng, Tsou, & Chen, 2000; Kohlhauser, et al., 2000). For example, Van Haastert, De Vries, Helders, and Jongmans (2006) compared the means of the Alberta Infant Motor Scale scores of 800 children born preterm with the norm-referenced values derived from term infants on this scale, the preterm infants scored significantly lower from 1 ($t = -2.45, p < .05$) to 18 months ($t = -2.01, p < .05$) compared to those born full term. Others have investigated Developmental Coordination Disorder (DCD) among children born with LBW (DCD is common in 5-9% of children in the typical population). Holsti, Grunau, and Whitfield (2002) investigated the prevalence of DCD in a cohort of extremely LBW (born at <800 grams) at eight years of age. Seventy-three children were included in the study group, along with 18 children born full term (matched controls). The authors discovered that of the 73 children born extremely LBW, 37 (51%) were classified as having DCD. In another study by Wood and colleagues (2005), the authors found that 10% of 283 children born micro-premature (e.g., born at less than 25 weeks gestation) had a severe motor disability in one or more functional domains (e.g., unable to walk, sit, use hands together, or control head movements).

Socioemotional delays. Children born preterm are not only at an increased risk of experiencing delays in language and motor development, but delays in socio-emotional developmental are also more common (Clark, et al., 2008; Loe, et al., 2011; Spittle, et al., 2009). Socioemotional delays include dysregulation (e.g., eating disturbances and negative responding, or negative emotionality), behavior (e.g., hyperactivity and impulsivity), and internalizing problems (e.g., social distress) all of which can contribute to increased levels of parental stress (Essex, Klein, Cho, & Kalin, 2008; Moss, Rousseau, Parent, St-Laurent & Saintonge, 1998). Clark, Woodward, Horwood, and Moore (2008),

found that compared to infants born full term, infants born very preterm (born <30 weeks gestation) demonstrated poorer self-regulation as evidenced by their inability to sustain attention on parent-child directed tasks (Cohen's $d = .21$, $p < .01$).

Likewise, Bhutta and colleagues (2002), discovered that school-age children who were born preterm had a significantly higher prevalence of hyperactive, impulsive, and attention problems compared to peers born full term (a 2.65-fold greater risk). A study that compared internalizing behaviors of children born very preterm (30 weeks gestation) and children born full term at two years corrected age (i.e., adjusted age based on the infant's due date) suggest that children born preterm demonstrate significantly higher internalizing scores on the ITSEA than children born full term (Cohen's $d = .35$, $p < .05$) (Spittle, et al., 2009). Similarly, Loe et al. (2011) discovered that children born late preterm had significantly higher internalizing problem scores compared to children born full term on the CBCL, however, the effect size was small (Cohen's $d = .18$, $p < .05$).

Cognitive delays. In addition to delays in language, motor, and socio-emotional functioning, children born preterm are also more likely to have delays in cognition. By preschool age, many children born preterm continue to lag behind their peers in terms of cognitive development (Duerden, et al., 2013). Cognitive deficits are more prevalent in males than females (Brummelte, 2011; Marlow, Wolke, & Bracewell, 2005).

Breeman, et al. (2015) conducted a longitudinal study that followed children born preterm into adulthood and investigated differences in cognitive level between those born very preterm and full-term. First, the researchers found that almost 27% of adults born very preterm and/or LBW, but only 3.9% of adults born full-term, were diagnosed with severe cognitive impairment on various cognitive assessments. Furthermore, for

individuals born very preterm and/or LBW, correlations between childhood IQ scores and having a cognitive impairment in childhood were all in the moderate to strong range (5 months: $r=-.48$; 20 months: $r=-.64$; 4 years: $r=-.63$; 6 years: $r=-.67$; 8 years: $r=-.71$). The results suggest that adult IQ could be predicted moderately well ($r > .50$) from age 20 months into adulthood for children born very preterm or LBW.

Other researchers suggest that not only are children born preterm more likely to exhibit cognitive delays compared to those born full-term, but cognitive level may decrease as the child ages. For instance, Brummelte, et al. (2011) found a significant decrease in the Mental Development Index (MDI) of the BSID from 8 to 18 months in a sample of preterm children, but not children born full term (Cohen's $d=.30$; $p<.001$). Furthermore, there was a significant decline in cognitive level of preterm boys (Cohen's $d=-.41$; $p<.001$).

Abundant studies suggest that children born at earlier gestational ages and at LBW are at greater risk of having medical complications and developmental delays (e.g., Anderson & Doyle, 2008; Duerden, Taylor, & Miller, 2013; Taylor, 2010). Due to the increased probability of having complex medical conditions and developing delays in language, motor and social-emotional function, and cognition, parental stress can be even higher for parents who have children born preterm and/or LBW (Brummelte, Grunau, Synnes, Whitfield, & Petrie-Thomas, 2011; Grunau, et al., 2009; Robson, 1997; Singer, et al., 1999). In fact, many researchers have discovered that child developmental delays among children born preterm, diagnosed by using norm-referenced, clinician-administered assessments, predict parental stress in longitudinal studies; parental stress either increased as the child aged or was found significant when the child was in early

childhood, not infancy or toddlerhood (Brummelte, et al., 2011; Grunau, et al., 2009; Robson, 1997; Singer, et al., 1999). The following sections discuss these research findings in greater detail.

Parental Stress and Children Born Preterm

Investigators suggest that levels of parental stress differ depending on the degree of prematurity and/or LBW, and the medical complications children born preterm experienced (Lessenberry & Rehfeldt, 2004; Schappin, Wijnroks, Venema, & Jongmans, 2013). Since children born preterm are more likely to have medical complications and neurodevelopmental deficits that often lead to developmental delays (Brummelte, et al., 2011; Lowe, et al., 2014; Woodward, et al., 2005) these children's parents are more likely to exhibit higher levels of stress (Cutrona & Troutman, 1986; Halpern & MacLean, 1997; Secco, Askin, & Yu, 2006; Warfield, Shonkoff, & Krauss, 2001). Several researchers conducted longitudinal studies to investigate if actual developmental delays, determined by a clinician-administered norm-referenced assessment, contribute to increased levels of parental stress within preterm populations (Brummelte, et al., 2011; Treyvaud, 2011).

Robson (1997) investigated whether developmental delays among 59 children born preterm were associated with parental stress in a longitudinal study. She found that 'total' stress on the PSI was negatively correlated with the MDI of the BSID when the children were one year old ($r=-.28$) and the General Cognitive Index (GCI) of the McCarthy Scales of Children Abilities when the children were 5.5 years old ($r=-.47$). This finding suggests that as child cognitive level decreased, parental stress increased (e.g., the effect sizes increased as time progressed). Furthermore, hierarchical regressions revealed that developmental delay at age 5.5 significantly predicted parental stress on the

PSI (total stress score) ($R^2 = .32$). These findings suggest that the child's developmental level predicted parenting stress at age 5.5, but not at age one.

Likewise, Singer et al., (1999) researched these variables in a sample of 206 children born preterm/LBW and 123 children born full term at ages: 8-months, 1-year, 2-years, and 3-years on the BSID and parental psychological distress on the Brief Symptom Inventory (BSI) and parental stress (total score) on the PSI. The authors sampled three groups: children born full-term, preterm/LBW and low-risk, and preterm/LBW and high-risk. Low-risk preterm infants were defined as those with the following: (1) weighed less than 1,500 grams at birth and (2) required oxygen supplementation for less than 14 days. High-risk preterm infants were defined as those with all the following: (1) diagnosis of Bronchopulmonary Dysplasia (BPD), (2) birth weight of less than 1,500 grams, (3) supplementary oxygen requirement for more than 28 days because of lung immaturity at birth, and (4) radiographic evidence of chronic lung disease. The authors found mothers of infants born preterm who had BSID standard scores in the Intellectually Disabled range (less than 70) reported 21% more psychological distress (e.g., somatic symptoms, depression, and anxiety) than those mothers of infants born preterm, but low risk, or those born full term, at 8-months. Two years later, mothers of low-risk preterm infants did not differ from mothers who had full term children, while mothers of high-risk infants continued to report psychological distress. Three years later, mothers of high-risk preterm children did not differ from mothers of low risk or full-term children in distress symptoms, but parenting stress (total stress) was greater on the PSI (e.g., for the high-risk VLBW group; parental stress increased as child aged [$t = 2.1$; $p < .05$]), suggesting that 'total' parenting stress increased as children identified as Intellectually Disabled aged.

More recently, others have found similar results. Grunau, et al., (2009) investigated maternal stress and developmental delays in a sample of 137 children born preterm and 74 children born full term at ages 8 months and 18 months, finding that lower parenting stress on the PSI-III (total score) ($\beta = -.19, p < .05$) was associated with higher MDI of the BSID at 18 months *only*, not 8 months. This finding suggests that lower levels of development are associated with increases in parenting stress as the child ages. Similarly, Brummelte, Grunau, Synnes, Whitfield, and Petrie-Thomas (2011) investigated developmental delays among a sample of 98 children born preterm and 54 children born full term at 8 and 18 months and reports parental stress among primary caregivers. Hierarchical regressions revealed that children who had decreasing MDI scores on the BSID from 8 to 18 months chronological age had parents who reported higher levels of parenting stress (child domain score) on the PSI-III (in the group of children born preterm, but not children born full term). Lower MDI at 18 months predicted higher parenting stress ($\beta = -.26, p < .05$) on the child domain of the PSI-III (e.g., Distractibility, Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood, Acceptability), especially from 8 to 18 months ($\beta = -.30, p = .01$). This decrease in the children's cognitive performance from 8 to 18 months predicted higher scores on the PSI in both the child (e.g., Distractibility, Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood, Acceptability) and parent domain (e.g., Competence, Isolation, Attachment, Health, Role Restriction, Spouse/Parenting Partner Relationship) in preterm children, whereas for full-term children the number of children in the home and child behavior were the main predictors of parenting stress.

Others have studied additional familial factors such as family functioning and burden, in addition to parental stress, and developmental delays in children born preterm. Treyvaud, et al., (2011) investigated parental stress on the PSI, family functioning and family burden on the Impact on Family Scale (IFS), and child developmental delays on the BSID at age two in a sample of 184 children born very preterm and 71 children born full term and their parents. In contrast to previous studies, there was little evidence that having a child born very preterm with a developmental delay was associated with poorer family functioning or parenting stress. However, having a child born very preterm with a developmental delay was associated with higher family burden (e.g., “we see family and friends less because of my child” and “our family gives up things because of my child”) (Cohen’s $d=.40$; $p<.05$). Perhaps, a reason that this study failed to find an association between developmental delays and parental stress is because it assessed children at 2 years of age, not older. Developmental delays in older children can be more apparent and affect them outside the home, perhaps having a greater impact on parental stress (Robson, 1997; Singer, et al., 1999).

Although many studies have found associations between developmental delays, measured by norm-referenced assessments, among children born preterm and parental stress, only one study was found that investigated how the *perception* of dysregulated behavior among children born preterm can impact parental stress. Mantymaa, Puura, Luoma, Salmelin, and Tamminen (2006) investigated perceived child ‘difficult’ temperament and parental stress with 124 mother-child dyads in a Finnish sample of the European Early Promotion Project (EEPP). A mother’s perception of her infant’s temperament was assessed with the Infant Characteristics Questionnaire (ICQ) and

parental stress was assessed using the PSI. Total parental stress accounted for 24% of the variance in perceived infant difficultness. However, a more objective, observational measure was not administered, so there was no way of knowing if the mother's perceptions accounted for more of the variance in parental stress, compared to an objective measure.

Gaps in Literature

Although extant studies suggest child developmental disabilities impact parental stress (Cutrona & Troutman, 1986; Halpern & MacLean, 1997; Secco, Askin, & Yu, 2006; Warfield, Shonkoff, & Krauss, 2001), fewer studies have specifically investigated whether developmental delays impact parental stress among children born preterm, who are already at greater risk of having neurodevelopmental deficits. Furthermore, whether a *perceived* child developmental delay impacts parental stress in preterm samples, as much or more than an actual developmental delay, has not been studied. Although neurodevelopmental difficulties can become more apparent as the child ages (Anderson & Doyle, 2007; Maupin, 2012), no studies were found that investigated whether actual or perceived developmental performance in children born preterm predicts the change in parental stress over time and whether child medical complications experienced at birth (e.g., child birth weight and use of mechanical ventilation) predict parental stress across early childhood including when the child is 18-29 and 36-65 months.

Current Study

The purpose of this study was to investigate previously untested associations between medical variables (i.e., birth weight and mechanical ventilation), parenting stress, perceived child development, and objectively measured child development in very

premature children. Data were collected at 18-29 months and 36-65 months on 22 children born at or prior to 30 weeks gestational age and one of their parents. Parent perceived developmental delay was assessed at 18-29 months using item #4 of the Child Development Review (i.e., “Does your child have any problems or disabilities?”). Parenting stress was assessed using the Parenting Stress Index, 3rd edition, Short Form (PSI-III-SF) when children were 18-29 months and by the Parenting Stress Index, 4th edition, Short Form (PSI-IV-SF) when children were 36-65 months. Actual developmental performance was assessed by the Brigance Early Head Start Screen (Brigance Screen) at 18-29 months.

Research Questions and Hypotheses

1. Do medical complications experienced by the child at birth (e.g., birth weight and use of mechanical ventilation) contribute to the prediction of parenting stress?

Hypothesis 1a: There will be a negative bivariate correlation between child birth weight and parental stress at 18-29 months and 36-65 months.

Hypothesis 1b: Use of mechanical ventilation will predict higher parental stress at 18-29 and 36-65 months

2. Does a parent perceived developmental delay in their child born preterm (at 18-29 months) predict parental stress at 18-29 and 36-65 months, beyond actual developmental performance at 18-29 months, after controlling for birth weight and use of mechanical ventilation?

Hypothesis 2: Perceived developmental delays in children born preterm will make a unique contribution in predicting parenting stress at 18-29 and

36-65 months after controlling for their actual development, birth weight, and use of mechanical ventilation.

3. Does actual developmental performance (at 18-29 months) and perceived child developmental delay (also assessed at 18-29 months), predict the *change* in parental stress from 18-29 months to 36-65 months?

Hypothesis 3: Actual and perceived developmental delays measured at 18-29 months will make a unique contribution in predicting the change in parenting stress from 18-29 to 36-65 months, after controlling for child birth weight and use of mechanical ventilation, when children were 18-29 months.

Chapter III

Method

Participants

Original study. The data used for this study were gathered from a larger, longitudinal project. The purpose of the original study was to follow a cohort of children born preterm (born at 30 weeks or less) from 18-29 months to 36-65 months to examine their neurodevelopmental outcomes and the effects of these outcomes on parental stress. Biological parents of children born preterm followed in a high-risk infant comprehensive care clinic at the University of Texas Health Science Center in Houston were recruited for the original study. Fifty-five parent-child dyads participated in the study when the children were 18-29 months (time one). Of these parent-child dyads, 22 participated in a follow-up study when the children were approximately 36-65 months (time two). The following describes the setting in which participant data were initially collected to conduct the larger study.

The high-risk infant clinic. The participants in this study were recruited from the High-Risk Infant Clinic (HRIC) at the University of Texas Health Science Center. The clinic provides primary care services to children born preterm and other children with chronic medical needs based on the following criteria: (a) enrollment in a neonatal research study; (b) born at or less than 30 weeks gestational age, regardless of medical complexity; (c) born at greater than 30 weeks and presenting with medical complexities (e.g., discharged on equipment, history of extracorporeal membrane oxygenation, hypoxic-ischemic encephalopathy and cooling therapy, Grade IV intraventricular hemorrhage, periventricular leukomalacia, central nervous system anomalies, non-cardiac

congenital anomalies); (d) previous fetal center patients; and/or (e) sibling multiples of babies meeting any of the above criteria. Children are not eligible for HRIC follow-up services if they present with complex congenital heart disease. Of those offered HRIC service, approximately 60%–70% choose to enroll; approximately 80% of children in the clinic were born prior to 30 weeks gestational age, approximately 11% were born 30–36 weeks gestational age, and approximately 9% were born after 37 weeks gestational age but were followed in clinic because of other medical risk factors. The clinic services children with Medicaid (approximately 73% of patients), Medicaid and an additional form of insurance (approximately 18% of patients), and other forms of insurance or payment (e.g., private insurance, military insurance, self-pay, international billing, approximately 9%). Many of these children also participate in other research studies.

Current study. For the current study, parent-child dyad data that were collected for use in the larger study at the HRIC on children born at or less than 30 weeks gestation and one of their parents was used to analyze parental stress, child medical variables, perceived developmental delay, and actual developmental performance. The participant data taken from the larger study included parent-child dyad data when the children were 18-29 months (time 1) and 36-65 months (time 2). Fifty-seven parent-child dyads participated in the first phase of the original study (time one) and 55 of those participants completed measures appropriate for use in the current study. Of those participants, 28 were contacted by telephone to participate in the follow up study (time two), 22 agreed to participate and these data were drawn for the current study.

Measures

Original study, time one. Research assistants gathered demographic information including parent marital status, child gender and ethnicity during time one of the original study. With HIPAA release, a medical information form that included child gestational age, birth weight, and medical conditions was completed by medical staff. A norm-referenced assessment administered to assess potential child developmental delays in the original sample was the Brigance Early Head Start Screen (0-35 months) (Brigance Screen). Self- and child-report measures included the Parenting Stress Index, 3rd edition, Short-Form (PSI-III-SF), a standardized measure used to assess parental stress, the Eyberg Child Behavior Inventory (ECBI), a comprehensive, behaviorally-specific rating scale that measures the current frequency and severity of disruptive behaviors in children two to sixteen years of age in the home, and the Child Development Review (CDR), a questionnaire that screens for health, development, and behavior problems of children ages eighteen months to five years of age. Those measures administered to participants in time one of the original study that were used in the current study are discussed in more detail later.

Original study, time two. The norm-referenced assessments that were administered during time two of the original study included the Individual Growth and Development Indicators (IGDIs) measure, a tool used to screen and monitor the progress of early literacy and numeracy development in preschoolers and the Brigance Early Childhood Screen, 3rd edition (3-5 years) (Brigance Screen-III), to assess potential developmental and academic delays in children three to five years of age (the 3- and 4-year assessments were used). In addition, the Differential Ability Scale, 2nd edition,

Early Years (DAS-II), a cognitive measure used to assess verbal and non-verbal reasoning in children two years, six months to eight years, eleven months of age was also administered. Self- and child-report measures included the Parenting Stress Index, 4th edition, Short-Form (PSI-IV-SF), a standardized measure used to assess parental stress, the Eyberg Child Behavior Inventory (ECBI), a comprehensive, behaviorally-specific rating scale that measured the current frequency and severity of disruptive behaviors of children ages two to sixteen years in the home, and the Behavior Rating Inventory of Executive Function, Preschool Version (BRIEF-P), which assessed executive functioning, including inhibition, shifting, emotional control, working memory, and planning/organization in children two to five years of age. Measures administered to participants in time two of the original study that were used in the current study are discussed in more detail in the following sections.

Current study, time one. Data from the following measures were used from time one of the original study.

Parenting Stress Index, 3rd edition, Short-Form. The Parenting Stress Index (PSI) has been the most commonly used self-report measure of parental stress (Abidin, 1986). The Parenting Stress Index, 3rd edition, Short-Form (PSI-III-SF) was originally derived from the PSI and is a shorter version of the Parenting Stress Index, 3rd edition (PSI-III), which provides information about both stressors related to perceptions of a specific child and stressors related to self-perceptions of parental competence and mood. The PSI-III-SF takes less time to administer (e.g., ten minutes) than the PSI-III, due to a reduction in items. It is a standardized measure that permits the identification of levels of stress outside the typical range. It consists of 36 items divided into three 12-item

domains: Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI), and Difficult Child (DC). The PSI-III-SF yields a fourth score, the Total Stress score, from the three scales. In addition, it has a Defensive Responding (DR) scale. It is used for parents of children 12 years or younger. The normal range for scores is within the 15th to 84th percentiles; high scores are considered to be scores at the 85th to the 89th percentile and scores in the 90th percentile or higher are considered clinically significant (Abidin, 1995).

The PSI-III-SF was developed through a series of replicated factor analyses, based on two samples, which resulted in a three-factor solution (N=800) (Abidin, 1995; 2005). Whiteside-Mansell et al. (2007) found the PSI-III-SF had high internal consistency among the four domains: Parental Distress = .79; Parent-Child Dysfunctional Interaction = .80; Difficult Child = .78; and Total Stress = .90. In addition, test-retest reliability was assessed over a 6-month period and the coefficient for the Total Stress scale was .84, Parental Distress was .85, Parent-Child Dysfunctional Interaction was .68, and Difficult Child was .78. A regression analyses supported the construct validity of the PSI-III-SF. It has acceptable to excellent convergent and discriminant validity. All subscale scores of the PSI-III-SF correlate highly with the original, longer, version (Total Stress =.94, Parent Distress =.92, Difficult Child =.87, Parent-Child Dysfunctional Interaction =.73). Moreover, in one study assessing predictive validity, the scores were related to parent reports of child behavior one year later (Haskett, Ahern, Ward & Allaire, 2010). The following sections describe each subscale in more detail.

Defensive Responding. Parent respondents who score high on this scale may be trying to minimize any problems, stress, or negativity in their child. A score on this scale

of 10 or less indicates responding in a defensive manner, therefore, caution should be used in interpreting any of the sub-scale or total stress scores when Defensive Responding is elevated (Haskett, et al., 2006).

Parental Distress. This scale determines to what extent a parent is experiencing stress in their role as a caregiver as a function of personal factors that are directly related to parenting (Abidin, 1995). It measures parental competence, stressors associated with parental restrictions in life, relationship conflict with partner, lack of social support, and depression. When the parent endorses a Parental Distress score at or above the 90th percentile in combination with a Difficult Child score below the 75th percentile, it is likely the parent is experiencing personal adjustment difficulties that may be independent of the parent-child relationship (Haskett, et al., 2006).

Parent-Child Dysfunctional Interaction. This scale measures the extent to which a parent believes their relationship with their child needs improvement. A score at or above the 85th percentile can indicate that the parent sees the child as disappointing, feels a sense of rejection, or has not properly bonded with their child (Haskett, et al., 2006).

Difficult Child. This scale indicates how easy or difficult the parent perceives their child. Scores at or above the 90th percentile indicate concerns with child behavior for toddlers, and could indicate problems with self-regulatory processes in infants (Haskett, et al., 2006).

Total Stress. This scale indicates the overall level of parenting stress a parent is experiencing. The Total Stress score reflects the stresses reported in the areas of personal parental distress, stresses derived from the parent's interaction with the child, and stresses that result from the child's behavioral characteristics. A parent with a score at or above

the 90th percentile is experiencing clinically significant levels of stress (Haskett, et al., 2006).

The PSI-III-SF yields raw scores and percentile ranks. Total Stress t-scores were used to assess parental stress for the current study. To calculate t-scores, Total Stress raw scores were deducted from the normative Total Stress mean and divided by the standard deviation. Lastly, this score was multiplied by 10 and, then, 50 was added to produce a t-score. Due to the longitudinal nature of the current study, t-scores provided a standardized way to compare parental stress across two-time points. Total Stress percentile ranks were also reported.

Brigance Early Head Start Screen (0-35 months). The Brigance Early Head Start Screen, (Brigance Screen), 0 to 35 months version, was designed to assess child development of children 0 to 2 years, 11 months through direct assessment and observation and can be administered in approximately 15 minutes (Glascoe, 2010). The Brigance Screen assesses language development (receptive/expressive language), physical development (gross/fine motor), and adaptive behavior (self-help and social emotional skills) in children 12-23 months (“Toddler Screen”) and language development (receptive/expressive language) and physical health/development (gross motor and fine motor/visual-motor) in children 24-35 months of age (“Two-Year-Old Screens”). The “Two-Year-Old Screens” are divided into two sections: a section for children ages 24 to 29 months and a section for children ages 30 to 35 months. Only the Toddler Screen (12-23 months) and the Two-Year-Old (24 to 29 month) Screen were used in the original study. The Brigance Screen was standardized using a diverse sample of 1,366 children. Of those children, 207 were 12-23 months, 75 were 24 to 29 months of age. Groups were

drawn from populations of diverse ethnic, geographical, and socioeconomic status (Aygün, et al., 2011).

The Brigance Screen has a high degree of internal consistency (.94-.98) and acceptable to excellent test/retest reliability (.73-1.0) for children 12-35 months of age. Factor analysis revealed a three-factor solution for the Toddler Screen and a two-factor solution for the Two-Year-Old Screen. It has been found to have good criterion validity. The screens are excellent at detecting children with delays (sensitivity at 75-82%) and those without delays (specificity at 85-86%) (Glascoe, 2010). Moreover, it was found to have excellent sensitivity (1.00) and moderate specificity (.60) in a medical sample of children born extremely preterm when the children were 18-29 months of age (Dempsey, Abrahamson, & Keller-Margulis, 2015).

Items on the Brigance Screen were weighted according to importance of each skill area at a given age. The Total score (raw score) is used to determine if a child has scored below the set cutoff for a potential developmental delay, indicating a need for a referral for a full evaluation. In addition to the Total raw score, raw scores for each of the Domains (e.g., Language and Physical [and Adaptive Behavior for toddlers]) can also be calculated. The raw scores for the Total score and Domain scores can be converted into composite scores (standard scores), which provides a child's performance relative to the mean of the standardized sample. In order to attain composite scores, a child's chronological age must be determined. For children 29 months of age or younger, and who were 4 or more weeks premature, adjustments were made to chronological age (e.g., subtracting the number of weeks the child was premature from the child's actual age) to produce a corrected age. Many researchers suggest that adjustments to chronological age

no longer need to be made after a child's two-year birthdate. However, most recently the American Academy of Pediatrics recommends that age correction should be applied for preterm children up to 3 years of age (Wilson-Ching, Pascoe, Doyle, & Anderson, 2014).

Data from children assessed for developmental delays with the Brigance Screen between 18 to 29 months were assessed. Different assessments and data sheets were used depending on the child's age. Those children 18-23 months were assessed using the Toddler assessment and children two years to two years, five months (24-29 months) were assessed using the Two-Year-Old to Two-Year, Five-Month-Old child assessment. For the current study, Total standard scores were taken from the Toddler data sheet (based on children who were 18-23 months) and Total standard scores from the Two-Year-Old to Two-Year, Five-Month-Old child data sheet were used for those children who were two years to two years, five months (24 to 29 months). Standard scores were used because the children assessed were different ages, so warranted one of two different assessments within the Brigance Screen. Standard scores provide a meaningful, standardized unit of measurement capable of comparing children of various ages.

Child Developmental Review. The Child Developmental Review (CDR) is a tool used to screen for health, development, and behavior problems of children ages 18 months to 5 years of age. The CDR was derived from research on the Child Developmental Inventory (CDI). The CDI consists of a 300-item booklet and an answer sheet for parents to complete. There are 270 statements relating to developmental skills of young children that are observable by parents in everyday situations. These items measure the child's development in eight areas: social, self-help, gross motor, fine motor, expressive language, language comprehension, letters, and numbers. It also

includes a General Development Scale (composed of the eight areas) and 30 items to identify parent's concerns about their child's health and growth, vision and hearing, development and behavior (Ireton, 1992).

The norm sample was obtained from 568 parents in South Saint Paul, Minnesota, a primarily white, working class community. The children ranged in age from one to six years, three months. Most parents were high school graduates (83%), some were college graduates (14%) and a few did not complete high school (3%). Cronbach's alpha-internal consistency for children ages 18-24 months ranged from .68 to .94. The scales were not derived by factor analysis (Ireton, 1992), but in one study that incorporated participants from South Saint Paul Early Childhood Screening, which provides early identification and early intervention for children ages two to six with special educational needs, sensitivity was found to be 73%, however, specificity was not discussed. The CDR was found to have poor sensitivity (.44) and acceptable specificity (.80) in a medical sample of children born extremely preterm when they were 18-29 months of age (Dempsey, et al., 2015).

The CDR is a screening measure that provides information about a child's health, development and behavior, and parental functioning. The parent completes the front side of the CDR, which includes two sections: 1) six open-ended questions and 2) a 26 item 'possible problems' checklist. The six questions include: a) Describe your child briefly, b) What has your child been doing lately? c) What are your child's strengths? d) Does your child have any special problems or disabilities/What are they? e) What questions or concerns do you have about your child? f) How are you doing as a parent at this time? The possible problems list includes a checklist on health, growth, hearing, vision, eating,

toileting, sleeping, aches and pains, energy, motor symptoms, language symptoms, behavior, and emotional problems (Ireton & Vader, 2004). Raw scores and standard scores are not reported.

The back side of the CDR contains a Child Development Chart for the first five years of age that helps to determine the child's development across five domains assessed through parent report and clinician observations of a child's skills: social, self-help, gross-motor, fine motor, and language (Ireton & Vader, 2004). The behaviors on the chart are placed at the age level during which at least 70% of children display the skill (e.g., walks without help is at 13-14 months). This chart is based on parent-report of the child's present skills along with clinician observations. The Child Development Chart results are classified as "typical" for age, as "borderline" (1.5 standard deviations below the mean, or 25% below typical development) or "delayed" (2.0 standard deviations below the mean, or 30% below typical development) in one or more areas of development (Ireton & Vader, 2004). Since the chart is based on both parent-report *and* clinician observation, it was *not* used as part of the current study.

Initially, to capture parents who endorsed a concern that their child may have a developmental delay, items #4 and #5 were assessed to determine 'perceived developmental delay' in the child by parents (e.g., "Does your child have special problems or disabilities/what are they?" or "What questions or concerns do you have about your child?"). The purpose was to eliminate the possibility of potentially missing parents who endorsed a concern that their child may have a developmental delay on one question, but not the other. A t-test was conducted to determine if there was a significant difference in responses between items. The t-test determined that there was low

variability in responses ($t=.30, p>.05$) between the questions (e.g., parents who did not endorse a concern on one item also did not endorse a concern on the other item), so only item #4 was used, which was intended to:

Identify any 'condition' of the child that has been identified by the parent or some professional as a significant, possibly major, problem or 'disability'. In the CDR research, this question was answered with some reported problem by 15% of parents. Only 3% of parents described a problem that was classified as a major problem or disability. Reported problems or disabilities ranged from 'left-handed' to 'allergies' to 'hearing' to 'multiple disabilities'. The majority were physical-health problems that could interfere with learning (Ireton & Vader, 2004, p. 6).

To determine whether perceived developmental performance predicted parental stress, this variable was dummy coded by coding a “no” response as “0” and a “yes” response as “1”.

Current study, time two. Data from the Parenting Stress Index, 4th edition, Short-Form (PSI-IV-SF) were gathered to analyze parental stress when the children were 36-65 months for the current study, instead of the PSI-III-SF, which was used during time one of the study.

Parenting Stress Index, 4th edition, Short-Form. The Parenting Stress Index, 4th edition, Short-Form (PSI-IV-SF) resulted from the Parenting Stress Index, 4th edition (PSI-IV), which was derived from the PSI. The PSI-IV-SF consists of 36 items divided into three 12-item domains: Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI), and Difficult Child (DC). The PSI-IV-SF yields the Total Stress score from the three scales. It also has a Defensive Responding (DR) scale. It is used for

parents of children 12 years or younger. The normal range for scores is within the 15th to 84th percentiles; high scores are considered to be scores at or above the 85th to 89th percentile and scores in the 90th percentile or higher are considered clinically significant (Abidin, 1995)

Internal consistency alphas for the PSI-IV-SF are near .90. Test-retest reliability was assessed over a 6-month period and produced the following coefficients: .84 for the Total Stress scale, .85 for Parental Distress, .68 for the Parent-Child Dysfunctional Interaction scale, and .78 for the Difficult Child scale. Correlations between the PSI-SF and PSI-IV-SF were .99 for the Total Stress and Parental Distress scales, .98 for Parent-Child Dysfunctional Interaction scale, and .97 for the Difficult Child scale. Correlations between the PSI-IV and PSI-IV-SF were .98 for the Total Stress scale, .94 for the Parental Distress scale, .91 for the Parent-Child Dysfunctional Interaction scale, and .82 for the Difficult Child scale.

Unlike the PSI-III-SF, the PSI-IV-SF provides t-scores in addition to percentile ranks. A few items were changed or moved to a different item number on the PSI-IV-SF from the PSI-III-SF. One item was altered to match new terminology (e.g., “spouse/parenting partner” instead of “male/female friend”) and another item was altered to specify child behavior (“my child is more of a problem than I expected” to “my child’s *behavior* is more of a problem than I expected”). One item on the Difficult Child scale was removed (e.g., “my child does a few things which bother me a great deal”) and one item was added to the Parent-Child Dysfunctional Interaction scale (e.g., “compared to the average child, my child has a great deal of difficulty in getting used to changes in

schedules or changes around the house”). For the sake of consistency, the subscales are listed again for review.

Defensive Responding. Parent respondents who score high on this scale may be trying to minimize any problems, stress, or negativity in their child. A score on this scale of 10 or less indicates responding in a defensive manner, therefore, caution should be used in interpreting any of the sub-scale or total stress scores when Defensive Responding is elevated (Haskett, Ahern, Ward, & Allaire, 2006).

Parental Distress. This scale determines to what extent a parent is experiencing stress in their role as a caregiver as a function of personal factors that are directly related to parenting (Abidin, 1995). It measures parental competence, stressors associated with parental restrictions in life, relationship conflict with partner, lack of social support, and depression. When the parent endorsed a Parental Distress score at or above the 90th percentile in combination with a Difficult Child score below the 75th percentile, it is likely the parent is experiencing personal adjustment difficulties that may be independent of the parent-child relationship (Haskett, et al., 2006).

Parent-Child Dysfunctional Interaction. This scale measures the extent to which a parent believes their relationship with their child needs improvement. A score at or above the 85th percentile can indicate that the parent sees the child as disappointing, feels a sense of rejection, or has not properly bonded with their child (Haskett, et al., 2006).

Difficult Child. This scale indicates how easy or difficult the parent perceives their child. Scores at or above the 90th percentile indicate concerns with child behavior for toddlers, and could indicate problems with self-regulatory processes in infants (Haskett, et al., 2006).

Total Stress. This scale indicates the overall level of parenting stress a parent is experiencing. The Total Stress score reflects the stresses reported in the areas of personal parental distress, stresses derived from the parent's interaction with the child, and stresses that result from the child's behavioral characteristics. A parent with a score at or above the 90th percentile is experiencing clinically significant levels of stress (Haskett, et al., 2006).

The PSI-IV-SF yields raw scores, t-scores, and percentile ranks. Total Stress t-scores were used to assess the relationship between child measures and parental stress for the current study. Total Stress percentile ranks were also reported. As mentioned previously, due to the longitudinal nature of the current study, t-scores provided a standardized way to compare parental stress across the two-time points.

Procedure

Original study, time-one. The original study was approved by the Institutional Review Boards at the University of Texas Health Science Center in Houston and the University of Houston. Parents whose children received medical services from the HRIC at the University of Texas Health Science Center in Houston were asked to participate in the larger study by the clinic coordinator or research nurse during a non-sick visit (e.g., well-child check, follow-up appointment, or research appointment) when the children were approximately 18-29 months. Study procedures were conducted at the HRIC. Parents of the child participants were given consent forms. If parents consented, they completed a background/demographic information form (e.g., information regarding the educational and developmental history of the children) and questionnaires (ECBI, CDR, PSI-III-SF) while a member of the research team administered the direct child assessment

(Brigance Screen). Participant families were given parking reimbursement and \$10 gift cards for their participation.

Original study, time-two. Parent-child dyads participated in time-two of the original study when the children were approximately 36-65 months if: a) they participated in time one of the original study, b) parents consented to be re-contacted for participation in future studies, c) parents were contacted by phone and agreed to participate, and d) the parent-child dyads arrived at the HRIC for participation. After consenting, parents were provided a background/demographic information form (e.g., information regarding the educational and developmental history of the children) and questionnaires (ECBI, BRIEF-P, PSI-IV-SF) to complete. While parents completed their forms, children were administered direct assessments (IGDIs, Brigance Screen-III, DAS-II) by a member of the research team. Participant families were given parking reimbursement and \$100 gift cards for their participation.

Current study. The current study used data drawn from time-one and two of the original study upon Institutional Review Board approval at the University of Houston. The Brigance Screen, CDR, and PSI-III-SF data were drawn from time-one of the original study. The PSI-IV-SF data were drawn from time-two of the original study. Only the parent-child dyad data of those participants who participated in both time points (time-one and time-two) of the original study were included.

Chapter IV

Results

Descriptive Statistics

There were 22 parent-child dyads in this study. Sixty-six percent of the parents in the sample were married (N=15) and 13% were single (N=3). Four parents did not specify their marital status. Fifty percent of the children were female (N=11) and male (N=11). Fifty-nine percent of children were African American (N=13), 27% were Caucasian (N=6), and 14% were Hispanic (N=3). Ninety-five percent (N=21) of children were reported to have used mechanical ventilation as a treatment/life-saving procedure and one, reportedly, did not use the procedure (N=1). Fifty-five percent (N=12) of parents reported concerns that their child had a development delay, as opposed to 45% (N=10) who did not report a concern. During time one of the study, 10% (N=2) of parents endorsed at-risk levels of stress and 5% (N=1) endorsed clinically significant levels of stress. The remaining 18 mothers reported typical levels of parental stress. During time-two, 14% (N=3) of parents endorsed at-risk levels of stress, while no parents endorsed clinical levels of stress. The remaining 19 mothers reported typical levels of parental stress. The mean child actual developmental performance standard score on the Brigance Screen for this sample of children was 76. Please see Table A1 to view descriptive information on additional variables.

Assumptions

To make conclusions about hierarchical regressions, it is assumed the sample data have certain characteristics necessary to give unbiased estimates (Van Voorhis & Morgan, 2007). One assumption is that the predictor and outcome variables are

continuous, interval level data. However, this hypothesis has not been specifically addressed and some researchers advocate their ordinal nature (Jamieson, 2004).

Nevertheless, investigators who engage in psychological research continue to use rating scales under the assumption that the data retrieved from these measures are interval data (Carifio & Perla, 2007). The following sections discuss these assumptions in detail.

Outliers. The data were checked for outliers. Values above or below three standard deviations were designated as outliers. Box plots were analyzed and no outliers were found for child birthweight, parental stress at time-one or time-two, as assessed by the PSI-3-SF and PSI-4-SF, or actual child delay, as assessed by the Brigance Screen. Use of mechanical ventilation at birth and perceived developmental delay as assessed by item #4 on the CDR were nominal variables and were not subject to outliers.

Risk of Type 1 and Type II Errors. A key consideration for interpreting non-significant findings is statistical power (Field, 2009). Twenty-two parent-child dyads, were included in this study. This was enough power to detect almost a moderate association in bivariate analyses (power=.41) and more than a moderate association in the multivariate analysis (power=.61). It is important to note that there was a 59% chance of committing a Type II error within the bivariate analyses and a 39% chance within the multivariate analyses in this study. Since there was a small effect size in the multivariate analysis used to assess change in parental stress, the power was only .30, therefore, there was a 70% chance of committing a Type II error during this analysis. Due to the seven regressions that were run, the Type I error rate was .21. In other words, there was a 21% chance that a significant association between variables would occur, when in fact, the association was not significant.

Normality. The Shapiro-Wilk test was conducted to assess for residuals and to determine whether distributions were considered non-normal ($p < .05$). A histogram was also used to assess normality; a bell-shaped curve indicated a normal distribution (Abrams, 2002). Shapiro-Wilk scores were not statistically significant from the normal distribution; therefore, the hypothesized assumption of normal data was not rejected and data were analyzed without making any corrections for non-normal distributions.

Linearity. A visual inspection of a scatterplot was used to assess linearity, which proposes that the relationship between the predictor variables and outcome variable is linear. To assess linearity between the predictors and outcome variables, a bivariate scatterplot was examined. All the variables were linearly related; no curvilinear relationships were found.

Homoscedasticity. The residuals exhibited homoscedasticity, meaning there was a constant variance across values of each predictor (i.e., residuals were evenly distributed throughout the regression line). Heteroscedasticity would have been indicated by a funnel-shape (Field, 2009). The residuals were uncorrelated (or independent), meaning one did not depend on the other. A Durbin-Watson test was conducted to test for correlations between residuals. If a score is approximately 2, the Null Hypothesis is not rejected because the residuals are considered independent. The value of parent stress at time one, as assessed by the PSI-3-SF, was 2.04 and the value of parent stress at time two, as assessed by the PSI-4-SF, was 2.40. A value greater than 2 indicates a negative correlation between adjacent residuals and a value less than 2 indicates a positive relationship (Field, 2009); therefore, a slight negative correlation existed between the

residuals of parent stress at time two. However, this was not considered sufficient deviation to necessitate a change in the data or analysis.

Multicollinearity. The presence of multicollinearity implies that the predictor variables were redundant with one another; therefore, one predictor variable does not add any predictive value over another predictor variable (Abrams, 2002). Multicollinearity was examined by determining the tolerance values and the Variance Inflation Factors (VIF). Tolerance values below 0.1 and VIF scores greater than 10 indicated that there may be a concern with multicollinearity (Field, 2009). To determine if correlations between variables had an adverse effect on the analyses, tolerance and Variance Inflation Factors (VIF) were assessed. All variables produced a tolerance value larger than .10 (i.e., 1.00) and a VIF value smaller than 10 (i.e., 1.00), meaning the correlations did not have an adverse effect on the parameter estimates in the multivariate analysis because multicollinearity was not detected.

Statistical Analysis

Throughout all analyses, statistical inference was based on change in R-squared to determine statistical significance and the magnitude of effects, and Beta-weights were reported to examine the direction of the relationship. The following sections describe each statistical analysis, based on the hypotheses of the current study.

Bivariate correlation. Two bivariate correlations were used to determine if there was a negative correlation between child birth weight and parental stress when the children were 18-29 (Y1) months and 36-65 (Y2) months in SPSS version 22. Parental stress was assessed using the PSI-III-SF total stress T-score when the children were 18-29 months and the PSI-IV-SF total stress T-score was used when the children were 36-65

months. Due to the longitudinal nature of the current study, T-scores provided a standardized way to compare parental stress across two time points. The bivariate beta coefficient was squared to determine an effect size comparable to the other analyses discussed within this section (i.e., the total percent explained variance) and a beta-weight was provided to examine the direction of the relationship.

In the current study, $Y1$ was parental stress as measured by the total stress T-score of the PSI-III-SF when the children were 18-29 months and $Y2$ was parental stress as measured by the total stress T-score of the PSI-IV-SF when the children were 36-65 months. $X1$ was birth weight of the child born preterm.

The first bivariate correlation is formulaically represented below and represents the relationship between $Y1$ (parental stress at time 1) and $X1$ (birth weight):

$$a. Y1 = (\beta_0 + \beta_1 X1) + \epsilon$$

$Y1$ is the outcome variable (parental stress as assessed by the total stress T-score of the PSI-III-SF during the time the children were 18-29 months) and β_0 is the intercept or the average of Y when the predictor (birth weight) was zero. β_1 indicates the increase in Y for every unit increase in the predictor variable. β_1 is the regression slope of 'child birth weight' ($X1$).

This equation was entered into SPSS as the following:

$$a. \text{PSI-III-SF} = \text{BW}$$

The second bivariate correlation is formulaically represented below and represents the relationship between $Y2$ (parental stress at time 2) and $X1$ (child birth weight):

$$a. Y2 = (\beta_0 + \beta_1 X1) + \epsilon$$

Y_2 is the outcome variable (parental stress as assessed by the total stress T-score of the PSI-IV-SF during the time the children were 36-65 months) and β_0 is the intercept or the average of Y when the predictor (birth weight) was zero. β_1 indicates the increase in Y for every unit increase in the predictor variable. β_1 is the regression slope of 'child birth weight' (X_1).

This equation was entered into SPSS as the following:

a. $PSI-IV-SF = BW$

Bivariate regression. A regression is an analysis used to describe the relationship between a criterion/dependent variable and a predictor/independent variable. A regression line or equation that best fits a straight line that can be drawn through data points in a scatterplot is created (Meyers, Gamst, & Guarino, 2006). The simplest form of regression is a bivariate regression, in which one variable is the outcome (Y) and one is the predictor (X). The correlation coefficient squared (R^2), refers to the amount of variance in one variable accounted for by the other (Meyers, et al., 2006).

Two bivariate regressions were examined to determine if mechanical ventilation at birth predicted higher parental stress at two different time points. These analyses were examined in SPSS version 22 using an independent variable (X_1) (e.g., mechanical ventilation after birth [0= No/Reference Group, 1= Yes/Group of Interest]), which was dummy coded, and a dependent variable (parental stress as assessed by the total stress T-score of the PSI-III-SF when the children were 18-29 [Y_1] months or the PSI-IV-SF when the children were 36-65 [Y_2] months). As previously reported, due to the longitudinal nature of the current study, t-scores provided a standardized way to compare parental stress across two time points. R-squared was used to determine statistical significance

and magnitude of effects, and beta-weights were reported to examine the direction of the relationship. The following section describes these two regression models further.

The bivariate regression investigating whether use of mechanical ventilation by the child after birth predicted parental stress at 18-29 months is formulaically represented below:

$$a. Y1 = (\beta_0 + \beta_1 X1) + \epsilon$$

$Y1$ is the outcome variable (parental stress as assessed by the total stress t-score of the PSI-III-SF during the time the children were 18-29 months) and β_0 is the intercept or the average of Y when the predictor (use of mechanical ventilation after birth) was zero. β_1 indicates the increase in Y for every unit increase in the predictor variable. β_1 is the regression slope of 'use of a mechanical ventilator by the child after birth' ($X1$). The change in R-squared and the B-weight were assessed.

This equation was entered into SPSS as the following:

$$a. \text{ PSI-III-SF} = \text{MechVent}$$

The bivariate regression investigating whether use of mechanical ventilation by the child after birth predicted parental stress at 36-65 months is formulaically represented below:

$$a. Y2 = (\beta_0 + \beta_1 X1) + \epsilon$$

$Y2$ is the outcome variable (parental stress as assessed by the total stress t-score of the PSI-IV-SF during the time the children were 36-65 months) and β_0 is the intercept or the average of Y when the predictor (use of mechanical ventilation by the child after birth) is zero. β_1 indicates the increase in Y for every unit increase in the predictor variable. β_1 is the regression slope of 'use of a mechanical ventilator by the child after birth' ($X1$). The change in R-squared and the B-weight were assessed.

This equation was entered into SPSS as the following:

a. PSI-IV-SF = MechVent

Sequential multiple regressions. A sequential multiple regression is utilized when several variables are used to predict a value on a quantitatively measured criterion variable (Meyers, et al., 2006). The variable that is the focus of a sequential multiple regression is the one being predicted (outcome/dependent variable), or *Y* variable (Meyers, et al., 2006). Sequential regressions were examined in SPSS version 22 to determine if parent-perceived child delays predicted parental stress above actual child developmental performance at two time points and whether parent-perceived child delays and child developmental performance predicted the change in parental stress across two time points. Covariates include child birth weight (*X1*) and use of mechanical ventilation (*X2* [0= No, 1= Yes]), which was dummy coded. Predictors included actual developmental performance, as assessed by the total standard score of the Brigance Screen, and parent perceived child developmental delay, as assessed by item #4 of the CDR (“Does your child have any problems or disabilities/What are they?” [0= No/Reference Group, 1= Yes/Group of Interest]), which were dummy coded. Standard scores were used to assess actual developmental delay because they provided a standardized unit of measurement capable of comparing children of various ages on different assessments. As mentioned previously, due to the longitudinal nature of the current study, t-scores were used to assess parental stress during two time points, which provided a standardized way to compare parental stress across time. The following describes these models further.

Sequential multiple regression #1 and #2. Two sequential multiple regressions were used to examine if parental perceived child developmental delay, as assessed by

item #4 on the CDR, predicted parental stress when the children were 18-29 months, as assessed by the total stress t-score of the PSI-III-SF, *and* when the children were 36-65 months, as assessed by the total stress t-score of the PSI-IV-SF, above and beyond actual developmental skills, as assessed by the total standard score on the Brigance Screen, after controlling for child birth weight and use of mechanical ventilation. First, the covariates (child birth weight [X1] and use of mechanical ventilation [X2- dummy coded]) were added to the regression model to determine how much variance they contributed, followed by the predictors (parent perceived child developmental delay at 18-29 months [X3] as assessed by item #4 of the CDR [dummy coded] and actual developmental performance at 18-29 months [X4] as assessed by the total standard score of the Brigance Screen to determine how much variance they contribute to the outcome variable (parental stress either at 18-29 [Y1] or 36-65 [Y2] months).

The first sequential multiple regression is formulaically represented below and represents the analysis between actual child developmental performance and parent perceived child developmental delay (the predictors) and parental stress (the outcome variable) when the children were 18-29 months, while controlling for child birth weight and use of mechanical ventilation:

- a. *Step 1:* $Y1 = (\beta_0 + \beta_1X1 + \beta_2X2) + \epsilon$
- b. *Step 2:* $Y1 = (\beta_0 + \beta_1X1 + \beta_2X2 + \beta_3X3) + \epsilon$
- c. *Step 3:* $Y1 = (\beta_0 + \beta_1X1 + \beta_2X2 + \beta_3X3 + \beta_4X4) + \epsilon$

Y1 is the outcome (dependent) variable (reports of parental stress when the child is 18-29 months) as measured by the total stress t-score of the PSI-III-SF and β_0 is the intercept or the average of Y when the predictors (child birth weight 'BW' [X1], use of mechanical

ventilation ‘MechVent’ after birth [X2], actual developmental performance ‘Brigance’ at 18-29 months [X3], and parental perceived child developmental delay ‘CDR’ at 18-29 months [X4] are zero. β_1 , β_2 , β_3 , and β_4 indicate the increase in Y for every unit increase in the predictor variable (reports of parental stress when the children were 18-29 months). β_1 is the regression slope of child birth weight (X_1), β_2 is the regression slope of use of mechanical ventilation (dummy coded) (X_2), β_3 is the regression slope of actual developmental performance as assessed by the total standard score of the Brigance Screen at 18-29 months (X_3), and β_4 is the regression slope of parental perceived child developmental delay as assessed by item #4 of the CDR (dummy coded) at 18-29 months (X_4). To determine whether parental perceived child developmental delay at 18-29 months, as assessed by item #4 on the CDR, predicts the outcome variable (parental stress when the child is 18-29 months as assessed by the total stress t-score of the PSI-III-SF) above and beyond actual developmental performance at 18-29 months, as assessed by the total standard score of the Brigance Screen, while controlling for child birth weight and use of mechanical ventilation, the change in R-squared and the B-weights were assessed.

This equation was entered into SPSS as the following:

- a. $PSI-III-SF = BW + MechVent$
- b. $PSI-III-SF = BW + MechVent + Brigance$
- c. $PSI-III-SF = BW + MechVent + Brigance + CDR$

The second sequential multiple regression is formulaically represented below and represents the analysis between actual child developmental performance and parent perceived child developmental delay (the predictors) and parental stress (the outcome

variable) when the children were 36-65 months, while controlling for child birth weight and use of mechanical ventilation:

- a. *Step 1:* $Y2 = (\beta_0 + \beta_1X1 + \beta_2X2) + \epsilon$
- b. *Step 2:* $Y2 = (\beta_0 + \beta_1X1 + \beta_2X2 + \beta_3X3) + \epsilon$
- c. *Step 3:* $Y2 = (\beta_0 + \beta_1X1 + \beta_2X2 + \beta_3X3 + \beta_4X4) + \epsilon$

$Y2$ is the outcome (dependent) variable (reports of parental stress when the children were 36-65 months) as measured by the total stress t-score of the PSI-IV-SF. β_0 is the intercept or the average of Y when the predictors (independent) variables (child birth weight ‘BW’ [X1], use of mechanical ventilation ‘MechVent’ after birth [X2], actual developmental performance ‘Brigance’ at 18-29 months [X3], and parental perceived child developmental delay ‘CDR’ at 18-29 months [X4] are zero. β_1 , β_2 , β_3 , and β_4 indicate the increase in Y for every unit increase in the predictor variable (reports of parental stress when the children were 36-65 months). β_1 is the regression slope of child birth weight ($X1$), β_2 is the regression slope of use of mechanical ventilation (dummy coded) ($X2$), β_3 is the regression slope of actual developmental performance as assessed by the total standard score of the Brigance Screen at 18-29 months ($X3$), and β_4 is the regression slope of parental perceived child developmental delay as assessed by item #4 of the CDR (dummy coded) at 18-29 months ($X4$). To determine whether parental perceived child developmental delay at 18-29 months, as assessed by item #4 of the CDR, predicts the outcome variable (parental stress when the child is 36-65 months as assessed by the total stress t-score of the PSI-IV-SF) above and beyond actual developmental performance at 18-29 months, as assessed by the total standard score of the Brigance Screen, while

controlling for child birth weight and use of mechanical ventilation, the change in R-squared and B-weights was assessed.

This equation was entered into SPSS as the following:

- a. $PSI-IV-SF = BW + MechVent$
- b. $PSI-IV-SF = BW + MechVent + Brigance$
- c. $PSI-IV-SF = BW + MechVent + Brigance + CDR$

Sequential multiple regression #3. The third sequential multiple regression was conducted to examine if actual developmental performance as assessed by the total standard score on the Brigance Screen (at 18-29 months) and parent perceived developmental delays as assessed by item #4 of the CDR (at 18-29 months) made a unique contribution in predicting parenting stress at 36 to 65 months on the PSI-IV-SF (T-score) after controlling for medical variables. First, parental stress t-scores at time-two were deducted from parental stress t-scores at time-one to determine the change in parental stress (this was the dependent variable). T-scores were utilized since two separate measures were used (e.g., PSI-3 and PSI-4) and provided standardization in scores. The average report of parental stress at time-two was a t-score of 45 and the average reported parental stress at time-one was a t-score of 49, which produced an average of -4, suggesting that parents were slightly less stressed during time-two of the study. Next, the covariates (child birth weight ‘BW’ [X1] and use of mechanical ventilation ‘MechVent’ [X2- dummy coded]) and were added to the regression model to determine how much variance they contributed to the change in parental stress. Then, the predictors (actual developmental performance ‘Brigance’ at 18-29 months [X3] as assessed by the total standard score of the Brigance Screen and parental perceived child

developmental delay ‘CDR’ at 18-29 months [X4,] as assessed by item #4 of the CDR) were entered into the model to determine how much variance they contributed to the outcome variable (the change in parental stress [ΔY]).

The sequential multiple regression is formulaically represented below and represents the analysis between actual child developmental performance and parent perceived child developmental delay at 18-29 months and change in parental stress from the time the child was 18-29 to 36-65 months, by controlling for child birth weight and use of mechanical ventilation:

- a. *Step 1:* $\Delta Y = (\beta_0 + \beta_1 X1 + \beta_2 X2) + \epsilon$
- b. *Step 2:* $\Delta Y = (\beta_0 + \beta_1 X1 + \beta_2 X2 + \beta_3 X3) + \epsilon$
- c. *Step 3:* $\Delta Y = (\beta_0 + \beta_1 X1 + \beta_2 X2 + \beta_3 X3 + \beta_4 X4) + \epsilon$

ΔY is the outcome (dependent) variable (change in parental stress). β_0 is the intercept or the average of ΔY when the predictors (independent) variables (child birth weight ‘BW’ [X1], use of mechanical ventilation ‘MechVent’ after birth [X2]), actual developmental performance ‘Brigance’ at 18-29 months [X3], and perceived child developmental delay ‘CDR’ at 18-29 months [X4] are zero. $\beta_1, \beta_2, \beta_3, \text{ and } \beta_4$ indicate the increase in Y for every unit increase in the predictor variable (the change in parental stress). β_1 is the regression slope of child birth weight ($X1$), β_2 is the regression slope of use of mechanical ventilation (dummy coded) ($X2$), β_3 is the regression slope of actual developmental performance as assessed by the total standard score of the Brigance Screen at 18-29 months ($X3$), β_4 is the regression slope of parent perceived child developmental delay as measured by item #4 of the CDR at 18-29 months ($X4$). To determine whether actual developmental performance and parent perceived

developmental delay contributed to an increase in parental stress from the time the child is 18-29 months to the time the child is 36-65 months after controlling for child birth weight, use of mechanical ventilation, and parental stress when the child is 18-29 months, the change in R-squared and B-weights were examined.

The equation was entered into SPSS as the following:

- a. $\Delta\text{PSI} = \text{BW} + \text{MechVent}$
- b. $\Delta\text{PSI} = \text{BW} + \text{MechVent} + \text{Brigance}$
- c. $\Delta\text{PSI} = \text{BW} + \text{MechVent} + \text{Brigance} + \text{CDR}$

Covariates

Child birth weight and use of mechanical ventilation were used as covariates to determine how much variance they contributed to the sequential hierarchical regression models. This was done since previous studies suggest they account for much of the variance when predicting parenting stress due to the medical complications associated with low birth weight and use of mechanical ventilation (Hack & Fanaroff, 1999; Msall & Tremont, 2002; Schmidt, et al., 2003; VanMarter, et al., 2002; Vohr & Msall, 1997). Covariate results are discussed below.

Correlation Results

A correlation matrix (Table A2) was created to determine the degree of associations between the variables. Some significant correlations between the variables will be discussed next, please see Table A2 for the remaining correlations. As mentioned previously, the degree of the relationship between child birth weight and parental stress (at two time points) and use of mechanical ventilation at birth and parental stress (at two time points) were analyzed because those variables could have explained the associations

between the outcome variables of interest (e.g., parental stress at two-time points) and the predictor variables, based on past research. Mechanical ventilation at birth was significantly correlated with parental stress at time one ($R^2=.16$, $\beta=.40$, $p<.05$), however, this correlation lost its significance ($R^2=.06$, $\beta=.26$, $p>.05$) when children were 36-65 months of age. There was a non-significant, moderately positive correlation ($r=.34$, $p>.05$) between parent perceived child developmental delay and reports of parental stress when children were toddlers (18-29 months of age). This correlation, between perceived child developmental delay and reports of parental stress, gained strength and significance ($r=.48$, $p<.05$) when children were older, at 36-65 months of age. There was a non-significant, very small negative correlation ($r=.01$, $p>.05$) between an actual child developmental delay and reports of parental stress when children were toddlers (18-29 months of age). This correlation, between an actual developmental child delay and parental stress, grew in strength, but remained non-significant ($r=.17$, $p>.05$) when children were 36-65 months of age. Correlations specific to Hypothesis 1a (parental stress and child birth weight) will be discussed below, along with the regression analyses.

Hypotheses Results

Parental stress and child birth weight. To determine if child birth weight contributed to the prediction of parenting stress at two time-points, bivariate correlations and regressions were analyzed. There was not a significant negative correlation between child birth weight and parental stress when children were 18-29 months, or at 36-65 months. However, contrary to expectations, there was a non-significant, positive correlation when the children were 18-29 months ($R^2=.09$, $\beta=.30$, $p>.05$) and 36-65 months ($R^2=.01$, $\beta=.11$, $p>.05$). Regression analyses revealed that child birth weight

accounted for 9% ($\beta=.30$) of the variance in parental stress when children were 18-29 months and 1% ($\beta=.11$) of the variance in parental stress when children were 36-65 months. These results were not significant possibly due to low power. Please see Table A2 for correlations and Table A3 and A4 for regression analyses.

Parental stress and mechanical ventilation. To determine if use of mechanical ventilation at birth contributed to the prediction of parenting stress at two time-points, bivariate regressions were analyzed. Although use of mechanical ventilation at birth did not *significantly* predict higher reports of parental stress when the children were 18-29 months, or at 36-65 months, it did account for 16% ($\beta=.40$) of the variance when children were 18-29 months via PSI-III-SF scores. Mechanical ventilation accounted for 6% ($\beta=.26$) of the variance in PSI-IV-SF scores when children were 36-65 months of age. Please see Table A5 and A6.

Parental Stress and perceived developmental delay. To determine if parent perceived developmental delay at 18-29 months predicted parental stress when children were 18-29 and 36-65 months, above actual developmental performance assessed at 18-29 months, after controlling for birth weight and use of mechanical ventilation, two separate hierarchical sequential regressions were conducted.

Although non-significant, after controlling for child birth weight and use of mechanical ventilation, which together accounted for 25% of the variance, a perceived developmental delay accounted for about the same amount variance as actual developmental delay in children at time one. Perceived developmental delay accounted for 12% ($\beta=.45$) compared to the 11% ($\beta=-.35$) that actual developmental delay accounted for in reports of parental stress when children were 18-29 months,

respectively. Please see Table A7. However, after controlling for child birth weight and mechanical ventilation, which together accounted for 8% of the variance in reports of parental stress (less than the variance that was accounted for when children were younger), perceived child delay accounted for 22% ($\beta=.50$; $p<.05$) of the variance, above what an actual developmental delay accounted for (14%; $\beta=-.39$) in parent reports of parental stress when children were older (36-65 months of age). Thus, the relationship between perceptions and stress may grow over time. Please see Table A8 for more details.

Actual and perceived developmental delay and change in parental stress. The average change in parental stress decreased slightly from time-one ($\bar{X}=49$) to time two ($\bar{X}=45$). To determine if actual and perceived developmental delay contributed to the variance in the change of parental stress from time one to time two, parental stress at time two was deducted from time one. Actual developmental delay and perceived developmental delay did not significantly predict the change in parental stress from time one to time two. Actual developmental delay accounted for 1% ($\beta=-.12$) of the variance in the change in scores and perceived delay accounted for 2% ($\beta=.17$) of the variance in the change in scores. Moreover, the variables that were controlled for, use of mechanical ventilation at birth and child birth weight, accounted for more of the variance in the change of parental stress (19%), although not significantly.

Chapter V

Discussion

Extant studies suggest child developmental disabilities impact parental stress (Cutrona & Troutman, 1986; Halpern & MacLean, 1997; Secco, Askin, & Yu, 2006; Warfield, Shonkoff, & Krauss, 2001). However, fewer studies have specifically investigated whether developmental delays impact parental stress among children born preterm, who are already at greater risk of having neurodevelopmental deficits. Furthermore, whether a perceived child developmental delay impacts parental stress in preterm samples, as much or more than an actual developmental delay, has not been studied. Although neurodevelopmental difficulties can become more apparent as the child ages (Anderson & Doyle, 2007; Maupin, 2012), no studies were found that investigated whether actual or perceived developmental performance in children born preterm predicts the change in parental stress over time and whether child medical complications experienced at birth (e.g., child birth weight and use of mechanical ventilation) predict parental stress across early childhood including when the child is 18-29 and 36-65 months. Therefore, the purpose of this study was to investigate previously untested associations between medical variables (i.e., birth weight and mechanical ventilation), parenting stress, perceived child development, and actual child development in those children born at 30 weeks or younger. The results suggest that the relationship between birth weight, mechanical ventilation, perceived development, actual development, and parental stress is complex, and the impact of perceptions on stress may grow in importance over time.

Controlling for Medical Variables

As mentioned previously, child medical complications (e.g., child birth weight and use of mechanical ventilation at birth) were included in the regression analyses because those variables could have explained the associations between the outcome variables (e.g., parental stress at two-time points) and the predictor variables, based on previous research findings (Hack & Fanaroff, 1999; Msall & Tremont, 2002; Schmidt, et al., 2003; VanMarter, et al., 2002; Vohr & Msall, 1997). Researchers have suggested that birth weight status is associated with medical complications in children born at LBW (e.g., the lower the birthweight, the more likely the child will develop delays in development) (Laptook, et al., 2005; Vohr, 2000), which is likely to impact parental stress. Therefore, it was hypothesized that there would be a significant negative correlation between child birth weight and parental stress. However, there was not a significant correlation between these variables at either time point, and moreover, the relationship was slightly positive. This correlation was strongest when children were younger and decreased in intensity when children were older in age. The unexpected positive correlations between birth weight and parental stress is hard to explain and could be due to peculiarities in a small sample. There could also be some contextual factors impacting the results. For instance, because all the children in this sample were receiving medical supports by staff in a high-risk infant clinic, parents may not have reported increased levels of stress related to medical issues. Nevertheless, parenting stress related to low-birth weight could have some small influence, but it was not detected owing to low power to find small effects in this study. This could be a significant factor in a larger study.

Use of mechanical ventilation at birth was significantly correlated with parental stress when children were 18-29 months; therefore, it was controlled for in regression analysis. Use of mechanical ventilation at birth was also positively correlated with parental stress at time two, but this correlation was not significant. The positive associations between mechanical ventilation at birth and parental stress at both time points is understandable because parents of children who are placed on mechanical ventilation are more likely to experience elevated levels of stress due to the potential adverse medical outcomes that may result from their child's use of mechanical ventilation (e.g., infections) (Schmidt, et al., 2003). The strength of the association between these variables decreased in intensity when the children were older, suggesting that as children aged, use of mechanical ventilation at birth became less of a factor on parent stress. However, these analyses should be interpreted with caution due to only one child receiving mechanical ventilation. Related variables (e.g., child birthweight, Brigance standard score, reported parental stress at two time points) associated with this participant were investigated; however, no outliers were found.

Associations Between Main Variables

Although many researchers have found a strong negative association between children placed on mechanical ventilation and low birth weight (Hack & Fanaroff, 1999; Msall & Tremont, 2002; VanMarter, et al., 2002), there was a non-significant association between those variables in this study. During time one, there was a *non-significant*, but moderately positive correlation between a parent *perceived* child developmental delay and reports of parental stress, compared to a *non-significant*, small negative correlation between an *actual* child developmental delay and reports of parental stress when children

were toddlers (18-29 months of age). There was a positive, and *significant* ($R^2\Delta=.22$), correlation between a parent perceived child developmental delay and reports of parental stress when children were older, at 36-65 months of age. There was a small, *non-significant* negative correlation between an actual developmental child delay and reports of parental stress when children were 36-65 months of age (although this negative correlation was larger compared to when children were 18-29 months of age). The significant correlation suggests that those parents who perceived their child had a developmental delay endorsed higher stress levels (particularly when children were 36-65 months). In contrast, those children with higher standard scores on the Brigance Screen, hence, with greater developmental skills, had parents who reported lower levels of stress, consistent with previous research results (Cutrona & Troutman, 1986; Halpern & MacLean, 1997; Secco, Askin, & Yu, 2006; Warfield, Shonkoff, & Krauss, 2001). These results suggest that perceived disability in a child is more likely to increase parental stress than the actual disability itself, consistent with the results of prior research studies (Gupta & Singhal, 2004; Smith, et al., 2014).

Predictor Variables Contributing to Parental Stress

Regressions conducted to analyze whether child birth weight significantly accounted for reports of parental stress when children were 18-29 and 36-65 months were not significant. However, effect sizes suggest that child birth weight accounted for 9% of the variance in parental stress when children were 18-29 months and 1% of the variance in parental stress when children were 36-65 months. However, these beta weights were positive, hence, the greater the child birth weight, the higher the reported parental stress, particularly at 18-29 months of age, which is inconsistent with the hypothesis based on

prior research that suggests children born at earlier ages experience greater developmental concerns (Hack & Fanaroff, 1999; Lupton, O' Shea, Shankaran, & Bhaskar, 2005; Msall & Tremont, 2002; Vohr & Msall, 1997). As mentioned previously, the children in this study were conveniently sampled from a clinic that provides medical support to children born preterm or at low birth weight and/or with medical complications. Hence, their parents may have reported lower levels of stress because these children received the medical supports needed to enhance their wellbeing.

Regression analyses were conducted to determine whether mechanical ventilation significantly accounted for the variance in reports of parental stress when children were 18-29 and 36-65 months. Although use of mechanical ventilation at birth did *not* significantly predict higher reports of parental stress when the children were 18-29 months, or at 36-65 months, it accounted for 16% of the variance in parental stress when children were 18-29 months. Mechanical ventilation accounted for only 6% of the variance in parental stress when children were 36-65 months of age. Although not significant, these results suggest that use of mechanical ventilation at birth accounted for a greater amount of the variance in parental stress when children were toddlers, and the variance lessened as the children grew older. However, mechanical ventilation accounted for a greater portion of the variance in parental stress when children were toddlers *and* in early childhood, compared to child birth weight; although, both child birth weight and use of mechanical ventilation accounted for more of the variance in parental stress when children were younger (and less as children aged). This may have occurred as parent concerns shifted from medical issues and survival, to developmental issues and the impact of their children on their lives.

To determine if parent perceived developmental delay at 18-29 months predicted parental stress at 18-29 and 36-65 months, above actual developmental performance at 18-29 months, two separate hierarchical sequential regressions were conducted. After controlling for child birth weight and use of mechanical ventilation, which together accounted for 25% of the variance in parental stress, when children were 18-29 months, this regression was not significant. Parent perceived developmental delay accounted for only slightly more of the variance than an actual developmental delay in children, accounting for 12% compared to 11% of the variance in reported parental stress, respectively, when children were 18-29 months. This result suggests that both perceived child developmental delay and an actual developmental child delay accounted for approximately the same amount of the variance in parental stress when children were toddlers.

In contrast, perceived developmental delay significantly accounted for 22% of the variance in parental stress, above actual developmental performance (14%), when children were in early childhood (36-65 months). This finding is consistent with results other researchers found who have investigated whether parent cognitions increase parental stress more than actual child problems or deficits (Hassell & McDonald, 2005; Jones & Passey, 2004; Smith, et al., 2014). For example, Jones and Passey (2004) found that parental locus of control predicted parental stress above actual behavior problems in young children diagnosed with a neurodevelopmental disorder. In a similar study, Mantymaa et al. (2006), found that mother's perception of their infant's temperament predicted 24% of the variance in parental stress, although an objective, observational

measure was not administered to compare perceptions to actual child temperament, thus, the current study expanded on the Mantymaa et al. study.

Child birth weight and mechanical ventilation accounted for only 8% of the variance in reports of parental stress (less than the variance that was accounted for when children were younger). As children aged, perceived child developmental delay accounted for more of the variance in parental stress than actual child delay, and more than child birth weight and use of mechanical ventilation. Moreover, both parent perceived and actual child developmental delay accounted for more of the variance in parental stress during time two (compared to child birth weight and use of mechanical ventilation). However, perceived child developmental delay accounted for most of the variance (almost double).

Finally, to determine if actual and perceived developmental delay contributed to the variance in the change in parental stress from time one to time two, 'total' parental stress t-scores at time two were deducted from time one. The Mean t-score of parental stress decreased from time-one (t-score=49) to time-two (t-score=45). Actual developmental delay and perceived developmental delay did *not* significantly predict the change in parental stress from time one to time two; although these predictor variables may have accounted for a significant amount of the variance in the change in parental stress had the sample been larger. Actual developmental delay accounted for 1% ($\beta=-.12$) of the variance in the change in scores and perceived delay accounted for 2% ($\beta=.17$) of the variance in the change in scores. Although not significant and small, perceived developmental delay accounted for more variance in the change in scores. Moreover, the variables that were controlled for, use of mechanical ventilation at birth and child birth

weight accounted for most of the variance in the change of parental stress (19%), although not significantly. Based on the b-weights, parents who endorsed lower parental stress had children with higher standard scores on the Brigance Screen and those parents who endorsed lower perceived developmental delays in their children, reported lower levels of stress. Mean parental stress may have decreased slightly in this sample of parents because their children received ongoing medical support from the HRIC. Therefore, the medical complications that the children endured at birth were treated and monitored by staff at the clinic, possibly decreasing reported parental stress levels.

In summary, none of the null hypotheses were rejected, except for Hypothesis 2. Child birth weight and parental stress were positively correlated; as child birth weight increased, parental stress increased. This result is inconsistent with previous research findings that suggest children born at younger ages experience greater developmental concerns (Laptook, et al., 2005; Vohr, 2000) which would likely increase parental stress levels. This discrepancy might be related to the unique treatment circumstances, such as the children in this sample receiving medical supports, so parents may not have reported as much stress related to medical issues (e.g., birth weight) compared to previous studies.

As expected, although not significant, effect sizes suggest that use of mechanical ventilation at birth accounted for higher reports of parental stress, particularly when children were younger. This was anticipated, as children with respiratory conditions are placed on mechanical ventilation at birth and may continue to experience adverse medical effects well passed their first year of life (Joseph, 2015). The association between these variables may not have been significant because the children in this sample were

provided with ongoing medical support that may have aided in decreasing reported levels of parental stress as the children aged.

In accordance with previous research findings (e.g., Gupta & Singhal, 2004), parents who perceived their child had a developmental delay were more likely to endorse elevated levels of stress. Reports of perceived developmental delay accounted for a greater portion of the variance in reports of parental stress than an actual developmental delay, as assessed by a standardized measure. This variance increased and became significant as children aged. These results suggest that parental cognitions and perceptions are more likely to increase parental stress than an actual child disability, consistent with former research findings.

Contrary to expectations, and previous research results (Blacher, Neece, & Paczkowski, 2005; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Gerstein, Crnic, Blacher, & Baker, 2009), parental stress levels decreased from time one to time two. Moreover, child actual developmental delay and perceived developmental delay did not account for a significant amount of the variance in the change. However, child birth weight and use of mechanical ventilation accounted for much of the variance in the change of parental stress, although not a significant amount. Parental stress levels may have decreased from time one to time two because parents become accustomed to caring for a child over time (Deater-Decker, 2004). Moreover, as mentioned previously, children in this sample received ongoing medical support from the clinic. Therefore, the medical complications that these children endured at birth were continuously treated and monitored by staff, possibly decreasing reported parental stress levels in these parents over time.

Overall, most predictors accounted for less of the variance in parental stress during time two, indicating that they contributed less to parental stress as children aged. Child birth weight, use of mechanical ventilation, and actual developmental delay decreased their predictability of parental stress as children grew older. However, parental perceived perception of a child developmental delay accounted for more of the variance in reports of parental stress as children aged, accounting for more of the variance in parental stress as time progressed. These findings indicate, as previous researchers have discovered, perceptions and cognitions are powerful tools in accounting for stress, more so than objective measures.

Practical Implications

The results of the study provide several implications for clinical practice. It is important to study cognitions in parents because maladaptive perceptions can lead to elevated stress levels. Increased stress can affect parent-child interactions, which can ultimately impact child wellbeing (Cutrona & Troutman, 1986; Halpern & MacLean, 1997; Secco, Askin, & Yu, 2006). Researchers have reported that parental stress can lead to emotional disorders such as depression and anxiety (Pearson, Blanchard, & Blanchard, 2011; Alfonso, Frasca, & Flugge, 2005; Fuchs & Flugge, 2011). Impaired emotional and mental functioning can affect parental actions regarding daily activities and medical decisions concerning the child (Mantymaa, Puura, Luoma, Salmelin, & Tamminen, 2006). Therefore, identifying parental stress levels, particularly among parents who have a child born preterm, who are already at-risk of developing neurodevelopmental concerns due to prematurity is important. Medical practitioners (e.g., physicians, nurses, pediatric psychologists) in primary care settings should consider screening parents for elevated

levels of stress during well child visits. For example, the Parenting Stress Index, 4th edition, short form (PSI-IV-SF) can be administered in 10 minutes and is a useful method to identify parents who are experiencing high stress levels associated with caring for a child. Once identified, these parents should be provided strategies to reduce their stress levels in clinic by qualified personnel or provided outside referrals.

Several things can be done to reduce stress levels in parents. Parents whose children have no actual developmental delay but are experiencing elevated levels of stress due to a *perception* their child has a developmental delay should receive psycho-educational classes to enhance their understanding of early child development to provide accurate expectations of their child's developmental level. Information can be disseminated during pediatric medical visits, through referrals to practitioners providing classes on child development, or via internet sources. The Centers for Disease Control and Prevention offers information on child development and positive parenting tips to enhance child development on their website: www.cdc.gov/ncbddd/childdevelopment (CDC, 2017).

Alleviating parental stress in caretakers who have a child with an *actual* developmental delay is also important. Reducing parental stress, particularly in parents of children with actual developmental delays, is important because elevated levels of stress may have adverse effects on parenting, which could negatively affect the outcomes of children *already* experiencing developmental concerns (Halpern, Brand, & Malone, 2001; Lazinski, Shea, & Steiner, 2008; Steinberg & Bellavance 1999). For parents whose children have an actual developmental delay in motor, language, or cognitive functioning, enhancing positive coping and parental self-efficacy using evidence based

therapies (e.g., Cognitive Behavioral Therapy [CBT]) can decrease parent stress levels and enhance well-being (Beck, 2011). Parents who experience lower stress levels will develop better parent-child interactions (Deater-Deckard, 2011), whereby improving the developmental outcomes of their children.

Moreover, providing parents with resources about government agencies that provide assistance in improving child development (e.g., Early Childhood Intervention Services) and internet sources that inform them of advocacy programs (e.g., Exceptional Lives [<https://exceptionallives.org>]) that help parents who have children with disabilities gain access to services and supports may empower parents by increasing their knowledge and decreasing their stress levels. For children experiencing delays in socio-emotional functioning, parenting stress can be reduced through evidence-based interventions such as parent management training (Kazdin, 2005), particularly for parents whose children exhibit severe behavioral concerns. Several studies (Allen & Marshal, 2015; Axelrad, Garland, & Love, 2009; Gomez, et al., 2014) have found that interventions such as parent-child interaction therapy (PCIT) and Brief Behavioral Intervention (BBI) both reduce undesired child behaviors (e.g., whining, screaming, aggression) while improving prosocial interactions in children and decreasing stress levels in parents.

Limitations and Future Directions

Several limitations existed in this study. Research suggests that children with greater lung impairments are more likely to be placed under mechanical ventilation and have a greater probability of experiencing developmental concerns (Schmidt, et al., 2003); therefore, increasing parental stress levels. However, in the current sample, all but one child received mechanical ventilation at birth. The data drawn from the parent who

did not endorse child use of mechanical ventilation at birth may have invalidated the sample due to differential outcomes associated with parental stress or child development. The medical complications experienced by this child may have been less severe than those children placed on neonatal mechanical ventilation, thus possibly affecting child development and parental stress. In addition to internal validity concerns, the external validity of the study was also affected by this variable. Children born at or below 30 weeks gestational age are typically born with complex medical issues, including lung impairments, that warrant use of mechanical ventilation at birth. The fact that this child did not require this medical procedure indicates that the child differed from other children born preterm, specifically those born at or below 30 weeks gestational age, affecting the generalizability of the sample.

Furthermore, another threat to the generalizability of the sample was noted. Data were drawn from a pre-existing data set of parents who had children born preterm, making this a non-random procedure and limiting the generalizability of the results. In addition, data for this study were drawn from a clinic that tracks the medical needs of children born at high risk (e.g., born preterm) and medical staff provide coordinated clinical services for them after discharge from the NICU. Parents in this sample may not have experienced elevated levels of stress because they were receiving medical assistance for their children's medical needs, perhaps differentiating them from other parents who have children born preterm in the general population, not receiving these services. Future studies should attempt to randomly select their participants from clinics servicing this population throughout the country.

Construct validity may have been of concern in this study. Some parents may not be aware of certain delays or not be willing to report them (e.g., social desirability bias). Moreover, some parents may not want to report that they are experiencing elevated levels of stress, hence affecting the internal validity of the study. Also, although most parents did not report high levels of stress, it is not possible to discern if the stress levels these parents reported was directly caused by parental challenges, or if other sources of stress exacerbated actual 'parental stress' for those that did report elevated levels. Future studies could do a more in-depth measurement of knowledge of child development and assess for social desirability bias.

A main limitation of this study was in the lack of measurement of actual child developmental delay and perceived child delay during time two of the study. Brigance screen standard scores administered during time one were used to assess actual developmental delay during time *two*, when the children had aged. Similarly, the CDR, administered during time one of the study, was used to assess perceived developmental delay during time *two*. Ideally, it would have been best to measure perceived developmental delay and actual developmental performance, not only at time one, but also during time two of the study to get a more accurate measure of these constructs when children were 36-65 months of age, not only at 18-29 months of age. Actual developmental delay standard scores may have changed when children were 36-65 months, and, most importantly, perceptions of child developmental delay may have changed when children were 36-65 months. For example, parents who indicated a concern of child developmental delay during time one may not have indicated a concern of child delay during time two. This may have impacted the results of the analyses.

Future studies should attempt to measure all variables at both time points, lessening the likelihood of internal validity problems.

A potential bias in this study could arrive from heavy reliance on maternal report. All responders in this study were mothers. Researchers could include samples of partners, or specifically, fathers, to increase their sample. Information about paternal stress could be valuable in determining if their stress levels are more likely to be predicted by actual or perceived developmental delays in their children.

There appears to be a threat to statistical conclusion validity in this study because there were only twenty-two parent-child dyads included. Twenty-two parent-child participants provided 78% power, for a large effect. Since previous studies have found mainly large effects, the current study was adequately powered with twenty-two participants. However, most of the effects observed in this study were in the small to moderate range. Therefore, future studies should aim to increase their sample size to detect small effects. Researchers could include samples of partners, or specifically, fathers, to increase their sample. Information about father stress could be valuable in determining if their stress levels are more likely to be predicted by actual or perceived developmental delays in their children.

Future studies should attempt to select the participants for their sample randomly, instead of using a convenience sample. Participants in future studies should be selected from various medical clinics throughout the country to be more representative of the population. Furthermore, other studies should investigate how specific coping strategies moderate the relation between actual and perceived developmental delays and parental stress. Studies have found that certain coping strategies are more adaptive than others

when dealing with the challenges of raising children with disabilities (Mantymaa, et al., 2006; Noojin & Wallander, 1997). For example, the use of ‘approach’ coping strategies as opposed to ‘avoidance’ coping strategies have been associated with better parent and child outcomes (Noojin & Wallander, 1997).

In summary, it is important to study cognitions of parents who have a child with a disability because previous studies suggest perceptions can increase parental stress levels (Copper, et al., 1996; Dole, et al., 2003; Zhu, et al., 2010), impacting child developmental functioning and outcomes (Crnic & Acevedo, 1995; Deater-Deckard, 2004). It is particularly important to study parental perceptions in parents who have children born preterm because these children are already at-risk of having medical concerns and developmental delays (Msall & Tremont, 2002; VanMarter, et al., 2002). Results of this study indicated that parent perceived developmental delays in children born preterm predicted parental stress above actual child developmental performance when children were 36-65 months, not when children were 18-29 months. Actual developmental skills and perceived developmental delays did not significantly predict the change in parental stress from the time the children born preterm were toddlers to early childhood. Child birth weight was not significantly correlated with parental stress, and mechanical ventilation did not significantly contribute to the variance in parental stress at either time point. The results of the study suggest it is important to consider a parent’s perception of their child’s disability, beyond actual disability, when examining child and family functioning during pediatric medical visits. Future studies should focus on the use of larger and more representative samples, the inclusion of partners and fathers as respondents, and the repeated measurement of variables of interest.

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Appendix A

Tables

Table A1

Descriptive Statistics of Primary Variables

	N	Range	Min.	Max.	Mean	Std. Dev.	T-group diff	Skewness		Kurtosis	
								Statistic	SE	Statistic	SE
Weeks Born Preterm	22	6	11	17	15.05	1.65	.71	-1.21	.49	1.72	.95
Child Gest Age (weeks)	22	6	23	29	25	1.65	-.71	1.21	.49	1.72	.95
Child Age T-1 (weeks)	22	10	18	28	22	3.14	-.15	.07	.49	-.96	.95
Corrected Age (visit 1)	22	10	14	24	19	3.39	.03	-.07	.49	-1.11	.95
Child BW (grams)	22	432	548	980	732	120.06	-1.35	.34	.49	-.67	.95
Child Mech Vent	22	1	0	1	.95	.21	.52	-4.69	.49	22	.95
Actual Delay	18	34	60	94	76	11.37	.74	.10	.55	-.99	1.06
Perceived Delay	22	1	0	1	.55	.51	.78	-.20	.49	-1.17	.95
Parent Stress T-1 t-score	21	39	29	68	49	10.80	.43	-.38	.50	-.45	.97
Parent Stress T-1 %	21	95	2	97	48	30	.61	-.16	.50	-1.20	.97
Child Age T-2 (weeks)	22	28	37	65	48	7.19	N/A	.89	.49	.93	.95
Parent Stress T-2 t-score	22	28	32	60	45	9.55	N/A	.04	.49	-1.43	.95
Parent Stress T-2 %	22	80	4	84	37	28	N/A	.29	.49	-1.37	.95

Note. PSI-III-SF= Parent Stress Index, 3rd edition, short-form; PSI-IV-SF= Parent Stress Index, 4th edition, short-form; Brigance= Brigance Early Head Start Screen (0-35); CDR= Child Developmental Review; T-1= time-one; T-2= time-two; T-group diff is for difference between groups (time one versus time two)

Table A2

Correlation Matrix

	1	2	3	4	5	6	7	8	9	10
1.Child Gest Age (weeks)	-	-	-	-	-	-	-	-	-	-
2.Child Age T-1 (weeks)	.05	-	-	-	-	-	-	-	-	-
3.Corrected Age (visit-1)	.04	1.00**	-	-	-	-	-	-	-	-
4. Child BW (grams)	.59**	-.15	-.18	-	-	-	-	-	-	-
5.Child Mech Vent	-.01	-.12	-.12	-.01	-	-	-	-	-	-
6.Actual Delay Standard Score	.52*	-.51*	-.50*	.64**	.14	-	-	-	-	-
7.Percieved Delay	-.03	-.05	-.02	-.25	.24	-.14	-	-	-	-
8.Parent Stress T-1	-.07	.03	-.06	.30	.40*	.01	.34	-	-	-

9.Child Age T-2	.19	-.25	-.19	.31	.19	.28	.33	.01	-	-
10.Parent Stress T-2	.06	.06	-.02	.11	.26	.17	.48*	.62**	.17	-

Note. *Correlation is significant at the .05 level; **Correlation is significant at the .01 level. Child Gender (0=M,1=F), Child Age, Child Gestational (Gest) Age, Child Birth weight, and Use of Mechanical Ventilation at Birth (Mech Vent) were extracted from the parent demographic survey collected during time 1. Parent Stress (time 1) scores were taken from the PSI-III-SF and Parent Stress (time 2) scores were taken from the PSI-IV-SF. Actual Child Delay standard scores were extracted from the Brigance Early Head Start Screen (0-35) and Perceived Child Delay nominal scores were taken from the Child Developmental Review Item #4.

Table A3

Bivariate Regression: Child Birth Weight and Parent Stress (time one)

Predictor	R	R ²	B	SE B	β
Constant	-	-	29.37	14.61	-
BW	.30	.09	.03	.02	.30

Note. BW= Child Birth Weight

Table A4

Bivariate Regression: Child Birth Weight and Parent Stress (time two)

Predictor	R	R ²	B	SE B	β
Constant	-	-	38.54	13.10	-
BW	.11	.01	.01	.02	.11

Note. BW= Child Birth Weight

Table A5

Bivariate Regression: Child use of Mechanical Ventilation and Parent Stress (time one)

Predictor	R	R ²	B	SE B	β
Constant	-	-	29.52	10.42	-
Mech Vent	.40	.16	20.16	10.66	.40

Note. Mech Vent= Use of Mechanical Ventilation at birth

Table A6

Bivariate Regression: Child use of Mechanical Ventilation and Parent Stress (time two)

Predictor	R	R ²	B	SE B	β
Constant	-	-	34.00	9.46	-
Mech Vent	.26	.06	11.48	9.69	.26

Note. Mech Vent= Use of Mechanical Ventilation at birth

Table A7

Hierarchical Regression: Predictors of Parental Stress (time one)

Predictors	R	R ²	R ² Δ	B	SE B	β
Constant	-	-	-	14.02	19.64	-
BW, Mech Vent	.50	.25	.25	19.55	11.60	.39
Brigance	.61	.37	.11	-.43	.28	-.35
CDR	.70	.49	.12	7.47	4.92	.45

Note. BW= Child Birth Weight, Mech Vent= Use of Mechanical Ventilation at birth, Brigance= Brigance Early Head Start Screen (0-35), CDR= Child Developmental Review

Table A8

Hierarchical Regression: Predictors of Parental Stress (time two)

Predictors	R	R ²	R ² Δ	B	SE B	β
Constant	-	-	-	29.94	17.28	-
BW, Mech Vent	.28	.08	.08	9.56	10.21	.21
Brigance	.47	.22	.14	-.41	.24	-.39
CDR	.66	.44	.22*	9.28	4.33	.50

Note. BW= Child Birth Weight, Mech Vent= Use of Mechanical Ventilation at birth, Brigance= Brigance Early Head Start Screen (0-35), CDR= Child Developmental Review
 * significant at the 0.05 level

Table A9

Hierarchical Regression: Change in parental stress

Predictors	R	R ²	R ² Δ	B	SE B	β
Constant	-	-	-	21.66	17.97	-
BW, Mech Vent	.44	.19	.19	.03	.03	.47
Brigance	.45	.20	.01	-.09	.26	-.12
CDR	.47	.22	.02	2.81	4.83	.17

Note. BW= Child Birth Weight; Mech Vent= Use of Mechanical Ventilation at birth;
 Brigance= Brigance Early Head Start Screen (0-35); CDR= Child Developmental Review