The Influence of Family Factors on Neuropsychological Outcome in a Clinical Sample of Preschool Children

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THE INFLUENCE OF FAMILY FACTORS ON NEUROPSYCHOLOGICAL OUTCOME IN A CLINICAL SAMPLE OF PRESCHOOL CHILDREN

by

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A Dissertation submitted to the Faculty of the Graduate School,
Marquette University,
in Partial Fulfillment of the Requirements for
the Degree of Doctor of Philosophy

Milwaukee, Wisconsin
May 2010

ABSTRACT
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Children impacted by neurological insult or disorder are at risk for impaired neuropsychological functioning; however, there is substantial variation in outcome, with many affected children doing very well. The factors that explain the variation in outcome in children with compromised neurological functioning are poorly understood. The present study examined the nature of relationships among family factors, including primary caregivers' appraisals of stress (i.e., primary caregivers' injury/medical condition-related stress, parenting stress, psychological distress, and relationship quality) and the primary caregiver-child relationship, and neuropsychological outcomes (i.e., intellectual functioning; language skills; adaptive, socio-emotional, and behavioral functioning). A clinical sample of 72 preschool children whose neurological development had been compromised and their primary caregivers participated in the study. Primary caregivers completed rating scales and a structured clinical interview about perceived stress as well as their child's behavioral, socio-emotional, and adaptive functioning. Children were administered standardized measures of intellectual and language functioning. Primary caregiver-child dyads participated in a semi-structured play interaction. Results revealed significant associations among primary caregivers' appraisals of stress and children's internalizing and externalizing behaviors. Significant associations were not found between primary caregiver's appraisals of stress and children's language or intellectual functioning. Primary caregivers' appraisals of stress were related to ratings of primary caregiver intrusiveness in the primary caregiver-child interaction. Several characteristics of the primary caregiver-child relationship were related to children's outcomes. After controlling for the severity of a child's neurological insult, the quality of the primary caregiver-child relationship accounted for a significant amount of unique variance in predicting children's overall intellectual functioning, verbal reasoning ability, total language, receptive language, and expressive language but not nonverbal reasoning ability. Significant interaction effects between primary caregivers' appraisals of stress and the quality of the primary-caregiver child relationship were found when examining predictors of language abilities. Results underscore the value of assessing multiple dimensions of family functioning to better understand how the factors that influence children's outcomes.

ACKNOWLEDGEMENTS

Kara Leiser, B.A., M.S.

I would first like to thank God for His grace, help, and love on this endeavor. I would like to thank my dissertation director and advisor, Dr. Astrida Kaugars, for the many hours she has invested as a teacher and mentor, for providing me with guidance in not only the completion of this dissertation, but also more broadly in my development as a researcher and clinician. I would like to thank Dr. Amy Heffelfinger not only for the opportunity to collect this data in the Preschool and Infant Neuropsychological Testing Clinic at the Medical College of Wisconsin, but especially for her mentorship and wisdom in shaping my development as a budding pediatric neuropsychologist. I would also like to extend my thanks and appreciation to the other members of my dissertation committee, Dr. John Grych and Dr. Kristy Nielson, for their time, commitment, and valuable feedback to help bring this dissertation to fulfillment. I would like to thank the faculty and staff of the Pediatric Neuropsychology Clinic at Froedtert and the Medical College of Wisconsin for their assistance in recruitment, research space, and administrative support. I especially thank my graduate and undergraduate student research assistants – without them, this project would not have been possible. In addition, I would like to thank my parents, siblings, extended family, and friends for their unceasing support and encouragement. Finally, I would like to thank my loving husband, Ives Leiser, for having unconditional faith in me.

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Introduction

Background

Children impacted by neurological insult or disorder are at extreme risk for impaired neuropsychological functioning, which may manifest in global delays (Yeates et al., 2002) or specific areas of deficit such as language (Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2001; Nass, 1997), visual-spatial impairments (Akshoomoff, Feroleto, Doyle, & Stiles, 2002), and/or long term attention and executive dysfunction (Ewing-Cobbs, Prasad, Kramer, & Landry, 1999; Max et al. 2003; Taylor et al., 1999; Yeates et al., 2002). Children with neurological disorders are also at increased risk of poor psychological and social adjustment. Sequelae of traumatic brain injury (TBI), for example, may include behavioral change, psychiatric disorders, and declines in social competence and adaptive functioning (Fletcher, Ewing-Cobbs, Miner, Levin, & Eisenberg, 1990). Children with epilepsy have been shown to have lower self-esteem, higher levels of depression, and more behavior problems than children with asthma (Austin, 1988; Hoare, 1984). Within the pediatric age range, most studies examining different age groups have identified higher mortality rates and less favorable neurobehavioral outcomes in infants and preschoolers (Raimondi & Hirschauer, 1984; Luerssen, Klauber, & Marshall, 1988; Michaud, Rivara, Grady, & Reay, 1992). For example, children aged two to seven years at the time of TBI are more susceptible to deficits in expressive language, attention, and academic achievement compared with children injured at later ages (Anderson, Catroppa, Haritou, Morse, & Rosenfeld, 2005; Barnes, Dennis, & Wilkinson, 1999; Dennis, Wilkinson, Koski, & Humphreys, 1995;

Ewing-Cobbs & Barnes, 2002; Ewing-Cobbs et al., 1997; Ewing-Cobbs, Miner, Fletcher, & Levin, 1989; Morse et al., 1999; Verger et al., 2000).

Though any disruption to typical neural development has the potential to result in specific and/or global neurobehavioral dysfunction, there is substantial variation in outcome, with many affected children doing very well. Dennis (2000) posited that neurobehavioral outcome or *cognitive phenotype* (i.e., the appearance of mental and behavioral skills) may be thought of as an outcome algorithm that expresses the *biological risk* associated with a medical condition; *age and development factors* (e.g., age at head injury); *time since onset* of the condition; and by the *reserve* available within the child, family, school, and the community. This concept of *reserve* refers to factors that are available to either buffer or exacerbate neurobehavioral dysfunction. The factors that explain the variation in outcome in children with compromised neurological functioning are poorly understood. Though it might be expected that medical factors such as severity of an injury would be the most important determinants of outcome, research has shown that there is not a direct relationship between severity of the factor that disrupts performance and the degree of disruption in performance (e.g., Hodgman, McAnarney, & Myers, 1979; Cohen, Parmelee, Sigman, & Beckwith, 1988).

Fletcher, Ewing-Cobbs, Francis, and Levin (1995) also acknowledged the family environment as a major contributor to variability in neurobehavioral outcomes. According to Fletcher and colleagues, this variability may stem from: 1) premorbid characteristics of the child and family; 2) the postinjury environment which may include the family's material and psychological well-being as well as the effects of the injury on the family; and 3) various interventions which may include rehabilitation, somatic

interventions, educational placements, and parent training and education. Similarly, Bernstein and colleagues (1990; 2000) put forward that a child's neurobehavioral functioning cannot be understood without reference to the context in which s/he behaves, that is, the *child-world system* (Bernstein, 2000; Bernstein & Waber, 1990). Accordingly, family forms the context in which response to developmental insult, injury, and/or disease takes place. Family factors, unlike other aspects of cognitive reserve (e.g., premorbid ability, socio-economic status) are often ignored. For children, family forms the primary context from which their life experiences stem.

The family environment is important to outcome in both typically developing children and in children whose neurological development has been disrupted (i.e., premature birth; neurological insult or disease). In typically developing children, generalized and situation-specific perceived parental stress, parental attitudes, and psychological distress have been shown to influence parenting behavior (e.g., Abidin, 1990; Belsky, 1984; Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Easterbrooks & Goldberg, 1984; Pianta & Egeland, 1990). If parenting behavior is compromised due to generalized and specific stressors, psychological distress, poor attitude, and/or relationship distress, a child's functioning may be indirectly compromised through interaction with that parent. For children whose neurological development has been disrupted, included under the broad umbrella of family factors that have been shown to contribute to the variability in children's neuropsychological outcomes are the manner in which parents perceive the stress and burden of their child's injury, parenting stress in general, level of psychological distress, and factors specific to the interaction of the parent-child dyad and/or broader family system (e.g., cohesiveness; control).

Significant links between pediatric neurological insult and family factors have been well documented, particularly among school-aged children with traumatic brain injury (TBI). Several studies have shown that pediatric TBI has a profound negative impact on both the caregiver and the family; specifically, severe TBI has been found to be associated with both acute and long-term burden (e.g., Stancin et al., 2002; Taylor et al., 2002; Taylor et al., 2001; Wade, Taylor, Drotar, Stancin, & Yeates, 1998; Wade et al., 2001; Wade et al., 2002; Wade, et al., 2006; and Taylor et al., 1999). Moreover, earlier studies by Rivara and colleagues (1992; 1993; 1994; 1996) showed links between family factors and children's functioning. Family variables (i.e., high level of family cohesion, positive family relationships, and low level of control (family hierarchy and rules that are rigid)) were found to be significant predictors of outcome in multiple domains (including behavioral, academic, activities of daily living, and social competence) independent of injury severity. Yeates and colleagues (1997) also found that family variables accounted for variance in school-aged children's behavior problems, adaptive functioning, and cognitive outcomes. Moreover, the preinjury family environment was found to be a significant moderator of the negative cognitive and behavioral effects of TBI, buffering the impact of such effects in high-functioning families and exacerbating them in low-functioning families.

In a recent publication by Stancin and colleagues (2008), parents of young children (ages 3 through 6 years) with severe and complicated mild TBI reported experiencing significantly greater overall injury-related stress as well as greater stress associated with a child's injury, than those in an orthopedic control group. Further, parents of children with severe TBI reported significantly greater psychological distress

and depressive symptoms than did parents of young children with an orthopedic injury. As well, parents of children with TBI reported more stress with spouses and siblings relative to an orthopedic control group.

In families of children with epilepsy, significant associations have been found linking poor family functioning with academic performance, executive functioning, and/or behavioral outcomes. Fewer family resources and an increased number of challenging life events were associated with behavioral problems and caregiver depression (Austin, 1988; Austin, Risinger, & Beckett, 1992). Hoare and Kerley (1991) found family stress in children with epilepsy to be significantly associated with parent and teacher ratings of children's behavior; moreover, maternal attitudes towards children's medical diagnoses were associated with poor adjustment. Using observational assessment, Lothman and Pianta (1993) found elements of the mother-child interaction (i.e., maternal supportiveness, availability of affective expressions, and child's self-reliance in interaction with the mother) predictive of children's adjustment in a sample of seven to thirteen year olds with epilepsy. Among other disorders, family cohesion was found to be predictive of adjustment in children with myelomeningocele (Lavigne, Nolan, & McLone, 1988).

Family factors are not only important to a child's independent functioning. They are also essential for understanding how a parent functions and how the primary caregiver-child dyad functions within the context of the parent-child relationship. Two decades ago, Sroufe (1989) asserted that most clinical disturbances in the first three years of life, although poignantly expressed as child behavior problems, are more usefully conceptualized as relationship disturbances. Zeanah, Larrieu, Heller, and Valliere (2000)

adapted Emde's outline of salient functional domains in the infant-parent relationship (1989, as cited in Zeanah et al., 2000) that considers relationship adaptation and disturbances in specific areas, including: 1) Emotional availability; 2) Nurturance/valuing/empathic responsiveness; 3) Protection; Comforting/response to distress; 4) Teaching; 5) Play; 6) Discipline/limit setting; and 7) Instrumental care/structure/routines.

In studies that have assessed family functioning in children with a neurological insult, common constructs that have been examined include emotional expressiveness, intimacy, control, and cohesion (e.g., Rivara et al., 1992; Rivara et al., 1993; Rivara et al., 1994; Rivara et al., 1996; Lothman & Pianta, 1993). These constructs are consistent with the functional domains in Emde's model (1989, as cited in Zeanah et al., 2000). Each of these constructs encompasses a dynamic or process of relating that is exhibited in a parent-child dyad, as well as in the broader family system. Further, these dyadic elements are important to child outcome. There is evidence that parent-infant/child interactions have an impact on the child's developmental outcome. Warm, responsive care from the mother helps foster optimal development (Jennings & Connors, 1989). Among preterm infants, Cohen and Parmelee (1983) found that preterm infants whose caregivers scored high on responsive, reciprocal, and autonomy-promoting care had improved developmental scores from age nine months to five years; those whose caregivers had low scores had a decrease in performance. In a study of 18-month-old pretem children, 22% of the variance in receptive language scores was predicted by a combination of father-child interactions at 3 months of age, mother-child interactions, and infant sex (Magill-Evans & Harrison, 1999). These findings are consistent with earlier research that

social and environmental factors may have greater impact on developmental outcomes than do perinatal complications (Aylward, Verhulst, & Bell, 1989; Lee & Barratt, 1993; Liaw & Brooks-Gunn, 1993), particularly in the area of language development (Lukeman & Melvin, 1993). The studies reviewed support the argument that variations in parent-child interactions should be investigated as one explanation for variation in child outcome.

Just as with young children whose neural development may have been compromised due to being born prematurely, for children affected by neurological insult or disease in early childhood, the well-being of a parent as an individual, and in the context of the parent-child interaction, is likely of significant value. As children develop skills and/or rehabilitate, the therapeutic environment is expected to give a young child a feeling of being loved and cared for, encourage interest and curiosity, and reduce uncertainty (Sellars, Vegter, & Ellerbusch, 1997). One central way preschoolers attain cognitive skills is by internalizing social processes in their everyday interaction with adults or older children (Vygotsky, 1978). This effect applies to a broad selection of social and cognitive skills. Special attention should therefore be paid to the style and content of interaction that everyday communication partners (e.g., parents/primary caregivers) have with young children. In this way, part of effective rehabilitation for children whose neurological development has been compromised involves ensuring that their parents/primary caregivers are as knowledgeable and skilled as possible in facilitating children's ongoing acquisition of knowledge and cognitive skills.

Young children's learning and cognitive growth may, in fact, be compromised if primary caregivers experience significant stress, be it psychological distress, stress

specific to their caregiving, and/or relational stress. For example, studies have found that depressed mothers often find it difficult to provide contingent responses and optimal levels of stimulation (Field et al., 1985; Field et al., 1988; Field, Healy, Goldstein, & Guthertz, 1990). Mothers who reported experiencing increased life stress have been shown to perceive their children's behavior as more deviant than low-stress mothers (see Crnic and Acevedo, 1995, for a review). Among sample of four-year-olds born preterm, Magill-Evans and Harrison (2001) found that a mother's parenting stress related to a child's distractibility was the strongest predictor of expressive language development, whereas parent-child interactions were a less stable predictor. It may be that mothers who perceive their children as distractible may provide less frequent conversational interactions that are the basis for language development. It is also possible that mothers who perceive their children as having communication delays and/or deficits may experience more stress.

Primary caregivers may also experience stress and/or dissatisfaction in their romantic/marital relationship that may directly and/or indirectly impact their child's functioning. More specifically, marital dissatisfaction has been associated with child behavior problems, poor child psychological adjustment, and negative parent-child interactions both in the general population and among families of children with disabilities (e.g., Cummings & Davies, 1994; Fishman & Meyers, 2000; Floyd & Zmich, 1991). The mechanism by which marital disharmony may lead to child adjustment problems has been hypothesized to be through the association between the marital relationship and the parent-child relationship (e.g., Grych & Fincham, 1990). In this regard, Fishman and Meyers (2000) demonstrated that mothers who experienced marital

dissatisfaction were less involved with their children, which in turn was associated with greater child psychological distress. Notably, this mediated pathway was not shown for fathers.

Though a number of studies have explored relationships among family factors and outcomes in children who have experienced a neurological insult, these studies have largely been conducted with school-aged children and adolescents (e.g., Stancin et al., 2002; Taylor et al., 1999; Taylor et al., 2001; Taylor et al., 2002; Wade et al., 1998; Wade et al., 2001; Wade et al., 2002; and Wade et al., 2006). The study of family factors and their influence on very young children of preschool age (under six years) represents an emergent and important area of study. Moreover, those studies conducted with school-aged children are limited by the measurement of family factors in that family functioning has been assessed broadly making it difficult to differentiate what aspects of family functioning are most relevant to outcome, and consequently to rehabilitation efforts. Another limitation of existing studies exploring family factors and outcomes in children impacted by head injury (e.g., Rivara et al., 1992; Rivara et al., 1993; Rivara et al., 1994; Rivara et al., 1996) is the potential for significant reporter bias given that most studies have relied solely on parents' self-report of family functioning. Parents' self-report may be influenced by the level of stress or psychological distress they are experiencing.

A better data source for assessing contributions of family factors is likely direct observation of the parent-child interaction. While a clinic-based assessment of this interaction could be subject to the influence of a novel environment, it nonetheless may be quite useful in providing a standardized procedure in which to evaluate dyads (Zeanah et al., 2000). Observation of the parent-child dyad entails examining specific

contributions of the parent, specific contributions of the child, and elements specific to dyadic activity. Identification of specific elements in this interaction may be beneficial to the development of interventions to promote positive parent-child interaction that may, in turn, improve outcomes among children with and without neurological impairment.

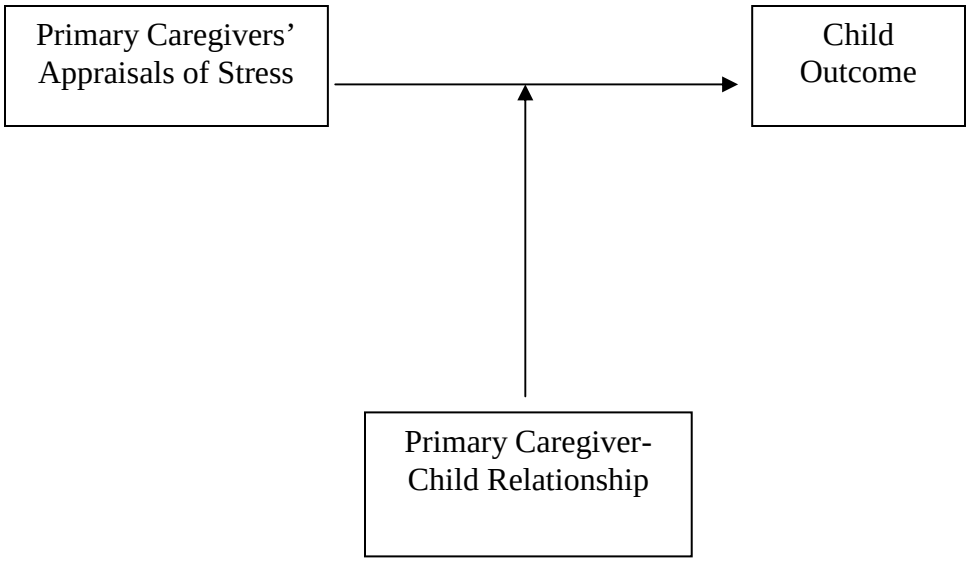
Purpose

The present study examined the nature of relationships among family factors, including primary caregivers' appraisals of stress (i.e., primary caregivers' injury/medical condition-related stress, general parenting stress, psychological distress, and relationship stress) and the primary caregiver-child relationship, with neuropsychological outcomes (i.e., intellectual functioning; language skills; adaptive, emotional, and behavioral functioning) in a clinical sample of preschool children whose neurological development had been compromised (e.g., preterm birth; TBI; epilepsy; anoxic event). Rationale to include such a heterogeneous sample stemmed from the idea that the neurobehavioral functioning of all children who suffer from a neurological insult has the potential to be disrupted, albeit with varying degrees of impact. Notably, for all children in the sample, the family context remains the primary context from which their early learning experiences stem.

This study used a moderational model (Figure 1) to examine whether and how family factors, including primary caregivers' appraisals of stress and the primary caregiver-child relationship, were related to a child's neuropsychological outcomes. It was hypothesized that the quality of the primary caregiver-child relationship would moderate the association between primary caregivers' appraisals of stress and child outcome, such that under conditions where the primary caregiver-child relationship was

strong (i.e., greater positive affect, less negative affect, better instructional quality, increased caregiver confidence, and greater attunement), neuropsychological outcomes would be less likely to be compromised by the felt stress of primary caregivers. Under conditions where the primary caregiver-child relationship was poor, the felt stress of a primary caregiver was expected to be more likely to compromise child outcome.

Figure 1. Proposed Moderational Model with the Primary Caregiver-Child Relationship Moderating the Association between Primary Caregivers' Appraisals of Stress and Child Outcome.



The rationale for the moderating role of the primary caregiver-child relationship between primary caregivers' appraisals of stress and neuropsychological outcomes stems from earlier work by Dennis (2000) with regard to *reserve* theory. As described previously, the concept of *reserve* refers to factors that are available to either buffer or exacerbate neurobehavioral dysfunction and include factors within the child, family, school, and community. The model for the current study considers factors within the family (i.e., primary caregivers' appraisals of stress; the primary caregiver-child relationship) independently as direct contributors to variability in children's neuropsychological outcomes, and also as interacting together to influence children's outcomes. Yeates and colleagues (e.g., 1997) examined family factors as a moderator between injury severity and outcome. As reviewed earlier, the preinjury family environment was found to be a significant moderator of the negative cognitive and behavioral effects of TBI, buffering the impact of such effects in high-functioning families and exacerbating them in low-functioning families. The present study controlled for injury severity based on the hypothesis that family factors will be associated with child outcome above and beyond the variance contributed by injury severity.

Hypotheses

I. Primary caregivers' appraisals of stress will be associated with child outcome (i.e., cognitive, language, behavioral, and socio-emotional functioning).

   a. Greater primary caregiver stress specific to a child's medical condition (**Total Frequency Score and Total Difficulty Score** on PIP) will be associated with increased report of socio-emotional problems (**Internalizing Problems** and **Externalizing Problems** on CBCL or

BASC-2), poorer adaptive functioning (**Adaptive Behavior Composite** on VABS-II), poorer language skills (**Total Language** on PLS-4 or CELF PRE-2), and poorer overall cognitive functioning (**Overall Intellectual Functioning** on DAS-II, Mullen, or WPPSI-III).

b. Greater primary caregiver parenting-related stress (**Total Stress** on PSI) will be associated with increased report of socio-emotional problems (**Internalizing Problems** and **Externalizing Problems** on CBCL or BASC-2), poorer adaptive functioning (**Adaptive Behavior Composite** on VABS-II), poorer language skills (**Total Language** on PLS-4 or CELF PRE-2), and poorer overall cognitive functioning (**Overall Intellectual Functioning** on DAS-II, Mullen, or WPPSI-III).

c. Greater primary caregiver psychological distress (**Global Severity Index** on BSI) will be associated with increased report of socio-emotional problems (**Internalizing Problems** and **Externalizing Problems** on CBCL or BASC-2), poorer adaptive functioning (**Adaptive Behavior Composite** on VABS-II), poorer language skills (**Total Language** on PLS-4 or CELF PRE-2), and poorer overall cognitive functioning (**Overall Intellectual Functioning** on DAS-II, Mullen, or WPPSI-III).

d. Greater dissatisfaction in the primary caregivers' romantic relationship (**Quality of Marriage Index**) will be associated with increased report of socio-emotional problems (**Internalizing Problems** and **Externalizing Problems** on CBCL or BASC-2), poorer adaptive functioning (**Adaptive Behavior Composite** on VABS-II), poorer language skills (**Total**

Language on PLS-4 or CELF PRE-2), and poorer overall cognitive functioning (**Overall Intellectual Functioning** on DAS-II, Mullen, or WPPSI-III).

II. Primary caregivers' appraisals of stress will be associated with characteristics of the primary caregiver-child relationship.

a. Greater primary caregivers' stress specific to a child's medical condition (**Total Frequency Score and Total Difficulty Score** on PIP) will be associated with **poorer Primary Caregiver Supportive Presence, greater Primary Caregiver Intrusiveness, greater Primary Caregiver Hostility, poorer Primary Caregiver Quality of Instruction, poorer Primary Caregiver Confidence, poorer Quality of Relationship,** and **greater Boundary Dissolution** (as rated on the Teaching Tasks)**.**

b. Greater general primary caregiver parenting-related stress (**Total Stress** on PSI) will be associated with **poorer Primary Caregiver Supportive Presence, greater Primary Caregiver Intrusiveness, greater Primary Caregiver Hostility, poorer Primary Caregiver Quality of Instruction, poorer Primary Caregiver Confidence, poorer Quality of Relationship,** and **greater Boundary Dissolution** (as rated on the Teaching Tasks)**.**

c. Greater primary caregiver psychological distress (**Global Severity Index** on BSI) will be associated with **poorer Primary Caregiver Supportive Presence, greater Primary Caregiver Intrusiveness, greater Primary Caregiver Hostility, poorer Primary Caregiver Quality of Instruction,**

poorer Primary Caregiver Confidence, poorer Quality of Relationship, and **greater Boundary Dissolution** (as rated on the Teaching Tasks)**.**

d. Greater dissatisfaction in the primary caregivers' romantic relationship (**Quality of Marriage Index**) will be associated with **poorer Primary Caregiver Supportive Presence, greater Primary Caregiver Intrusiveness, greater Primary Caregiver Hostility, poorer Primary Caregiver Quality of Instruction, poorer Primary Caregiver Confidence, poorer Quality of Relationship,** and **greater Boundary Dissolution** (as rated on the Teaching Tasks)**.**

III. Characteristics of the primary caregiver-child relationship will be associated with child outcome (i.e., cognitive, language, behavioral, and socio-emotional functioning) such that **poorer Primary Caregiver Supportive Presence, greater Primary Caregiver Intrusiveness, greater Primary Caregiver Hostility, poorer Primary Caregiver Quality of Instruction, poorer Primary Caregiver Confidence, poorer Quality of Relationship,** and greater **Boundary Dissolution** (as rated on the Teaching Tasks) will be associated with increased report of socio-emotional problems (**Internalizing Problems** and **Externalizing Problems** on CBCL or BASC-2), poorer adaptive functioning (**Adaptive Behavior Composite** on VABS-II), poorer language skills (**Expressive Language** on PLS-4 or CELF PRE-2), and poorer overall cognitive functioning (**Overall Intellectual Functioning** on DAS-II, Mullen, or WPPSI-III).

IV. Characteristics of the primary caregiver-child relationship (**Total Observation Composite**) will significantly contribute to child cognitive and linguistic outcomes (**Overall Intellectual Functioning, Verbal Reasoning Ability,** and **Nonverbal Reasoning Ability** on DAS-II, Mullen, or WPPSI-III; **Total Language, Receptive Language, and Expressive Language** on PLS-4 or CELF PRE-2) after controlling for severity of a child's medical condition.

V. Characteristics of the primary caregiver-child relationship (**Total Observation Composite**) will moderate the relationship between primary caregivers' appraisals of stress (**Total Stress Composite**) and child cognitive and linguistic outcomes (**Overall Intellectual Functioning** on DAS-II, Mullen, or WPPSI-III; **Total Language** on PLS-4 or CELF PRE-2).

Method

Institutional Review

This study was conducted with the approval of the Institutional Review Board (IRB) of Children's Hospital of Wisconsin (CHW) and Marquette University. With approval by the IRB of both institutions, recruitment commenced in February 2008 in accordance with the methods described below.

Participants

Participants were recruited from among children and their primary caregivers who were referred to the Preschool and Infant Neuropsychological Testing (PINT) Clinic at Froedtert Hospital and the Medical College of Wisconsin for a neuropsychological evaluation during the time period from February 2008 until the end of April 2009.

Criteria for inclusion were as follows: 1) Disruption to typical neural development; 2) Age at clinic visit between 2 years, 0 months and 5 years, 11 months; and 3) Residence in an English-speaking household. During this time period, 194 children and their primary caregivers were scheduled for neuropsychological evaluations within the preschool specialty clinic.

Of those scheduled for clinic visits, 134 children and their primary caregivers met inclusion criteria for the study. The primary caregivers of 93 of these children agreed to be contacted about participation in the study. Thirty-nine primary caregivers were not approached about the study for reasons including: 1) No show to scheduled clinic visits; 2) A clinical observation was not planned as part of the evaluation; 3) Delays in a child's functioning were so significant that tasks included as part of the clinical observation would not be feasible to complete; 4) The neuropsychological evaluation was being conducted for legal purposes; 5) The discretion of the clinical provider due to sensitive nature of evaluation; 6) The primary caregiver did not participate in the evaluation; or 7) Unknown. Two additional primary caregivers of children eligible for the study agreed to be contacted about participation, but for unknown reasons, were not later asked to consent to participate.

Of the 93 primary caregivers who agreed to be contacted about study enrollment, four did not consent to participation in the study, citing reasons including: 1) Uncomfortable with videotaping; 2) Belief that the secondary caregiver would not approve of participation; and 3) Not interested. Subsequently, 89 primary caregivers consented to participating in the study with their child. Of note, one of these primary caregivers consented to participation in the study at two time points. As such, data from

this primary caregiver and child was only included from their initial clinic visit, leaving the resultant sample to be comprised of 88 children and their primary caregivers. Only children with complete observational data and questionnaire data regarding primary caregivers' appraisals of stress (i.e., Pediatric Inventory for Parents; Parenting Stress Index – Long Form; Brief Symptom Inventory) were considered in the present analyses, which resulted in a sample size of 72 children and their primary caregivers.

Procedure

The present study was incorporated into the standard clinic visits for children and families seen in the PINT Clinic. Data was collected over a series of three clinic visits, each one week apart. At the first visit, children's primary caregivers arrived to the clinic at the Medical College of Wisconsin independent of their child for a clinical interview with a neuropsychological provider. The provider attained primary caregivers' written consent to participate in the present study, emphasizing that their family's decision whether or not to participate would not impact the medical care provided during their clinic visits. The provider also conveyed potential risks and benefits of the study. Then, the provider conducted a clinical interview to obtain relevant background information and administered a structured interview of the child's adaptive functioning. Prior to the initial visit, most primary caregivers completed a measure of the child's behavior and socio-emotional functioning. If the primary caregivers had not completed this measure by the first visit, they completed it by the conclusion of the second visit.

At the second and third visits, all children completed a similar battery of tests, which were administered by a psychometrist well trained in standardized administration techniques. Measures of general intellectual ability and language ability were selected

and administered based on the age of the patient and/or capability to complete various measures (see specific descriptions that follow). All testing was completed in the same clinic setting during two 2-hour testing appointments, typically separated by one week. In general, the battery administered included measures of general cognitive ability, language, fine motor skills, attention, and early executive functioning. Only data from the measures of general intellectual functioning and language were included in the current analyses.

While children were being tested during the second and third visits, primary caregivers who had consented to participation in the study independently completed up to four questionnaires in the clinic waiting area. These questionnaires consisted of rating scales designed to assess primary caregivers' stress related to caring for a child with a medical condition, general parent stress, personal psychological distress, and degree of satisfaction in his or her romantic relationship. These questionnaires are described in greater detail in the methods section.

Also in the context of clinic visits, the primary caregiver and child together participated in a standardized semi-structured play interaction based upon the Teaching Tasks developed by Erickson, Sroufe, and Egeland (1985). The play interaction consisted of a short series of semi-structured play segments: 1) Snack; 2) Teaching Tasks; and 3) Toy Play. Each segment lasted approximately five minutes in length. During the snack segment, the examiner provided the child and primary caregiver with a bowl of goldfish crackers and a juice box at a small table. The examiner instructed, "Here is a snack for you to enjoy," before exiting the room to watch the interaction from behind a one-way mirror. During the teaching tasks segment, the primary caregiver was encouraged to

motivate the child to complete a series of increasingly difficult puzzles, which were pre-selected by the examiner according to the child's developmental level. During the toy play segment, the primary caregiver and child were provided with a bin of toys and were instructed to play freely as they normally would. These interactions were videotaped only if a family had consented to participation in the study. Only data from the teaching tasks segment were included in the analyses that follow.

Measures

Demographic and Injury Variables

The medical record of each participating child, together with a developmental questionnaire (completed by the primary caregiver), were reviewed to extract information regarding a child's medical condition and family demographic characteristics. Data collected included children's developmental history and educational status, as well as primary caregivers' relationship to the participating child, education, and relationship status. A complete listing of the medical conditions associated with participating children's atypical neural development can be found in Table 1.

Table 1

Neurological Disorders and/or Conditions Associated with Atypical Neural Development for which Sample Participants were Referred for a Neuropsychological Evaluation

Neurological Disorder and/or Medical Condition	*N*
Brain Hemorrhage	4
Brain Tumor	6
Cancer with Associated Neurotoxic Effects of Chemotherapy	1
Cardio-pulmonary Problems with Associated Anoxic Event(s)	4
Cephalic Disorder	3
Cerebrovascular Accident (Stroke)	4
Chromosomal Abnormality	2
Congenital Malformation	2
Infectious Process	4
In Utero Substance Exposure	3
Neuro-muscular and –motor Disorders	5
Prematurity (<36 Weeks Gestation)	15
Seizures/Epilepsy	39
Traumatic Brain Injury	2
Ventricular Insult	8
Other	4

Note. Conditions above may be co-morbid.

Of note, due to the heterogeneous nature of medical conditions associated with atypical neural development in the participating sample, a standardized measure of injury severity appropriate for all referring conditions was not available in existing form. As such, the Pediatric Cerebral Performance Category Scale (Task Force of the American Academy of Pediatrics, 1995) was used for the purpose of establishing a severity rating for participants in this sample. The Pediatric Cerebral Performance Category Scale was

initially described by Fiser (1992) and can be used to summarize the level of neurologic function in a pediatric patient. Assessment ratings on this scale are made on the basis of medical record review or interview with caretaker; thus, this was deemed a feasible measure for the current study. Fiser and colleagues (2000) evaluated the utility of the Pediatric Cerebral Performance Category Scale as a tool for effectively quantifying disability after a child's critical illness or injury in pediatric intensive care patients. Their findings supported the Pediatric Cerebral Performance Category Scale as a brief and easily completed measure for providing useful information regarding probable outcomes. In unmodified format, the Pediatric Cerebral Performance Category Scale quantifies disability on the following 6-point scale: 1) Normal; 2) Mild disability; 3) Moderate disability; 4) Severe disability; 5) Coma or vegetative state; and 6) Death (for details of each category, see Appendix A.)

As children participating in the current study were evaluated in an outpatient clinic setting, ratings consistent with two categories, 5) Coma or vegetative state, or 6) Death, were not appropriate for the sample. Further, as all children meeting inclusion criteria for recruitment presented with a history of disruption to typical neural development, a category score of 1) Normal, was also not appropriate. As such, only category classifications of 2) Mild disability, 3) Moderate disability, and 4) Severe disability, were used as approximations for injury severity. Scores of 1, 2, and 3, were assigned to mild, moderate, and severe categories of disability, respectively. Severity scores were assigned by the primary investigator based on review of medical records together with primary caregivers' ratings of a child's adaptive functioning on the Vineland Adaptive Behavior Scales, Second Edition (Sparrow, Cicchetti, & Balla, 2005).

Primary Caregivers' Appraisals of Stress

Pediatric Inventory for Parents (PIP; Streisand, Braniecki, Tercyak, & Kazak, 2001). The PIP was designed to assess parental stress related to caring for a child with chronic illness. It contains 42 items that ask parents to describe the frequency and intensity with which they experience stress related to caring for their child's illness across the domains of communication, emotional functioning, child's medical care, and role functioning. Items are rated on a 5-point Likert scale with higher scores reflecting higher frequency of difficult events experienced by parents in the past seven days and greater perceived difficulty of the events in the past week, or in general. The **Total Frequency Score** and **Total Difficulty Score** comprise the total sum of the frequency of difficult events in all four domains and the total difficulty experienced by the events in all four domains, respectively.

Studies using data from the PIP have shown high internal consistency and construct validity as demonstrated by significant associations with a measure of state anxiety and also with parenting stress. When general parenting stress and demographic variables were controlled for, PIP scores showed strong independent associations with state anxiety (Streisand et al., 2001). The PIP has been used with parents of children as young as two with a variety of medical conditions including various pediatric cancers (Streisand et al., 2001; Streisand, Tercyak, & Kazak, 2003), Type 1 diabetes (Streisand, Swift, Wickmark, Chen, & Holmes, 2005; Lewin et al., 2005), sickle cell disease (Logan, Radcliffe, & Smith-Whitley, 2002), and short stature (Preston et al., 2005). Given the mixed etiology of children included in the samples of previous studies using the PIP, the PIP was determined to be applicable to the stress and burden experienced by the primary

caregivers of the children in the current study. Cronbach's α for the Total Frequency Score in the present sample was .87. Cronbach's α for the Total Difficulty Score was .89.

Parenting Stress Index-Short Form (PSI-SF; Abidin, 1990). The PSI-SF is a well-validated measure of parent-child relationships and child and parent characteristics. It contains 36 statements rated on a 5-point Likert scale. The PSI-SF is reported to have satisfactory internal consistency and test-retest reliability and good concurrent validity with the full version. The Total Stress score, designed to provide an indication of the overall level of parenting stress an individual is experiencing independent of other life roles and life events, was used in the present study. A parent's **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 total raw score greater than 90 indicates elevated stress, as it falls above the 90th percentile in the normative group (Abidin, 1990). Of the 72 primary caregivers who completed this measure, 24 primary caregivers' endorsements were elevated. Within this sample, Cronbach's α for the **Total Stress** score was .80.

Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983). The BSI is a 53-item self-report checklist of symptoms of psychological distress which has well-documented reliability and validity. Items are rated on a five-point scale of distress (0-4) ranging from "not at all" (0) at one pole to "extremely" (4) at the other. The **Global Severity Index (GSI),** which represents the sum of reported distress on nine symptom dimensions (e.g., Depression, Interpersonal Sensitivity, Anxiety) and four additional items divided by the total number of responses, was utilized in the current study. The BSI has frequently been used as an index of psychological distress experienced by parents

with children suffering from traumatic brain injury (e.g., Wade, Taylor, Drotar, Stancin, & Yeates, 1996; Taylor et al., 1999; Conley, Caldwell, Flynn, Dupre, & Rudolph, 2004). A *T*-score greater than or equal to 63 on the **GSI** indicates clinically elevated distress (Derogatis & Melisaratos, 1983) the 72 primary caregivers who completed this measure, 23 primary caregivers' endorsements were clinically elevated.

Quality of Marriage Index (QMI; Norton, 1983). The QMI is six-item self-report measure of the degree of satisfaction one feels in various areas of one's romantic relationship. The first five items are rated on a seven-point scale (1 to 7) with one representing very strong disagreement with an item and seven representing very strong agreement with an item. The sixth item requires the rater to rate the degree of happiness that best describes his/her relationship on a scale of 1 to 10 with anchor points at 1 (Unhappy), 5-6 (Happy), and 10 (Perfectly happy). The **Total Score** of all items from this index was used to reflect primary caregivers' satisfaction in his/her present romantic relationship. Higher scores on this index reflect greater satisfaction. In the current study, Cronbach's α for this six-item scale was .97.

Descriptive characteristics for all measures of primary caregivers' appraisals of stress for the present sample can be found in Table 2. Pearson correlations were calculated among measures representing primary caregivers' appraisals of stress. As higher scores on the **Total Score** of the QMI reflected greater relationship satisfaction, this score was reverse coded for subsequent analyses so that higher scores would reflect greater distress in the likeness of higher scores on the PIP, PSI-SF and BSI. Significant positive relationships were found among the **Total Frequency** and **Total Difficulty** scores on the PIP, the **Total Stress** score on the PSI-SF, and the **Global Severity Index**

on the BSI (see Table 3). The **Total Score** of the QMI was not significantly correlated with the PIP, PSI-SF, or BSI indices. As such, the QMI Total Score was excluded from the calculation of a stress composite variable to be used in subsequent analyses. Due to the differences in scaling for the PIP, PSI-SF, and BSI, the scores from each of these measures were converted to standard scores (*z*) and then summed together to form the **Total Stress Composite** variable.

Table 2

Descriptive Characteristics for Primary Caregiver Stress Measures

Measure	*n*	*Minimum*	*Maximum*	*M*	*SD*
Pediatric Inventory for Parents					
Total Frequency of Stressors	72	50	167	104.89	27.17
Total Difficulty of Stressors	72	51	192	102.66	29.76
Parenting Stress Index Short Form Total	72	39	155	82.66	23.79
BSI Total Severity Index (*T*-score)	72	32	78	55.21	11.94
QMI Total	66	6	45	35.21	8.99

Note. For all values but the QMI, higher values reflect greater distress. On the QMI, higher values reflect greater marital satisfaction.

Table 3

Intercorrelations among Primary Caregiver Stress Measures

Stress Measure	1	2	3	4	5
1. PIP Total Frequency of Stressors	-	.82** *n* = 72	.65** *n* = 72	.62** *n* = 72	-.19 *n* = 66
2. PIP Total Difficulty of Stressors		-	.62** *n* = 72	.67** *n* = 72	.01 *n* = 66
3. PSI-SF Total			-	.64** *n* = 72	.05 *n* = 66
4. BSI Total Severity Index				-	.07 *n* = 66
5. QMI Total					-

Note. The QMI was re-coded for these analyses such that higher values for all measures reflect greater distress.
*$p < .05$. **$p < .01$

Primary Caregiver-Child Relationship

Teaching Tasks. The Teaching Tasks coding scheme focuses on the partnership between the mother and child. The Teaching Tasks were originally designed by the Blocks and their colleagues (Harrington, Block, & Block, 1978). However, the most current version of the Teaching Tasks, as utilized in the present study, was adapted and revised by Egeland and collegues (1995). The coding scheme for the Teaching Tasks is grounded in attachment theory as it extends into preschool. This coding scheme consists of fourteen rating scales. Five of these scales focus on mother behavior, seven scales focus on child behavior, and two scales assess dyadic characteristics. All scales except one are seven-point scales; one scale is a three-point scale. The scales of interest in the current study were: **Mother (Primary Caregiver) Supportive Presence, Mother**

(Primary Caregiver) Intrusiveness, Mother (Primary Caregiver) Hostility, Mother (Primary Caregiver) Quality of Instruction, Mother (Primary Caregiver) Confidence, Quality of Relationship, and Boundary Dissolution.

The majority of research has been done using the Teaching Tasks scales as dependent variables, as mediator and moderator variables, and as independent variables within the Minnesota Mother-Child Project, thereby providing broad evidence for the validity of the scales in research. In fact, Pianta and Egeland (1994) utilized mother ratings from the Teaching Tasks to predict deviations in children's IQ and found that a composite variable of all the maternal scales accounted for a significant amount of variance in predicting changes in IQ scores. In another study, Pianta and colleagues (1990) differentiated children who would later be referred for special services in the early school years with scales from the Teaching Tasks.

Coding Procedures. To establish gold standard ratings for the selected codes in the current sample, the primary investigator and an advanced undergraduate research assistant rated approximately 20 percent of the data (i.e., 16 tapes). Through in-depth discussion and extensive tape review, a gold standard rating for each scale was determined that was thought to best represent each of the codes used. The primary investigator did not code additional tapes after gold standard ratings had been established. An additional two undergraduate research assistants participated in extensive training and rated the 16 tapes with established gold standard ratings in order to achieve 80 percent categorical agreement that was within one point of the gold standard ratings.

All tapes were viewed and coded independently by at least two undergraduate research assistants blind to the study's hypotheses. Coding pairs were assigned on a

rotating basis, which ensured that all possible coding pairs within the group were represented. Each week coding pairs reviewed the scores each coder had assigned to a tape, and if there were disagreements greater than one point, they were resolved through discussion, review of notes from the tape, and/or watching actual segments of the tape. A third coder was also present for score review as was the primary investigator in order to serve as a moderator of the group discussion. Disagreements of one point were averaged. Through this conferencing process, the coders arrived at one score for each scale that they believe best represented the events of the Teaching Task segment.

In addition to the pair coding, a tape was intermittently coded by the entire group. For this tape, each member of the group coded the tape independently, and consensus was reached in a manner similar to that used with pair tapes. The individual scores were recorded, and through scale by scale discussion, the group arrived at one set of scores they believed best represented the events of the Teaching Tasks segment. This scoring exercise served as ongoing training, helped prevent coding drift within the group, and served as a forum for discussion of issues pertaining to the scales and how to code particularly ambiguous situations. These coding procedures were in accordance with those set forth by the developers of the coding scheme.

Interrater Reliability on the Coding Scales. Interrater reliability was determined using the original scores assigned by the coders of each tape. Intraclass correlations were used to determine reliability on all data tapes for all scales but the **Primary Caregiver Confidence** scale. Reliability in interval rating scales is best evaluated by using intraclass correlations, as statistics such as Kappa are intended primarily for use with ordinal data

(Egeland et al., 1995). Since the **Primary Caregiver Confidence** scale was a three-point scale, unlike other scales, reliability for this scale was evaluated with Kappa.

Intraclass correlations for **Primary Caregiver Confidence, Primary Caregiver Quality of Instruction, Quality of Relationship**, and **Boundary Dissolution** were good across coder pairs and groupings. Intraclass correlations varied across coder pairs and groupings for **Primary Caregiver Intrusiveness** and **Primary Caregiver Hostility**. A detailed summary of the intraclass correlations for each scale can be found in Table 4. Kappas for the three-point Primary **Caregiver Confidence** scale also varied across coder pairs and groupings (see Table 5), but typically they were below acceptable standards although consistent with previous reports (e.g., Egeland et al., 1995).

Table 4

Interrater Reliabilities

Scale	n	Intraclass Correlation
Primary Caregiver Supportive Presence		
All Coders	16	0.934
Three Coder Combination	23	0.911
Coding Pair A	39	0.880
Coding Pair B	36	0.850
Coding Pair C	43	0.877
Primary Caregiver Intrusiveness		
All Coders	16	0.621
Three Coder Combination	23	0.616
Coding Pair A	39	0.673
Coding Pair B	36	0.510
Coding Pair C	43	0.768

Primary Caregiver Hostility		
All Coders	16	0.860
Three Coder Combination	23	0.769
Coding Pair A	39	0.639
Coding Pair B	36	0.852
Coding Pair C	43	0.566
Primary Caregiver Quality of Instruction		
All Coders	16	0.940
Three Coder Combination	23	0.881
Coding Pair A	39	0.879
Coding Pair B	36	0.801
Coding Pair C	43	0.764
Quality of Relationship		
All Coders	16	0.927
Three Coder Combination	23	0.892
Coding Pair A	39	0.848
Coding Pair B	36	0.869
Coding Pair C	43	0.842
Boundary Dissolution		
All Coders	16	0.921
Three Coder Combination	23	0.871
Coding Pair A	39	0.893
Coding Pair B	36	0.828
Coding Pair C	43	0.702

Table 5

Interrater Reliabilities: Kappas

Scale	n	Kappa
Primary Caregiver Confidence		
Coding Pair A	39	0.238
Coding Pair B	36	0.514
Coding Pair C	43	0.285
Coding Pair D	16	0.407
Coding Pair E	16	0.377
Coding Pair F	16	0.143

Descriptive Statistics for the Coding Scales. According to the scale developers, the expected means, standard deviations, and frequencies of the scores vary with the nature of each scale. Many of the scales are designed to be normally distributed within the population (i.e., **Primary Caregiver Supportive Presence; Primary Caregiver Quality of Instruction; Primary Caregiver Confidence; Quality of Relationship**). Some of the scales, however, are designed to capture behaviors that are highly meaningful when present, but they are not expected to be normally distributed in the population. These scales are designed to be quadratic (i.e., **Primary Caregiver Intrusiveness; Primary Caregiver Hostility; Boundary Dissolution**). **Primary Caregiver Supportive Presence, Primary Caregiver Intrusiveness, Primary Caregiver Hostility, Primary Caregiver Quality of Instruction,** and **Boundary Dissolution** showed negatively skewed distributions. So as not to violate assumptions of normalcy for subsequent analyses, data from these scales were transformed according to

guidelines as set forth by Tabachnick and Fidell (2001). Given their substantial negative skewness, these scale variables were first reflected, and then a logarithmic transformation was applied. For interpretative purposes, the transformed variables were reflected once more. Results of the transformation were overall consistent with normally distributed data across scales. Descriptive statistics for these scales in the present sample are found in Table 6. Notably, **Primary Caregiver Intrusiveness**, **Primary Caregiver Hostility**, and **Boundary Dissolution** ratings were reverse coded from their original scale in order that higher numbers would represent more desirable caregiving (i.e., less intrusiveness, less hostility, and completely clear primary-caregiver child boundaries). The means and standard deviations were calculated following these code reversals.

Table 6

Observational Codes Descriptive Statistics: Means and Standard Deviations (n=72)

Scale	*M*	*SD*
Primary Caregiver Supportive Presence	5.66	1.20
Primary Caregiver Intrusiveness*	5.31	1.42
Primary Caregiver Hostility*	6.33	1.03
Primary Caregiver Quality of Instruction	5.14	1.46
Primary Caregiver Confidence	2.26	0.72
Quality of Relationship	4.76	1.51
Boundary Dissolution*	5.77	1.47

*Primary Caregiver Intrusiveness, Primary Caregiver Hostility, and Boundary Dissolution ratings were reverse coded from their original scale in order that higher numbers would represent more desirable caregiving (i.e., less intrusiveness, less hostility, and completely clear primary-caregiver child boundaries). The means and standard deviations were calculated following these code reversals.

Pearson correlations were calculated between the individual Teaching Tasks scales and a composite variable that represented the sum of all ratings in the Teaching Tasks segment (see Table 7). All scales were significantly related in the expected direction. Remarkably, the **Quality of Relationship** and composite variable were significantly correlated with a nearly perfect positive linear relationship. Due to the strong relationship between these variables, it was determined that only the **Quality of Relationship** data would be utilized in subsequent analyses in order to avoid problems with multicollinearity, though the initial intent was to use the composite variable.

Table 7

Intercorrelations among Primary Caregiver-Child Observational Codes (*n* = 72)

Code	1	2	3	4	5	6	7	8
1. Supportiveness	-	.30*	.43**	.72**	.59**	.73**	.37**	.78**
2. Intrusiveness[a]		-	.48**	.38**	.33**	.39**	.19	.49**
3. Hostility[b]			-	.39**	.39**	.55**	.21	.60**
4. Quality of Instruction				-	.75**	.77**	.51**	.86**
5. Confidence					-	.73**	.42**	.86**
6. Quality of Relationship						-	.31**	.96**
7. Dissolution of Boundaries[c]							-	.47**
8. Observation Total								-

[a,b,c]Higher values on these scales reflect less intrusiveness and less hostility.
*$p < .05$. **$p < .01$

Neuropsychological Outcomes

Overall intellectual functioning. The selection of the measure of overall intellectual functioning administered to each child was typically made on the basis of a child's age and estimated level of functioning. In most instances, children who were 3-years, 6-months of age or older were administered the Differential Abilities Scale, Second Edition (DAS-II; Elliot, 2007). Children who were less than 3 years of age or who were functioning below a 3-year, 6-month age equivalency level were administered the Mullen Scales of Early Learning (Mullen, 1995). Occasionally, children were administered the Wechsler Preschool and Primary Scale of Intelligence – Third Edition (WPPSI-III; Wechsler, 2002) due to guidelines set forth in a treatment protocol for children with specific medical conditions (e.g., as set forth by the Children's Oncology Group).

The *Differential Ability Scales, Second Edition* (DAS-II; Elliot, 2007) is a comprehensive, individually-administered battery of cognitive abilities for children 3-years, 6-months through 6-years, 11-months of age. The measure yields an overall composite score (General Conceptual Abilities standard score) and subscale cluster scores labeled Verbal Ability and Nonverbal Ability. The DAS-II provides normative data collected on a large representative national sample and possesses adequate standardization. Test structure is empirically-derived and contains excellent internal consistency, test-retest reliability, and the scores correlate highly with other commonly used measures of cognitive abilities.

The *Mullen Scales of Early Learning* (Mullen, 1995) is a commonly used individually-administered measure of cognitive abilities with acceptable standardization.

Normative data collected on a representative national sample is available for individuals aged 1 month through 69 months. The Mullen consists of four scales that assess Visual Reception, Fine Motor, Receptive Language, and Expressive Language skills. T-scores are yielded for each scale, and the Early Learning Composite provides an overall developmental quotient standard score.

The *Wechsler Preschool and Primary Scale of Intelligence – Third Edition* (WPPSI-III; Wechsler, 2002). The WPPSI-III is a comprehensive, individually-administered battery of cognitive abilities for children 2-years, 6-months through 7-years, 3-months of age. The measure yields an overall composite score (Full Scale Intelligence Quotient) and subscale cluster scores labeled Verbal Intelligence Quotient and Performance Intelligence Quotient. The WPPSI-III provides normative data collected on a large representative national sample and possesses adequate standardization. Like the Differential Ability Scales, test structure is empirically-derived and contains excellent internal consistency, test-retest reliability, and the scores correlate highly with other commonly used measures of cognitive abilities, including the Differential Ability Scales.

Descriptive characteristics for all measures of intellectual functioning for the present sample can be found in Table 8. For the purpose of describing cognitive functioning in the sample as a whole, an **Overall Intellectual Functioning** variable was created by using the overall reasoning scores from the respective intellectual functioning measures administered to each child (i.e., DAS-II General Conceptual Abilities standard score; Mullen Early Learning Composite raw score; and WPPSI-III Full Scale Intelligence Quotient) and converting them to *z*-scores. A **Verbal Reasoning Ability** variable was created using the verbal cluster subscale scores from the respective

intellectual functioning measures administered to each child (i.e., DAS-II Verbal Ability; WPPSI-III Verbal Intelligence Quotient) and converting them to *z*-scores. A **Nonverbal Reasoning Ability** variable was created using the nonverbal cluster subscale scores from the respective intellectual functioning measures administered to each child (i.e., DAS-II Nonverbal Ability; WPPSI-III Performance Intelligence Quotient) and converting them to *z*-scores.

Table 8

Descriptive Characteristics for Measures of Intellectual Functioning

Measure	*n*	*Minimum*	*Maximum*	*M*	*SD*
DAS-II Lower Preschool Version (Standard Scores)					
General Conceptual Abilities	8	67	92	75.88	9.03
Verbal Ability	8	69	94	79.50	8.96
Nonverbal Ability	8	67	106	77.63	13.55
DAS-II Upper Preschool Version (Standard Scores)					
General Conceptual Abilities	33	38	111	84.70	17.31
Verbal Ability	34	38	115	87.06	16.23
Nonverbal Ability	33	59	127	89.64	14.32
Mullen Scales of Early Learning (Raw Score)					
Early Learning Composite	28	40	129	87.18	22.94
WPPSI-III (Standard Scores)					
Full Scale Intelligence Quotient	2	57	81	69.00	16.97
Verbal Intelligence Quotient	2	75	83	79.00	5.66
Performance Intelligence Quotient	2	51	86	68.5	24.75

Language abilities. Consistent with the selection of the measure of general cognitive abilities administered to each child being made on the basis of their age and estimated level of functioning, so, too, was the selection of a measure of language abilities made. In most instances, children who were administered the Differential Abilities Scale, Second Edition (Elliot, 2007) as the measure of overall intellectual functioning were administered the Clinical Evaluation of Language Fundamentals Preschool – Second Edition (CELF Pre-2; Wiig et al., 2004). When children were less than 3 years of age or functioning below a 3-year, 6-month age equivalency and administered the Mullen Scales of Early Learning (Mullen, 1995), they were generally administered the Preschool Language Scale – Fourth Edition (PLS-4; Zimmerman, Steiner, & Pond, 2002). Moderate correlations between the CELF PRE-2 and the PLS-4 have been found in an ethnically diverse sample of 3-6 year-olds (Wiig, Secord, & Semel, 2004). On rare instances when a comprehensive language measure was administered (i.e., either due to a provider's judgment or due to the guidelines of a treatment protocol), targeted measures of receptive or expressive language were administered using the Peabody Picture Vocabulary Test-Fourth Edition (PPVT-4; Dunn & Dunn, 2007) or Expressive Vocabulary Test – Second Edition (EVT-2, Williams, 2007).

The *Clinical Evaluation of Language Fundamentals Preschool*-2 (CELF PRE-2; Wiig et al., 2004) is an individually administered test of receptive and expressive language ability for children 3-6 years of age. The test yields standard scores for receptive subtests (sentence structure, concepts and following directions, and basic concepts/word classes) and expressive subtests (word structure, expressive vocabulary,

and recalling sentences) and composite scores for total language, receptive language, expressive language, language content, and language structure. All the appropriate subtests were used to calculate these composite scores according to the publication manuals. The CELF PRE-2 provides normative data standardized on a representative sample from the United States.

The *Preschool Language Scale – Fourth Edition* (PLS-4; Zimmerman et al., 2002). The PLS-4 is a comprehensive measure of receptive and expressive language skills. The PLS-4 manual reports that the three standard scores it yields (Auditory Comprehension, Expressive Language, Total Language) significantly differentiated a group of children under age three years with a language delay from a matched sample of typically developing children.

The *Peabody Picture Vocabulary Test-Fourth Edition* (PPVT-4; Dunn & Dunn, 2007) and the *Expressive Vocabulary Test – Second Edition* (EVT-2, Williams, 2007) are targeted measures of receptive and expressive language, respectively, that are individually administered to persons ages 2 years, 0 months to over 90 years of age. The PPVT-4 and EVT-2 have normative data from the same large sample (>5,500 individuals) that matches demographic parameters from the national population with regard to gender, race/ethnicity, geographic region, socioeconomic status (SES), and clinical diagnosis or special-education placement.

Descriptive characteristics for all language measures can be found in Table 9. For the purpose of describing overall language in the sample as a whole, a **Total Language** variable was created by using the overall language scores from all of the language measures administered to each child (i.e., CELF PRE-2 Core Language standard score;

PLS-4 Total Language raw score), and converting them to *z*-scores. A **Receptive Language** variable was created using the receptive language subscales from all of the language measures administered to each child (i.e., CELF PRE-2 Receptive Language; PLS-4 Auditory Comprehension; PPVT-4 Receptive Language), and converting them to *z*-scores. An **Expressive Language** variable was created using the expressive language subscales from all of the language measures administered to each child (i.e., CELF PRE-2 Expressive Language; PLS-4 Expressive Language; EVT-2 Expressive Language), and converting them to *z*-scores.

Table 9

Descriptive Characteristics for Measures of Language

Measure	*n*	*Minimum*	*Maximum*	*M*	*SD*
CELF PRE-2 (Standard Scores)					
Core Language	33	48	114	81.94	17.60
Receptive Language	31	50	115	81.77	16.38
Expressive Language	33	45	111	80.61	17.01
PLS-4 (Raw Scores)					
Total Language	27	21	85	52.26	14.89
Auditory Comprehension	27	10	42	26	7.61
Expressive Language	27	11	43	26.26	8.13
PPVT-4 (Standard Score)					
Receptive Language	7	64	103	76.86	12.92
EVT-2 (Standard Score)					
Expressive Language	3	68	98	81	15.39

Intercorrelations among all cognitive measures of intellectual functioning and language can be found in Table 10.

Table 10

Intercorrelations among Cognitive and Language Abilities

Cognitive Ability	1	2	3	4	5	6
1. Overall Intellectual Functioning	-	.85** *n* = 43	.80** *n* = 43	.82** *n* = 58	.80** *n* = 60	.77** *n* = 59
2. Verbal Reasoning Ability		-	.57** *n* = 43	.86** *n* = 33	.74** *n* = 36	.83** *n* = 35
3. Nonverbal Reasoning Ability			-	.67** *n* = 33	.59** *n* = 35	.57** *n* = 34
4. Total Language				-	.87** *n* = 57	.93** *n* = 59
5. Receptive Language					-	.79** *n* = 59
6. Expressive Language						-

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

Behavioral and socio-emotional functioning. Children's socio-emotional functioning was attained via parent report on behavioral rating questionnaires and via psychometrist report on a behavioral rating scale. The *Child Behavior Checklist for Ages 1½ to 5* (CBCL; Achenbach, 2000). The CBCL is a widely-used broad-band questionnaire that assesses parent and teacher perceptions of a wide variety of behaviors. Excellent reliability and validity have been demonstrated (Rescorla, 2005), and normative data on an extensive national sample is available. Based on the pattern of responses, the

CBCL provides *T*-scores that classify the number of symptoms endorsed as being at normal, at-risk, or clinical levels. In the current analyses, only data from the primary caregiver (parent) report of the **Internalizing Problems** and **Externalizing Problems** scales were included. The parallel versions of the parent and teacher CBCL have been used extensively as measures of socio-emotional and behavioral functioning in studies investigating child outcome in the context of a medical condition (e.g., Rivara et al. 1992; Rivara et al., 1993; Rivara et al., 1994; Rivara et al.,1996; Rodenburg, Meijer, Dekovic, & Aldenkamp, 2005, 2006; Taylor et al., 1999; Taylor et al., 2002). Due to the guidelines set forth by specific treatment protocols for one sample participant, the Behavior Assessment System for Children – Second Edition, Parent Rating Scales-Preschool (BASC-2 PRS-P; Reynolds & Kamphaus, 2004) was administered in place of the CBCL. As such, *T*-scores from the Internalizing Problems and Externalizing Problems scales on the BASC-2 PRS-P were used in current analyses for this one participant.

The Bayley Behavior Rating Scale (Bayley, 1993) was used to provide ratings of children's behavior/emotions during testing as observed by the psychometrist. The raw score from the **Total Observed Problems** subscale was used as an alternate report (other than by the primary caregiver) of the extent of interference caused by children's behavior problems. Psychometrists rated how problematic the presence of specific behaviors (e.g., Hyperactivity, Aggression, Inattention) were on a four-point scale with "1" indicating that the behavior caused no problems in the visit and "4" indicating that the behavior was highly problematic. Higher scores reflect more interference by these behaviors on the child's functioning during the clinic visit.

The Vineland Adaptive Behavior Scales-II (VABS-II, Sparrow, Cicchetti, & Balla, 2005) were used as a measure of adaptive functioning. The VABS-II measures personal and social skills necessary for daily living. The VABS-II was administered to the primary caregiver in interview format, revealing information on a child's level of adaptive functioning in the following domains: Communication, Daily Living Skills, Socialization, and Motor Skills. A **Total Adaptive Behavior Composite Score** was derived from the primary caregiver's report on the child's adaptive functioning in each of the above domains. This composite score was used as a factor in determining the severity rating of a child's medical condition as well as an outcome variable. Higher scores on this composite index are indicative of better overall adaptive functioning.

Descriptive statistics for behavioral and socio-emotional functioning measures can be found in Table 11. Intercorrelations among all measures of behavioral and socio-emotional functioning and language can be found in Table 12.

Table 11

Descriptive Characteristics for Measures of Behavioral and Socio-emotional Functioning

Measure	*n*	*Minimum*	*Maximum*	*M*	*SD*
CBCL (Standard Scores)					
Internalizing Problems	69	33	80	56.51	11.13
Externalizing Problems	69	32	89	58.74	13.21
BASC-2 PRS-P (Standard Scores)					
Internalizing Problems	1	47	47	47	
Externalizing Problems	1	59	59	59	
Bayley Behavior Rating Scale (Raw Score)					
Total Observed Problems	72	12	23	15.70	3.24
VABS-II (Standard Score)					
Adaptive Behavior Composite	66	53	108	77.61	11.81

Table 12

Intercorrelations among Behavioral and Socio-emotional Functioning Measures

Measure	1	2	3	4
1. Internalizing Problems	-	.61** *n* = 69	.14 *n* = 69	.21 *n* = 69
2. Externalizing Problems		-	.23 *n* = 69	.27* *n* = 69
3. Total Observed Problems			-	.90** *n* = 72
4. VABS-II Adaptive Behavior Composite[d]				-

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

Data Analytic Plan

Group Differences

Independent samples *t*-tests were conducted to determine if there were group differences on key demographic and outcome variables between sample participants whose data was included in the present analyses and consented participants who had incomplete data sets.

Confounding Variables

Bivariate correlations and independent samples *t*-tests were conducted to assess the possible confounding influence of demographic characteristics on key outcome variables that were included in subsequent analyses. The possible confounding influences of child characteristics (i.e., gender, ethnicity, education, gestational age, adoptive status, and medical condition severity) and mother characteristics (i.e., age, education, and relationship status) on primary caregivers' appraisals of stress, primary caregiver-child relationship quality, and cognitive, behavioral, and socio-emotional functioning were examined.

Inter-domain Relationships

Bivariate correlations assessing the hypothesized relationships among variables between each of the three data domains (Primary Caregivers' Appraisals of Stress, Primary Caregiver-Child Relationship Quality, and Child Cognitive, Behavioral, and Socio-emotional Functioning) were conducted. As the nature of hypotheses posed were unidirectional, one-tailed significance tests were used for all correlational analyses conducted between these domains. The hypothesized relationships were assessed in two ways. First, Pearson correlations were conducted to test the hypothesized relationships.

Then, partial correlations were conducted, controlling for any variance contributed by the severity of a child's medical condition. If a relationship that was clinically significant when using Pearson correlational analysis alone remained significant after the variance contributed by the severity of a child's medical condition was partialed out, then a hypothesized relationship was interpreted as a clinically significant finding.

Contributions to Child Cognitive Outcome

Hierarchical regression analyses were conducted to assess the contribution of the primary caregiver-child relationship (**Quality of Relationship**) to child cognitive outcomes (**Overall Intellectual Functioning, Verbal Reasoning Ability,** and **Nonverbal Reasoning Ability** on DAS-II, Mullen, or WPPSI-III; **Total Language, Receptive Language, and Expressive Language** on PLS-4 or CELF PRE-2) after controlling for severity of a child's medical condition and any significant confounding variables.

Moderation Analyses

Hierarchical regression analyses to test for significant interaction effects with the primary caregiver-child relationship (**Quality of Relationship**) as a moderator and the **Total Stress Composite** variable as the independent variable in predicting child cognitive outcomes, including **Overall Intellectual Functioning** and **Total Language**. The severity of a child's medical condition and any significant confounding variables were entered into the first and second steps of the regression equation. Next, the independent variable and moderator main effects were entered into the regression equation, followed by the interaction of the independent variable and the moderator. The independent variable and the moderator were centered in accordance with

recommendations by Aiken and West (1991) to eliminate problematic multicollinearity effects between first-order terms (i.e., the independent variable and the moderator) and the higher order terms (i.e., the interaction terms). Statistically significant interactions were interpreted by plotting simple regression lines for high and low values of the proposed moderator variables.

Results

Participants

Child participants were 61% male. Mean age at participation 48.25 months *(SD* = 13.25 months). Participants were ethnically diverse with 68% Caucasian, 22% African American, 6% Hispanic, 3% Asian, and 1% Other. Mean gestational age of children participating in the study was 37.41 weeks (*SD* = 4.23 weeks). Most children had exposure to early educational placement ranging from Birth to Three and Early Childhood services to Kindergarten. Using ratings from an adapted version of the Pediatric Cerebral Performance Category Scale, 36% of children's neurologic injuries were classified as mild, 46% were classified as moderate, and 18% were classified as severe.

Participating primary caregivers were 79% biological mothers, 10% adoptive mothers, 6% grandmothers, 3% foster mothers, 1% biological fathers, and 1% grandfathers. The majority of primary caregivers had some college education or more. Sixty-nine percent of primary caregivers were married, 17% were not together/never married, 4% were separated, 1% was divorced, and 8% relationship status was unknown.

Demographic characteristics of participating children and of their primary caregivers can be found in Tables 13 and 14, respectively.

Table 13

Child Demographic Characteristics

	M ± *SD*	*n* (%)
Gender		
Male		44 (61)
Female		28 (39)
Age (in months)	48.25 ± 13.52	
Ethnicity[a]		
Caucasian		47 (68)
African-American		15 (22)
Hispanic		4 (6)
Asian		2 (3)
Other		1 (1)
Gestational age[b] (weeks)	37.41 ± 4.23	
Birth weight[c] (ounces)	6.65 ± 2.13	
Educational Placement[d]		
Birth to three		8 (11)
Early childhood		25 (35)
Daycare		6 (8)
Preschool		4 (6)
4K		9 (13)

5K	7 (10)
None	12 (17)
Adopted	8 (11)
In Foster Care	2 (3)
Severity of Medical Condition[e]	
Mild	26 (36)
Moderate	33 (46)
Severe	13 (18)

[a]Ethnicity available *n* = 69
[b]Gestational age available *n* = 67
[c]Birth weight available *n* = 66
[d]School available *n* = 71
[e]Based on Pediatric Cerebral Performance Category Scale (adapted)

Table 14

Primary Caregiver Demographic Characteristics

	n (%)
Participating Primary Caregiver	
Biological Mother	57 (79)
Biological Father	1 (1)
Adoptive Mother	7 (10)
Foster Mother	2 (3)
Grandmother	4 (6)
Grandfather	1 (1)
Maternal Education (Highest Level Completed)	
Grade School	3 (4)
High School	17 (24)
Some College	14 (19)
Associate's Degree	8 (11)
Bachelor's Degree	22 (31)
Master's Degree	4 (6)
Doctoral Degree	1 (1)
Unknown	3 (4)
Maternal Relationship Status	
Married	50 (69)
Separated	3 (4)
Divorced	1 (1)
Not together/Never Married	12 (17)
Unknown	6 (8)

Group Differences

No significant differences in children's gender, age, ethnicity, gestational age, birth weight, injury severity, or overall intellectual functioning were detected using independent samples *t*-tests between the participants who data were included in all analyses (n = 72) and consented subjects whose data were not be used in subsequent analyses (n = 16) due to incomplete data. In addition, no significant differences between mother's age, father's age, and mother's relationship status were detected between groups.

Confounding Variables

Primary Caregivers' Appraisals of Stress

Bivariate correlational analysis revealed a significant negative association between mother's age and the total stress (i.e., composite stress variable) experienced by a primary caregiver (r = -.34, p < .01). As such, mother's age was controlled for in subsequent hierarchical regression analyses involving the total stress composite variable.

Primary Caregiver-Child Relationship Quality

Bivariate correlational analysis demonstrated a significant positive association between severity of a child's medical condition and the primary caregiver-child quality of relationship (r = .35, p < .01). Thus, the severity of a child's medical condition was controlled for in subsequent hierarchical regression analyses involving the primary caregiver-child relationship. Notably, the severity variable was reverse coded in the data set such that higher scores on the severity index indicated better (or less severe) functioning.

Cognitive, Language, Behavioral, and Socio-emotional Functioning

Bivariate correlational analysis revealed significant positive associations between the severity of a child's medical condition and overall intellectual functioning ($r = .41$, $p < .01$), verbal reasoning ability ($r = .41$, $p < .01$), nonverbal reasoning ability ($r = .48$, $p < .01$), total language ($r = .37$, $p < .01$), receptive language ($r = .31$, $p < .01$), and expressive language ($r = .31$, $p < .01$). Group differences were found using independent samples *t*-tests for Caucasian and non-Caucasian children with regard to overall intellectual functioning ($t(65) = -3.00$, $p < .01$), verbal reasoning ability ($t(40) = -3.63$, $p < .01$), total language ($t(54) = -2.47$, $p < .05$), receptive language ($t(56) = -2.43$, $p < .05$), and expressive language ($t(56) = -2.56$, $p < .05$). Caucasian children performed significantly better than non-Caucasian children on these outcome measures. Group differences were also found using independent samples *t*-tests for married and unmarried mothers with regard to children's overall intellectual functioning ($t(63) = -2.44$, $p < .05$), verbal reasoning ability ($t(39) = -2.10$, $p < .05$), and expressive language ($t(54) = -2.16$), $p < .05$). Children of married mothers performed significantly better on these outcome measures than children of unmarried mothers. Thus, severity of a child's medical condition was controlled for in subsequent hierarchical regression analyses involving all cognitive outcomes. In addition, child ethnicity was controlled for in subsequent hierarchical regression analyses involving all cognitive outcomes except nonverbal reasoning ability. Marital status was controlled for in subsequent analyses involving overall intellectual functioning, verbal reasoning ability, and expressive language.

Significant positive associations were found between a child's age and internalizing problems ($r = .32$, $p < .01$), as well as between a child's age and

externalizing problems (r = .24, p < .05). In addition, significant negative associations were found between mother's education and externalizing problems (r = -.26, p < .05), and between a child's gestational age and adaptive functioning (r = -.30, p < .05). As such, children's age was controlled for in subsequent hierarchical regression analyses involving internalizing and externalizing problems. Mother's education was also controlled for in sequent hierarchical regression analyses involving externalizing problems. Gestational age was controlled for in subsequent hierarchical regression analyses involving adaptive functioning.

Inter-domain Relationships

Hypothesis I: Primary Caregivers' Appraisals of Stress will be Associated with Child Outcome (i.e., Cognitive, Language, Behavioral, and Socio-emotional Functioning)

Pearson correlations among primary caregivers' appraisals of stress and child outcomes can be found in Table 15. Partial correlations within this domain controlling for the severity of a child's medical condition can be found in Table 16. After controlling for the severity of a child's medical condition, partial correlations revealed significant positive associations (r = .36 to .54, p < .01) between primary caregivers' perceived stress related to their child's medical condition (PIP **Total Frequency** and PIP **Total Difficulty**) and a child's internalizing and externalizing problems (**Internalizing Behaviors** and **Externalizing Behaviors** composites on the CBCL or BASC-2). A significant negative association (r = -.27, p < .05) was found between the PIP **Total Frequency** score and a child's adaptive functioning (VABS-II **Adaptive Behavior Composite**). Significant positive associations (r = .52 to .62, p < .01) were found between a primary caregiver's parenting-related stress (**PSI-SF Total Stress**) and a

child's internalizing and externalizing problems (**Internalizing Behaviors** and **Externalizing Behaviors** composites on the CBCL or BASC-2). In addition, a significant positive relationship ($r = .26$, $p < .05$) was found between a primary caregiver's subjective psychological distress (**BSI Global Severity Index**) and a child's internalizing problems (**Internalizing Behaviors** composite on the CBCL or BASC-2). Significant associations were not found between a primary caregiver's relationship satisfaction and a child's cognitive, behavioral, or socio-emotional outcomes.

Table 15

Pearson Correlations between Primary Caregivers' Appraisals of Stress and Outcome

Code	1	2	3	4	5	6	7	8	9	10
1. PIP Total Frequency of Stressors	-	.80** *n* = 72	.65** *n* = 72	.63** *n* = 72	-.16 *n* = 66	.60** *n* = 69	.46** *n* = 69	-.13 *n* = 67	-.05 *n* = 59	.01 *n* = 70
2. PIP Total Difficulty of Stressors		-	.61** *n* = 72	.69** *n* = 72	.03 *n* = 66	.47** *n* = 69	.41** *n* = 69	-.16 *n* = 67	-.04 *n* = 59	.07 *n* = 70
3. PSI-SF Total			-	.64** *n* = 72	.06 *n* = 66	.60** *n* = 69	.71** *n* = 69	-.11 *n* = 67	-.06 *n* = 59	.07 *n* = 70
4. BSI Global Severity Index				-	.07 *n* = 66	.35** *n* = 69	.33** *n* = 69	-.12 *n* = 67	.03 *n* = 59	.14 *n* = 70
5. QMI Total					-	-.12 *n* = 64	.01 *n* = 64	-.11 *n* = 61	-.16 *n* = 53	-.01 *n* = 64
6. Internalizing Problems						-	.61** *n* = 69	-.18 *n* = 64	.04 *n* = 56	.13 *n* = 67
7. Externalizing Problems							-	-.23* *n* = 64	-.11 *n* = 56	.10 *n* = 67
8. VABS-II Adaptive Behavior Composite								-	.05 *n* = 55	.31** *n* = 65
9. Total Language									-	.82** *n* = 58
10. Overall Intellectual Functioning										-

Note. Greater values for all stress measures reflect greater distress (i.e., PIP; PSI-SF; BSI; QMI)
One-tailed. *$p < .05$. **$p < .01$

Table 16

Partial Correlations between Primary Caregivers' Appraisals of Stress and Outcome Controlling for Severity of Medical Condition

Code	1	2	3	4	5	6	7	8	9	10
1. PIP Total Frequency of Stressors	-	.80**	.60**	.61**	-.02	.54**	.39**	-.27*	-.06	.01
2. PIP Total Difficulty of Stressors		-	.57**	.64**	.11	.45**	.36**	-.07	-.08	.01
3. PSI-SF Total			-	.59**	.06	.52**	.62**	-.18	-.08	.02
4. BSI Global Severity Index				-	.09	.26*	.19	.05	-.15	.02
5. QMI Total					-	-.17	-.05	.04	-.19	-.04
6. Internalizing Problems						-	.63**	-.38**	.06	.18
7. Externalizing Problems							-	-.17	-.09	.02
8. VABS-II Adaptive Behavior Composite								-	.23	.18
9. Total Language									-	.81**
10. Overall Intellectual Functioning										-

Note. Greater values for all stress measures reflect greater distress (i.e., PIP; PSI-SF; BSI; QMI)
One-tailed. *$p < .05$. **$p < .01$

Hypothesis II: Primary Caregivers' Appraisals of Stress will be Associated with Characteristics of the Primary Caregiver-Child Relationship

Pearson correlations among primary caregivers' appraisals of stress and characteristics of the primary caregiver-child relationship can be found in Table 17. Partial correlations within this domain controlling for the severity of a child's medical condition can be found in Table 18. After controlling for severity, partial correlations revealed significant negative associations between primary caregivers' perceived stress related to their child's medical condition (PIP **Total Difficulty**) and **Primary Caregiver Intrusiveness** (r = -.30, p < .01), between a primary caregiver's parenting related stress (**PSI-SF Total Stress**) and **Primary Caregiver Intrusiveness** (r = -.39, p < .01), and between a primary caregiver's subjective psychological distress (BSI **Global Severity Index**) and **Primary Caregiver Intrusiveness** (r = -.26, p < .05).

Table 17

Pearson Correlations between Primary Caregiver-Child Relationship Characteristics and Primary Caregivers' Appraisals of Stress

Code	1	2	3	4	5	6	7	8	9	10	11	12
1. Supportiveness	-	.30*	.43**	.72**	.59**	.73**	.37**	-.04	-.08	-.18	-.11	-.12
2. Intrusiveness		-	.48**	.38**	.33**	.39**	.19	-.09	-.19	-.27*	-.16	.00
3. Hostility			-	.39**	.39**	.55**	.21*	.13	.08	-.01	.12	.12
4. Qual. of Instruction				-	.75**	.77**	.51**	.04	-.04	-.05	.04	-.16
5. Confidence					-	.73**	.42**	-.04	-.13	-.06	-.05	-.02
6. Qual. of Relationship						-	.31**	.04	-.04	-.15	.06	-.10
7. Diss. of Boundaries							-	.06	.03	.07	.07	.03
8. PIP Total Frequency of Stressors								-	.79**	.65**	.63**	-.16
9. PIP Total Difficulty of Stressors									-	.61**	.69**	.03
10. PSI-LF Total										-	.64**	.06
11. BSI Global Severity Index											-	.07
12. QMI Total												-

Note. Greater values for all stress measures reflect greater distress (i.e., PIP; PSI-SF; BSI; QMI). For correlations using the QMI, $n = 66$. One-tailed. *$p < .05$. **$p < .01$

Table 18

Partial Correlations between Primary Caregiver-Child Relationship Characteristics and Primary Caregivers' Appraisals of Stress Controlling for Severity of Medical Condition

Code	1	2	3	4	5	6	7	8	9	10	11	12
1. Supportiveness	-	.26*	.41**	.71**	.57**	.70**	.39**	-.04	-.11	-.18	-.13	-.14
2. Intrusiveness		-	.45**	.34**	.30**	.37**	.17	-.15	-.30**	-.39**	-.26*	-.01
3. Hostility			-	.38**	.38**	.56**	.24*	.09	.03	-.07	.09	.12
4. Qual. of Instruction				-	.76**	.77**	.52**	.04	-.06	-.07	.01	-.19
5. Confidence					-	.71**	.47**	.00	-.13	-.07	-.08	-.06
6. Qual. of Relationship						-	.31**	.07	-.05	-.14	.05	-.15
7. Diss. of Boundaries							-	.08	.03	.11	.07	.01
8. PIP Total Frequency of Stressors								-	.80**	.65**	.63**	-.15
9. PIP Total Difficulty of Stressors									-	.61**	.70**	.05
10. PSI-SF Total										-	.62**	.06
11. BSI Global Severity Index											-	.07
12. QMI Total												-

Note. Greater values for all stress measures reflect greater distress (i.e., PIP; PSI-SF; BSI; QMI). For correlations using the QMI, $n = 66$.
One-tailed. *$p < .05$. **$p < .01$

Hypothesis III: Characteristics of the Primary Caregiver-Child Relationship will be Associated with Child Outcome (i.e., Cognitive, Language, Behavioral, and Socio-emotional Functioning)

Pearson correlations among characteristics of the parent-child relationship and children's outcomes can be found in Table 19. Partial correlations within this domain controlling for the severity of a child's medical condition can be found in Table 20. After controlling for severity of a child's medical condition, partial correlations revealed a positive significant relationship (r = .25, p < .05) between **Primary Caregiver Quality of Instruction** and a child's internalizing problems (**Internalizing Behaviors** composite on the CBCL or BASC-2). A negative significant relationship (r = -.26, p < .05) was found between **Primary Caregiver Intrusiveness** and a child's externalizing problems (**Externalizing Behaviors** composite on the CBCL or BASC-2). A negative significant relationship (r = -.27, p < .05) was also found between **Primary Caregiver Confidence** and adaptive functioning (VABS-II **Adaptive Behavior Composite**). Positive significant relationships were found between a child's overall language functioning (**Total Language** scores on CELF PRE-2 or PLS-4) and **Primary Caregiver Confidence** as well as **Quality of Relationship** (r = .25 to .28, p < .05). In addition, positive significant relationships were found between a child's overall intellectual functioning (**Overall Intellectual Functioning** from DAS-II, Mullen, or WPPSI-III) and **Primary Caregiver Confidence** as well as **Quality of Relationship** (r = .36 to .41, p < .01).

Table 19

Pearson Correlations between Primary Caregiver-Child Relationship Characteristics and Outcome

Code	1	2	3	4	5	6	7	8	9	10	11	12
1. Supportiveness	-	.30* *n* = 72	.43** *n* = 72	.72** *n* = 72	.59** *n* = 72	.73** *n* = 72	.37** *n* = 72	-.07 *n* = 69	-.12 *n* = 69	.18 *n* = 67	.19 *n* = 59	.23* *n* = 70
2. Intrusiveness[a]		-	.48** *n* = 72	.38** *n* = 72	.33** *n* = 72	.39** *n* = 72	.19 *n* = 72	.01 *n* = 69	-.29** *n* = 69	.00 *n* = 67	.21 *n* = 59	.12 *n* = 70
3. Hostility[b]			-	.39** *n* = 72	.39** *n* = 72	.55** *n* = 72	.21* *n* = 72	-.01 *n* = 69	-.14 *n* = 69	.10 *n* = 67	.13 *n* = 59	.23* *n* = 70
4. Qual. of Instruction				-	.75** *n* = 72	.77** *n* = 72	.51** *n* = 72	.08 *n* = 69	-.00 *n* = 69	.07 *n* = 67	.29* *n* = 59	.30** *n* = 70
5. Confidence					-	.73** *n* = 72	.42** *n* = 72	.09 *n* = 69	-.01 *n* = 69	.14 *n* = 67	.37** *n* = 59	.39** *n* = 70
6. Qual. of Relationship						-	.31** *n* = 72	.02 *n* = 69	-.19 *n* = 69	.12 *n* = 67	.44** *n* = 59	.49** *n* = 70
7. Diss. of Boundaries							-	.07 *n* = 69	.11 *n* = 69	.13 *n* = 67	.13 *n* = 59	.14 *n* = 70
8. Internalizing Problems								-	.61** *n* = 69	-.18 *n* = 64	.04 *n* = 56	.13 *n* = 67
9. Externalizing Problems									-	-.23 *n* = 64	-.11 *n* = 56	.10 *n* = 67
10. VABS-II Adaptive Behavior Composite										-	.05 *n* = 55	.31** *n* = 65
11. Total Language											-	.82** *n* = 58
12. Overall Intellectual Functioning												-

[a,b]Higher values on these scales reflect less intrusiveness and less hostility.
One-tailed. *$p < .05$. **$p < .01$

Table 20

Partial Correlations between Primary Caregiver-Child Relationship Characteristics and Outcome Controlling for Severity of Medical Condition

Code	1	2	3	4	5	6	7	8	9	10	11	12
1. Supportiveness	-	.31*	.47**	.73**	.56**	.73**	.27*	.06	-.01	-.06	.05	.12
2. Intrusiveness[a]		-	.54**	.35**	.26*	.42**	.23	.05	-.26*	-.15	.09	.07
3. Hostility[b]			-	.34**	.33**	.52**	.10	-.00	-.15	-.16	.03	.12
4. Qual. of Instruction				-	.68**	.71**	.43**	.25*	.06	-.13	.13	.22
5. Confidence					-	.63**	.27*	.21	.01	-.27*	.25*	.36**
6. Qual. of Relationship						-	.12	.10	-.21	-.15	.28*	.41**
7. Diss. of Boundaries							-	.17	.17	-.09	-.03	.00
8. Internalizing Problems								-	.66**	-.43**	.10	.27
9. Externalizing Problems									-	-.23	-.04	.03
10. VABS-II Adaptive Behavior Composite										-	.18	.15
11. Total Language											-	.79**
12. Overall Intellectual Functioning												-

[a,b]Higher values on these scales reflect less intrusiveness and less hostility.
One-tailed. *$p < .05$. **$p < .01$

Hypothesis IV: Characteristics of the Primary Caregiver-Child Relationship will Significantly Contribute to Child Cognitive and Language Outcomes after Controlling for Severity of a Child's Medical Condition

Hierarchical regression analyses revealed that when severity of a child's medical condition, child ethnicity, and primary caregiver relationship status were held constant, the primary caregiver-child **Quality of Relationship** accounted for a significant amount of unique variance in predicting **Overall Intellectual Functioning** (see Table 21). The entire model accounted for 43% of the variance in children's **Overall Intellectual Functioning**, with **Quality of Relationship** uniquely accounting for 10% of the variance ($F(4,57) = 10.79$, $p < .01$). With severity of a child's medical condition, child ethnicity, maternal education level, and primary caregiver relationship status held constant, the primary caregiver-child **Quality of Relationship** accounted for a significant amount of unique variance in predicting **Verbal Reasoning Ability** (see Table 22). The entire model accounted for 53% of the variance in children's **Verbal Reasoning Ability**, with **Quality of Relationship** uniquely accounting for 8% of the variance ($F(5,32) = 7.91$, $p < .01$). Primary caregiver-child **Quality of Relationship** did not account for a significant amount of unique variance in predicting **Nonverbal Reasoning Ability** when the severity of a child's medical condition was held constant (see Table 23).

Table 21

Summary of Hierarchical Regression Analysis for Contribution of Quality of Relationship to Overall Intellectual Functioning (n = 61)

Variable	*B*	*SE B*	*β*	R^2	ΔR^2
Step 1				.25	
Severity	.68	.15	.50**		
Step 2				.33	.08
Severity	.62	.15	.45**		
Child Ethnicity	.38	.25	.18		
Primary Caregiver Relationship Status	.37	.27	.16		
Step 3				.43	.10
Severity	.46	.15	.33**		
Child Ethnicity	.23	.23	.11		
Primary Caregiver Relationship Status	.28	.25	.12		
Quality of Relationship	.23	.07	.36**		

Note. Severity index is comprised of scores from the Cerebral Performance Category Scale. Child Ethnicity value reflects whether child is Caucasian or not. Primary Caregiver Relationship Status value reflects whether the primary caregiver is married or not. Quality of Relationship value represents the quality of relationship between the primary caregiver and child.
*$p < .05$. **$p < .01$.

Table 22

Summary of Hierarchical Regression Analysis for Contribution of Quality of Relationship to Verbal Reasoning Ability (n = 37)

Variable	*B*	*SE B*	*β*	R^2	ΔR^2
Step 1				.27	
Severity	.91	.25	.52**		
Step 2				.45	.18
Severity	.74	.24	.42**		
Child Ethnicity	.65	.26	.36*		
Maternal Education Level	.10	.10	.17		
Primary Caregiver Relationship Status	.02	.37	.01		
Step 3				.53	.08
Severity	.61	.23	.35*		
Child Ethnicity	.54	.25	.30*		
Maternal Education Level	.10	.09	.18		
Primary Caregiver Relationship Status	-.07	.35	-.03		
Quality of Relationship	.18	.08	.31*		

Note. Severity index is comprised of scores from the Cerebral Performance Category Scale. Child Ethnicity value reflects whether child is Caucasian or not. Primary Caregiver Relationship Status value reflects whether the primary caregiver is married or not. Quality of Relationship value represents the quality of relationship between the primary caregiver and child.
*$p < .05$. **$p < .01$.

Table 23

Summary of Hierarchical Regression Analysis for Contribution of Quality of Relationship to Nonverbal Reasoning Ability (n = 42)

Variable	*B*	*SE B*	*β*	R^2	ΔR^2
Step 1				.23	
Severity	.88	.25	.48**		
Step 2				.27	.04
Severity	.80	.26	.44**		
Quality of Relationship	.14	.10	.19		

Note. Severity index is comprised of scores from the Cerebral Performance Category Scale. Quality of Relationship value represents the quality of relationship between the primary caregiver and child.
*$p < .05$. **$p < .01$.

When only severity of a child's medical condition and child ethnicity were held constant, the primary caregiver-child **Quality of Relationship** accounted for a significant amount of unique variance in predicting **Total Language** (see Table 24). The entire model accounted for 29% of the variance in **Total Language**, with **Quality of Relationship** uniquely accounting for 8% of the variance ($F(3,52) = 7.15$, $p < .01$). When the same variables were held constant, the primary caregiver-child **Quality of Relationship** also accounted for a significant amount of unique variance in predicting **Receptive Language** (see Table 25). The entire model accounted for 30% of the variance in children's **Receptive Language**, with **Quality of Relationship** uniquely accounting for 13% of the variance ($F(3,54) = 7.86$, $p < .01$). After the severity of a child's medical condition, child ethnicity, child gestational age, and primary caregiver relationship status were held constant, the primary caregiver-child **Quality of Relationship** accounted for a significant amount of unique variance in predicting **Expressive Language** (see Table 26). The entire model accounted for 44% of the variance in children's **Expressive Language**, with **Quality of Relationship** uniquely accounting for 10% of the variance ($F(5,45) = 7.15$, $p < .01$).

Table 24

Summary of Hierarchical Regression Analysis for Contribution of Quality of Relationship to Total Language (n = 55)

Variable	*B*	*SE B*	*β*	R^2	ΔR^2
Step 1				.14	
Severity	.45	.15	.38**		
Step 2				.21	.07
Severity	.41	.15	.34**		
Child Ethnicity	.47	.23	.26*		
Step 3				.29	.08
Severity	.25	.15	.21		
Child Ethnicity	.37	.22	.20*		
Quality of Relationship	.18	.07	.33*		

Note. Severity index is compromised of scores from the Cerebral Performance Category Scale. Child Ethnicity value reflects whether child is Caucasian or not. Quality of Relationship value represents the quality of relationship between the primary caregiver and child.
*$p < .05$. **$p < .01$.

Table 25

Summary of Hierarchical Regression Analysis for Contribution of Quality of Relationship to Receptive Language (n = 57)

Variable	*B*	*SE B*	*β*	R^2	ΔR^2
Step 1				.10	
Severity	.45	.18	.32*		
Step 2				.17	.07
Severity	.41	.18	.29*		
Child Ethnicity	.55	.26	.26*		
Step 3				.30	.13
Severity	.19	.18	.13		
Child Ethnicity	.39	.25	.18		
Quality of Relationship	.26	.08	.41**		

Note. Severity index is comprised of scores from the Cerebral Performance Category Scale. Child Ethnicity value reflects whether child is Caucasian or not. Quality of Relationship value represents the quality of relationship between the primary caregiver and child.
*$p < .05$. **$p < .01$.

Table 26

Summary of Hierarchical Regression Analysis for Contribution of Quality of Relationship to Expressive Language (n = 50)

Variable	*B*	*SE B*	*β*	R^2	ΔR^2
Step 1				.17	
Severity	.58	.18	.41**		
Step 2				.34	.17
Severity	.55	.18	.39**		
Child Ethnicity	.20	.29	.09		
Child's Gestational Age (Weeks)	-.07	.03	-.29*		
Primary Caregiver Relationship Status	.46	.30	.21		
Step 3				.44	.10
Severity	.35	.18	.25		
Child Ethnicity	.02	.28	.01		
Child's Gestational Age (Weeks)	-.08	.03	-.34**		
Primary Caregiver Relationship Status	.40	.28	.18		
Quality of Relationship	.22	.08	.38**		

Note. Severity index is comprised of scores from the Cerebral Performance Category Scale. Child Ethnicity value reflects whether child is Caucasian or not. Relationship Status value reflects whether the primary caregiver is married or not. Quality of Relationship value represents the quality of relationship between the primary caregiver and child.
*$p < .05$. **$p < .01$.

Hypothesis V: Characteristics of the Primary Caregiver-Child Relationship will Moderate the Relationship between Primary Caregivers' Appraisals of Stress and Child Cognitive and Language Outcomes

Hierarchical regression analyses to test for significant interaction effects with the primary caregiver-child relationship (**Quality of Relationship**) as a moderator and the **Total Stress Composite** variable as the independent variable revealed significant interaction effects between the **Total Stress Composite** and **Quality of Relationship** when language abilities were the dependent variable. With the severity of a child's medical condition and child ethnicity held constant, a significant interaction effect was shown with **Total Language** as a dependent variable (see Table 27). The entire model accounted for 42% of the variance in predicting children's **Total Language**, with the interaction between the **Total Stress Composite** and **Quality of Relationship** uniquely accounting for 12% of the variance ($F(5,50) = 7.26$, $p < .01$). Also with the severity of a child's medical condition and child ethnicity held constant, a significant interaction effect was shown with **Receptive Language** as a dependent variable (see Table 28). The entire model accounted for 37% of the variance in predicting children's **Receptive Language**, with the interaction between the **Total Stress Composite** and **Quality of Relationship** uniquely accounting for 6% of the variance ($F(5,52) = 6.01$, $p < .01$). In addition, when severity of a child's medical condition, child ethnicity, child's gestational age, and primary caregiver relationship status were held constant, a significant interaction effect was found with **Expressive Language** as a dependent variable (see Table 29). The entire model accounted for 53% of the variance in predicting children's **Expressive Language**, with the interaction between the **Total Stress Composite** and **Quality of Relationship**

uniquely accounting for 8% of the variance ($F(7,43) = 6.86$, $p < .01$). Significant interaction effects between **Quality of Relationship** and the **Total Stress Composite** variable were not found when measures of **Overall Intellectual Functioning**, **Verbal Reasoning Ability**, and **Nonverbal Reasoning Ability** were dependent variables.

Table 27

Summary of Hierarchical Regression Analysis for Interaction Variables Predicting Total Language (n = 55)

Variable	*B*	*SE B*	*β*	R^2	ΔR^2
Step 1				.14	
Severity	.45	.15	.38**		
Step 2				.21	.07
Severity	.41	.15	.34**		
Child Ethnicity	.47	.23	.26*		
Step 3				.30	.09
Severity	.26	.16	.21		
Child Ethnicity	.37	.22	.20		
Total Stress (centered)	-.02	.03	-.06		
Quality of Relationship (centered)	.18	.07	.32*		
Step 4				.42	.12
Severity	.15	.15	.13		
Child Ethnicity	.50	.21	.28*		
Total Stress (centered)	-.04	.03	-.16		
Quality of Relationship (centered)	.11	.07	.19		
Total Stress X Quality of Relationship[a]	-.07	.02	-.41**		

Note. Severity index is comprised of scores from the Cerebral Performance Category Scale. Child Ethnicity value reflects whether child is Caucasian or not. Quality of Relationship value represents the quality of relationship between the primary caregiver and child.
[a]Interaction of centered Total Stress and Quality of Relationship variables.
*$p < .05$. **$p < .01$.

Table 28

Summary of Hierarchical Regression Analysis for Interaction Variables Predicting Receptive Language (n = 57)

Variable	*B*	*SE B*	*β*	R^2	ΔR^2
Step 1				.10	
Severity	.45	.18	.32*		
Step 2				.17	.07
Severity	.41	.18	.29*		
Child Ethnicity	.55	.26	.26*		
Step 3				.31	.14
Severity	.19	.18	.13		
Child Ethnicity	.38	.25	.18		
Total Stress (centered)	.02	.04	.05		
Quality of Relationship (centered)	.26	.08	.41**		
Step 3				.37	.06
Severity	.09	.18	.06		
Child Ethnicity	.48	.25	.23		
Total Stress (centered)	-.01	.04	-.04		
Quality of Relationship (centered)	.21	.08	.34*		
Total Stress X Quality of Relationship[a]	-.05	.02	-.28*		

Note. Severity index is comprised of scores from the Cerebral Performance Category Scale. Child Ethnicity value reflects whether child is Caucasian or not. Quality of Relationship value represents the quality of relationship between the primary caregiver and child.
[a]Interaction of centered Total Stress and Quality of Relationship variables.
*$p < .05$. **$p < .01$.

Table 29

Summary of Hierarchical Regression Analysis for Interaction Variables Predicting Expressive Language (n = 50)

Variable	*B*	*SE B*	*B*	R^2	ΔR^2
Step 1				.17	
Severity	.58	.18	.41**		
Step 2				.34	.17
Severity	.55	.18	.39**		
Child Ethnicity	.20	.29	.09		
Child's Gestational Age (Weeks)	-.07	.03	-.29*		
Primary Caregiver Relationship Status	.46	.30	.21		
Step 3				.45	.11
Severity	.35	.18	.25*		
Child Ethnicity	.00	.28	.00		
Child's Gestational Age (Weeks)	-.09	.03	-.35**		
Primary Caregiver Relationship Status	.44	.28	.20		
Total Stress (centered)	.03	.04	.11		
Quality of Relationship (centered)	.23	.08	.39**		
Step 4				.53	.08
Severity	.24	.17	.18		
Child Ethnicity	.14	.27	.07		
Child's Gestational Age (Weeks)	-.09	.03	-.38**		
Primary Caregiver Relational Status	.34	.27	.15		
Total Stress (centered)	.00	.04	.01		
Quality of Relationship (centered)	.18	.08	.31*		
Total Stress X Quality of Relationship[a]	-.06	.02	-.32*		

Note. Severity index is comprised of scores from the Cerebral Performance Category Scale. Child Ethnicity value reflects whether child is Caucasian or not. Relationship Status value reflects whether the primary caregiver is married or not. Quality of Relationship value represents the quality of relationship between the primary caregiver and child.
[a]Interaction of centered Total Stress and Quality of Relationship variables.
*$p < .05$. **$p < .01$.

High and low **Quality of Relationship** groups were initially created based on scoring a ½ standard deviation above or below the mean, respectively. When these group distinctions were applied to this sample, the size of groups was not sufficient to allow for decomposing the interaction, thus distinctions in groups were made according to a median split. Simple regression lines for high and low values of **Quality of Relationship** with **Total Language** as a dependent variable, and the **Total Stress Composite** as an independent variable can be found in Figure 2. Simple regression lines for high and low values of **Quality of Relationship** with **Receptive Language** as a dependent variable, and the **Total Stress Composite** as an independent variable can be found in Figure 3. In addition, simple regression lines for high and low values of **Quality of Relationship** with **Expressive Language** as a dependent variable, and the **Total Stress Composite** as an independent variable can be found in Figure 4.

Figure 2. Primary Caregiver-Child Relationship Quality Moderates the Relationship between Primary Caregiver Stress and Total Language.

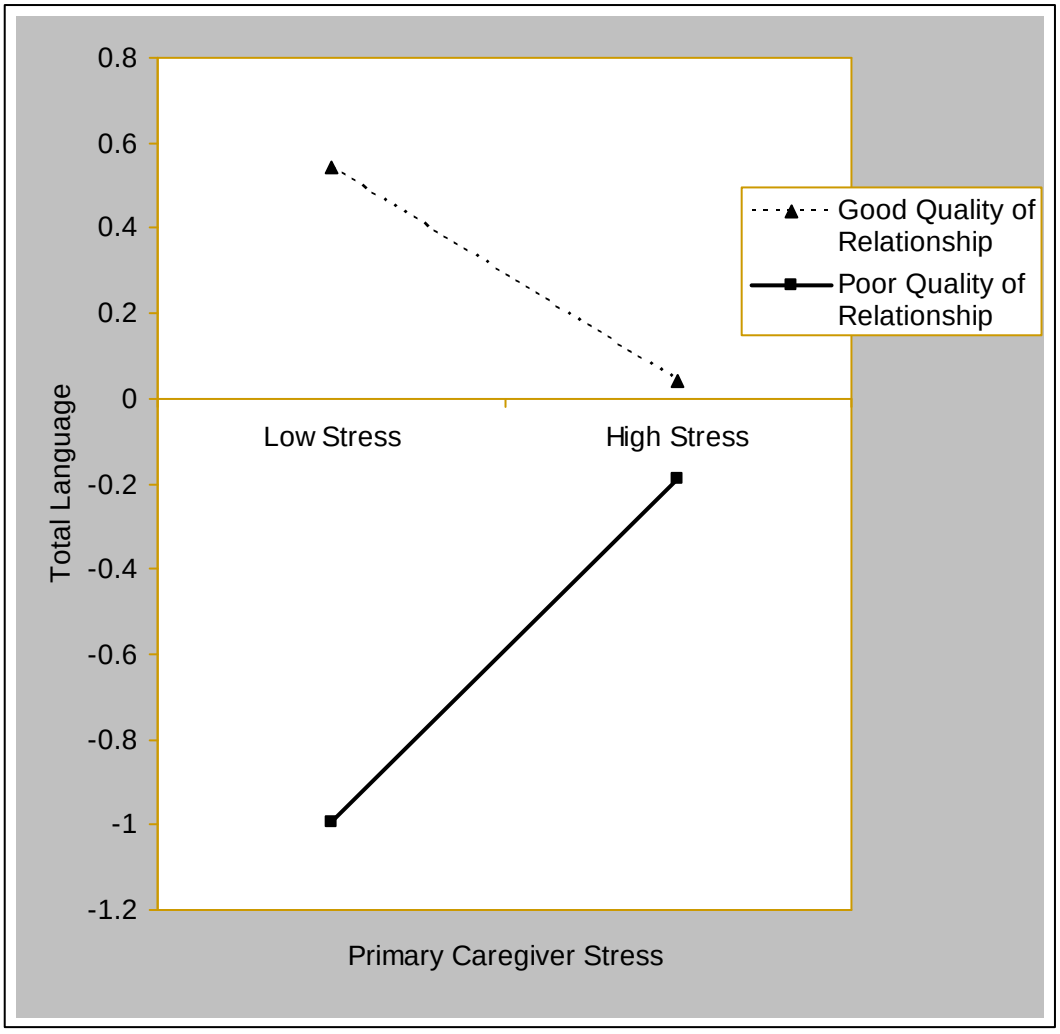


Figure 3. Primary Caregiver-Child Relationship Quality Moderates the Relationship between Primary Caregiver Stress and Receptive Language.

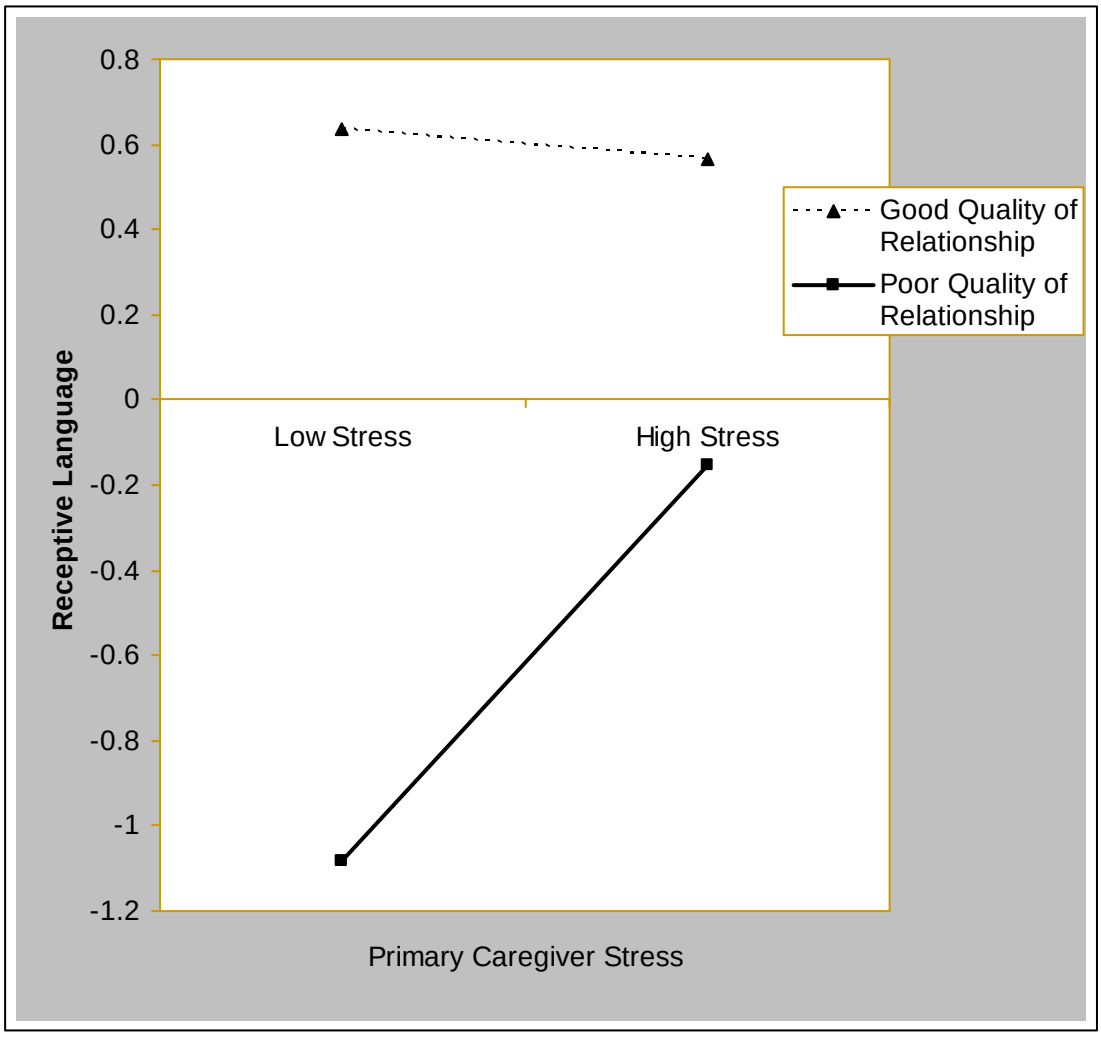
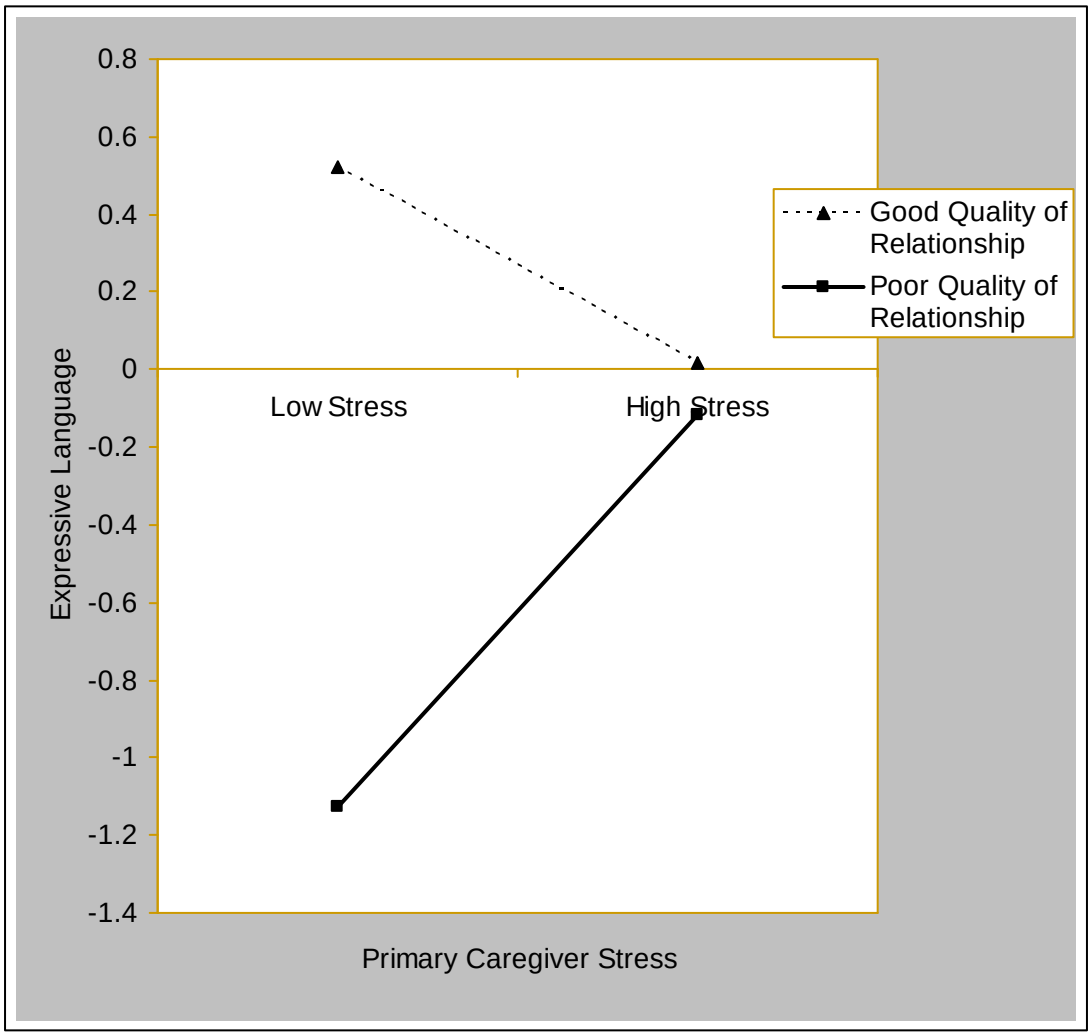


Figure 4. Primary Caregiver-Child Relationship Quality Moderates the Relationship between Primary Caregiver Stress and Expressive Language.



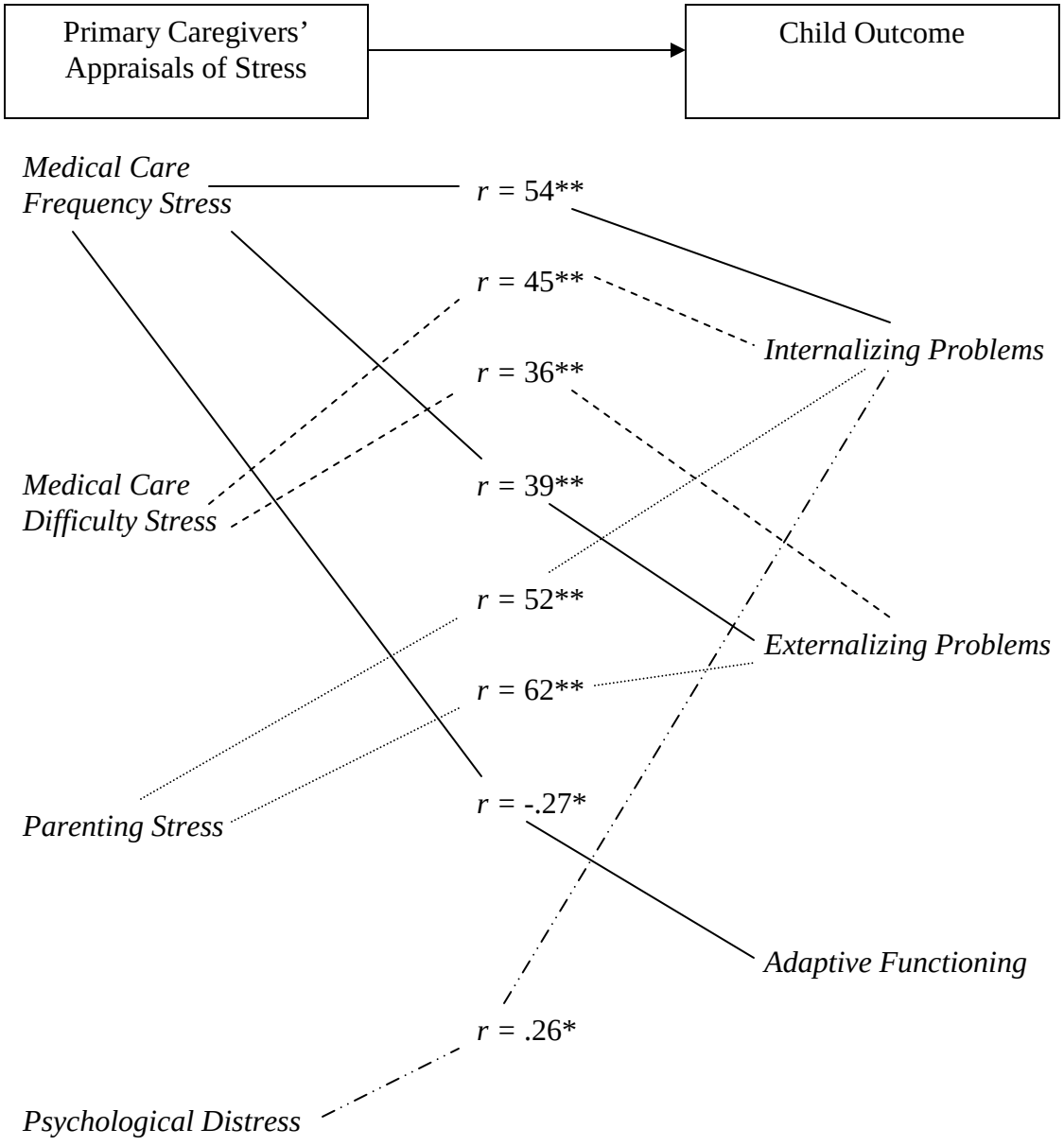
Discussion

Hypothesis I: Primary Caregivers' Appraisals of Stress will be Associated with Child Outcome (i.e., Cognitive, Language, Behavioral, and Socio-emotional Functioning)

A graphic summary of significant findings specific to Hypothesis 1 is depicted in Figure 5. Consistent with expectations, greater perceived stress by the primary caregiver regarding caring for their medically compromised children (both with regard to frequency and intensity) was associated with greater primary caregiver report of children's internalizing and externalizing problems. Greater parenting-specific stress and higher levels of psychological distress were also associated with increased report of children's internalizing and externalizing problems. Greater frequency with which primary caregivers reported experiencing stress around caring for their medically compromised children was associated with poorer adaptive functioning.

These findings are consistent with previous research showing that mothers who reported experiencing increased life stress have been shown to perceive their typically developing children's behavior as more deviant than low-stress mothers (see Crnic & Acevedo, 1995, for a review). In a school-aged sample of children with traumatic brain injury (TBI), higher parent distress at six months post injury, predicted more child behavior problems at 12 months, even after controlling for earlier behavior problems (Taylor et al., 2001). However, in the same study, more behavior problems at 6 months, predicted poorer family outcomes at 12 months, controlling for earlier family outcomes.

Figure 5. Primary Caregivers' Appraisals of Stress are Associated with Child Outcome.



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

Though causality cannot be determined because information regarding primary caregivers' appraisals of stress and child outcome was collected at the same time point, it is possible that the experience of stress for primary caregivers manifests in poor coping strategies that are modeled for children. Thus, when children are facing their own stressors, they may respond according to the example of their primary caregiver, thus accounting for the link between primary caregivers' appraisals of stress and internalizing and externalizing behavior problems. It might also be that the direction of effect is reversed, such that it might be stressful to parent children with more significant behavioral problems.

Regarding the association between the frequency with which primary caregivers experience stress around caring for their medically compromised children and poorer adaptive functioning, it is important to consider that adaptive functioning, like internalizing and externalizing behaviors, was based on ratings provided by the primary caregiver. As such, a primary caregiver who often experiences stress related to his or her child's medical care may rate his or her child's adaptive functioning as poorer, because of the medical needs to which s/he must attend.

Contrary to expectation, significant relationships were not found between primary caregivers' relationship satisfaction with their romantic partner and any child outcomes. When considering research by Fishman and Meyers (2000), mothers who experienced marital dissatisfaction were less involved with their children, which in turn was associated with greater child distress. The primary caregivers in the current study *were* involved with their children, as indicated by their commitment to participate in the study, and more broadly, their commitment to their child's medical care. However, the extent of

satisfaction reported by primary caregivers on the QMI (Norton, 1983) in the current sample did not significantly differ from mean satisfaction scores reported in other studies by individuals without medically-compromised children (e.g., Fincham, Paleari, & Regalia, 2002) . Another hypothesis is that primary caregivers who are dissatisfied in their romantic relationship may seek satisfaction in alternate relationships, such as in the relationship with their child, which in turn might translate to better child outcomes. Of additional note, this measure of global marital satisfaction was administered with three measures of primary caregivers' appraisals of stress. When the QMI was initially included in the current study, it was thought that primary caregivers' report of greater satisfaction in their marriages would be indicative of less stress in romantic relationship, and that less reported satisfaction in a relationship would be suggestive of greater stress. That the QMI does not significantly correlate with any of the other stress indices used in the current study, suggests that this measure should not be classified as an appraisal of stress and likely assesses a different construct.

Most surprisingly, none of the measures utilized as indices of primary caregivers' appraisals of stress were related to children's language or intellectual functioning. It was expected that, at the very least, primary caregiver psychological distress would have significant associates with language or intellectual functioning. In a longitudinal investigation of a large, heterogeneous sample, the NICHD Early Child Care Research Network (1999) discovered that children whose mothers reported depressive symptoms performed more poorly on measures of cognitive and linguistic functioning than did children of mothers who never reported depressive feelings. Ciccheti, Rogosch, and Toth (2000) conducted a study of cognitive development in the offspring of depressed mothers

and found that at a post-intervention follow-up with a sample of children who were three years of age as compared to 20 months at baseline, a relative decline in IQ was found in children with depressed mothers who did not receive the intervention.

Impact of parental depression on the development of children

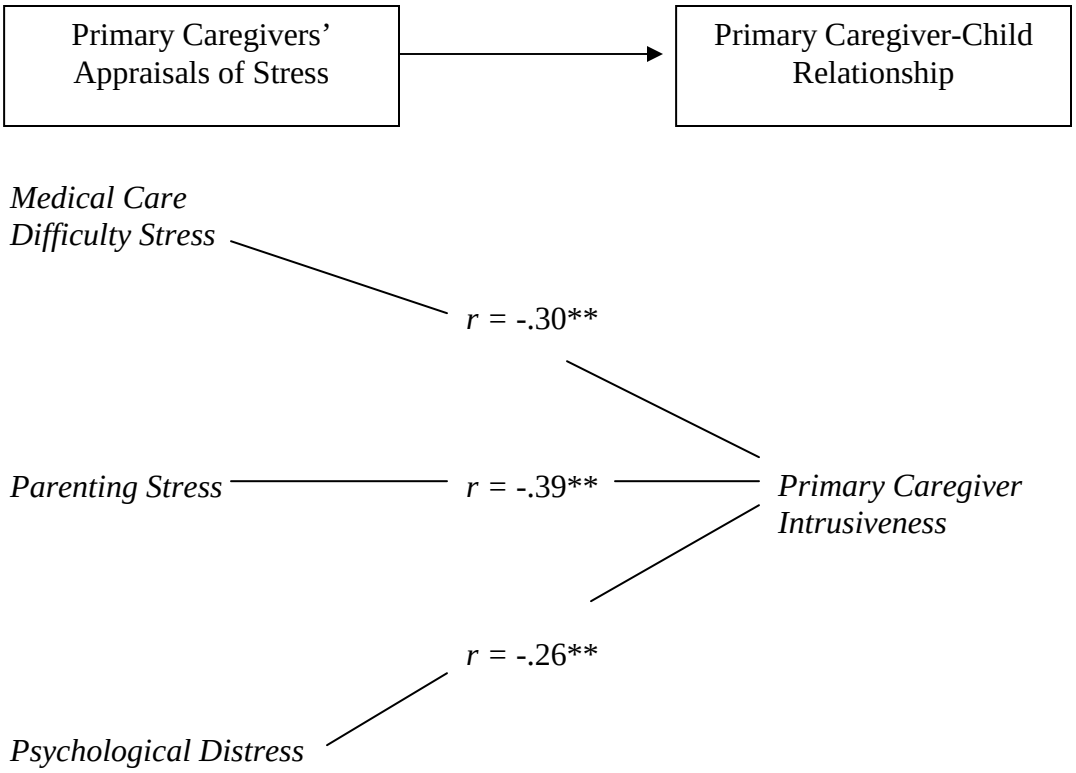
It may be that there is something specific about depression as a form of primary caregiver psychological distress that relates to children's cognitive and linguistic functioning. In the current study, psychological distress was measured broadly using the Global Severity Index of the Brief Symptom Inventory which incorporates symptoms of not only depression but also anxiety, somatization, and interpersonal sensitivity among other domains. While broad spectrum psychological distress may be associated with children's behavioral functioning, the diversity of problems that this index assesses may not have significant links to children's intellectual and linguistic functioning as results from the current study seem to demonstrate. Moreover, in previous studies of children with early brain insults, family factors (which have been most commonly assessed via measures of parental distress) were more consistently associated with behavioral measures than with cognitive skills (e.g., Taylor & Schatschneider, 1992).

In addition, in an extensive longitudinal study with healthy working-class mothers and their infants conducted by Bee and colleagues (1982), measures of family ecology (level of stress, social support) and parent perception of the child, were strongly related to child IQ and language within a low-education subsample, but not among mothers with more than high school education. As most primary caregivers in the current study had some college education, significant associations between primary caregivers' appraisals of stress and child cognitive and linguistic outcomes may not have been found.

Hypothesis II: Primary Caregivers' Appraisals of Stress will be Associated with Characteristics of the Primary Caregiver-Child Relationship

A graphic summary of significant findings specific to Hypothesis 2 is depicted in Figure 6. The intensity of perceived stress by the primary caregiver regarding caring for a medically compromised child was related to intrusiveness in the primary caregiver-child relationship, such that greater perceived stress was associated with more intrusive behavior on the part of the primary caregiver. Similarly, greater parenting-specific distress and psychological distress were also significantly associated with an increase in intrusive behavior. The relationship between primary caregivers' appraisals of stress and intrusiveness is not surprising when considering the content of the intrusiveness code by which this behavior was observed. According to the Teaching Tasks Administration and Scoring Manual (Egeland et al., 1995), a primary caregiver who is high in intrusiveness lacks respect for the child as an individual and fails to understand and recognize the child's effort to gain autonomy and self awareness. The scoring manual specifies that an intrusive primary caregiver's behavior is guided more by his or her own agenda rather than the child's needs. In this way, it may be that a distressed primary caregiver is less aware of a child's needs and efforts to gain autonomy and self-awareness. Another possibility is that a distressed primary caregiver may attempt to drive an interaction without regard for a child's needs in efforts to gain control, albeit in a maladaptive manner.

Figure 6. Primary Caregivers' Appraisals of Stress are Associated with Characteristics of the Primary Caregiver-Child Relationship.



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

No support was found for the proposed relationships between indices of the primary caregivers' appraisals of stress and other primary caregiver-child interaction characteristics (i.e., Supportiveness, Hostility, Quality of Instruction, Primary Caregiver Confidence, Quality of Relationship, and Dissolution of Boundaries). This may, too, be related to the lack of specificity of the psychological distress measure. Perhaps specific types of psychological distress, when at clinical levels, have implications for behavior in the primary caregiver-child dyad, but this may not be true for a diversity of symptoms at low levels. Regarding general parenting stress, perceived stress related to attending to a child's medical needs, and/or stress in the romantic relationship of the primary caregiver, the ramifications of these stressors may be most strongly manifest in intrusive behaviors, but less intensely in other primary caregiver-child behaviors.

The lack of association between indices of the primary caregivers' appraisals of stress and other primary caregiver-child interaction characteristics may, in fact, be adaptive and in a child's best interests. These findings suggest that primary caregivers are capable of monitoring their stress levels and regulating their emotions and behavior in the context of interactions with their children. In this way, relations between primary caregivers and their children may be preserved even when the primary caregivers are experiencing heightened levels of stress.

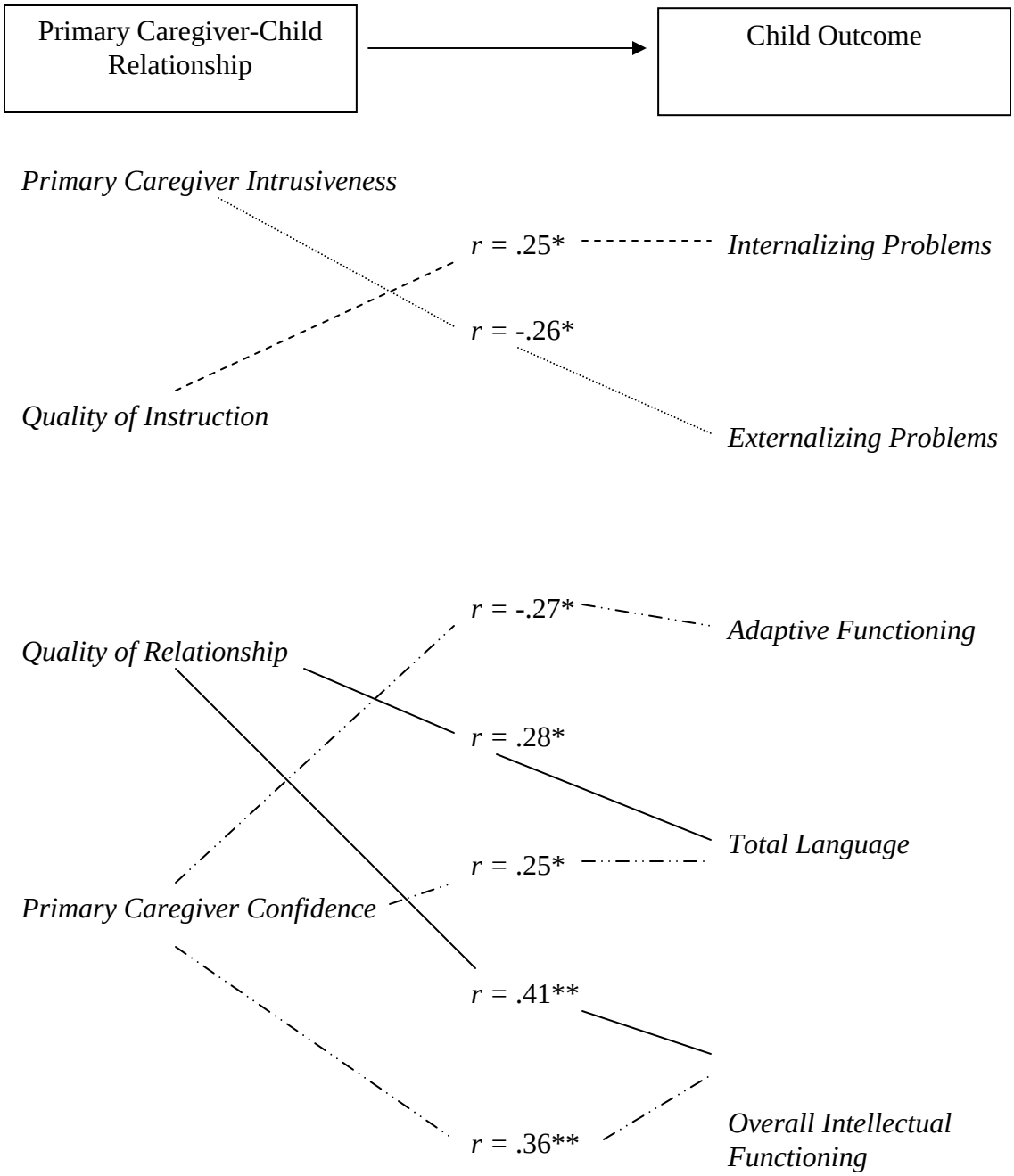
Hypothesis III: Characteristics of the Primary Caregiver-Child Relationship will be Associated with Child Outcome (i.e., Cognitive, Language, Behavioral, and Socio-emotional Functioning)

A graphic summary of significant findings specific to Hypothesis 3 is depicted in Figure 7. Several characteristics of the primary caregiver-child relationship were

significantly related to cognitive, language, behavioral, and socio-emotional indices of child outcome. The greater the presence of intrusive behavior on the part of the primary caregiver, the greater the difficulties with externalizing behaviors were reported. This association, much like the link between primary caregivers' appraisals of stress and child outcome, can likely be explained by social learning theory (Bandura, 1977). While not all observed behaviors are maladaptive or problematic, consistent modeling of intrusive behavior by a primary caregiver may be internalized by the child and later externalized such that the child becomes emotionally and behaviorally dysregulated.

Interestingly, better quality of instruction was associated with an increase in internalizing problems. One possibility for this finding is that, though young children may be guided optimally by their primary caregivers around how to complete tasks (i.e., they are provided with adequate feedback in such a way that they can achieve success and come to a solution, feeling confident in their abilities), the primary caregivers providing the instruction may perceive that their children are anxious about completing tasks and are in greater need of quality instruction. The reverse may also be true such that children who receive better quality of instruction are more conscientious about their performance and perceive greater demands placed upon them.

Figure 7. Characteristics of the Primary Caregiver-Child Relationship are Associated with Child Outcome.



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

The more confidence a primary caregiver had in his or her ability to relate to their child was associated with poorer adaptive functioning, better language skills, and better intellectual functioning. The finding of an association between caregivers' confidence with poorer adaptive functioning is somewhat perplexing, but it may be that the greater confidence a primary caregiver has in providing for their child's needs, the greater needs they perceive their child as having. Alternatively, the less functional a primary caregiver perceives a child to be, the more motivated they may be to present themselves confidently and provide for their child's needs. Notably, the interrater reliability for the confidence scale was generally below acceptable levels. As such, these findings are interpreted with caution.

Consistent with expectation, better primary-caregiver child relationship quality was associated with more advanced language skills, and more advanced intellectual functioning. Other aspects of the primary caregiver-child relationship (i.e., Supportiveness, Hostility, and Dissolution of Boundaries) were not found to have significant associations with any indices of child outcome. This is consistent with previous research documenting associations between caregiver-child interactions and developmental/cognitive outcomes. For example, Magill-Evans and Harrison (1999) found that in a study of 18-month-old preterm children, 22% of the variance in receptive language scores was predicted by a combination of father-child interactions at 3 months of age, mother-child interactions, and infant sex. Cohen and Parmelee (1983) found that among preterm infants whose caregivers scored high on responsive, reciprocal, and autonomy-promoting care had improved developmental scores from age nine months to five years; those whose caregivers had low scores had a decrease in performance. In a 4-

year longitudinal study with a sample of healthy working-class mothers and their infants, assessments of mother-infant interaction and general environmental quality were among the best predictors of language and IQ at each age tested (Bee et al., 1982). In another study investigating the relationship between mothers and their typically developing young children, the affective quality of the mother child-relationship when the child was 4 years of age was significantly correlated with mental ability at age 4, school readiness at ages 5-6, and IQ at age 6 (Estrada, Arsenio, Hess, & Holloway, 1987).

Likely, when the primary caregiver-child interaction is such that primary caregivers are emotionally available to their children and provide an environment that is stimulating and structured, but not too rigid, young children feel as if they have a secure base from which to explore their world, to develop cognitive skills, and enhance their self concept. These tasks are all of significance for not only children who have suffered a neurological insult, but also typically developing children.

Hypothesis IV: Characteristics of the Primary Caregiver-Child Relationship will Significantly Contribute to Child Cognitive and Language Outcomes after Controlling for Severity of a Child's Medical Condition

When severity of a child's medical condition and other relevant confounding variables were controlled for, the quality of the primary caregiver-child relationship did, in fact, account for a significant amount of unique variance in predicting overall intellectual functioning and verbal reasoning ability. However, the quality of the primary caregiver-child relationship did not account for a significant amount of unique variance in predicting nonverbal reasoning ability. With regard to language, when severity of a child's medical condition and other relevant confounding variables were controlled for,

the quality of the primary caregiver-child relationship accounted for a significant amount of unique variance in predicting total, receptive, and expressive language.

Although these regression analyses of concurrent data cannot establish causality, the assignment of variables as predictors and criteria presumed a primary direction of influence between them. The current study's formulation of intellectual functioning and language as outcome measures that are predicted by the primary caregiver-child interaction is consistent with Vygotsky's social development theory (1978), in that one central way preschoolers attain cognitive skills is by internalizing social processes in their everyday interaction with adults or older children. The primary caregiver acts as a scaffold to a child's development of skills, providing structure and guidance to the development of skills. This effect applies to a broad selection of social and cognitive skills, but particularly language-based skills. As such, that the quality of the primary-caregiver-child relationship did not account for a significant amount of unique variance in predicting nonverbal reasoning ability is not surprising.

Though the quality of the primary caregiver-child relationship accounted for a significant amount of unique variance in predicting language-based skills, it is notable that Quality of Relationship scale is not, in and of itself, language-based. It is a dyadic, global scale focusing on *affective* and *reciprocity* aspects of the primary caregiver-child relationship. By definition, high scores on this scale suggest "a strong sense of relatedness and mutual engagement between mother and child, with both explicitly acknowledging and responding to one another. This may be evidenced with affective *and/or* verbal sharing (i.e. sharing gazes, smiling, vocalizing or conversing) and contingent responding to each other" (Egeland et al., 1995). In contrast, a low score on

this scale would reflect the absence of a core sense of emotional relatedness with a primary caregiver and child not acting responsively, evidenced by rejection, ignoring, or dismissal by either the primary caregiver or the child. To this end, findings from this study are of particular value as they suggest that verbally-based skill development can be influenced by both verbal and nonverbal modes of communication, even in children whose level of intellectual and language functioning is below age-expectation. The core sense of *emotional relatedness* and *dyadic responsivity* seems to be of essential importance. Notably, even in samples of deaf and hard of hearing toddlers, maternal sensitivity (characterized by the ability to read child cues and respond appropriately and the ability to resolve affective mismatch) has been found to predict expressive language gain (Pressman, Pipp-Siegal, Yoshinaga-Itano, & Deas, 1999).

As noted above, though causality cannot be determined due to the cross-sectional nature of data collected in this study, consideration for different directions of influence between parent/caregiver stressors and outcomes in very young children who are neurologically compromised is worthy of further discussion. Children whose parents/caregivers report higher stress in the parent-child relationship may be exposed to poorer quality interactions with their parents/caregivers and may not be provided an optimal environment for learning and rehabilitation. However, children with head injuries who have compromised cognitive, behavioral, socio-emotional, and/or adaptive functioning may not have the same capacity to interact with their parents/caregivers as their siblings do, which may frustrate their parents/caregivers and contribute to increased stress. Consideration for even bidirectional pathways may be of particular importance over the long-term as while perceived parent/caregiver stress and burden due to the initial

impact of the injury and/or general parenting stress may initially influence children's outcomes, the nature of children's outcomes may reinforce perceived stress and burden in parents/caregivers over time. Taylor and colleagues (2001) provided preliminary support for bidirectional influences in a study of school-aged children with TBI, though their findings were interpreted cautiously secondary to limited sample size precluding the use of structural equation modeling.

Hypothesis V: Characteristics of the Primary Caregiver-Child Relationship will Moderate the Relationship between Primary Caregivers' Appraisals of Stress and Child Cognitive and Language Outcomes

When relevant confounding variables were controlled for, significant interaction effects were found between primary caregivers' appraisals of stress and quality of the primary caregiver-child relationship in predicting total, receptive, and expressive language. Consistent with expectation, when the quality of the primary caregiver-child relationship was good and primary caregivers' perceived stress was low, language outcomes were better. When primary caregiver-child relationship was poor but primary caregivers' perceived stress was low, language outcomes were poorer. This finding may reflect the influence, or lack of influence, of an uninvolved parent. The interaction effect may be more heavily influenced by the poor primary-caregiver child relationship and consistent with the above findings, that is, the primary caregiver-child relationship accounted for a significant amount of unique variance in predicting language outcomes. Responsivity and reciprocity would not be characteristic of an uninvolved parent, thereby suggestive of poor primary caregiver-child relationship quality, and subsequently poorer outcomes.

Contrary to expectation, when the primary caregiver-child relationship was good but primary caregivers' perceived stress was high, language outcomes were poorer. In this case, though responsivity and reciprocity were present in the primary caregiver-child dyad, the potential negative effects of perceived stress may have been a stronger contributor. Also contrary to expectation, when the primary caregiver-child relationship was poor and primary caregivers' perceived stress was high, language outcomes were better. This finding is perplexing but may reflect the resilience in this sub-group of children, that is, they show the capacity to be successful despite their challenging circumstances. In accordance with literature on resilience (e.g., Masten, Best, & Garmezy, 1990), children who experience chronic adversity fare better or recover more successfully when they have a positive relationship with a competent adult, they are good learners and problem-solvers, they are engaging to other people, and they have areas of competence and perceived efficacy valued by self or society. As such, the children in this sub-group may have poorer quality of relationship with their primary caregivers and be exposed to those caregivers' high stress; however, they may have a better quality of relationship with an alternate caregiver or competent adult that is more responsive, which may then contribute to better language outcomes.

It is also important to consider possible statistical confounds in interpreting these interaction effects. The number of participants included in each sub-group (i.e. good primary caregiver-child relationship/low stress; poor primary caregiver-child relationship/low stress; good primary caregiver-child relationship/high stress; poor primary caregiver-child relationship/high stress) was limited such that a median split was conducted in order to assign individuals to high and low status in order to demonstrate

the direction of effect. This contrasts with preferred methods of interaction dissection in which group assignment is determined based on levels of at least one-half standard deviation above and below the mean. The smallest sub-group size was found for the poor primary caregiver-child/high stress sub-group. As such, it is possible that the effects for each individual sub-group would not be found statistically significant if independent regression analyses for each sub-group were analyzed.

Limitations

This study has several limitations. First, defining severity of neurological injury is very difficult as any specific indicator of severity has the potential to be confounded by factors unrelated to the neurological injury itself. Previous studies have been criticized for lack of definition of severity of injury (Fletcher et al., 1995; Satz et al., 1997), but use of standardized and reliable but sensitive test measures, while strongly advocated by Satz et al. (1997), is particularly challenging in the preschool age range due to variability in development. In the current study, defining severity of neurological injury was especially challenging as the severity index needed to be generalized across neurological conditions, as well as had to be applicable to the preschool age range. Ultimately, the measure used in the current study met criteria for generalizability and was applicable for young children, but outcome measures such as level of adaptive functioning and intellectual functioning were utilized as factors in determining the rating of the control variable. As such, to an extent, the severity rating may be a better index of impact of injury as opposed to severity of condition.

It should also be noted that classifying severity may not be so critical when considering the heterogeneity of the current sample. Though the referring conditions were

diverse, all conditions were remarkable for some extent of atypical neurological development or insult. In studies comparing stress in parents of school-aged children with varying levels of TBI (i.e., mild, moderate, severe) to stress in parents of uninjured children, parents of injured children suffered greater stress than control parents *regardless* of injury severity (e.g., Hawley, Ward, Magnay, & Long, 2003).

An additional challenge in interpreting the findings from the present study is that neither time since injury nor age at injury were controlled for in analyses, in part, due to the co-morbid neurological conditions with which many children presented. Many children presented with neurological issues that were secondary to a previous injury. Further, for several children, complications of prematurity were the reasons for atypical neurological development. As such, it was an impossible to determine one value for time since injury for every child. On the one hand, time since injury is important because outcomes may be worse in children with preinjury behavior or learning problems than in children who were functioning normally prior to insult (Farmer et al., 1996; Max et al., 1997). However, even with the identification of time since injury, after very severe injuries, children may experience uneven neurologic improvement for many months or years. Moreover, young children with neurological insults may also experience delayed developmental consequences to their injuries (e.g., Eslinger, Grattan, Damasio, & Damasio, 1992; Mateer and Williams, 1991). A longitudinal follow-up study conducted by Ewing-Cobbs and colleagues (1997) with head-injured children ages 4 months to 7 years at injury found that age at injury was unrelated to test scores. Costeff, Groswasse, and Goldstein (1990) also found that age at injury was not predictive of long-term

outcome following severe TBI. In summary, there is conflicting findings regarding the importance of these variables in existing outcome studies.

As noted above, the cross-sectional nature of this data presents its own unique challenges as well. All variables (primary caregivers' appraisals of stress, characteristics of the primary caregiver-child interaction, neuropsychological outcome) were assessed at the same time post-injury. Thus, it is uncertain whether differences in distress, relationship quality, or functioning existed prior to the neurological insult. Moreover, it is not possible to determine the direction of causality (i.e., poorer functioning in children leads to greater perceived stress by primary caregivers).

Additional limitations that must be noted are that only the primary caregiver completed the stress questionnaires, and that same primary caregiver participated in the interaction with the child. A bias may have been created in not seeking responses from additional family members. The stress level and relationship quality of other caregivers of children who have experienced a neurological injury are also possible contributors to children's overall outcomes. Children who have the support of a secondary caregiver with whom they have a positive relationship may fare better, particularly when the primary caregiver is unavailable or significantly distressed.

Also, only family variables were considered as moderators of the sequelae of neurological injury. Other potential moderators include age at injury, gender, ethnicity, social factors such as socio-economic status, and children's behavioral and learning status prior to injury. In addition, family variables may alternatively be conceptualized as *mediators* than *moderators* of the effect of primary caregivers' perceived stress on child outcome. The mechanism of the relationship between primary caregivers' appraisals of

stress, primary caregiver-child relationship status, and child outcome may be different such that the primary caregiver-child relationship may be the means through which primary caregivers' perceived stress affects outcome. In fact, Morisset, Barnard, Greenberg, Booth, and Spieker (1990) found that in a sample of high social risk families (e.g., low educational level, low income, low social support, psychiatric diagnosis), the impact of environmental risk on young children's cognitive and linguistic competence was mediated by the quality of early mother-child interaction. Within this high risk sample, the quality of interactive experiences was more strongly predictive of child outcome than was family social status or mother's life stress, social or psychological functioning. A mother's ability to provide positive and responsive interactive experiences was, in part, a function of her own stress. A mother's tendency to provide stimulating and positive interactive experiences was related to children's mental and linguistic abilities at both 24 and 36 months of age. Future studies could consider the primary caregiver-child relationship quality as a mediator between primary caregivers' appraisals of stress and outcome.

Implications for Intervention and Future Research

Despite the above limitations, this is among the first studies examining associations between the family environment and neuropsychological outcome in very young children. Results suggest that family factors, particularly primary caregivers' appraisals of stress and the relationship quality between the primary caregiver and child, as well as injury factors are relevant in identifying risks for adverse child outcomes following neurological insult or disease. After serious injuries, parents report that their initial concern is the survival of their child (Rosenthal & Young, 1988). When survival

seems assured, parents turn their attention to acquiring information about the possible long-term consequences of an injury or condition. Findings from this study offer hope and empowerment to parents and caregivers in providing information about what they can do to maximize outcomes for their child's functioning.

For interventions to be most effective, it will be important that efforts be made to integrate appropriate strategies for rehabilitation when the window for neurological recovery is greatest. Most recovery of function after a neurological injury takes place in the first six months following the injury and plateaus within one year of the injury (Jaffe et al., 1995; Yeates et al., 2002). Longitudinal follow-up within the first six months postinjury that emphasizes family functioning, cognitive development, and psychological development is crucial to planning appropriate interventions. Involvement of the family in rehabilitation efforts during the first six months following injury or diagnosis may improve recovery of injured functions or buffer the impact of the injury on both child and family adjustment post-injury.

More positive family coping styles and cohesiveness might enable parents to deal with the demands of parenting a neurologically vulnerable toddler. Parenting stress is likely compounded when multiple negative parental, child, and dysfunctional family characteristics coexist. Secco, Askin, and Yu (2007) found that for biologically vulnerable toddlers (i.e., having a serious chronic illness or developmental disability), child cognitive ability was the strongest determinant of parenting stress. The authors indicated that this finding suggests that parents of toddlers with lower cognitive ability are especially prone to parenting stress and likely require stress-lowering interventions. As children's cognitive functioning fails to improve, parenting stress may increase only

to perpetuate cognitive and behavioral impairments which may further perpetuate parenting stress. Supports needed to optimize recovery might be lacking in families with higher levels of stress, discord, or burden, and the absences of these supports may contribute to poorer outcomes in children over time. By learning more about how the specific parent and family factors impact outcomes in children who have suffered from a neurological injury, children at highest risk for poor outcomes could be identified in the acute phases post injury so that additional support could be offered to these families.

Studies are needed to aid in the development of valid and practical clinical assessment tools for detecting risk and vulnerability in families of very young children impacted by neurological insult. Multidimensional research programs are essential to reinforce the complexity of the impact of neurological injury on very young children and their families, and to follow children over the years post-injury to determine the significance of the range of factors impacting the injured child and their role in ultimate outcome. The effects of interventions after the subacute phase of neurological injury are largely unknown. Most children return to their homes and to school, but there is wide variation in the types of services available and received. Typically, only the most severely injured receive inpatient and rehabilitation services. Interventions that strengthen the relationship quality between the primary caregiver and child may not only promote more positive outcomes for the neurologically injured child, but they may also facilitate positive outcomes for the primary caregivers and others who make up the family system. Since the effects of rehabilitation programs, be it including somatic intervention programs, educational placements, and/or parent training and education, have received little attention, it is essential that studies be conducted to understand what components

would be beneficial in such programs so that children and their families can receive maximal benefit.

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Appendix A

Pediatric Cerebral Performance Category Scale*

Score	Category	Description
1	Normal	Age-appropriate level of functioning; preschool-aged child developmentally appropriate; school-aged child attends regular classes
2	Mild disability	Can interact at an age-appropriate level; minor neurologic disease that is controlled and does not interfere with daily functioning (eg, seizure disorder); preschool-aged child may have minor developmental delays, but more than 75% of all daily living developmental milestones are above the 10th percentile; school-aged child attends regular school, but grade is not appropriate for age, or child is failing appropriate grade because of cognitive difficulties
3	Moderate disability	Below age-appropriate functioning; neurologic disease that is not controlled and severely limits activities; most activities of preschool-aged child's daily living developmental milestones are below the 10th percentile; school-aged child can perform activities of daily living but attends special classes because of cognitive difficulties or a learning deficit
4	Severe disability	Preschool-aged child's activities of daily living milestones are below the 10th percentile, and child is excessively dependent on others for provision of activities of daily living; school-aged child may be so impaired as to be unable to attend school; school-aged child is dependent on others for provision of activities of daily living; abnormal motor movements for preschool- and school-aged children may include nonpurposeful, decorticate, or decerebrate responses to pain
5	Coma or vegetative state	Unawareness
6	Death	

*Worst level of performance for any single criterion is used for categorizing. Deficits are scored only if they result from a neurologic disorder. Assessments are made on the basis of medical records or interview with caretaker.

From *Recommended Guidelines for Uniform Reporting of Pediatric Advanced Life Support: The Pediatric Utstein Style; Statement for Health Care Professionals* from the Task Force of the American Academy of Pediatrics, the American Heart Association, and the European Resuscitation Council; *Pediatrics* 96(4):765–779, 1995.