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Predictors of Caregiver Confidence in Caring for Their Hospitalized Child Following Pediatric Acquired Brain Injury

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PREDICTORS OF CAREGIVER CONFIDENCE IN CARING FOR THEIR HOSPITALIZED
CHILD FOLLOWING PEDIATRIC ACQUIRED BRAIN INJURY

by

MARGARET B. HUDEPOHL

Under the Direction of Robin D. Morris

ABSTRACT

There is a robust body of research regarding outcomes following pediatric acquired brain injury (ABI). However, these studies generally explore medium-term outcomes (i.e., 3 to 12-months postinjury), whereas functioning during acute stages following ABI is poorly understood. In particular, there is limited knowledge regarding caregiver functioning during a child's hospitalization immediately after ABI. This study sought to identify and model caregiver and child predictors of 'caregiver confidence' in caring for their hospitalized child. Caregivers of 45 children with diverse types of new-onset acquired brain injuries completed self-report measures of their own psychological functioning, stress, and confidence levels, as well as their perceptions of their child's stress and coping. Results showed that caregiver psychological functioning was negatively associated with caregiver confidence, and caregiver perceptions of child coping were

positively associated with caregiver confidence. Child functional status did not serve as a significant mediator in this relationship as per the hypothesized model.

INDEX WORDS: Acquired brain injury, Pediatric, Parenting, Psychological functioning, Stress, Confidence

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A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

in the College of Arts and Sciences

Georgia State University

2013

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Margaret Banks Hudepohl
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For Adam, with love and appreciation.

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1 INTRODUCTION

Pediatric acquired brain injury (ABI) results in many acute and post-injury changes in a child (Anderson et al., 2006) that frequently negatively impacts a child's functioning. Research in this area has focused on the nature of these deficits and factors that influence these outcomes, such as family functioning (e.g., Taylor et al., 1999; Wade et al., 1998, 2002; Yeates et al., 2010). Little research has focused on the nature or impact of a child's ABI on caregiver (i.e., parent, extended family members) functioning. Additionally, most such research explores post-injury outcomes (e.g., 3, 6, 12 months) rather than functioning during the acute stages of hospitalization (e.g., Aitken et al., 2009; Taylor et al., 2001; Yeates et al., 2010). As a result of these historical trends, there continues to be a need for increased understanding regarding the relationship between child and caregiver functioning during the acute phases of recovery. Understanding these influences can ultimately help inform the design and implementation of family-based interventions focused on improving child and family outcomes as early as possible after pediatric brain injury.

1.1 Acquired Brain Injury

ABI is an umbrella term that encompasses many different types of brain injury. Oftentimes within the brain injury literature, studies focus on a specific subset of ABI, such as traumatic brain injury (TBI) or stroke. There are certainly good reasons for doing so, namely for the sake of having a neurologically "pure" sample in order to reduce sources of methodological variance. Despite the neurological differences that exist between these various brain injury groups, this study was intentionally broadly inclusive in its sampling of ABI types to maximize variance in the sample's acute functioning following ABI so that more generalizable results regarding the

full range of caregiver's responses to their child's injury could be identified. Although the specific nature of a child's ABI is not a critical component of this study, a brief overview is provided regarding the common types of childhood brain injuries so that the sample evaluated in this study can be placed within the larger context of ABI.

TBI is the most common source of acquired brain injury in children with nearly half a million emergency department visits per year (Faul et al., 2010), with the highest prevalence rates in the youngest (0-4; 1188.5/100,000) and adolescent (15-21; 917.5/100,000) ages groups (Brown et al., 2008). As such, TBI also has the greatest body of empirical work and frequently forms the basis for this review of the ABI literature. Cerebrovascular events (CVAs, ischemic and hemorrhagic) are the second most common type of pediatric ABI but occur much less frequently, in approximately 1 to 8 per 100,000 children per year. They frequently occur secondary to other medical conditions such as sickle cell disease and other hematologic disorders, but also occur related to previously undetected conditions, such as vascular malformations, heart defects, respiratory failure, and metabolic disorders (Lopez-Vicente et al., 2010). The third most frequent etiology of pediatric ABI is CNS infection, of which the most common are meningitis and encephalitis. Meningitis is a viral or bacterial infection and inflammation of the meningeal membranes that occurs in approximately 1,000 children per year (CDC, 2009). Encephalitis, an invasion of brain tissue by a virus or other microorganism resulting in acute inflammation and, oftentimes, neuronal damage and death, occurs more frequently, with an average of 20,000 new cases reported annually across the lifespan. Secondary effects of these infections often include increased intracranial pressure, hydrocephalus, and cerebral edema, which cause further injury to the brain tissue. The fourth most common brain injury is anoxic/hypoxic injury, which is caused by events that restrict oxygen to the brain leading to oxygen levels at the tissue or cellular level

that are too low to maintain normal functioning. Specific prevalence rates are not available; however, common causes include respiratory failure (e.g., immersion, suffocation, heart-related complications) and toxic exposures (e.g., toxic combustion products during a fire). Finally, brain tumors occur in approximately 2,000 to 4,000 children per year in the United States (Margolin et al., 2002) and cause lesions that are generally focal in nature (e.g., posterior fossa, supratentorial low-grade tumors); however, a common consequence of brain tumors is hydrocephalus, which, along with the typical treatment (i.e., shunting), can lead to a more diffuse impact.

Across all of these ABI subtypes, a shared and fundamental variable critical to this study is the unexpected nature of the event/diagnosis, which results in sudden hospitalization and an acute change in a child's cognitive and behavioral functioning. Therefore, rather than focus on a specific subtype of ABI, this study aimed to gather information early during hospitalization in acute disorders in order to capture the temporal impact of the brain injury event on the child's behavior and functioning and the resulting relationship with caregiver functioning.

1.2 Relationships between Caregiver Functioning and Child Functioning

When considering childhood brain injury, Taylor et al. (2001) proposed an important bidirectional relationship between parent psychological distress and aspects of child functioning. They state that this relationship begins at injury and persists over time. Their findings support the presence of a negative spiral in which perceived child functioning affects caregiver distress and adjustment, which impacts child functioning (e.g., behavior problems), and which ultimately increases parental stress levels (Taylor, Yeates, Wade, et al., 2001). Specifically, their empirical results revealed a mutual influence of caregiver distress and child behavior problems at 6 months and 12 months post-injury. Given this bidirectional relationship, Taylor and colleagues assert

the importance of positive parent-child interactions, and notably emphasize that the relationship between parent and child functioning may be strongest immediately after injury/illness.

This theoretical model, and the authors' findings at 6 and 12 months post-injury, highlights the importance of examining relationships between caregiver and child functioning in the acute hospitalization and early recovery phase of a child's injury/illness to determine the nature and effects of parent-child interactions. This is further underscored when one considers that much of the existing literature on caregiver functioning explores longer-term outcomes, as mentioned above, that are compared to information on pre-injury functioning gathered from parents early during hospitalization (e.g., Wade et al., 2006; Yeates et al., 2010). At these later time points, caregivers and patients have typically been back in their home environments for some amount of time, allowing for changes in both patient and caregiver functioning that were not present in the acute period or setting. Therefore, there is a clear theoretical need for studies to explore caregiver functioning in the acute period after their child's ABI.

1.3 Caregiver Psychological Functioning after Pediatric ABI

Pediatric ABI often occurs in an unexpected fashion (e.g., sudden, life-threatening illness; accidental injury) that can be distressing for the child, their caregivers, and family members. After their child's illness/injury, caregiver psychological functioning can be affected by multiple factors, including injury sequelae and severity. Injury sequelae, particularly a child's functional capabilities, also influences caregiver psychological functioning (e.g., Wade et al., 1998). Such changes can result in a child's increased dependence on the caregiver and other support resources, which often amplifies caregiver stress levels and exacerbates any caregiver psychopathology. For example, Youngblut and Brooten (2006, 2008) observed increased parent stress levels and poor psychological well-being in mothers of children after TBI, with evidence

of a dose-response relationship using a subjective measure of the parents' perception of their child's injury severity (1 to 5 scale, 5 = most sick possible). Wade et al. (1998) found that parent psychological symptoms varied as a function of their child's injury severity, with increased symptomatology at moderate (GCS = 9-12) to severe (GCS = 3-8) TBI. On long-term follow-up, 40 percent of parents of children with severe TBI, and 29 percent of parents of children with moderate TBI, had clinically significant psychological symptoms. However, other studies have suggested that the actual severity of a brain injury does not correlate strongly with caregiver-reported distress levels (e.g., Hawley et al., 2003), and only accounts for some of the variance in other outcomes (Fletcher et al., 1995). Taken together, these results highlight the role of other factors that influence parental outcomes after their child's ABI.

In addition to increased stress levels, which impact caregivers' abilities to parent effectively and families to function well (Kraus, 1995), brain injury outcome research has demonstrated the impact of child ABI on other aspects of caregiver emotional functioning. Kirton and others (2007) discuss the significant guilt expressed by parents, particularly mothers, after their child has sustained a stroke. Caregivers of children undergoing treatment for brain tumors report elevated levels of depressive and anxiety symptoms compared to caregivers in an off-treatment brain tumor group, although both groups endorsed elevated levels of parenting stress (Hutchinson et al., 2009). Research has consistently shown that caregivers of children with traumatic brain injuries experience increased symptoms of anxiety and depression (Tartar, 1990; Wade et al., 2004; Youngblut & Brooten, 2006), as well as stress (Hawley et al., 2003), for months after their child's hospitalization. Armstrong and Kerns (2002) also observed that parents of children after TBI report many unmet needs, including a lack of professional, social, and community support, which impacted their mental health. These studies suggest that these nega-

tive effects on caregiver psychological functioning are frequently observed across all types of ABI. Unfortunately, nearly all of these studies that consider caregiver factors such as stress, depression, and anxiety explore these effects months or years post-injury when a child's functional status is typically more stable than during the acute or early recovery periods. This further highlights the need for studies of caregiver functioning during acute phases of their child's hospitalization, given the changes they are experiencing in their children during early hospitalization and rehabilitation.

Important, relevant findings can also be garnered from the pediatric psychology literature that documents caregiver psychological stress during other types of acute and chronic illnesses without acute ABI. For example, pediatric cancer research has shown that caregiver psychological distress (e.g., anxiety, depression, post-traumatic stress) is associated with receiving their child's medical diagnoses (e.g., Fuemmeler, Mullins, & Marx, 2001), similar to findings within brain injury research. Furthermore, studies with childhood chronic illnesses have documented that parental distress is highest at time of diagnosis and decreases over time (Steele et al., 2003). A study by Dahlquist et al. (1996) showed that a decrease in parent distress was associated with parent's adjustment to their child's new condition. These findings strongly point to the need to investigate caregiver psychological functioning in the acute phases following a child's acquired brain injury, rather than waiting until the post-acute recovery period. Ultimately, a better understanding of caregiver psychological functioning, and its relationship with child functioning during these early phases of an injury/illness, can help inform interventions designed to reduce or possibly prevent clinically significant psychological dysfunction for the brain injured child and his/her family.

1.4 Caregiver Confidence During their Child's Hospitalization

During a child's hospitalization and treatment/recovery from an illness or injury, their caregiver plays an important role. They are often the sole connection to home and the child's previous life experiences. Caregivers can provide unique comfort and care for their child during hospitalization. This makes caregivers a vital part of their child's care team, which highlights the importance of assessing their comfort level with their caregiving responsibilities during their child's hospitalization and recovery.

Caregiver confidence, the belief in their ability to care for their child during hospitalization, is a construct that has previously been explored in some pediatric populations, although not specifically in the ABI literature. The few studies that exist point to a relationship between caregiver psychological clinical symptoms and role uncertainty after pediatric injury/illness. Miles et al. (1989) found that increased caregiver anxiety was associated with unexpected hospital admissions, greater perceived illness, and increased stress about parental role alteration. Ramritu and Croft (1999) describe qualitative feedback from parents expressing uncertainty about their role during hospitalization, and the desire for information about how to best help their child.

In response to such findings, Melnyk formally operationalized this construct by creating the Parental Beliefs Scale (PBS; 1991) after noticing this gap in the literature and a lack of available and relevant measures. Melnyk discussed developing the PBS in order to be able to assess this specific aspect of parental coping, which allows the researcher to empirically assess parent confidence about their role and ability to care for their child during hospitalization (Melnyk et al., 2001b). Melnyk utilized the PBS to assess samples of parents with unexpected, critically ill (non-ABI) children. Using structural equation modeling to test their model, Melnyk and colleagues (2001a, 2007) found positive associations between both parent mental health and child

psychosocial functioning and parent confidence. These findings highlight the potential for exploring this aspect of coping (i.e., caregiver confidence) in caregivers of children with new-onset ABI, particularly because of previous findings that caregiver confidence is related to both caregiver and child functioning.

1.5 Caregiver Perceptions of Child Functioning after Pediatric ABI

During a child's development, caregivers are typically asked to report on their child's functioning in many different settings. As a child matures, it becomes developmentally appropriate to request a child's self-report of their own functioning as well, thus a number of child-report measures are available. After pediatric brain injury, particularly in an acute rehabilitation setting, a child's decreased functional status (e.g., cognitive, behavioral, physical abilities) typically impacts their ability to accurately self-report; as such, the field relies on caregiver report following pediatric ABI. As would generally be expected after brain injury, studies describing caregiver report of their child show a decrease in their child's functioning. Caregivers also endorse increased child psychological problems following ABI, and report that these problems cause more distress for both patients and family members than other types of post-injury deficits, such as their physical and cognitive impairments (Anderson et al., 2006), with such reports often persisting over time (Jaffe et al., 1995; Yeates et al., 2004).

The pediatric psychology literature again provides helpful information regarding models of child stress and coping that inform the current study with its focus in the acute time period. Studies show that, based on caregiver report, anywhere between 6 and 45 percent of children develop acute stress and/or post-traumatic stress symptoms after medical trauma (Enlow, Kassam-Adams, & Saxe, 2010; Mackley et al., 2010). Studies have also shown that presentation of acute stress symptoms in children often does not occur until they are transferred from the pediatric

ICU (Ward-Begnoche, 2007), pointing to the importance of assessing acute stress and coping during the acute time period. Compas et al. (2012) revealed that caregivers report that coping with an unexpected cancer diagnosis is particularly difficult initially for both themselves and their child, and found a negative relationship between a perceived controllability of the stressor and effective coping of the caregiver and child. In general, parental coping strategies that use avoidance are associated with poorer adjustment in children with cancer (Frank et al., 1997).

Some studies have also demonstrated that caregiver psychopathology, particularly depression and anxiety, can distort caregiver ratings of their child's functioning (Chi & Hinshaw, 2002). For example, depressed and anxious caregivers are more likely to report emotional and behavioral problems in their children after hospitalization (Briggs-Gowan et al., 1996; Frick et al., 1994; Najman et al., 2000; Richters, 1992). Although caregiver-report remains the best option for gathering information regarding a child's psychological functioning during acute recovery after ABI, these findings do raise questions regarding the relationship between caregivers' perceptions and children's functional status. Thus, there is a need to better understand caregiver perceptions of child psychological functioning in the acute phases of recovery after brain injury, and their confidence in providing appropriate caregiving. A need also exists to explore relationships between caregiver/child psychological functioning and child functional status, which will be discussed further below.

1.6 Measuring Functional Status in Children after Pediatric ABI

During acute rehabilitation, many standard measures of adaptive functioning (e.g., ABAS-II, Vineland-II) are not appropriate assessments of functional abilities in children due to the nature of their questions (e.g., items about school, leadership abilities) in the context of the child's absence and/or delayed return to typical home, school, and community environments.

To this point, neuropsychological studies have primarily focused on injury sequelae and functional status months or even years post-injury, when outcomes are much more stable than during early recovery periods (e.g., Anderson et al., 1997; Bedell, 2008; Stancin et al., 2002; Yeates et al., 2001, 2004).

During the acute time period, the child's functional recovery and level of independence can be repeatedly assessed from the time of admission to discharge with the Functional Independence Measure for Children (WeeFIM; Braun, 1998). The WeeFIM is an independent rating of child functioning, as it is completed by the rehabilitation therapy team. It is well established as a functional outcome measure in the rehabilitation setting, and captures changes in functional abilities that children undergo during inpatient rehabilitation. For example, recovery trajectories were provided using WeeFIM scores for a sample of pediatric traumatic brain injury patients by Forsyth, Salorio, and Christensen (2010). They found that WeeFIM recovery curves were generally characterized by an initial slow phase, sharper mid-phase recovery, followed by a late plateau.

Despite its widespread use during inpatient rehabilitation, there is very little research with the WeeFIM, during the acute recovery phase during initial hospitalization. In a non-acute sample of patients with physical disabilities (i.e., cerebral palsy, spina bifida), decreased functional independence was associated with increased parental communication with their child's healthcare professionals (Cavallo et al., 2009). This finding suggests an important relationship between child functional status and caregiver healthcare usage behaviors. Unfortunately, there has been no exploration of such relationships during the acute time period, a clear gap in available research. There has also been no exploration regarding how children's changes in functional

status during their initial recovery period may be related to their caregiver's coping and psychological functioning, or vice versa.

1.7 Current Study

The lack of research regarding child and caregiver functioning during the acute stages of hospitalization and recovery after a child's ABI has limited strategies during this crucial time period for interventions designed to improve outcomes (Taylor et al., 2001). In order to better understand child and caregiver functioning during these acute time points, and their interrelationships, caregivers of children with a new-onset ABI were recruited for this study during their child's admission to an inpatient rehabilitation unit. This study gathered data during an acute time point from caregivers regarding their own psychological functioning, their report of their child's psychological functioning, as well as an independent clinical measure of their child's functional status. The study examined the relationship between a caregiver's confidence about their ability to care for their child during hospitalization, and child and caregiver psychological functioning. Additionally, given the importance of functional status and recovery trajectories, child functional status was examined as a mediator of the relationship between child and caregiver psychological functioning and caregiver confidence. A multivariate model was proposed to better understand these interrelationships, and to establish whether psychological variables directly affect caregiver confidence, or indirectly affect it through child functional status.

This study can be viewed as a first step in assessing interrelationships between caregiver and child functioning in the acute rehabilitation setting after pediatric acquired brain injury. With the identification of predictors of caregiver confidence, it is hoped that this study can ultimately inform the design and implementation of family interventions that address caregiver and child needs and difficulties during the acute phase of pediatric ABI recovery.

Aims.

This study aimed to establish the extent to which caregiver and child psychological variables predicted caregiver confidence. Caregiver psychological functioning (BSI Composite, PSI) was expected to be negatively related to caregiver confidence (PBS), and caregiver perceptions of child psychological functioning (CSDC, CHIC) were proposed to be positively related to caregiver confidence. That is, as caregiver distress decreases, caregiver confidence is predicted to increase, and as child psychological functioning (coping, stress) improves, caregiver confidence is expected to improve.

Secondly, this study aimed to explore a multivariate mediational model to establish whether caregiver and child psychological functioning variables either directly affected caregiver confidence, or indirectly affected it through child functional status. Child functional status (WeeFIM) was predicted to mediate the relationship between caregiver psychological functioning and caregiver perceptions of child psychological functioning (predictors) and caregiver confidence (see Figure 1).

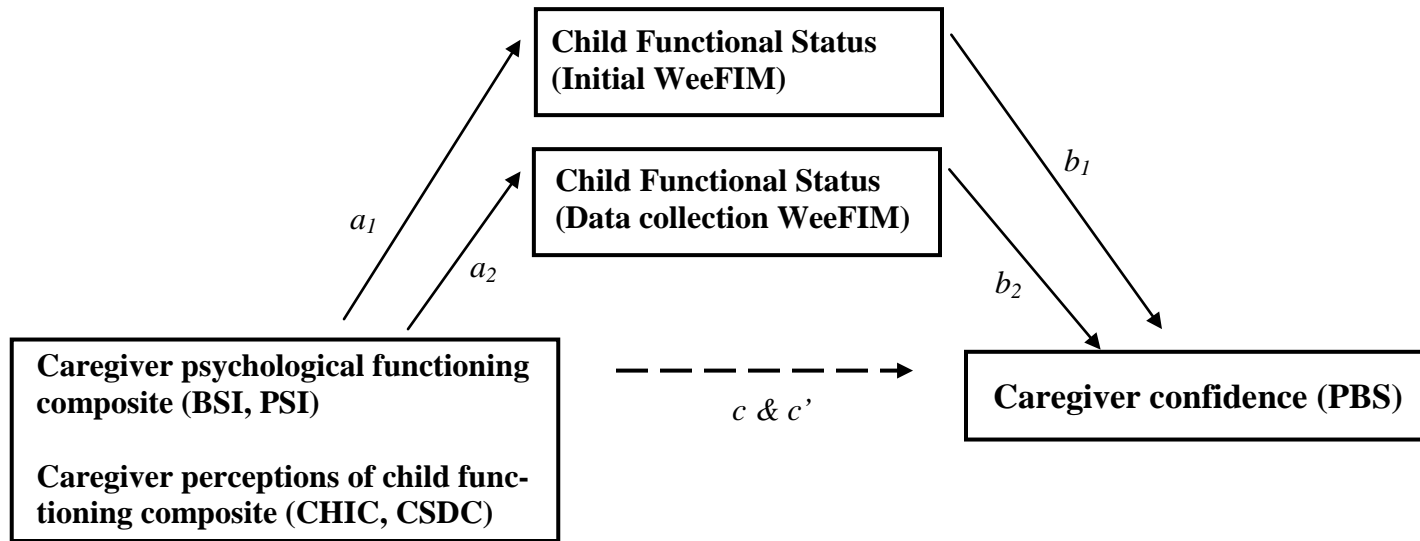


Figure 1 *Multiple mediational model examining the relation between caregiver emotional functioning and perceptions of their child's emotional functioning (predictors) and caregiver confidence (outcome) when mediated by child functional status*

2 METHOD

2.1 Participants

Data for this study was collected from caregivers recruited during their child's admission to a pediatric inpatient medical and rehabilitation unit located within a children's hospital in the southeastern United States. Patients are typically admitted to the rehabilitation unit as soon as medically stabilized in the intensive care unit (e.g., initial neurosurgical and orthopedic surgeries completed). The children participate in at least three hours of individual speech/language, occupational, and physical therapy daily, and are monitored 24 hours by nursing and physician staff until stable enough for discharge. In this setting, caregivers are required to participate in training to learn how to best assist and promote the recovery process during their child's daily rehabilitation therapies (e.g., learning how to do a wheelchair transfer; performing muscle strengthening exercises with child).

Inclusion in the current study was contingent upon children being between the ages of 4 and 17 years at the time of admission. Only children who had an identifiable and present caregiver (e.g., mother, father, grandparent) who spoke English as a first language were eligible to participate. Additionally, children who had a prior history of brain insult, neurological condition (e.g., Neurofibromatosis, epilepsy), or developmental/medical condition or treatment with neurological implications were excluded. Prior to enrollment, all patients were oriented based on age-normed scores on the Children's Orientation and Amnesia Test (COAT).

Participants included 45 primary caregivers of previously healthy children between the ages of 4.2 and 13.8 ($M = 9.7$ years, $SD = 3.1$ years; see Table 1) who sustained an acquired brain injury. Previous characterization data for the rehabilitation facility indicates that patients admitted after ABI most commonly sustain a non-traumatic brain injury (e.g., brain tumor, hy-

poxia; 26.4 percent of all patients) followed by traumatic brain injury (23.6 percent), stroke (8.4 percent) and other neurological conditions. In the current study, the children of all participating caregivers were receiving rehabilitation for one of these types of new-onset ABI (see Table 2). Caregiver was defined as the adult who took on the primary role of caring for the healing child, who was trained and educated by the rehabilitation staff. This included mothers, fathers, and grandparents in the current study. Families were predominantly Caucasian, followed by African-American and Latino (see Table 3).

Table 1

Child Demographic and Medical Information (N = 45)

	<i>M (SD)</i>
Mean age at injury	9.7 (3.1)
Female to male ratio	18:27
Mean length of inpatient rehabilitation hospitalization	16.8 (9.4)
Mean length of total rehabilitation care	37.6 (28.9)

Note. Age at time of injury in years. Length of inpatient and total rehabilitation care in days.

Table 2

Child Injury Characterization

Primary Injury Type	<i>N (%)</i>
Traumatic Brain Injury (TBI)	27 (60.0)
Stroke	4 (8.9)
Brain Tumor	5 (11.1)
Cerebral Infection	6 (13.3)
Anoxic-hypoxic Event	1 (2.2)
Other neurological condition	2 (4.4)

Table 3

Caregiver Demographic Information

	<i>N</i> (%)
Relationship to Child	
Mother	40 (88.9)
Father	3 (6.7)
Grandparent/Other	2 (4.4)
Race/Ethnicity	
White	30 (66.7)
African American	13 (28.9)
Latino	2 (4.4)

2.2 Measures***Brief Symptom Inventory.***

The Brief Symptom Inventory (BSI; Derogatis, L., 1993) was completed by the caregiver, and is a short, 53-item questionnaire assessing the rater's psychological distress. The BSI yields 9 symptom scales including Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism. The BSI also generates three Global indices, including the Global Severity Index, which is a measure of overall psychological distress, the Positive Symptom Distress Index, a measure of the intensity of symptoms, and the Positive Symptom Total, an indicator of the number of self-reported symptoms of the individual. Responses to items are chosen from a 5-point rating scale ("Not at all" to "Extremely") based on the rater's experience in the past 7 days. Raw scores are converted to T-scores; T-scores of 60/standard scores of 115 or above are considered indicators of distress. Given that past research in ABI has shown elevated depression and anxiety in caregivers at follow-up time points after their child's ABI, the Depression and Anxiety scales are used in the current study as indicators of caregiver psychological symptoms and distress. Additionally, a BSI

composite score was created for each caregiver that represented the average of their reported levels of depression and anxiety (average z-score of Depression and Anxiety subscale z-scores).

Studies have revealed adequate psychometric data for the BSI (Derogatis, L., 1993). The validity of the BSI has been demonstrated through high correlations with the comparable dimensions of its caregiver instrument, the SCL-90, and relevant dimensions of the MMPI. The measure has also demonstrated high internal consistency, with reliability coefficients ranging from .71 to .85, as well as adequate test-retest reliability.

Children's Stress Disorder Checklist.

The Child Stress Disorders Checklist (CSDC; Saxe et al., 2003) is a 30-item caregiver-report questionnaire assessing their perception of acute stress and posttraumatic symptoms in their child after illness/injury. The caregiver is prompted to think about their child's illness/injury now or within the past month, and respond to each item using a 3-point rating scale (Not True, Somewhat/Sometimes True, Very/Often True). The CSDC yields five dimensions related to post traumatic symptoms (Re-experiencing, Avoidance, Numbing/Dissociation, Increased Arousal, Impairment in Functioning), and a Total Score. Higher scores indicate more post traumatic symptoms, and thus greater risk for a stress disorder.

Analyses have revealed acceptable psychometric data for this relatively new measure (Saxe et al., 2003). The test-retest reliability was .84, with Cronbach alpha's ranging from .83 to .86 when assessing internal consistency. Inter-rater reliability between parents and nurses was .44, which is acceptable given inter-rater reliability data from similar observer-report measures (e.g., CBCL; Achenbach, 1991). Correlations with other established measures (e.g., Child PTSD Reaction Index, Child Dissociation Checklist) ranged from .26 to .59.

The CSDC was specifically chosen because of its documented use in pediatric medical populations (i.e., burns, MVA) and assessment of acute period variables. The questionnaire contains items that are relevant for pediatric ABI patients in *acute* rehabilitation, unlike many of the common, well-known pediatric parent-report measures. The Total score is used in the current study as an indicator of caregiver perception of their child's acute/posttraumatic stress level related to new-onset illness/injury.

Coping Health Inventory for Children.

The Coping Health Inventory for Children (CHIC; Austin, et al., 1991) is a 45-item caregiver-report measure assessing health-related coping in children with medical conditions. The caregiver is asked to indicate how often their child displays a certain behavior in response to stress from their medical condition and associated problems. Responses are given on a 5-point rating scale (Never, Almost Never, Sometimes, Often, Almost Always). The CHIC provides information on 5 coping behaviors: Develops Competence, Feels Different and Withdraws, Irritability, Complies with Treatment, and Seeks Support, which are then combined into Positive (Competence, Complies, Seeks Support) and Negative Coping (Feels Different, Irritability) composite scores (Dunn, Austin, & Huster, 1999).

Adequate psychometric data has been obtained for the CHIC (Austin, Patterson, & Huberty, 1991). Analyses found test-retest data ranging from .68 to .91 for mothers and .57 to .84 for fathers in a reliability sample. Internal consistency ranged from .75 to .88 between the 5 subscales. Correlations with other established measures (e.g., indices from CBCL) were moderately high indicating strong validity.

Similar to the CSDC above, the CHIC was also chosen for its documented use within pediatric medical populations, and its inclusion of questions that are relevant for patients in acute

medical settings. The Positive Coping composite score is used in the current study as an indicator of caregiver perception of their child's coping abilities related to their medical status.

Functional Independence Measure for Children.

The Functional Independence Measure for Children (WeeFIM; Braun, 1998; Granger & McCabe, 1990) is an 18-item instrument commonly used on a serial basis by rehabilitation therapists to independently assess functional performance in three domains: Self-Care, Mobility, and Cognition. The Self-Care domain assesses skills such as eating, grooming, dressing, and bladder management. The Mobility domain focuses on locomotion and transfers to common settings, such as the wheelchair and toilet. The Cognition domain assesses basic skills including comprehension, expression, social interaction, problem-solving, and memory. Each item is scored on a 7-point scale based on assistance with the item. A score of one indicates total assistance and a score of seven indicates complete independence. The range for a patient's total score on the WeeFIM is 18 to 126 with lower scores indicating greater dependence and higher scores indicating greater self-sufficiency.

The measure was originally standardized and validated in a sample of children ages 6 months to 7 years; however, this standardization has since been extended to older children and adolescents (Msall, DiGaudio, & Duffy, 1993). The WeeFIM has adequate psychometric data, including excellent test-retest and interrater reliability and has been validated across multiple populations, showing adequate validity in a population of children with brain injuries (Ziviani et al., 2001) in particular. Msall et al. (1994) demonstrated reliability across domains of the WeeFIM. Test-retest coefficients for the three domains were .89, .97, and .99, compared to the Total WeeFIM score test-retest reliability, which was .99. Similarly, inter-rater reliability for the three domains were .87, .80, and .96, compared to the Total score inter-rater reliability of .95.

Total Scores from the initial WeeFIM and the WeeFIM administration that fell closest to the time that caregivers completed the study measures are used in the current study as a clinical indicator of the patient's current level of functioning and change in functioning.

Parental Beliefs Scale for Parents of Hospitalized Children.

The Parental Beliefs Scale for Parents of Hospitalized Children (PBS; Melnyk, 1994) is a 20-item caregiver questionnaire assessing caregiver confidence and belief in their role and ability to care for their child during hospitalization. Each question is answered using a 5-point Likert scale where 1 is Strongly Disagree and 5 is Strongly Agree. Higher scores indicate increased confidence and stronger beliefs in their ability to care for their hospitalized child.

This measure was created by Melnyk to fill a gap in the literature on parenting/caregiving during hospitalization. Although the PBS does not have copious reliability and validity data, it captures a unique construct that was considered theoretically important to measure in the current study. That said, Melnyk et al. (2003) have compiled psychometric information based on data obtained during three intervention studies. Strong content and face validity were established across these studies and by a panel of experts. A Principal Components Analysis with varimax rotation was used to determine construct validity and factor analyses demonstrated support for two factors, caregiver confidence about their role and beliefs about their hospitalized child. Good internal consistency was noted with a Cronbach alpha of .89 for the scale.

The PBS total score is used in the current study as an indicator of parental confidence.

Parenting Stress Index.

The Parenting Stress Index (PSI; Abidin, 1990) is a questionnaire intended to screen for stress in the caregiver-child relationship. This 101-item measure can be completed by the caregiver in approximately 15 to 25 minutes. Results yield a Total Stress score, Child Domain total,

and Parent Domain total, in addition to 6 child and 7 caregiver subscales. The child subscales assess characteristics of a child that may lead to difficulty parenting, including distractibility/hyperactivity, adaptability, reinforces parent, demandingness, mood, and acceptability. The parent subscales assess sources of stress and potential dysfunction for the caregiver and include competence, social isolation, attachment of child, health, role restriction, depression, and spouse. Responses are chosen from various scales, including yes/no items, a number based Likert scale (1 to 4 or 1 to 5), and a 5-point qualitative Likert scale (Strongly Agree to Strongly Disagree). The scores within the Child and Parent Domains, respectively, are summed to yield the domain scores, which are then summed to obtain the Total Stress score. Normative data are provided for each subscale and domain score; scores above one standard deviation from the mean (i.e., > 85th percentile) are considered Clinically Significant, indicating greater distress and often feelings of being overwhelmed and inadequate.

Adequate psychometric data have been obtained for the PSI (Abidin, 1990). The internal consistency coefficients for the child and caregiver domains were .90 and .93, respectively, with a .95 Cronbach's alpha for the Total Stress scale. When the scale was given to individuals every one to three months for a one year period, test-retest reliabilities ranged from .65 to .96. The validity of the scale was indicated by its correlation with related measures; for example, the child domain on the PSI correlated moderately (.56) with the Achenbach Child Behavior Checklist.

The Total Stress Index score on the PSI is used in the current study as an indicator of stress in the caregiver-child relationship.

2.3 Procedures

This study was approved by the Institutional Review Boards of Georgia State University (H11150) and CHOA (10-153). Caregivers consented prior to participating in this study. Prior

to contact, all children admitted to the inpatient rehabilitation unit at an urban children's hospital in the southeastern United States were reviewed for study eligibility through information gathered from electronic medical records. These reviews frequently occurred over the course of a number of days, as patients' stabilized after admission. As soon as possible and appropriate, patients who were identified as potentially eligible had their COAT results reviewed to assess their orientation. Families were deemed eligible once the child obtained an orientation score in the average range, or met their age-related cut-off score, in an attempt to ensure that all caregivers were equally able to report on their child's behavior (e.g., a caregiver cannot truly report on a child's coping ability if the child is still extremely disoriented and agitated). At that time, the caregiver(s) were approached about the study and, if interested in participating, caregiver consent was obtained and caregivers were asked to sign an Authorization to Release Protected Health Information for Research Purposes form. After the consent process, the primary caregiver was established, and asked to answer any necessary questions regarding the exclusionary criteria (as described in the Participant section above).

Once enrolled, the caregiver was provided with a packet of questionnaires containing the BSI, CSDC, CHIC, PBS, and PSI. They were asked to complete the questionnaires within the next 3 to 5 days. Compensation for time and effort was provided. Information was also gathered from the patient's medical chart.

3 RESULTS

3.1 Overview of Analyses

Preliminary analyses were conducted to describe the sample, and examine associations among study variables. Linear regression analyses were used to determine individual predictors of caregiver confidence. Bootstrap analyses were conducted in accord with Preacher and Hayes (2004, 2008) to examine a multivariate mediational model to establish whether caregiver and child psychological functioning variables indirectly affected caregiver confidence through child functional status. Data were deleted pairwise in some analyses in order to eliminate data loss; however, it is important to note that only two subjects in the database had missing data, which was very limited (i.e., one subject was missing the BSI score, one was missing the CSDC score).

3.2 Descriptive Analyses

Data were analyzed using SPSS. Descriptive statistics (e.g., means, standard deviations, frequencies) were calculated to characterize the sample (see Tables 1-3). Means and standard deviations for all the study measures (i.e., child and caregiver functioning, caregiver confidence) were also obtained (Table 4). As seen in Table 4, the overall caregiver anxiety and depression means were in the normal range based on the BSI-defined cut-off ($SS \geq 119$). Twenty and 22 percent of the sample, respectively, reported levels of anxiety and depression that fell above the cut-off. Compared to the general population prevalence, the current sample had a similar rate of anxiety (population rate = 18.1%), but a much higher rate of depression (population rate = 6.7 percent; Kessler et al., 2005). When depression and anxiety were considered together, 36 percent of caregivers had a BSI composite score beyond the cut-off. Overall parenting self-reported stress level (PSI) was in the normal range and 7 percent of caregivers reported parenting stress

levels that fell beyond the PSI cut-off ($SS \geq 115$). Finally, caregivers also reported on their perceptions of their child's coping and acute stress levels, of which 11 and 13 percent, respectively, fell beyond 1.5 standard deviations from the mean.

Table 4
Means, Standard Deviations, and Percentage Beyond Cut-off for Study Variables

Measure	<i>M (SD)</i>	% Beyond Cutoff
BSI Anxiety <i>Caregiver anxiety</i>	110.57 (16.39)	20
BSI Depression <i>Caregiver depression</i>	105.64 (14.74)	22
BSI Composite <i>Caregiver psychological functioning</i>	108.07 (14.25)	36
PBS Total <i>Caregiver confidence</i>	76.98 (11.87)	4
PSI Total <i>Parenting stress</i>	91.58 (17.61)	7
CHIC Positive Coping <i>Parent perception of child coping</i>	3.62 (.54)	11
CSDC Total <i>Parent perception of child acute stress</i>	10.11 (7.29)	9
WeeFIM Initial <i>Child functional status at admission</i>	54.60 (19.74)	--
WeeFIM Data Collection <i>Child functional status at data collection</i>	84.96 (15.96)	--
WeeFIM Change <i>Change in child functional status</i>	30.36 (11.95)	--
WeeFIM Time Lapse <i># days between WeeFIM administrations</i>	18.80 (12.38)	--

Note. Abbreviations: BSI=Brief Symptom Inventory (standard scores), PSI=Parent Stress Index (standard scores), CHIC=Coping Health Inventory for Children (raw score), CSDC=Child Stress Disorder Checklist (raw score), WeeFIM=Functional Independence Measure for Children (raw score), PBS=Parental Beliefs Scale (raw score). % below average was defined as the percentage of participants who reported symptoms at or below 1.5 SDs (CHIC, PBS) or at or above 1.5 SDs (CSDC), except the BSI ($SS \geq 119$) and PSI ($SS \geq 115$), which had cut-offs defined by the measure/authors.

Prior to conducting analyses, the assumptions of regression were tested (Lewis-Beck, 1980). Data were visually inspected to ensure that a linear model was applicable. This revealed significant skew in two variables. To address the skew in the BSI Distress Composite and Post-traumatic Stress variables, square-root transformations were performed. Following transformation, normality was tested and achieved for both the BSI Distress Composite ($D(44) = .09, p = .20$) and Post-traumatic Stress variable ($D(44) = .12, p = .16$) using the Komogorov-Smirnov test (Field, 2009). One outlier (>3 SDs) on one variable was identified, which was resolved through the aforementioned data transformation process. The residuals were independent, and approximately normally distributed, and the assumption of homoscedasticity was met; therefore, the model appears to be both accurate for our sample, and generalizable to the population.

Correlation analyses were conducted with the measures to determine the presence or absence of multicollinearity (Table 5). Multicollinearity is a phenomenon that arises when two or more predictor variables in a multiple regression model are highly correlated, which results in the distortion or deflation of partial regression coefficients. No correlation between any two variables exceeded .8 (Field, 2009); however, WeeFIM scores at admission to rehab (WeeFIM Initial) and at the time of data collection (WeeFIM Data Collection) were very highly correlated at nearly .80 ($r = .79; p < .001$). As such, it is possible that multicollinearity may be present between these two variables. To eliminate this possibility, a “change” z-score was created that represented the change in a patient’s functional status from admission to data collection (i.e., WeeFIM Data Collection – WeeFIM admission). With the creation of the WeeFIM Change score, however, information was lost regarding individual level of functioning. In order to retain and quantify this variance, a WeeFIM Time score was also created for each subject, which illustrated

Table 5

Correlation Matrix for Study Variables

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. BSI Composite	--									
2. CHIC Positive Coping	-.46**	--								
3. CSDC Total	.55**	-.49**	--							
4. PBS Total	-.48**	.46**	-.29	--						
5. PSI Total	.45**	-.50**	.54**	-.45**	--					
6. WeeFIM Initial	-.12	.22	-.22	.11	-.22	--				
7. WeeFIM Data Collection	-.07	.17	.01	-.07	-.06	.79**	--			
8. WeeFIM Change	.06	-.08	.32*	-.29	.25	-.32	.32*	--		
9. WeeFIM Time Lapse	-.14	.13	.20	.07	-.04	-.43**	-.15	.51**	--	
10. Age	-.3	.25	-.03	-.09	-.17	-.02	.06	0.12	.23	--

Note. Abbreviations: BSI=Brief Symptom Inventory, PSI=Parent Stress Index, CHIC=Coping Health Inventory for Children, CSDC=Child Stress Disorder Checklist, WeeF-

IM=Functional Independence Measure for Children, PBS=Parental Beliefs Scale.

* Correlations significant at $p < .05$.

** Correlations significant at $p < .01$

the amount of time elapsed between the initial WeeFIM administration (at admission) and the WeeFIM closest to the data collection time point (see Table 4; range: 2 to 56 days). Based on the remaining correlations and collinearity diagnostics (i.e., variance inflation factor and tolerance), multicollinearity does not appear to be present.

3.3 Regression Analyses

For the first specific aim and hypothesis, linear regression analyses were utilized to establish how caregiver and child psychological functioning are related to caregiver confidence. Specifically, hypothesis 1 posited that caregiver psychological distress would be negatively related to caregiver confidence, and caregiver perceptions of child psychological functioning (coping, stress) would be positively related to caregiver confidence. Prior to computing all regression models, scores were converted to z-scores based on the current sample. Standardizing these variables automatically centers the values (i.e., creates scores with a mean of 0), which reduces likelihood of multicollinearity (Aiken & West, 1991).

A regression was conducted with caregiver confidence (PBS) as the outcome variable, and caregiver psychological functioning (i.e., BSI Composite) and parenting stress (i.e., PSI) as predictor variables (see Table 6 for full results). Both were significant predictors. Caregiver psychological functioning was able to explain 23 percent of the variance in caregiver confidence ($b = -0.35$, $SE = 0.15$, $p = .022$). Parenting stress explained an additional 7 percent of the variance in caregiver confidence ($b = -0.30$, $SE = 0.15$, $p = .048$). A second regression was conducted with caregiver confidence (PBS) as the outcome variable, and caregiver perceptions of child coping (CHIC Positive Coping) and acute stress (CSDC Total) as predictor variables (Table 7). Child coping was a significant predictor, and explained 21 percent of the variance in caregiver

confidence ($b = 0.48$, $SE = 0.14$, $p = .002$). Child stress did not explain additional systematic variance in caregiver confidence ($b = -0.08$, $SE = 0.16$, $p = .598$).

Table 6
Regression Analysis: Caregiver Psychological Functioning as Predictors of Caregiver Confidence

	<i>b</i>	<i>SE</i>	<i>t</i>	<i>p</i>
Step 1				
Caregiver psychological functioning	-0.48	0.14	-3.54	.001
Step 2				
Caregiver psychological functioning	-0.35	0.15	-2.38	.022
Parenting stress	-0.30	0.15	-2.04	.048

Note. $R^2 = .23$ for Step 1; $\Delta R^2 = .07$ for Step 2 ($p < .05$).

Table 7
Regression Analysis: Child Psychological Functioning as Predictors of Caregiver Confidence

	<i>b</i>	<i>SE</i>	<i>t</i>	<i>p</i>
Step 1				
Caregiver perceptions of child coping	0.48	0.14	3.38	.002
Step 2				
Caregiver perceptions of child coping	0.44	0.16	2.66	.011
Caregiver perceptions of child stress	-0.08	0.16	-0.53	.598

Note. $R^2 = .21$ for Step 1 ($p < .05$); $\Delta R^2 = .005$ for Step 2 ($p > .05$).

3.4 Mediation Analyses

To evaluate the mediational hypothesis, bootstrapping was utilized (Preacher & Hayes, 2004, 2008). Bootstrapping is a nonparametric statistical technique that does not utilize normal distribution assumptions during calculations. Given that indirect effects (i.e., *ab* pathway) are not typically normally distributed, the use of bootstrap estimation accounts for the non-normality

of sampling distributions of the mediated effects. It increases power of the analysis, and is believed to provide the most accurate confidence intervals for indirect effects (see Preacher & Hayes, 2004; Shrout & Bolger, 2002). This nonparametric approach allows the user to analyze smaller samples with much greater confidence than when using the traditional Baron and Kenny method.

The bootstrap macro (Preacher & Hayes, 2004, 2008) was used in SPSS to estimate indirect effects. With the mediational model, there are multiple pathways of interest (see Figure 2). The c pathway, or total effect, indicates the relationship between the independent variable(s) (IV) and dependent variable (DV). The c' , or direct effect, refers to the effect of the IV on the DV, after controlling for the mediator. The a pathway denotes the effect of the IV on the mediator, and the b pathway denotes the effects of the mediator on the DV. Finally, the ab pathway, or indirect effect, is the product of the a and b pathways, which was herein tested according to Preacher and Hayes (2004; 2008), which calculates effects similarly to the Baron and Kenny (1986) method, but provides much increased statistical power, as described above. The number of bootstrap samples was set of 5,000, meaning that 5,000 samples of the current n of 45 were taken, and the ab pathway was calculated for each. The mean of these 5,000 samples was then used to calculate bias-corrected and accelerated 95% confidence intervals. When zero is not within the confidence interval provided, this means that the null hypothesis (i.e., that the ab pathway is not significantly different from zero) can be rejected.

As seen in Figure 2, the mediation model was slightly modified based on results from the preliminary and regression analyses. First, child functional status, WeeFIM scores collected at admission to inpatient rehabilitation and at the time of data collection, were very highly correlated ($r = .79, p < .001$), such that there was very little variance remaining that was not redundant.

Therefore, the decision was made to create the aforementioned composite change in WeeFIM scores to encapsulate data from both time points into one variable¹. Second, based on the second regression analysis, caregiver report of their child's stress was not a significant predictor of caregiver confidence (see Table 7). For this reason, child stress was removed from the mediational model².

The final model predicted that child functional status (WeeFIM) would mediate the relationship between caregiver psychological functioning and child coping (predictors) and caregiver confidence (outcome). Using bootstrapping, three models were run in order to test each of the three predictors while controlling for the remaining two (Preacher and Hayes, 2008). Unstandardized coefficients (as recommended for causal models by Preacher & Hayes, 2004, 2008) and confidence intervals are presented in Table 8 below; as can be seen, child functional status did not act as a mediator in this relationship. For each of the three predictors, the confidence intervals crossed or equaled 0, albeit only slightly, indicating that mediation was not present³.

¹ Including both WeeFIM scores (i.e., admission, data collection) did not change the pattern of results in any way. Additionally, using the WeeFIM standardized residuals as the mediator did not change the pattern of results at all.

² Including child stress in the model did not change the results in any way.

³ Analyses were also run incorporating the WeeFIM Time variable as a covariate; results did not change in any way.

Table 8
Analysis of Mediation Model: Coefficients for mediation of caregiver confidence

DV	a	b	c	c'	ab	BCa 95% CI for ab	
						Lower	Upper
Caregiver Psychological Distress	-.02 (.11)	-.31 (.21)	-.28 (.15)	-.28 (.15)	.01 (.04)	-.05	.12
Caregiver Stress	.23 (.15)*	-.32 (.21)	-.24 (.16)	-.17 (.16)	-.07 (.07)	-.32	.00
Child Coping	.07 (.12)	-.31 (.21)	.22 (.16)	.24 (.16)	-.02 (.04)	-.17	.03

Note. BCa – bias-corrected and accelerated bootstrapping confidence intervals; 5,000 bootstrap samples.

* $p < .05$

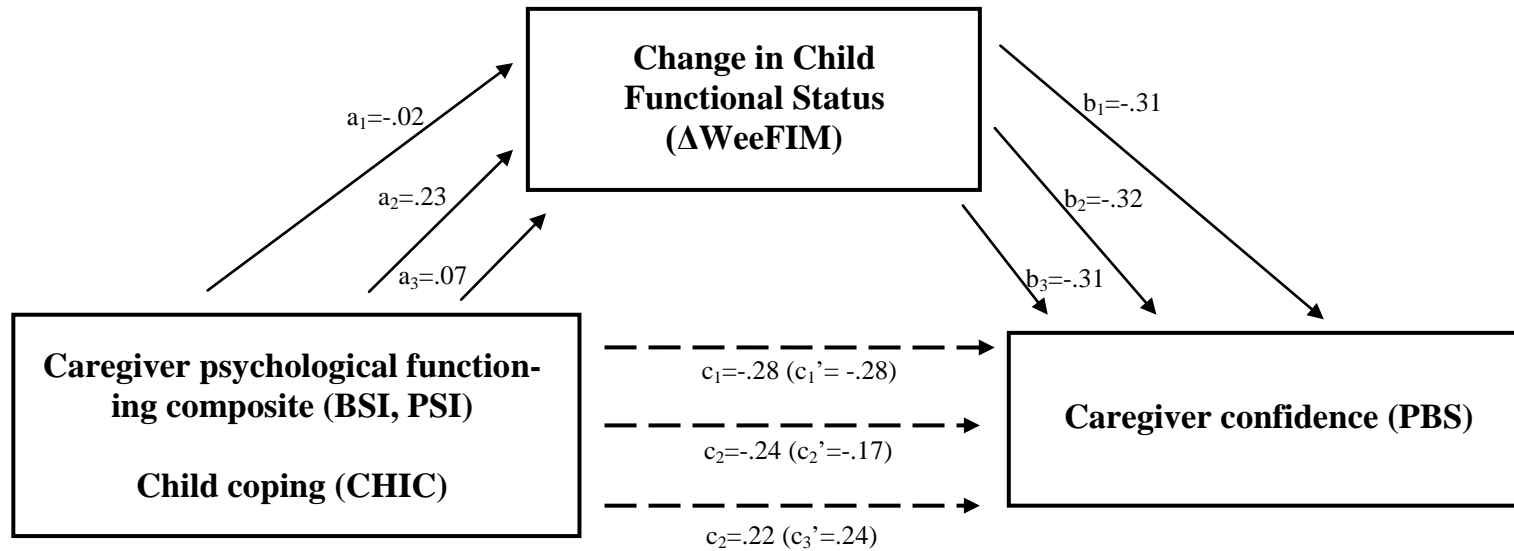


Figure 2 *Unstandardized coefficients for the modified mediational model examining the relation between caregiver psychological functioning and child coping (predictors) and caregiver confidence (outcome) when mediated by change in child functional status*

DISCUSSION

There is little research about child and caregiver functioning during the acute stages of recovery after a child's ABI, yet Taylor et al. (2001) discuss the importance of this time for intervention and improvement of outcomes. As such, the central aim of this study was to take a first step in assessing interrelationships between caregiver and child functioning in the acute rehabilitation setting after new-onset ABI. Specifically, this study identified predictors of caregiver confidence about their ability to care for their hospitalized child in order to better characterize psychological functioning in this population. This study also examined child functional status as an independently rated measure by hospital personnel, as opposed to the caregivers' perception of their child's functioning, as a mediator of the relationship between child and caregiver psychological functioning and caregiver confidence.

4.1 Caregiver and Child Functioning

Given the lack of research currently available regarding psychological functioning of children after ABI and their caregivers during the acute stages of recovery, descriptive data from this study may be particularly valuable and will first be briefly discussed. Notably, the rate of depression was elevated among caregivers of children with new-onset ABI, with a notable proportion (22 percent) of the sample reporting clinically significant levels as compared to the general population. However, levels of anxiety (20 percent) were similar to the general population prevalence, and levels of parenting stress were low (7 percent elevated). Caregivers also reported on their child's coping and acute stress levels. Specific normative data were not available, although findings from comparison groups are presented. Eleven percent of caregivers reported diminished child coping. The mean coping score for this group was nearly identical to that of an earlier

study with a sample of adolescents with epilepsy (non-acute; Dunn, Austin, & Huster, 1999). Similarly, 9 percent of caregivers reported elevated child acute stress levels. The mean acute stress score for this sample was just one point lower than the findings from a sample of acute burn patients (Saxe et al., 2003).

This data is useful as a first step in characterizing this population, as well as providing information to rehabilitation clinicians (and other healthcare providers such as physicians and social workers) about what symptoms and behaviors to observe, assess, and provide treatment and/or referrals for. Notably, however, on the dimensions assessed, most of the current subjects were not as elevated in their levels compared to what the literature might suggest (see Table 4 for data). Although the levels of caregiver-reported child coping and stress were similar to samples with other types of medical conditions, the means for each variable presented were within the normal range, and relatively small proportions of the sample reported clinically elevated levels of symptoms, aside from symptoms of depression. This is somewhat surprising, given the consistent findings from pediatric cancer research, which have found increased caregiver psychological distress in the acute stage following diagnosis (e.g., Fuemmeler, Mullins, & Marx, 2001), and moderate to severe levels of post-traumatic stress symptoms in caregivers throughout active treatment (e.g., Kazak et al., 2005). This is also the case in long-term, post-discharge studies following ABI rehabilitation where studies have shown that many caregivers experience increased psychological distress long after their child's ABI (e.g., Hawley et al., 2003; Wade et al., 2004; Youngblut & Brooten, 2006).

The current sample, however, differs from the two aforementioned samples in an important way: the subjects were at a unique time point in the recovery process. In being assessed during their child's inpatient rehabilitation stay (at varying points in their length of stay), caregivers

were not in the immediate injury/diagnosis stage because of their child's previous PICU stay, unlike in the pediatric non-ABI studies, but also were not months or years removed from discharge/recovery, as in the long-term ABI studies. It is possible that caregiver functioning may be different at this unique and unstudied time point in their child's recovery process. Although the low prevalence of symptomatology could reflect 'denial' on the part of the caregivers, a phenomena described in the grief/loss literature (e.g., Bosquet-del Moral et al., 2012), this may also be a protective response that allows caregivers to focus their mental and emotional energy on caring for their child. From a qualitative standpoint, this is consistent with remarks that multiple caregivers made through the course of the study about needing to "just grind through until discharge." Several caregivers also talked about having little emotional support due to being away from home/family during the hospitalization. Although perhaps concerning, it appears that this may be a coping strategy that permits caregivers to focus entirely on their child and learning how to aid in the progress of their recovery during rehabilitation. Finally, it is also important to consider the discrepancy between what many caregivers initially thought would happen to their child as a result of their injury/illness – that they would die or be catastrophically injured for the rest of their life – and the both survival and positive change and growth that they have witnessed in their child during rehabilitation. Although it is a difficult and stressful time in many ways for caregivers, a child's inpatient rehabilitation stay can also be very hopeful and encouraging, which may have impacted findings for this study as well.

From a limitations standpoint, the current study did not have a comparison group for the ABI sample; thus, it is not known at this point whether these findings are significantly different from those of a similar, non-ABI sample (e.g., spinal cord injury, orthopedic injury). Including

such a comparison group in future studies would allow for commentary on how these relationships differ in ABI versus other acute medical populations.

Second, it was also predicted that caregiver psychological functioning would be negatively related to caregiver confidence, and child psychological functioning would be positively related to caregiver confidence. Findings partially supported this hypothesis. Caregiver psychological functioning was negatively associated with caregiver confidence (i.e., psychological functioning scores declined to normal as confidence increased). Furthermore, this study also demonstrated that caregiver perceptions of child coping were positively associated with caregiver confidence (i.e., perceptions of child coping increased as confidence increased). The support of the significant associations with caregiver confidence is encouraging, and provides new information regarding the psychological functioning of caregivers and children during the acute stages of recovery after a brain injury; however, a comparison group should be added for further exploration, as mentioned above.

In contrast, child acute stress, as rated by the caregiver, was not significantly associated with caregiver confidence. The lack of significant predictive validity for child acute stress was unexpected, and suggests that child stress level may contribute little additional variance to understanding caregiver confidence. Alternatively, it is possible that lack of findings here may be due to the timeframe within which the measure of acute stress was gathered. Specifically, the measure of acute stress (Child Stress Disorders Checklist; CSDC) asked caregivers to think about the past month when answering items. Although exact data are not available, children in the current sample had widely varying lengths of stay (LOS) in the intensive care unit *prior* to their admission to the inpatient rehabilitation unit. Moreover, there was also considerable variance in LOS within rehabilitation admissions (Inpatient rehabilitation LOS *range*: 4 – 46 days; Total rehabili-

tation LOS *range*: 4 – 134 days). Caregivers completed the measure of acute stress at varying timepoints in their LOS, ranging from 2 to 56 days following admission to inpatient rehab; thus, it is possible that this variance impacted the findings, although there is not a strong correlation between these variables. Second, as mentioned previously in the Methods section, the measures utilized in this study were selected because of their documented use within pediatric medical populations, and the inclusion of items that are relevant for patients in acute medical settings. That being said, after close review at the item-level, there are questions on the CSDC that describe symptoms and behaviors that are actually common in individuals following ABI, such as memory difficulties and confusion, trouble concentrating, sleep problems, general slowing, and irritability. Although very successfully used in other pediatric medical populations (e.g., burns, interpersonal injury), it is possible that specifically within the ABI population, this measure may not purely assess acute stress symptoms, which may explain its lack of predictive value in the current study, and again suggests the importance of including a comparison group in future studies.

4.2 Caregiver and Child Functioning, Caregiver Confidence, and Child Functional Status

The second primary aim of this study was to explore a multivariate model to establish whether child functional status was a mediator of the relationship between caregiver and child psychological functioning variables and caregiver confidence (Figure 2). It was predicted that child functional status (change from admission to data collection) would mediate this relationship. Findings did not support this hypothesis, and indicated that caregiver and child psychological functioning directly affect caregiver confidence, but do not indirectly affect it through child functioning status. The lack of support for this model was surprising. It is possible that variance in child functional status truly is not an important factor in the relationship between caregiv-

er/child psychological functioning and caregiver confidence at this acute time point during hospitalization. However, previous research has found relationships between caregiver psychological functioning and child functional status (e.g., Anderson et al., 2006). This discrepancy raises a number of possibilities regarding explanation of the current findings.

Regarding the sample, post-hoc power analyses were re-run to determine levels. Post-hoc power was 0.73 based on Cohen's f^2 effect size, the sample size, and number of predictors (Faul et al., 2010). This indicated that a larger sample size would have had some advantage in possibly detecting the desired effects, if the effect was truly present.

Additional sample considerations that may have impacted findings are the substantial variation in length of stay for participating families and the influence of the care and training that caregivers receive during their child's stay on the rehabilitation unit. Throughout the admission, caregivers routinely met with members of their child's care team (i.e., physicians, neuropsychologists, nurses, social workers, rehab therapists) to receive information about their child's condition, progress, and care. They received brain injury education from the neuropsychologist, and were required to attend rehab therapy sessions with their child to receive training around certain skills (e.g., how to perform stretching exercises with child; how to complete a wheelchair transfer). Qualitatively speaking, this information is invaluable for caregivers, as was voiced on many occasions during this study; however, this may very likely have increased caregiver confidence levels, and unexpectedly impacted the current results. Indeed, when results on the caregiver confidence scale from the current study are compared to results from past studies using the PBS, the average score from this study is consistently higher by 4 to 15 points (Melnyk et al., 2001, 2004, 2006). From a patient-care standpoint, this is a very encouraging finding, as it indicates that caregivers at this inpatient rehabilitation facility may feel more knowledgeable and

confident in their ability to care for their hospitalized child compared to other sites; however, from a research standpoint, this might have resulted in a “wash-out” effect on findings in the current study.

There are also possible concerns related to measurement that may have impacted the current findings. First, the WeeFIM Change variable (and other WeeFIM variables) was not correlated very highly with any of the other measures aside from the child stress measure (see Table 5), and accounted for only 1 to 5 percent of the variance in caregiver functioning and caregiver perceptions of child functioning. Based on those results, it is clear that, in this sample, the independent assessment of child functional status that the WeeFIM provided was not sensitive to the types of changes in functioning that caregivers are focused on in this setting, and which might impact caregiver functioning. This may be due to a number of factors. It may be that the typical length of time between WeeFIMs was not long enough for child functional changes to have a lasting impact on the caregiver. There was significant variation in this time difference, ranging from 2 to 56 days; however, the vast majority (82 percent) of WeeFIMs occurred within 24 days while the remaining 12 percent occurred over the course of 24 to 56 days; however, it is notable that the variable did not correlate highly with other measures, suggesting that it likely is not a large factor in these outcomes.

On a related note, it is also possible that the changes in child functional status simply do not impact caregiver perceptions of their functioning during hospitalization because of an “all-or-nothing” type of effect (i.e., my child is in the hospital vs. not in the hospital) that effectively reduces the impact that any variance in functioning might have, or perhaps as another emotionally protective coping strategy for caregivers (i.e., not putting weight on functional changes). This may be why child functional status has been used successfully in many ABI studies with long-

term outcomes (e.g., 6 – 12 months) when assessed with measures such as the Adaptive Behavior Assessment System, 2nd Edition (ABAS-II) and Vineland Adaptive Behavior Scales, 2nd Edition (VABS-2; e.g., Taylor et al., 1999; Yeates et al., 2010). Importantly, such measures do not assess functional status in an entirely appropriate manner for the acute rehabilitation setting, hence why they were not used for the current study.

Finally, it is also important to point out that caregiver perceptions of child functioning clearly have an impact on relationships with caregiver confidence, based on both the correlation and regression results presented above. The contrast to the lack of relationship with child functional status as assessed by the rehabilitation therapists suggests that caregivers' perceptions are a more important factor in caregiver confidence. Caregivers see their child change and improve on a large scale as they watch the team prepare for their child's discharge, but it seems that the relatively small changes that occur day-to-day and are documented by the rehabilitation therapists (i.e., child functional status) simply do not register as important to caregivers at this acute point in their child's recovery.

A second measurement concern relates to the relationships between the caregiver and child psychological functioning variables. In contrast to the lack of correlation with the WeeFIM variables, the correlations between these variables were relatively high, ranging from .45 to .55 (see Table 5). Although this level of correlation was not so high that multicollinearity was a factor (also, collinearity diagnostics were assessed), they do raise the question of whether these measures are assessing factors that are truly different from a conceptual standpoint. Given the high level of stress that caregivers are under during their child's inpatient rehabilitation stay, it may be that these measures simply all tapped into an underlying caregiver stress reaction, and were correlated for that reason. That is, the high stress/distress levels that caregivers were expe-

riencing may have, in effect, overridden measurement of the independent constructs that these measures were intended to assess.

Finally, there may also be theoretical concerns related to the model used in this study. It is possible that other, as yet unexplored factors are somehow influencing the model (e.g., economic resources, access to family/support system, presence of premorbid caregiver psychological issues, premorbid caregiver self-confidence, and child temperament). The current study does not have a large enough sample size to investigate these factors at this time, but they are important to consider for future research. It is also possible that the hypothesized model is simply not an accurate model for the ABI population at the acute time point during which this study took place. Although this model was conceptually based on the work of Taylor et al. (2001), findings from the Taylor studies were at later, non-acute time points. Those findings were discussed regarding the acute time point from a theoretical stance; however, in practice, it appears that there is a different relationship between variables than that which is present at post-recovery time points.

It is difficult to know exactly what differences may be the driving force here, although it is postulated that the contextual differences between the acute time point and long-term time points may be at play. Caregivers are in the process of going through many novel experiences at the acute time point: experiencing their child's sudden and severe illness/injury resulting in an unexpected and extended hospital stay, being away from home and separated from family members such as other children but also needing to manage some aspects of family life from afar, being without most or all sources of support (particularly from an emotional standpoint), financial concerns, preparing the child's home to meet their needs (e.g., adding wheelchair ramp, railings to bathtub), and learning certain skills to assist their child in day-to-day life. These concerns

have, by and large, dissipated at the longer-term time points that are commonly seen in past ABI research; thus, it may be that the samples from the current study, and those from the Taylor studies (1999, 2001) are simply too different from a conceptual standpoint.

As was discussed above, it also appears that independent ratings of child functional status may not be an important predictor/mediator variable in this population at this acute time point. When considering past non-ABI research occurring during the acute time point, there are important associations between child and caregiver functioning and caregiver confidence (e.g., Melnyk et al., 2007) that do not incorporate child functional status in the model. Perhaps it is more important from a theoretical standpoint to draw from previous studies/findings that have occurred at a similar time point for the contextual reasons outlined above, even though the sample populations differ in a critical way (i.e., ABI vs. non-ABI). This is also important to consider given that caregiver confidence is a novel construct in ABI. Again, it is difficult to say what variables may be in play, and this is an important area for future research, as is discussed below.

4.3 Future Directions

In light of the current findings and the limited research on child and caregiver functioning during acute stages of recovery after acquired brain injury, there are numerous directions for potential future research. Specifically, future research should seek to contrast child and caregiver psychological functioning after ABI to the psychological functioning of other critically-ill and hospitalized children. This is important in order to determine whether being post-ABI or having an extended hospital stay (i.e., critical care in PICU followed by inpatient rehabilitation) results in significantly different changes in psychological functioning that may call for specific or targeted intervention at the child, caregiver, or family level. Future research could also contrast caregiver confidence levels with a comparison group during the critical care time point and inpa-

tient rehabilitation time point to elucidate the impact the education received during inpatient rehabilitation. Additionally, longitudinal studies would be of interest to further characterize how child and caregiver psychological functioning may change over time, and if/how functioning during acute stages may predict functioning in later, post-acute time points.

Based on the current findings, which revealed that a proportion (caregiver psychological functioning composite – 23%; parenting stress – 7%; child coping – 21%), but not all, of the variance in caregiver confidence was explained by our set of predictors, future research should explore additional predictors, as discussed above, and other models based on findings from acute, non-ABI research. It may make sense to remove the independent rating of child functional status from the model given the acute time point, and investigate other factors that may be influencing the model, such as child temperament and age.

4.4 Conclusions

In summary, results from the present study showed that higher levels of caregiver psychological functioning, as well as caregiver perceptions of child coping, were associated with higher levels of caregiver confidence. However, child functional status based on assessment by rehabilitation therapists did not serve as a significant mediator in this relationship. The lack of significant findings regarding the multivariate model indicates that the framework may not have fit the experience of caregivers during inpatient rehabilitation after their child's ABI. Future research must make improvements in recruitment of larger sample sizes and comparison groups, construct measurement, and investigation of additional factors that may also be important in the dynamic interplay of caregiver and child functioning during acute recovery following pediatric ABI. This study did, however, provide preliminary evidence that caregiver confidence is an important factor to consider during the acute stages of recovery after child ABI. Although caregiver confi-

dence has been previously studied with multiple pediatric samples, such as critically-ill children and low-birth-weight premature infants (e.g., Melnyk et al., 1994; 2001a, 2004; 2007), this study is the first time that its exploration has been extended to individuals with new-onset ABI. Furthermore, as evidenced by previous studies in non-ABI samples, future research may be able to use these findings to inform new, family-based interventions that occur during inpatient rehabilitation in order to address caregiver and child needs as early as possible during the recovery period, such as the COPE intervention created by Melnyk et al. (2004).

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