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Neuropsychological Functioning, Parenting Behaviors, and Healthcare Behaviors Among Youth with Spina Bifida

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NEUROPSYCHOLOGICAL FUNCTIONING, PARENTING BEHAVIORS, AND HEALTHCARE BEHAVIORS AMONG YOUTH WITH SPINA BIFIDA

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CHAPTER ONE

STUDY OVERVIEW

The purpose of this study is to further understand factors that contribute to positive healthcare behaviors among preadolescents and adolescents with spina bifida. Specifically, the impact of higher order cognitive functions and parenting behaviors on medical adherence and medical autonomy outcomes will be explored.

Spina bifida is a common congenital birth defect with an overall prevalence rate of 3.1 cases per 10,000 live births in the United States (Shin et al., 2010). It originates during the early stages of gestation when one or more vertebrae fail to close normally. The severity of spina bifida varies depending on the nature and location of the spinal lesion, number of shunt revisions, and the presence of neurologic complications, such as Chiari II malformation (Bowman, McLone, Grant, Tomita, & Ito, 2001; Fletcher et al., 2004). Health complications associated with this condition include hydrocephalus, neurogenic bladder and bowel dysfunction, weakness and paralysis of the lower extremities, endocrine dysfunction, neurocognitive deficits, and seizure disorders (Bowman et al., 2001; Fletcher et al., 2004). As a result, children with spina bifida and their families must manage complex medical regimens that include catheterizations, skin checks to avoid pressure sores, bowel programs, use of ambulatory devices (e.g., orthotics, braces, wheelchairs), and monitoring for shunt malfunction or infection

Prior to more recent advances in healthcare and technology, most children with spina bifida did not live into adulthood (Bowman et al., 2001). Thus, few studies have investigated functional outcomes of youth with this condition as they begin to transition through preadolescence and adolescence. Given that at least 75% of children with spina bifida are expected to reach adult years (Bowman et al., 2001), it is imperative to gain further understanding of the factors that influence functional autonomy outcomes among youth with this condition. This study focuses on medical adherence and autonomy outcomes among preadolescents and adolescents with spina bifida. Medical adherence refers to the youth's compliance to their prescribed medical regimen (e.g., bowel program, medications; e.g., Haynes, 1979). Medical autonomy, on the other hand, refers to an interpersonal process in which the preadolescent or adolescent begins to develop a greater capacity for independence on healthcare tasks in the context of continued parental support. Gaining insight into medical autonomy and adherence behaviors during the preadolescent and adolescent years is important, as life-long healthcare patterns including approach to general self-management, positive healthcare behaviors (e.g., diet, exercise) and risky healthcare behaviors (e.g., non-compliance to prescribed regimens) are often established and consolidated during this developmental period (Williams, Holmbeck, & Greenley, 2002).

Adherence behaviors of youth with chronic health conditions have received considerable attention by researchers (see La Greca & Mackey, 2009 for a review). However, few studies have investigated adherence behaviors among youth with physical disabilities, such as spina bifida (Holmbeck et al., 1998; Stepansky, Roache, Holmbeck, & Schultz, 2010). Health conditions that are both chronic and physically disabling are

often challenging to manage and require advanced cognitive skills. For example, children with spina bifida must learn treatment techniques that are quite complex (e.g., catheterization), attend to physicians' instructions, remember and integrate a treatment plan into daily living, and monitor daily activities. These healthcare tasks are likely more difficult for youth with spina bifida due, in part, to neuropsychological impairments that often accompany the condition. For example, several studies suggest that youth with spina bifida demonstrate specific deficits in the areas of attention and executive functioning, such as difficulty with planning and goal-directed behavior, problem solving, mental flexibility, conceptual reasoning, focused attention, ability to shift attention when necessary, response inhibition, and working memory (e.g., Dennis, Landry, Barnes, & Fletcher, 2006; Dennis, Spinopoli, Fletcher, & Schachar, 2008; Rose & Holmbeck, 2007; Wills, 1993). Despite a general understanding of the neurocognitive profile of youth with spina bifida (see Fletcher & Dennis, 2010), less is known in regards to the impact that neurocognitive impairments have on adaptive functioning outcomes. Thus, an aim of this study is to not only understand healthcare behaviors of youth with spina bifida, but also to gain additional understanding in regards to the specific types of neurocognitive impairments (i.e., attention, executive functioning) that lead to difficulty with medical adherence and autonomy.

In addition, this study also aims to gain further insight into the impact of parenting behaviors on healthcare behaviors among youth with spina bifida. Parenting behaviors during preadolescence and adolescence are important to understand, as transfer of medical responsibilities from the parent to the child often occurs during this developmental period (Williams et al., 2002). Moreover, prior researchers has found that

youth with spina bifida, as compared to typically developing youth, have less contact with peers and are more dependent on adults (Holmbeck et al., 2003). As a result, the family environment is believed to be particularly salient among youth with spina bifida, and parenting behaviors are expected to have a strong impact on healthcare behavior outcomes.

A developmental psychopathological framework will be employed to conceptualize the impact of both protective and vulnerability parenting factors on healthcare behaviors. Optimal development occurs when youth are granted sufficient psychological autonomy and acceptance and an age-appropriate level of behavioral control (e.g., Ainsworth, Blehar, Waters, & Wall, 1978; Barber & Harmond, 2002; Greenley, Holmbeck, & Rose, 2006; Holmbeck, Shapera, & Hommeyer, 2002). Thus, this study will investigate the impact of parental acceptance, behavioral control, and psychological control on adjustment outcomes. Specifically, parental acceptance and behavioral control are conceptualized as protective factors in this study, such that higher levels of parental acceptance and behavioral control are expected to buffer against the negative effects of inattention and executive dysfunction on medical adherence and autonomy. On the other hand, parental psychological control is conceptualized as a vulnerability factor, such that higher levels of psychological control are expected to increase the likelihood of maladjustment (i.e., lower levels of medical autonomy and adherence), in the context of neurocognitive deficits. In other words, higher levels of parental acceptance and behavioral control may buffer against the negative impact of inattention and executive dysfunction on the development of negative healthcare behaviors (i.e., lower levels of medical adherence and autonomy), yet higher levels of

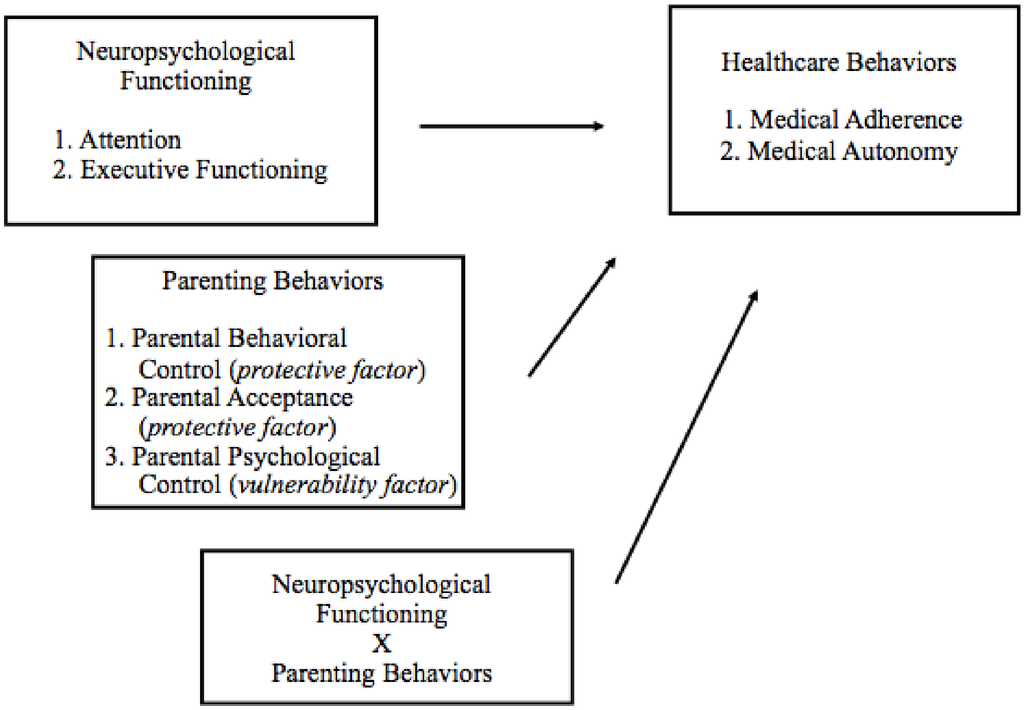
parental psychological control may exacerbate the impact of neurocognitive deficits on healthcare behaviors.

To build upon prior research on parenting behaviors and child outcomes, several factors will be considered in this study. First, models for understanding the impact of parenting behaviors on child adjustment have been conducted almost exclusively with younger children (e.g., Fastenau, Shell, Dunn, Perkins, Hermann, & Austin, 2004; Landry, Smith, & Swank, 2006). This study will investigate the influence of parental acceptance, behavioral control, and psychological control on adjustment outcomes among preadolescents and adolescents. Second, the vast majority of research on parenting behaviors and adolescent adjustment has investigated parents of typically developing youth (e.g., Baumrind, 1991a). The present study will investigate an illness-specific group of youth with spina bifida. This population is important to study for a number of reasons. Transitioning into adolescence is often more challenging for children with spina bifida, as these youth not only need to navigate the normative transitions of this developmental period, but they must do so in the context of chronic health condition and neurocognitive deficits. In addition, youth with spina bifida tend to be more dependent on adults, as compared to typically developing youth (Holmbeck et al., 2003). Thus, tasks that require increased levels of autonomy (e.g., responsibility for medical care) will likely be more challenging for these youth. It is predicted that parenting behaviors will intensify and/or hinder the child's increased dependence among youth in this population. Lastly, prior investigators of parenting behaviors have almost exclusively focused on maternal parenting style. This study explores the effects of both maternal and paternal parenting behaviors on youth healthcare behaviors.

In regard to the measurement of adherence, several limitations will be addressed. This study will utilize an illness-specific measure for adherence, such that healthcare tasks that are most relevant for youth with spina bifida will be investigated (e.g., bowel program, catheterization). In addition, rather than utilizing a categorical or unidimensional model of adherence, this study will investigate adherence as a multidimensional construct. In other words, relevant treatment tasks will be assessed separately including catheterization, bowel programs, medication, and keeping appointments. Lastly, youth adherence will be assessed by both mothers and fathers, rather than relying solely on maternal reports.

Taken together, this study will assess several hypotheses (refer to Figure 1). First, consistent with prior research, preadolescents and adolescents with spina bifida are expected to exhibit lower levels of attention and executive function ability in comparison to normative samples. Second, higher levels of attention and executive function ability among youth with spina bifida are expected to be associated with higher levels of medical adherence and autonomy. Third, higher levels of adaptive parenting behaviors (i.e., acceptance and behavioral control) and lower levels of maladaptive parenting behaviors (i.e., psychological control) are expected to be associated with higher levels of medical adherence and autonomy. Lastly, adaptive parenting behaviors (i.e., acceptance, behavioral control) are expected to buffer against the negative effects of inattention and executive dysfunction on healthcare behaviors, and maladaptive parenting behaviors (i.e., psychological control) are expected to exacerbate the negative effects of inattention and executive dysfunction on healthcare behaviors.

Figure 1. Proposed Model Examining the Influence of Neuropsychological Functioning and Parenting Behaviors on Healthcare Behaviors Among Youth with Spina Bifida.



CHAPTER TWO

LITERATURE REVIEW

Spina Bifida

Spina bifida is a congenital birth defect characterized by the failure of the neural tube to close or to remain closed during early embryogenesis. Neural tube defects that result in spina bifida occur in the first month of gestation, during the process of primary neurulation, in which the embryo's central nervous system (CNS; i.e., brain and spinal cord) begins to develop. Several types of spina bifida have been identified including spina bifida occulta, meningocele, and myelomeningocele.

During typical pregnancy, the human brain and spine begin as a flat plate of cells (i.e., neural plate), which migrate inward to form the neural tube. In general, complete fusion of the neural tube is believed to occur during the fourth week of gestation, often before women are aware they are pregnant (Menkes & Till, 1995). The mechanism of neural tube closure is not fully understood, although the prevailing theory posits that there are multiple sites of closure (e.g., cervical and lumbar regions), as opposed to prior theories of a single starting point in the cervical region that moves downward in a "zipping" fashion (van Allen et al., 1993). When this process is disrupted and the neural tube fails to fully close, it results in an opening in the spine or disruption of the tissue covering the spine.

The most severe type of neural tube defect, known as anencephaly, occurs when the neural tube fails to close at the caudal end. This type of neural tube defect is often fatal. In myelomeningocele spina bifida, the failure of spinal fusion causes a lesion on the spine, in which the meninges, parenchyma, and nerve roots herniate and form a cystic sac filled with cerebral spinal fluid (CSF) at the posterior midline. Myelomeningocele is the most common and severe form of spina bifida and accounts for approximately 90% of cases (Norman, McGillivray, Kalovsek, Hill, & Poskitt, 1995). This type of spina bifida often requires a more intense and complex medical regimen. A less severe form of spina bifida, known as meningocele, is characterized by the meninges protruding through the opening of the spine like a sac, but there tends to be less nerve damage. Lastly, lipomeningocele is characterized by a benign tumor that consists of fatty tissue over part of the spine and is associated with only minimal nerve damage (Menkes & Till, 1995).

Currently, no single etiology has been identified to explain for the development of spina bifida. Instead, researchers believe that spina bifida is a disorder with multifactorial etiologies. In particular, genetic (i.e., genetic variation, folate metabolism) and environmental (i.e., nutritional deficiencies, teratogens) factors have been implicated in the development of this condition (e.g., Fletcher & Dennis, 2010; Fletcher et al., 2004; Yeates, Fletcher, & Dennis, 2008). For example, advances in prenatal diagnosis and dietary fortification (e.g., folic acid, vitamin B) have contributed to a substantial reduction in spina bifida cases (Williams et al., 2002). Nonetheless, this condition remains the most common nonlethal neural tube birth defect. Incidence rates are particularly high in Mexico, Northern China, and Southeast Asian countries, where prenatal diagnosis and dietary interventions are less common (Botto, Moore, Khoury, &

Erickson, 1999). In addition maternal diabetes, obesity, excessive alcohol use, exposure to hypothermia, and use of anticonvulsants during early fetal development are associated with higher rates of spina bifida (Fletcher et al., 2004; Yeates et al., 2008). Studies that have investigated the role of genetics in spina bifida have found that children with a sibling with spina bifida have a risk of 2-5% of also being affected, which is 25-50 times higher than the population risk (Elwood, Little, & Elwood, 1992). Incidence of spina bifida also tends to vary depending on ethnicity, such that Caucasians and Hispanics are at greater risk than African Americans and Asians Americans (Yeates et al., 2008). Taken together, research suggests that a combination of environmental and genetic factors likely influences variability across prevalence rates.

The current standard of care for treating patients with spina bifida, particularly myelomeningocele, is to perform neurosurgical repair within 48 hours of birth. In order to prevent infection and to preserve nervous tissue and function, a neurosurgeon will reconstruct the closure of the spinal cord (McLone & Bowman, 2005). Some improvements in infants' ability to move have been observed following surgery, but most of the complications associated with incomplete formation of the central and peripheral nervous system are irreversible. Prior research suggests that prenatal repair of myelomeningocele may be a promising intervention for preserving neurologic functioning that would otherwise become disrupted during gestation (Bennett, Davis, Tulipan, & Bruner, 2006). Nonetheless, these surgeries continue to be associated with extensive risk to the fetus and mother. Given that spina bifida is no longer considered life threatening, prenatal surgery is not a standard practice. As advances in treatment and prevention of this condition continue to be made, it is essential that future research

continue to focus on increasing the quality of life of individuals currently afflicted with this complex medical condition, such as increasing the promotion of medical adherence and autonomy.

Spina bifida is often conceptualized as a medical condition characterized by specific neural, physical, and cognitive phenotypes (e.g., Fletcher & Dennis, 2010). These different phenotypes will be discussed in the following sections. Primary insults to the spinal cord and brain account for the different physical and neural phenotypes, respectively, and secondary insults to the brain account for the cognitive phenotype. The cognitive phenotype is believed to be dependent on the physical and neural phenotypes, as well as environmental factors (e.g., parenting behaviors).

Physical Phenotype

Spina bifida is generally considered a primary orthopedic disability, as most individuals experience problems with ambulation (Fletcher et al., 2004; Yeates et al., 2008). The severity of ambulatory difficulty often depends on the location of the spinal lesion, as motor and sensory functioning is typically impaired at and below this spinal insult. Although the sacral (S1 – S4) region is the most common area affected in spina bifida, lesions can occur at any level of the spine (Wills, 1993). Higher spinal lesions are associated with greater paralysis and worse upper- and lower-limb movement quality (e.g., Dennis, Fletcher, Rogers, Hetherington, & Francis, 2002; Landry, Lomax-Bream, & Barnes, 2003). For example, individuals with a lesion in the sacral region often only have mild weakness of the feet, ankles, and lower legs, as these motor and sensory nerves are located near the lower end of the spine. Yet, individuals with lesions in the lumbar region often have paralysis that affects the legs, as well as sensory loss and muscle weakness in

the abdomen (Liptak, 2002). Moreover, higher spinal lesions are associated with higher levels of neurocognitive impairment and greater number of neural anomalies, which will be discussed in the following section (Fletcher et al., 2005).

Depending on the degree of difficulty with ambulation, many individuals with spina bifida utilize assistive devices including orthotics, braces, and wheelchairs (Children's National Medical Center, 1995). In addition to ambulation difficulty, neurogenic bladder and bowel dysfunction is common within this population. The nerves regulating bladder and bowel function are located at the lower end of the spine, which is often disrupted in the vast majority of spina bifida cases (Children's National Medical Center, 2002; McLone & Bowman, 2005). Other complications associated with spina bifida include musculoskeletal abnormalities (e.g., scoliosis, kyphosis, club feet, hip deformities), loss of muscle tone, skin sores, obesity (due to decreased activity), and sexual dysfunction (Children's National Medical Center, 2002; Liptak, 2002; McLone & Bowan, 2005).

Neural Phenotype

Spina bifida disrupts brain development in several ways. First, the failure of neuroembroyogenesis results in brain malformations in specific regions of the brain. In particular, the majority of children with spina bifida have a congenital malformation of the cerebellum and hindbrain, known as Chiari II malformation. Chiari II malformation is characterized by the cerebellum and hindbrain being displaced downward toward the neck, which frequently blocks the flow of cerebrospinal fluid (CSF) in the third and fourth ventricle. As a result, hydrocephalus occurs in 80-90% of individuals with spina bifida (Dennis et al., 2006; Fletcher et al., 2004; Fletcher & Dennis, 2010). In fact, spina

bifida myelomeningocele is responsible for most cases of congenital hydrocephalus (Barkovich, 2005). Individuals with spina bifida often experience secondary injury to the brain as a result of hydrocephalus and the subsequent treatments. Independent of other CNS anomalies related to spina bifida, hydrocephalus is associated with hypoplasia of the cortex (particularly in the posterior regions), damage to the axons and myelin in the periventricular white matter, damage to the optic tract, and dysplasia of the corpus callosum (del Bigio, 1993).

Treatment of hydrocephalus involves diversionary shunting of the CSF for the vast majority of individuals with this condition. Although shunting can improve the long-term functional outcomes of individuals with hydrocephalus, and lead to some reversal of hydrocephalus-induced pathology (e.g., gross restoration of brain volume), most researchers have found that repair of neuronal and axonal damage is unlikely (del Bigio, 1993). Further difficulty managing CSF also tends to occur due to shunt malfunctions and infections and are associated with worse neuropsychological outcomes (Dennis et al., 2006; Hetherington, Dennis, Barnes, Drake, & Gentilli, 2006).

Independent from the disruptive impact of hydrocephalus, several other brain abnormalities are also associated with spina bifida. For example, for the majority of individuals with this condition there is partial dysgenesis of their corpus callosum, which likely has implications for increased functional deficits among these youth (Hannay, Dennis, Kramer, Blaser, & Fletcher, 2009). Also, approximately 17% of individuals with myelomeningocele develop a seizure disorder (Barkovich, 2005). As expected, the severity of damage to the CNS among youth with spina bifida is associated with the

degree of neuropsychological impairment. The following section will provide an overview of neuropsychological outcomes among youth with spina bifida.

Cognitive Phenotype

Prior to advances in the clinical management of spina bifida and the onset of shunt treatments for hydrocephalus, a high rate of survivors exhibited profound intellectual challenges (e.g., Foltz & Shurtleff, 1963; Shurtleff, Foltz, & Loeser, 1973). Nonetheless, in recent years, the neurocognitive prognosis of youth with spina bifida has improved considerably. Children with spina bifida and shunted hydrocephalus often function within the average to low average range on tests of general intellectual ability (Brookshire et al., 1996; Fletcher et al., 1992; Wills, Holmbeck, Dillon, & McLone, 1990). On the other hand, children with spina bifida, but without hydrocephalus, often do not exhibit as severe of neural morbidity, compared to children with spina bifida and hydrocephalus. Among youth with spina bifida and shunted hydrocephalus, relative strengths and weaknesses have emerged within the literature. For example, most verbal skills of youth with spina bifida tend to be relatively intact, with specific areas of verbal deficits (e.g., pragmatic language; Fletcher, Barnes, & Dennis, 2002) and general deficits on tasks of nonverbal abilities (Brookshire, Fletcher, Bohan, Landry, Davidson, & Francis, 1995). There is often a modest discrepancy between verbal intelligence and performance intelligence among these youth that range from .5 to 1.0 standard deviation (Hommet et al., 1999; Wills et al., 1990). Verbal intelligence scores tend to be in the average range, while performance intelligence scores tend to be in the low average range.

Specific deficits have emerged across several other areas of functioning, such as poor motor skills (Hetherington & Dennis, 1999), impaired visuospatial processing

(Dennis et al., 2002; Erickson, Baron, & Fantie, 2001), poor verbal fluency (Dennis et al., 2008), disrupted motor speech (Huber-Okrainec, Dennis, Brettschneider, & Speigler, 2002), impaired immediate and delayed explicit memory (Dennis et al., 2007; Scott et al., 1998; Yeates, Enrile, Loss, Blumenstein, & Delis, 1995) and poor prospective memory (Dennis et al., 2007). In terms of academic functioning, youth with spina bifida demonstrate less developed mathematical skills (Barnes, Pengelly, Dennis, Wilkinson, Rogers, & Faulkner, 2002) and poor reading comprehension (Fletcher et al., 2002). Variations within specific domains have also been documented. For example, these youth tend to demonstrate adequate competency in grammar and vocabulary, yet will have specific impairments in semantic and pragmatic skills (Fletcher et al., 2002). The overall pattern of deficits and assets observed among youth with spina bifida and hydrocephalus has been linked to what Rourke (1995) has described as a nonverbal learning disorder (NLD; Fletcher et al., 2004; Yeates et al., 2008). For example, NLD is a neuropsychological syndrome consisting of difficulty in visuospatial processing, visual-motor coordination, tactile perception, sustained attention, abstract reasoning, problem-solving, perception of emotions, and social communication. Relative academic problems in visuospatial aspects of math and mechanics of written language are common. Nonetheless, it is important to note that, as a group, youth with spina bifida exhibit remarkable variability and only approximately 50% of these individuals will exhibit the pattern of neurocognitive deficits and assets described above (Yeates, Loss, Colvin, & Enrile, 2003).

In addition to the above discussed cognitive strengths and weaknesses, several researchers have also identified deficits among youth with spina bifida on higher order

cognitive tasks, namely tasks of attention and executive function (e.g., Dennis et al., 2008; Yeates et al., 2008). Specific deficits with executive function and attention include planning, goal-directed behavior, problem solving, mental flexibility, conceptual reasoning, focused attention, increased inhibition of return, ability to shift attention when necessary, response inhibition, and working memory. These cognitive deficits are expected to have profound effects on medical adherence and autonomy behaviors. The following section will provide greater discussion of attention and executive function among youth with spina bifida.

There are several factors that contribute to the wide variability of neurocognitive outcomes among youth with spina bifida. First, as previously discussed, the presence of shunted hydrocephalus has been associated with more pronounced deficits. Second, the number of shunt revisions is likely a contributor to neurocognitive variability (Brown et al., 2008; Dennis et al., 2007; Hommeyer, Holmbeck, Wills, & Coers, 1999). For example, shunt revisions increase an individual's risk for infections and hydrocephalic complications (e.g., slit ventricle syndrome) and increases an individual's exposure to anesthesia (e.g., Wills, 1993). Nonetheless, while the number of shunt revisions may indicate a more severe disease process, it may also indicate appropriate shunt maintenance (McLone, Czyzewski, Raimondi, & Sommers, 1982; Yeates et al., 2008). Third, a multitude of studies suggest that the location of the spinal lesion is associated with neurocognitive outcomes. Specifically, lesion levels in the thoracic region are associated with greater neurobehavioral disruption than lesions in the sacral and lumbar regions (Fletcher et al., 2005). The severity and nature of brain dysmorphology also predicts neurocognitive deficits. Several researchers have found lower performance IQ

scores among individuals with asymmetric anterior-posterior brain thinning (Fletcher et al., 1996; Mahone, Zabel, Levey, Verda, & Kinsman, 2002). Other medical complications associated with spina bifida, such as seizure disorders, also likely contribute to increased neurocognitive deficits in this population (Brown et al., 2008).

Attention and Executive Functions

As presented above, several researchers have investigated the neurocognitive profile of youth with spina bifida (see Fletcher & Dennis, 2010 for a review). A specific aim of this study is to further investigate attention and executive function among youth in this population.

Attention and executive functions are complex constructs that have received substantial consideration across disciplines. Currently, the prevailing theory is that attention and executive functions are multidimensional constructs. For example, Mirsky (1996) proposed that there are five separate elements that regulate attention processes: focus/execute, sustain, stabilize, shift, and encode. The focus/execute component refers to the ability to attend to a specific task while screening out irrelevant information (e.g., select target information from an array). The shift component refers to the ability to change focus across stimuli. The next component, sustain, involves the ability to maintain focus and alertness over an extended period of time. The encode component relates to memory and learning, and represents the capacity to hold onto, manipulate, and utilize information. Lastly, the stability component relates to the reliability or consistency of attention effort over time (e.g., continuous performance tasks; Mirsky, 1996). The term executive function often refers to “top-down” cognitive functions that facilitate problem solving to achieve a future goal (e.g., Welsh & Pennington, 1988; Pennington, 2002;

Willcutt, 2010). Thus, executive functions represent a heterogeneous set of higher order cognitive processes that include self-regulation, planning, mental flexibility, inhibition, working memory, and organization of behavior (Eslinger, 1996; Rose & Holmbeck, 2007).

Attention and Executive Function Outcomes and Spina Bifida

There is substantial evidence for impaired attention and executive dysfunction among youth with spina bifida (Dennis et al., 2006; Dennis et al., 2008; Wills, 1993). In regard to attentional ability, deficits with shifting and focusing attention have emerged across several studies investigating youth with spina bifida (e.g., Fletcher et al., 1996). Moreover, lower levels of intellectual ability in this population cannot explain these deficits (Rose & Holmbeck, 2007).

Loss, Yeates, and Entrile (1998) utilized Mirsky's (1996) model to assess attention abilities among youth with spina bifida and congenital hydrocephalus, spina bifida without hydrocephalus, and typically developing youth. Neuropsychological assessments were conducted across four domains of attention: encode, sustain, focus/execute, and shift. Youth with spina bifida and hydrocephalus demonstrated significantly greater impairment on the encode, focus/execute, and shift components of attention, as compared to the sustain component. Similarly, other studies have also failed to find group differences (spina bifida versus comparison groups) on measures of sustained attention (Rose & Holmbeck, 2007; Swartwout, Cirino, Hampson, Fletcher, Brandt, & Dennis, 2008).

As previously discussed, Mirsky (1996) predicted that difficulty with the focus and shift components of attention would be associated with malfunction of neural

projections through the posterior brain area. This theory and subsequent research findings on attention outcomes of youth with spina bifida is consistent with the neural phenotype of many of these youth. Specifically, hydrocephalus and Chiari II malformations are characterized by dysmorphology of the midbrain and thinning of the posterior cortex (del Beligio, 1999), which are common conditions in this population.

More recent research has highlighted deficits with attention orientation among youth with spina bifida and hydrocephalus (Dennis et al., 2006). For example, Dennis and colleagues (2005a) found that school-aged children tend to orient more slowly to and take longer to disengage from what has captured their attention. However, this was only evident for stimuli that were cognitively uninteresting. Dennis and colleagues (2005b) also investigated inhibition of return (IOR) among youth with spina bifida. IOR refers to the increase in time necessary to react to a target in a previously attended to location. In general, children with hydrocephalus were expected to experience greater difficulty with IOR tasks due to dysmorphology of the midbrain, which is believed to be associated with control of IOR. As compared to typically developing age-matched controls, youth with spina bifida and hydrocephalus displayed attenuated IOR, but only on a vertical plane and not on a horizontal plane. In other words, they had demonstrated deficits with attentional orienting to salient information. As predicted, these deficits were associated with dysmorphology of the midbrain, namely tectal beaking (i.e., malformation of the mesencephalic tectum, a structure covering the dorsal area of the midbrain). Difficulty orienting to a stimuli has also been found among infants, such that infants with spina bifida (24 months and younger) take longer to shift from a perceptually salient stimulus to a face stimulus, as compared to typically developing infants (Landry et al., 2003).

Together, these studies provide substantial support for attention deficits that involve orienting to salient information among youth in this population.

Several studies have also investigated the association between spina bifida and ADHD. For example, researchers have found that 31-33% of youth with spina bifida meet diagnostic criteria for Attention-Deficit/Hyperactivity Disorder (ADHD; Ammerman, Kane, Slonaka, Relgel, Franzen, & Gadow, 1998; Burmeister, Hannay, Copeland, Fletcher, Boudousquie, & Dennis, 2005), which is considerably higher than prevalence rates of 3-7% in the general child population (American Psychiatric Association, 2000). Nonetheless, the behavioral presentation of youth with spina bifida tends to be better characterized by increased levels of inattention (e.g., ADHD, inattentive type), as opposed to hyperactivity and impulsivity. For example, researchers found that on the Child Symptom Inventory parents reported higher levels of inattention in their child with spina bifida, as compared to symptoms of hyperactivity and impulsivity (Ammerman et al., 1998), and prevalence rates of ADHD among youth with spina bifida only exceeded population prevalence rates for inattentive type (Burmeister et al., 2005). However, lower levels of hyperactivity may also be due, in part, to mobility limitations among youth with spina bifida.

To further understand the specific nature of the association between hydrocephalus and ADHD diagnoses, Brewer and colleagues (2001) investigated attention processes among 7 to 15 year olds with congenital hydrocephalus, same aged peers with an ADHD (combined type) diagnoses without hydrocephalus, and a typically developing comparison group. Participants were given a task that involved disengaging from a visual stimulus, moving focus to another stimulus, and then, reengaging with a

novel stimulus. Compared to the ADHD and comparison groups, youth with spina bifida demonstrated greater impairments with disengaging from a stimulus and moving their focus (i.e., focus and shift elements of attention processes). The ADHD group also had difficulty shifting attention, but their primary deficit was sustaining attention. Nonetheless, other studies have failed to find significant deficits in sustained attention within this population (e.g., Tucha et al., 2009). Taken together, there are many similarities, yet also differences, between the attention processes of youth with ADHD and congenital hydrocephalus. It is important to note that ADHD is a behaviorally defined disorder and the etiological and the validity of such a diagnosis is often called into question (e.g., Willcutt, 2010). Moreover, there are no clear etiological or neuropsychological markers of ADHD and several pediatric medical conditions, including spina bifida, often present with similar attention deficits (e.g., fetal alcohol syndrome, very low birth weight/very preterm birth, traumatic brain injury; see Yeates, Ris, Taylor, & Pennington, 2010 for review of pediatric neuropsychological conditions).

A few studies have also identified significant executive function deficits among youth with spina bifida. For example, Snow (1999) found that youth with spina bifida demonstrated difficulty on tasks of problem solving and abstraction. In addition, Mahone and colleagues (2002) obtained parent- and self-report ratings from 28 adolescents with spina bifida and hydrocephalus. These researchers found higher levels of parent-reported child difficulty on the Behavioral Rating Inventory of Executive Function (BRIEF; Gioia, Isquith, Guy, & Kenworthy, 2000a, 2000b), as compared to published norms, on items that are characteristic of executive dysfunction including behaviors assessing initiation, working memory, organization and planning, monitoring, and emotional control.

Although parent- and self-report scores on the BRIEF were moderately associated with each other, parents reported increased difficulty with planning/organizing behaviors in their adolescent, whereas adolescents indicated increased greater difficulty with inhibition and shifting behaviors. Fletcher and colleagues (1996) also found significant deficits in executive function among 116 school-aged children with spina bifida and shunted hydrocephalus. In particular, these youth exhibited impairments on tasks of novel problem solving. However, after examining the specific nature of errors on the executive function measures, deficits were attributed to slow response time and motor control. These researchers also suggested that executive function deficits were likely due to poor sustained attention. However, this theory was not formally tested, and recent studies have failed to find significant group differences between youth with hydrocephalus and non-neurologically impaired youth on measures of sustained attention (Rose & Holmbeck, 2007; Swartwout et al., 2008), similar to research on ADHD samples (e.g., Tucha et al., 2009).

Taken together, children and adolescents with spina bifida typically exhibit deficits with higher order regulatory abilities, namely attention and executive function. Moreover, research is necessary to further understand the impact of these deficits on adjustment outcomes.

Etiology of Attention and Executive Function Deficits

Although the specific mechanisms regulating attention and executive function are not fully understood, several brain structures and circuits have been identified as essential for different aspects of attention and executive function ability (e.g., Pennington, 2002; Willcutt, 2010). For example, Mirsky (1996) suggested that his proposed theory

regarding the five components of attention (e.g., focus/execute, sustain, stabilize, shift, and encode) is supported by projections between different brain regions. Briefly, it is postulated that some of these components are operated by projections through areas in the posterior brain (e.g., focus, shift), whereas other components are operated by projections through areas in the anterior brain (e.g., sustain). This model has been applied to several investigations of the attention processes among children and adolescents with spina bifida, which will be discussed in detail below (e.g., Brewer et al., 2001; Loss et al., 1998). In addition, the term executive function was initially used to characterize deficits associated with damage, disease, or disorder of the frontal lobes and frontal subcortical regions (Denckla, 1996). It is now widely accepted that executive dysfunction is the result of damage to neural circuits that disrupt projections between the prefrontal cortex (PFC) and other regions of the brain. More specifically, Snow (1999) postulated that the generalized neural deficits that tend to occur among youth with CNS damage, such as youth with spina bifida, often decrease the efficiency with which developmental processes occur (e.g., development of interconnections). Thus, secondary CNS deficits result due to disrupted interconnections that restrict the development of higher order cognitive functions, such as executive function. To illustrate this phenomenon, the damage of frontal-subcortical white matter tracts, which often occur due to hydrocephalus, can disrupt the projections between the PFC and other regions of the brain, resulting in executive dysfunction.

Neuroimaging and neuropsychological studies in the area of Attention-Deficit/Hyperactivity Disorder (ADHD) have greatly influenced current theories regarding the development of attention and executive function difficulties among youth

(Willcutt, 2010). Such studies have provided evidence for the theory that malfunctioning of neural brain circuits that involve the PFC negatively impact attention and executive function abilities (e.g., Pennington & Ozonoff, 1997). Given general CNS damage among youth with spina bifida, and more specifically damage to the PFC, the below studies provide valuable information regarding the possible etiology of attention and executive function deficits among these youth.

A primary neural circuit involved in attention and executive functions, identified as the frontal-striatal network, includes the thalamus, basal ganglia, and dorsolateral and ventrolateral regions of the PFC (Willcutt, 2010). Researchers have found that this circuit is essential for response selection, inhibition, planning and organization of behavior, and working memory, as well as other executive function processes.

On the other hand, the orbitalfrontal cortex circuit, which includes feedback loops among the ventromedial prefrontal cortex, limbic structures, and other areas of the PFC, is important in decision-making processes, such that it coordinates the interface between motivation and cognition (Willcutt, 2010). Moreover, this circuit is theorized to influence aversion to delay. Individuals who have damage in the orbitalfrontal cortex have increased difficulty incorporating negative and positive feedback from their environment to change behavior and maximize overall outcome, thus leading to difficulties in the ability to learn from mistakes and delay gratification (e.g., Rolls, 2004).

In addition to the neural circuits that involve the PFC, other neural systems have also been implicated in the regulation of attention and executive functions, such as projections through the anterior cingulate cortex regulating response selection, the cerebellum mediating timing processes, and basic neural mechanisms involved in

regulating cognitive arousal (e.g., Willcutt, 2010). Given the damage to the CNS among youth with spina bifida, it is not surprising that there are higher rates of inattention and executive dysfunction among these individuals.

Medical Adherence and Autonomy

Within the field of pediatric psychology, investigators have used varying definitions of medical adherence. One of the more common definitions cited by researchers was formulated by Haynes (1979). Haynes (1979) refers to medical adherence as "the extent to which a person's behavior … coincides with medical or healthcare advice" (pp. 2 -3). In addition to the variability in defining the construct medical adherence, there is even greater variability in researchers' operational definitions of medical adherence and their approach to measuring this construct (see La Greca & Mackey, 2009 for a review).

Two common approaches for operationally defining medical adherence have been the categorical approach and the dimensional approach (e.g., La Greca & Mackey, 2009). Earlier studies on medical adherence tended to employ a categorically approach, such that specific criteria and/or cut-off scores were created to define adherence versus non-adherence (e.g., Phipps & DeCuir-Whalley, 1990). This approach is problematic for several reasons. First, cut-off scores tend to be arbitrary and do not account for the large variability of adherence behaviors within a given population. Moreover, these arbitrary cut-off scores tend to be tailored to specific studies, thus creating challenges in drawing conclusions across different populations, illness groups, and studies. Second, complex medical conditions, such as spina bifida, require several different medical regimens (e.g., catheterization, bowel care), and categorical approaches fail to account for each of the

treatment tasks necessary for managing an illness. Rather, this approach assumes that if an individual is adherent (or non-adherent) to one component of their treatment, then that individual will also be adherent (or non-adherent) to the other components of their treatment. Lastly, a categorical approach does not capture the multidimensional nature of adherence (e.g., not only does the child complete a treatment task, but does so correctly and/or independently; Holmbeck et al., 1998). More recently, researchers have moved from employing a categorical approach to investigating medical adherence to a dimensional approach, by investigating adherence on a continuum (e.g., La Greca & Mackey, 2009). Nonetheless, these studies are not without their own limitations. Specifically, this approach continues to view adherence as a unitary construct, by collapsing multiple adherence indicators into an overall adherence index score. In other words, similar to the categorical approach, a dimensional approach is not sensitive to specific regimen tasks.

To address several of the limitations of prior methods of assessing medical adherence, researchers have developed multidimensional and multitask measurements of adherence behaviors (e.g., Holmbeck et al., 1998), which will be utilized in this study. A multidimensional, multitask approach to assessing medical adherence allows researchers to assess each regimen task separately on a multidimensional scale (e.g., whether the child performs the task correctly; frequency that the child has to be reminded to complete the task; Holmbeck et al., 1998). Moreover, this approach avoids the use of arbitrary criteria and cut off scores, allowing for comparisons to be made across samples and studies. Given that each child's treatment regimen is individualized based on their needs,

respondents on these questionnaires have the opportunity to endorse “not applicable” if the adherence task is not relevant to them.

In addition, several differing methods for measuring medical adherence in pediatric populations have been employed among researchers. Some researchers will utilize the direct and quantitative method of collecting assays to test the urine, blood, or saliva for the presence of and concentration of an individual’s prescribed drug. However, this method is not always feasible, due to the type of condition, the type of medical regimen and financial concerns, to name a few. Other measurements of adherence have included structured interviews, counting pills, daily writing in adherence diaries, ratings by healthcare providers, and electronic monitoring advice (e.g., refer to La Greca & Mackley, 2009 for a review). The majority of researchers utilize self-report methods, which tends to be the most efficient and inexpensive approach for measuring adherence. Moreover, questionnaire method that ask children and parents to rate specific adherence information on a variety of treatment tasks, which is the method utilized in this study, tends to be more accurate than having individuals rate overall adherence.

A multitude of other factors add to the complexity of studying pediatric adherence. In particular, developmental status, controlled for by age in this study, has a profound impact on medical adherence for a number of reasons. In general, adults tend to exhibit higher rates of adherence in comparison to children (e.g., DiMatteo, 2004), which is attributed to a combination of cognitive, emotional, social, and physical development factors. However, children often exhibit higher rates of adherence in comparison to adolescents (e.g., La Greca & Bearman, 2003; Rapoff, 1999). It is noteworthy that during the adolescent years, responsibility for disease management often shifts from the parent

to child and youth become more autonomous with decision-making (e.g., Holmbeck, Bauman, Essner, Kelly, & Zebracki, 2009). Increasing responsibility for disease management based on age has been demonstrated across several illness groups, including research on children with diabetes (Anderson, Auslander, Jung, Miller, & Santiago, 1990), asthma (McQuaid, Kopel, Klein, & Fritz, 2003), and spina bifida (Devine, Wasserman, Gershenson, Holmbeck, & Essner, 2011; Stepansky et al., 2010). During this transitional period, in which responsibility for disease management is transferred from the parent to child, ambiguity among family members regarding who is responsible for completing illness management tasks typically occurs and is associated with poor adherence outcomes. For example, several studies have found that, among families of youth with a chronic health condition, parents will frequently overestimate their adolescent’s actual involvement in medical management (Naar-King et al., 2009; Walders, Drotar, & Kercsmar, 2000). Not surprisingly, medical non-adherence is typically a consequence of parental overestimation of adolescent responsibility. Thus, in addition to accounting for developmental levels, as will be assessed by age in this study, it is also essential to understand who is responsible for disease management.

Considering the importance of understanding both medical adherence and responsibility for healthcare tasks, this study will examine both medical adherence and autonomy among preadolescents and adolescents with spina bifida. In the pediatric literature, medical autonomy is conceptualized to an interpersonal process in which the preadolescent or adolescent begins to develop a greater capacity for healthcare independence in the context of continued parental support. Thus, the process of gaining autonomy is ideally a gradual process across childhood and adolescents. Moreover, prior

research suggests that while youth may take on greater responsibility for some treatment tasks, they may remain dependent on their parents for other treatment tasks (e.g., Stepansky et al., 2010). The measure utilized in this study considers these variability factors. Similar to the adherence measure, a multidimensional scale was employed to assess medical autonomy, rather than categorizing individuals as autonomous or not autonomous. Autonomy development was assessed across a variety of treatment tasks related to spina bifida (e.g., catheterization, bowel program) and parents and children rated each behavior on a three-point scale (parent versus child versus shared responsibility).

Healthcare Behaviors and Spina Bifida

Only a few researchers have investigated medical adherence and autonomy behaviors of children with spina bifida (e.g., Holmbeck et al., 1998; Stepansky et al., 2010). Yet, children with spina bifida are confronted with many challenging medical issues that require ongoing adherence to several treatment regimens, such as doing clean intermittent catheterizations, taking medications, managing a bowel control program, scheduling and attending medical appointments, identifying infections and shunt malfunctions, and managing pressures sores and rashes (e.g., Children's National Medical Center, 1995; Holmbeck et al., 1998; Wysocki & Gavin, 2006). Moreover, prior research suggests that youth with less advanced cognitive functioning often have greater difficulty managing their medical regimen (Dunbar-Jacob, Erlen, Schlenk, Ryan, Sereika, & Doswell, 2000). Given the complex nature of spina bifida, as well as the higher rates of neurocognitive deficits of youth with this condition, medical adherence and autonomy is likely more difficult for youth in this population to achieve.

Holmbeck and colleagues (1998) investigated the medical regimens among youth with spina bifida (based on parent-, teacher-, and healthcare professional-report). In general, mothers and fathers tended to report lower levels of adherence among their child with spina bifida, as compared to teachers and healthcare professionals. This finding is interesting considering that previous studies have found overestimates of youth adherence based on parent-report (La Greca & Mackley, 2009). Moreover, consistent with prior research (e.g., Dunbar-Jacob et al., 2000), Holmbeck and colleagues (1998) also found that parents often attribute lower levels of adherence to their child's neurocognitive challenges, such as a poor attention span, distractibility, and forgetfulness. Lower levels of motivation were also endorsed as a contributing factor. Taken together, this study provides preliminary support for the association between neurocognitive functioning and medical adherence among youth with spina bifida. Considering that this study relied on qualitative data of parents perceptions of factors that contributed to their child's non-adherence, quantitative analysis is necessary that specifically investigates the impact of attention and executive function on healthcare behaviors, based on multiple methods of neurocognitive functioning (i.e., parent/teacher- report, performance on neuropsychological tests).

Utilizing the same sample of participants as Holmbeck and colleagues (1998), Stepansky and colleagues (2010) employed a longitudinal design to highlight the influence of environmental factors on adherence outcomes among youth with spina bifida. Specifically, Stepansky and colleagues (2010) found that among youth with spina bifida during the preadolescent (8- to 9-year olds) through early adolescent years (12- to 13-year-olds), higher levels of family cohesion and lower levels of family conflict

predicted higher levels of adherence for catheterization tasks. To build upon this research, the present study will investigate specific parenting behaviors among preadolescents and adolescents with spina bifida.

Autonomy development, in general, is often a greater challenge for youth with spina bifida. Davis and colleagues (2006) investigated the acquisition of autonomy skills across several domains of functioning including autonomy with skills related to healthcare (e.g., independent toileting, making medical appointments, hygiene self-care behaviors, identifying signs of bowel problems). Study findings indicated that rate of skill acquisition among youth with spina bifida was about two to five years behind typically developing peers. This study also identified level of disability as a contributing factor for lower levels of autonomy. Specifically, youth with spina bifida who had higher lesion levels performed autonomy skills significantly later than youth with lower lesion levels. Similarly, in a longitudinal study, Zuckerman, Devine, and Holmbeck (2011) investigated youth from 14- to 15-years-old through 18- to 19-years-old, and a matched comparison sample of typically developing adolescents, and found that young adults with spina bifida were less likely than their non-neurologically impaired peers to achieve developmental milestones related to autonomy during the young adult years, such as leaving home, attending college, and maintaining employment. Relevant to this study, executive function abilities was a consistent predictor of the acquisition of such adult milestones.

Other researchers have also identified executive function as a significant predictor of autonomy among youth with spina bifida. Heffelfinger and colleagues (2008) investigated factors that contribute to autonomy among adolescents and young adults with spina bifida. A composite measure of general functional autonomy outcomes was

utilized in this study, which included items regarding self-care, mobility, problem solving, memory, and communication. These researchers found that age and lesion level was significantly associated with autonomy outcomes. Similar to the study by Zuckerman and colleagues (2011), executive function was also a significant predictor of autonomy. Moreover, the executive function construct emerged as a significant mediator for the relation between neurological severity and autonomy development. In other words, severity of neurologic deficits was associated with executive function ability, which was, in turn, associated with autonomy outcomes.

Taken together, prior research highlights the challenges youth with spina bifida confront regarding medical adherence and autonomy development. Moreover, these studies provide preliminary evidence for the influence of neurocognitive functioning on medical adherence and autonomy behaviors. Nonetheless, few studies to date have specifically investigated autonomy on healthcare tasks. Due to the limited number of studies that have investigated medical autonomy and adherence among youth with spina bifida, this study aims to further investigate the specific nature of deficits (and assets) that lead to maladaptive (and adaptive) healthcare behaviors.

In general, the family environment plays a significant role in healthcare outcomes of youth, particularly among youth with a chronic health condition. Adolescents with family members that provide increased support for the management of chronic health conditions exhibit higher levels of adherence (Cauce, Reid, Ladesman, & Gonzales, 1990), and increased parental involvement is associated with higher rates of adherence among adolescents (e.g., Wysocki & Gavin, 2006). Nonetheless, few studies have investigated the impact of parenting behaviors on healthcare behaviors among youth with

spina bifida. Thus, in addition to examining the role of neurocognitive deficits on healthcare behavior outcomes, this study will also examine the role of parenting behaviors during the preadolescent and adolescent developmental period for medical adherence and autonomy. Moreover, the moderating role of parenting behaviors for buffering against (or exacerbating) the association between neurocognitive deficits and healthcare behaviors will be examined. The following section will provide a review of parenting behaviors among parents of youth with spina bifida.

Parenting Behaviors: A Developmental Psychopathology Framework

In order to investigate the impact of parenting behaviors on healthcare behaviors, in the context of neurocognitive deficits, this study utilizes a developmental psychopathology framework. A developmental psychopathology framework recognizes that genetic and biological factors are probabilistic and not deterministic. Adjustment outcomes, such as healthcare behaviors, are conceptualized as the result of several developmental factors, including both biological and environmental, which interact and produce continuities and discontinuities in development (e.g., Cicchetti & Rogosch, 2002; Mash & Dozois, 2003; Rutter & Sroufe, 2000). The purpose of utilizing a developmental psychological approach in this study is to understand the processes by which maladaptive and adaptive healthcare behaviors emerge by identifying casual pathways in development.

The concept of casual pathways in development can be illustrated by the principles of equifinality and multifinality. Equifinality refers to the process by which a specific outcome will develop over time from different starting points; whereas, multifinality refers to the process by which diverse outcomes emerge in individuals who

have the same starting point. For example, suppose there are two children, Child A and Child B, with severe spina bifida and significant neuropsychological impairments. Child A has parents that are warm, responsive, and frequently attempt to promote autonomous behavior. Child A will likely fare much better than Child B whose parents are less responsive and frequently inhibit autonomous behavior. In other words, despite similar starting points, Child A will likely demonstrate adaptive outcomes (i.e., medical autonomy and adherence), whereas Child B will have more difficulty. Moreover, it is probable that a child with less severe spina bifida, Child C, could have developmental outcomes similar to Child B if exposed to similar risk factors. Taken together, to understand the developmental processes that lead to behavioral adjustment and maladjustment among youth with spina bifida, it is important to identify factors that interact to influence the developmental pathways of these youth, such as the interaction between neurocognitive deficits and parenting behaviors.

A developmental psychopathology perspective also emphasizes the influence of life transitions on developmental processes, as the manner in which individuals manage life transitions (e.g., childhood to adolescence) is believed to have important implications for later adjustment outcomes (Williams et al., 2002). For example, adolescence is a transitional period characterized by substantial biological, psychological, and social changes in development (Cicchetti & Rogosch, 2002). Given the magnitude of changes that occur during adolescence, this developmental period is likely critical for the development of positive healthcare behaviors. Consistent with this theory, prior research has found that throughout the adolescent years, individuals will establish and consolidate life-long patterns of positive health behaviors (e.g., exercise, diet), health risk behaviors

(e.g., substance use, risky sexual behaviors), and health-related autonomy (Williams et al., 2002). It is not surprising, given the variety of changes that occur during adolescence, that considerable continuities and discontinuities in development occur during the transition from childhood to adulthood. More specifically, a wide variety of individual and environmental factors impact the transition from childhood and adulthood, thus leading to diverse outcomes. This is particularly true among individuals with chronic illnesses and disabilities where variability is even more pronounced (Williams et al., 2002). Thus, this transition period (i.e., the preadolescent and adolescent years) is critical for furthering our understanding of healthcare behavior outcomes of youth with spina bifida.

The impact of parenting behaviors on child and adolescent adjustment has emerged as a crucial area of research, particularly among youth with chronic health conditions (e.g., Fastenau et al., 2004; Holmbeck et al., 2002a, 2002b; McKernon, Holmbeck, Colder, Hommeyer, Shapera, & Westhoven, 2001). Typically, three types of parenting behaviors have emerged as instrumental for promoting positive adjustment outcomes among children and adolescents. These parenting behaviors include high levels of acceptance, high levels of behavioral control, and low levels of psychological control (e.g., Ainsworth et al., 1978; Barber & Harmon, 2002; Greenley et al., 2006).

Parental acceptance refers to affective/emotional aspects of parenting behaviors, such as high levels of emotional support, expressions of affection toward their child, and low levels of harsh and intrusive behaviors (Greenley et al., 2006; Landry et al., 2006). Psychological control and behavioral control represent two distinct forms of parental control. Behavioral control (also referred to as parental demandingness) refers to the

expectations for and enforcement of age-appropriate child behavior. These types of parenting behaviors include parental willingness to confront their child if they disobey, age-appropriate supervision, and expectation for mature behavior (e.g., Baumrind, 1991a). Psychological control has been defined as parenting behaviors that are intrusive, critical, and manipulative of a child's thoughts and feelings (Barber & Harmond, 2002). These types of parenting behaviors also include parental stifling of the child's communication, encouragement of emotional and psychological dependence, and parental dominance over their child. Parents that utilize this form of behavior often do not allow their children to express their individuality (Steinberg, 1990). Generally, youth tend to be adversely affected by psychological control, whereas behavioral control elicits positive adjustment outcomes among youth (e.g., Barber & Harmon, 2002; Baumrind, 1991b; Steinberg, 1990). According to Steinberg (1990), lower levels of behavioral control often result in inadequate guidance and supervision of children. Youth exposed to this type of parenting are placed at risk for making poor decisions and are more likely to engage in risky activities. In addition, too much psychological control disrupts autonomy development among youth and facilitates dependency. Thus, optimal development occurs when youth are granted sufficient psychological autonomy and acceptance and an age-appropriate level of behavioral control.

In addition to investigating the impact of neuropsychological functioning on healthcare behavior outcomes, it is essential to understand how environmental factors interact with neuropsychological factors to influence healthcare behaviors among youth with spina bifida. The present study focuses on vulnerability and protective factors that contribute to positive healthcare outcomes, namely medical autonomy and adherence, in

the context of neurocognitive deficits. Vulnerability factors refer to moderating variables that increase the likelihood of maladjustment in the context of adversity (i.e., neurocognitive deficits; Holmbeck, Zebracki, & McGoron, 2009; Rutter, 1990). This study will investigate maladaptive parenting behaviors (i.e., high levels of psychological control) as potential vulnerability factors. It is hypothesized that maladaptive parenting behaviors may exacerbate the impact of neurocognitive deficits on medical autonomy and adherence. On the other hand, protective factors refer to variables that buffer against the negative impact of adverse contexts and promote adaptive functioning (Holmbeck, Zebracki, & McGoron, 2009; Rutter, 1990; Schwartz, Pantin, Coatsworth, & Szapocznik, 2007). This study will investigate adaptive parenting behaviors (i.e., high levels of acceptance, high levels of behavioral control) as potential protective factors. It is hypothesized that adaptive parenting will buffer against the negative impact of neuropsychological impairment on healthcare autonomy and adherence.

Parenting Behaviors and Chronic Health Conditions

This study will explore the direct effect of parenting behaviors on healthcare outcomes among youth with spina bifida, as well as the moderating role of parenting behaviors on associations between neurocognitive functioning and healthcare behaviors (i.e., medical adherence and autonomy; see Figure 1 on page 8). It is theorized that improved healthcare outcomes among youth with spina bifida will be observed among youth raised in an environment that provides greater support, as well as opportunities and expectations for autonomy development (such as environments characterized by high levels of parental acceptance, high levels of behavioral control, and low levels of psychological control).

The role of parenting behaviors on medical autonomy and adherence is a particularly important area of interest for youth with complex chronic health conditions, such as spina bifida. As previously discussed, transitions in responsibility among youth with chronic health conditions typically take place during the preadolescent and adolescent years, as illness management shifts from the parent to the child (Williams et al., 2002). Thus, adaptive parenting behaviors during this developmental period are essential for facilitating a positive transfer of care from the parent to the adolescent.

Many researchers have investigated the association between parenting behaviors and adjustment among children and adolescents. This review will focus on parenting behaviors within populations of youth with chronic health conditions and neurologic insult and/or complex medical regimens. Prior research has explored the association between parenting behaviors and healthcare outcomes among youth with type 1 diabetes, a condition that requires a complex medical regimen to maintain health. Specifically, Wysocki (1993) investigated the impact of family communication and conflict resolution skills among adolescents with insulin-dependent diabetes mellitus. Family communication and conflict resolution skills were both strongly associated with glycohemoglobin levels, which frequently is utilized as an assessment for medical adherence within this population. Similarly, Wysocki and colleagues (2008) conducted a randomized, controlled trial comparing standard care for type 1 diabetes versus six months of an educational support group versus behavioral family systems therapy among 11 to 16 year olds with type 1 diabetes. Analyses indicated that the behavioral family systems therapy group demonstrated significant improvements with communication and problem solving skills. Furthermore, higher levels of positive maternal communication

were associated with higher levels of treatment adherence and gylcemic control among the adolescents. This study provides support for the hypothesis that parenting variables can significantly influence healthcare behaviors of children and adolescents.

No study has investigated the influence of adaptive parenting behaviors on healthcare behaviors among preadolescents and adolescents with spina bifida. However, several studies have investigated parenting behaviors as significant risk (e.g., psychological control) and resource (e.g., acceptance, behavioral control) factors for psychosocial adjustment outcomes among youth with spina bifida. A study was conducted that investigated the influence of environmental factors on adjustment outcomes among young adults with spina bifida (Loomis, Javornisky, Monahan, Burke, & Lindsay, 1997). Perceived family encouragement was significantly associated with several positive outcome variables among adolescents with spina bifida, such as employment status, community mobility (e.g., independently uses public transportation or drives), and social activity. Holmbeck and colleagues (2002a) conducted a cross-sectional investigation of observed and perceived parental overprotection among parents of preadolescents with spina bifida. Parental overprotection was defined as an excessive amount of parental protection that surpassed the degree of protection necessary given a child’s developmental level. These authors point out that a higher degree of parental protection is likely adaptive within this population, as parents attempt to maintain their child's health in the context of a chronic illness that requires intensive medical management. However, the same circumstances that require increased levels of parental protection, also increases this population’s vulnerability to less adaptive, excessive protection. Thus, what begins as well intentioned parenting behaviors becomes

maladaptive as the child's self-governance skills are impeded (Anderson & Coyne, 1993). In support of this theory, Holmbeck and colleagues (2002a) found higher levels of observed and perceived overprotection among parents of youth with spina bifida, as compared with parents of medically healthy children. Furthermore, parental overprotection was associated with lower levels of behavioral autonomy, including lower levels of individual decision-making among the preadolescents.

Holmbeck and colleagues (2002b) also investigated psychological control, behavioral control, and acceptance among parents of children with spina bifida and a matched comparison group (2002b). This study found that mothers of children with spina bifida exhibited higher levels of psychological control, as compared to a matched comparison group. These parenting behaviors were associated with child outcome variables, as greater psychological control was also associated with psychosocial maladjustment across the groups. Moreover, high levels of parental acceptance were associated with positive adjustment outcomes among the preadolescents. This study suggests that parenting factors may have an important role in both adaptive and maladaptive adjustment outcomes among youth, particularly among youth with spina bifida, in which higher levels of maladaptive parenting behaviors (e.g., psychological control) were exhibited. A longitudinal study following the same group of participants investigated the influence of parenting behaviors (responsiveness, demandingness) and the family environment (cohesion, conflict) on the development of coping behavior among preadolescents with spina bifida (McKernon et al., 2001). Analyses indicated that maternal and paternal responsiveness and family cohesiveness were significant predictors of positive coping styles (i.e., problem solving coping) among youth with spina bifida.

Moreover, changes in parenting behaviors were concurrently associated with changes in the child's coping behaviors.

Despite support for the role of parenting behaviors on adjustment outcomes among children and adolescents, few studies have investigated the impact parenting has on healthcare behaviors. In addition, minimal research has investigated the extent to which parenting behaviors may interact with neuropsychological functioning to influence adjustment outcomes among children and adolescents. In fact, among the few studies investigating the moderating role of parenting behaviors on adjustment outcomes among youth at risk for maladjustment, none of these studies have been conducted among youth with spina bifida.

Nonetheless, there is preliminary support for the buffering effects of family factors on the relation between neurocognitive deficits and adjustment among other illness groups. Fastenau and colleagues (2004) investigated the neurocognitive functioning of school-aged children with epilepsy. Neurocognitive deficits had a significant effect on academic achievement scores for these youth, yet the family environment moderated the impact of these deficits on outcome variables. In general, neuropsychological deficits had less of an impact on children's academic achievement status if they came from a supportive and organized home, as compared to children from an unsupportive and disorganized home. In other words, this study supported the notion that family factors can significantly buffer against the negative impact of neurocognitive deficits on functional outcomes. Due to the variability in adjustment among youth with spina bifida, it is important to investigate the moderating effects of parenting behaviors

among preadolescents and adolescents with spina bifida who exhibit impaired attention and executive dysfunction.

Overall, these studies provide evidence that adaptive parenting behaviors are crucial for positive adjustment outcomes among youth with spina bifida. Generally, adaptive parenting behaviors are expected to be associated with medical adherence and autonomy. Moreover, several moderational hypotheses will be tested. It is expected that adaptive parenting behaviors (i.e., higher levels of acceptance, higher levels of behavioral control) will buffer against the negative effect of inattention and executive dysfunction has on medical autonomy and adherence behaviors among youth with spina bifida. On the other hand, maladaptive parenting behavior (i.e., higher levels psychological control), will likely exacerbate the negative effect inattention and executive dysfunction has on medical adherence and autonomy.

Study Hypotheses

Taken together, several hypotheses will be tested regarding the association between neurocognitive functioning, parenting behaviors, and healthcare behaviors:

Hypothesis 1. Children and adolescents with spina bifida will demonstrate higher levels of inattention and executive dysfunction, as compared to a normative data.

Hypothesis 2. Lower levels of inattention and executive dysfunction among children with spina bifida will be associated with higher levels of medical adherence and autonomy, after controlling for age, IQ, and level of disability.

Hypothesis 3. Observed and perceived adaptive parenting behaviors (i.e., higher levels of acceptance and higher levels of behavioral autonomy) will be associated with

higher levels of medical adherence and autonomy, after controlling for age, IQ, and level of disability.

Hypothesis 4. Observed and perceived maladaptive parenting behaviors (i.e., high levels of psychological control) will be associated with lower levels of medical adherence and autonomy, after controlling for age, IQ, and levels of disability.

Hypothesis 5. Adaptive parenting behaviors (i.e., higher levels of acceptance; higher levels of behavioral control) will buffer against the negative effects of inattention and executive dysfunction on medical adherence and autonomy, after controlling for age, IQ, and level of disability.

Hypothesis 6. Maladaptive parenting behaviors (i.e., psychological control) will exacerbate the negative effects of inattention and executive dysfunction on medical adherence and autonomy, after controlling for age, IQ, and level of disability.

CHAPTER THREE

METHODS

Participants

Participants are part of a larger longitudinal investigation at Loyola University Chicago, under the direction of Dr. Grayson Holmbeck and supported by March of Dimes and the National Institute of Child Health and Human Development (NICHD). This longitudinal study examines psychosocial adjustment, family and peer relationships, and neuropsychological functioning among children and adolescents with spina bifida. Data collection for the larger longitudinal study occurs every two years. This study includes analyses from the first wave of data (Time 1), when the children were 8 to 15 years old.

Families of youth with spina bifida were recruited from a metropolitan children's hospital, a specialty hospital for children with orthopedic conditions, a statewide spina bifida association, and a university-based medical center. Recruitment letters were sent to families and/or contact was initiated by phone to discuss the study and determine if the child met inclusionary criteria. In addition, in-clinic recruitment was conducted during spina bifida clinic days at both metropolitan hospitals. Eligible families were identified and approached by trained research assistants during clinic days with the help of coordinating nurses. Follow-up phone calls were conducted the week following clinic visits to schedule the first of two home visits. Families were included in the study if they

met the following inclusionary requirements: (1) diagnosis of spina bifida, (2) age 8 to 15 years at Time 1, (3) ability to speak English or Spanish, (4) at least one primary custodial caregiver, and (5) residence within 300 miles of Chicago. Families were excluded from participation if their child had any comorbid health conditions, if there was no parental involvement (e.g., ward of the state), if the family was non-English or non-Spanish speaking, or if the child was under that age of 8 or over the age of 15 by the completion of Time 1. In addition, child questionnaire data were excluded from analyses for this study if the child's IQ score was less than 70, based on the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1974). As a result, questionnaire data from a total of 26 children were excluded from analyses.

A total of 246 families were approached for participation in this study, and 163 families agreed to participate. Of these 163 families, 22 families were unable to be contacted or later declined and two families did not meet inclusion criteria. The resulting sample size was 139 families (57% participation rate). Analyses were conducted to compare the 139 families enrolled in the study with those who declined to participate across several medical variables. Specifically, these groups did not significantly differ from each other on the following: type of spina bifida (MM vs. other) ($\chi^2(1) = 0.0002$, *ns*), shunt status ($\chi^2(1) = 0.003$, *ns*,), or occurrence of shunt infections ($\chi^2(1) = 1.08$, *ns*).

Among the 139 families of children who participated, the sample was distributed relatively evenly across 8- to 15-year-olds [M(age) = 11.43, SD = 2.46]: 39 were 8 or 9 years old, 28 were 10 or 11 years old, 36 were 12 or 13 years old, and 36 were 14 or 15 years old. The sample was also evenly distributed across gender (i.e., 54.0% female, 46.0% male). Approximately half of the sample was Caucasian (54.0%), and the second

largest ethnic group was Hispanic (28.1%), then African American (12.2%), Mixed (4.3%), and Asian American (1.4%). Hollingshead (1975) four-factor index of socioeconomic status (SES) was utilized in this study to obtain an SES score based on parent education and occupation. The sample demonstrated considerable variability around a mean of 39.44 (SD = 15.90).

Medical chart reviews and maternal report provided information regarding a number of physical status variables: (a) spinal lesion (medical chart): 18.0% sacral, 63.3% lumbar, 15.1% thoracic, (b) spina bifida type (medical chart): 87.8% myelomeningocele, 9.4% lipomeningocele, 2.9% other (c) shunt status (maternal report): 78.4% with a shunt, and (d) hydrocephalus status (maternal report): 78.4% with hydrocephalus. The average number of shunt surgeries among children with shunts was 3.14 (SD = 5.07). Similar to prior studies (e.g., Wills et al., 1990), youth with spina bifida typically demonstrated a low average IQ. Specifically, youth had a mean score of 85.68 (SD = 16.58) on the WASI. Of the 139 children that participated in this study, 26 children (19.7%) had an IQ score less than 70. Child questionnaire data was not utilized for these 26 individuals.

Design and Procedures

Trained graduate and undergraduate research assistants conducted data collection in the homes of each participating family. A total of two in-home sessions occurred and each session lasted approximately three to four hours. At the beginning of the in-home session, parental consent and child assent were obtained, and the purpose and procedures of the study were reviewed with each participating family member. Parents were also asked to fill out and sign release forms for medical chart review, nurse participation, and

teacher participation, in order to obtain additional information regarding the family and child. Families were monetarily compensated at each visit (i.e., $50 for the first in-home session and $100 for the second in-home session), and nurses and teachers received $10 and $25, respectively, for their completion of questionnaires.

Children completed one hour and a half of neuropsychological evaluations at the first and second in-home sessions. During the first home visit, parents and children completed several questionnaires and were asked to participate in a set of audio and videotaped interaction tasks. During the second home visit, children with spina bifida were asked to invite a close friend to complete questionnaire data and also participate in a set of audio and videotaped interaction during the second home visit. Peer data was not utilized in this study, and thus, will not be discussed below.

The following family videotaped interaction tasks were completed with the child and at least one parent, without the presence of a researcher: (1) An *interactive game,* UNO Stacko, was utilized as a warm-up task to help families become comfortable being videotaped. The family was provided with game rules, and they were instructed to play until the game was complete. (2) A *conflict task* was administered, in which families were asked to discuss three to five conflict issues based on the parents' and children's responses on the Parent-Adolescent Conflict Scale (PAC; Prinz, Foster, Kent, & O'Leary, 1979). Scores were coded for each item on the questionnaire by multiplying conflict frequency and intensity across reporters. Items with the five highest scores were written down on note cards and presented to the family for discussion. The family was given 10 minutes to discuss the conflicts, with the goal of listening to each family member's point of view and attempting to reach a resolution. (3) A *vignette task* was administered and

families were asked to discuss two age-appropriate vignettes that incorporated social issues related to spina bifida. The family was instructed to first read a short story together and, then, discuss a series of seven questions (e.g., What are good ways to handle this situation?; If something like this were to happen to you in the future, what would you do?). The family was given 10 minutes to discuss both vignettes. (4) The *transfer of responsibility task* involved a discussion of disease-specific responsibilities that were currently managed by the parents, but for which the child would need to take responsibility for in the future. If the family was unable to identify a spina bifida-related task, then they were instructed to choose any responsibility that currently was managed by the parents and would be transferred to the child or adolescent in the future. After a responsibility was identified, the family was instructed to discuss when and how the transfer of responsibility would take place and how they would know when a successful transfer had occurred. Families were given five minutes to discuss the topic and to record their answers on a piece of paper. If they answered all the questions for one responsibility to be transferred from the parent to the child before time was up, they were instructed to discuss a second responsibility in the same way. For each family, the conflict task, vignettes, and the transfer of responsibility task were presented to families in a randomized order.

Measures

Demographics and Illness Severity

Demographic information was obtained from responses by parents that included gender of the child, ethnicity of family members, parental occupation, parental educational attainment, family annual income, developmental milestones, and family

structure. Furthermore, maternal-report and medical records were utilized to determine

the physical status of each participant, including type of spina bifida (medical chart), lesion level (medical chart), presence of hydrocephalus (maternal report), and number of shunt revisions/infections (maternal report). Nurses and research assistants conducted medical chart reviews for each participant that provided consent. To check reliability of medical chart reviews, approximately 10% of charts were coded by at least two research assistants.

Disability Level. The Gross Motor Function Classification System (GMFCS) for Spina Bifida provided a measurement of limitations in gross motor functioning among individuals with spina bifida. This scale was adapted from the GMFCS for Cerebral Palsy (Palisano, Rosenbaum, Walter, Russell, Wood, & Galuppi, 1997). This measure categorizes individuals across five-levels based on self-initiated movement, with an emphasis on sitting, transfers, and mobility. Timing of developmental milestones (e.g., before 2nd birthday, between 2nd and 4th birthday, between 4th and 6th birthday, between 6th and 12th birthday, between 12th and 18th birthday) is also considered. Level I classifies individuals with very minimal limitations in gross motor function, such as being able to walk at home, school, outdoors, and in the community. Level V classifies individuals with significant physical impairments and limitations, such as needing to be transferred in a manual wheelchair in all settings and limited ability to maintain antigravity head and trunk postures and control arm and leg movements. In order to assign individuals to the appropriate level of functioning, two trained research assistants independently evaluated medical charts and parent-report of the child's medical history to determine the child's limitations in gross motor functioning. Given the severity of disability required for a

Level V categorization, youth with spina bifida included in this study fell in the Level I to Level IV range only. Specifically 17 (12.2%) participants were categorized as Level 1, 33 (23.7%) as Level II, 30 (21.6%) as Level III, and 52 (37.4%) as Level IV.

Neurocognitive Functioning Measures

General Intellectual Ability. The Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999) was utilized in this study as a proxy for general intellectual functioning. The WASI includes tasks within the performance and verbal domains, and is frequently utilized to provide an intelligence quotient (IQ). Specifically, the Vocabulary and Matrix Reasoning subtests were administered to participants in the present study to obtain an estimate of IQ. The Vocabulary subtest is a 42-item measure that assesses for expressive vocabulary, verbal knowledge, and fund of information. In addition, it is a reliable measure of crystallized intelligence and general intelligence (e.g., Wechsler, 1999). On items one through four, the examinee is required to name pictures (e.g., bucket). On items five through 42, words are orally and visually presented, and the examinee is required to provide a definition (e.g., What is a car?). The Matrix Reasoning subtest assesses nonverbal abstract problem solving, inductive reasoning, and spatial reasoning skills. In addition, it is a reliable measure of nonverbal fluid intelligence and general intellectual ability (e.g. Wechsler, 1999). This subtest includes a series of 35 incomplete gridded patterns, in which the examinee is asked to complete by pointing to the correct pattern from five possible choices. In general, higher scores on these measures represent higher levels of intellectual abilities. Standardized norms for both of these subtests have been obtained across 2,245 individuals aged six through 89, and average

test-retest reliability coefficients of .89 (Vocabulary) and .92 (Matrix Reasoning) were obtained for children 6 to 16 years old (Wechsler, 1999).

Executive Function. The Behavior Rating Inventory of Executive Function (BRIEF; Gioia et al., 2000a, 2000b) is a parent- and teacher-report questionnaire that measures several domains of executive functions of children. It is composed of eight subtests including Inhibit (i.e., the ability to resist or not act on an impulse; e.g., Interrupts others), Shift (i.e., the ability to move freely from one situation, activity or aspect of a problem to another demand; e.g., Becomes upset with new situations), Emotional Control (i.e., the capacity to modulate emotional responses; e.g., Overreacts to small problems), Initiate (i.e., the capacity to begin a task or activity or independently generate ideas, responses, or problems solving strategies; e.g., Does not take initiative), Working Memory (i.e., the ability to hold information in mind for the purpose of completing a task; e.g., Has trouble remembering things, even for a few minutes), Plan/Organize (i.e., the ability to manage current and future-oriented task demands; e.g., Has good ideas but cannot get them on paper), Organization of Materials (i.e., orderliness of work, play, and storage spaces; e.g., Keeps room messy), and Monitor (i.e., work-checking habits; e.g., Makes careless errors) subtests. These subtests fall within two broad indices, Behavioral Regulation and Metacognition, which make up the overall Global Executive Composite Score. Mothers, fathers, and teachers completed all 86 items that comprise the BRIEF subtests. On each item, parents and teachers were instructed to circle whether their child has never, sometimes, or often demonstrated a particular behavior during the past six months. Higher scores on the BRIEF represent higher levels of executive dysfunction. For the regression analyses, the mean scores across all 86 items

were computed to obtain a global assessment of child executive function. Because the mother-, father-, and teacher-reports for the item mean scores were moderately correlated (r = .30 to .57), the mean across reporters was used when parent- and teacher-reports were available. Internal consistency for the entire combined scale was adequate (α = .98).

In order to compare youth with spina bifida's scores on the BRIEF with normative data, t-test analyses were conducted. To do so, scores were first transformed into T-scores. Given that normative data differs based on parent- versus teacher-report, T-scores were computed separately for parents and teachers. Missing data were handled based on the criteria of Gioia and colleagues' (2000a, 2000b), such that subtests with less than three items missing were replaced with the mean across the other items. Subtests missing greater than two items were not converted into T-scores and not included in analyses. After transforming raw scores into T-scores, several subscales of the BRIEF failed to reach adequate interrater reliability between parent- and teacher-reports (r = .15 to .47). Thus, subtests for the parent- and teacher-report on the BRIEF were investigated separately in the t-test analyses. Analyses were run separately for each of the eight subtests and two indices of the BRIEF. All of the subtests and indices for parent- and teacher-report demonstrated adequate scale reliability (α = .84 to .94).

Several neuropsychological measures were utilized as an assessment of executive functions. The Cognitive Assessment System (CAS; Naglieri & Das, 1997) is an assessment battery of tests that measure cognitive processing in children 5 to 17 years of age. Specifically, the Planned Connections subtest of the CAS was utilized as an

assessment of nonverbal executive function (i.e., planning). On this test, the examinee was first required to sequentially connect numbers that appear in a quasi-random order on a page, and then the examinee was required to connect both numbers and letters in serial order alternating between numbers and letters (e.g., 1-A-2-B-3). Each test was timed to provide an estimate of task efficiency. Scores were then computed into age scaled scores, and higher scores represented higher levels of executive function ability.

Selected subtests from the Delis Kaplan Executive Function System (D-KEFS; Delis, Kaplan, & Kramer, 2001) were also utilized as an assessment of executive function. The D-KEFS is a comprehensive battery of tests that measure higher-level cognitive functions including reasoning, problem solving, and planning. This study utilized the Verbal Fluency Test of the D-KEFS as a measure of verbal executive functions. The Verbal Fluency Test is comprised of three subtests including Letter Fluency, Category Fluency, and Category Switching. For each of these three conditions, the examinee was given 60 seconds to generate words fluently in an effortful, phonetic format (Letter Fluency), from over learned concepts (Category Fluency), and while shifting between over learned concepts (Category Switching). Letter and Category fluency scores were computed based on the total number of correct responses. On the Category Switching subtest, two scores were computed: total number of correct responses and total number of correct switches between concepts. Across all subtests, higher scores represented higher levels of executive function ability. All scores were computed into age scaled scores.

A composite score was created based on the mean age scaled scores across the neuropsychological test data that measure executive function. Items in this composite

score included the D-KEFS Verbal Fluency subtests (i.e., Letter Fluency, Category Fluency, Category Switching) and the Planned Connections subtest from the CAS. Adequate internal consistency was demonstrated across these items (α = .89).

Attention. The Swanson, Nolan, and Pelham – Fourth Edition (SNAP-IV; Swanson et al., 1983) questionnaire is a parent and teacher-report rating scale devised of items that measure inattention, impulsivity, and hyperactivity. Two subscales provide dimensional scaling of the diagnostic criteria for ADHD, based on the Diagnostic and Statistical Manual of Mental Disorder – Fourth Edition (DSM-IV): nine items that assess for inattention (e.g., "Can't pay attention," "Can't concentrate") and nine items that assess for hyperactivity/impulsivity (e.g., "Often fidgets with hands or feet or squirms in seat," "Often has difficulty awaiting turn"). Parents and teachers were instructed to rate each item on a 0 to 3 rating scale: Not at all = 0, Just a Little = 1, Quite a Bit = 2, Very Much = 3. The 9-items of the SNAP-IV that assess for inattention will be used in regression analyses as an assessment of child inattention. However, for descriptive purposes, item mean scores were computed for the inattention, hyperactivity/impulsivity, and combined scales, and descriptive analyses investigated parent- and teacher-reports separately. Higher scores on the SNAP-IV represent higher levels of impairment. A mean across items were obtained for each reporter. Mother-, father-, and teacher- report total item mean SNAP-IV scores were highly correlated on the inattentive (r = .41 to .72), the hyperactivity/impulsivity (r = .38 to .56), and the combined (r = .40 to .67) scales. The mean across reporters on the inattentive measure was utilized in regression analyses when parent- and teacher-reports were available. Internal consistency for the entire combined

scale was adequate for the inattentive subtest (α = .94). Given that descriptive analyses
investigate parent- and teacher-report separately, internal consistency were also computed separately for teacher-report and the mean of parent-reports. Parent- and teacher-report, respectively, on the inattentive (α = .95 to .94), hyperactivity/impulsivity (α = .86 to .88), and combined (α = .93 to .93) scales were all adequate.

Several neuropsychological measures were utilized as an assessment of attention. The Test of Everyday Attention for Children (TEA-Ch; Manly, Robertson, Anderson, & Nimmo-Smith, 1999) is a clinical battery that allows for the assessment of different components of attention including selective attention, attention control/switching, and sustained attention. Each task was standardized and normed across 293 children. The Sky Search task is an assessment of selective and focused attention in the visual domain. The examinee was required to quickly circle pairs of items in which both targets are the same, while being timed. Scores were computed based on accuracy and the total time to complete the task. The Score! task is an assessment of auditory sustained attention. The examinee listened for and counted the number of scoring sounds on an audiotape. Higher scores represent higher levels of attention ability. The Sky Search DT is a divided and sustained attention test in which the examinee is instructed to complete two tasks at once (i.e., a visual and an auditory task). The examinee was instructed to circle pairs of items when both items are the same, while simultaneously counting the number of scoring sounds on the audiotape. Scores were computed by combining the total accuracy score on each task, divided by the completion time. The Score DT task also assesses divided and sustained attention. Similar to the previous task, the examinee was instructed to listen for

and count the number of scoring sounds on an audiotape recorder, while simultaneously listening for an animal name during a news broadcast. In other words, the examinee was instructed to complete two auditory tasks at once. Scores were computed by combining the total accuracy score on each task. Across each task, previous research demonstrates adequate test-retest reliability (Manly et al., 1999). All scores were computed into age scaled scores for data analyses, with higher scores representing higher levels of attention ability.

The Number Detection subtest of the CAS was administered to provide an assessment of visual attention. On this test, the examinee was required to underline a particular stimulus (e.g., the numbers 1, 2, and 3 in a specific font) on a page containing several distracters (e.g., the same numbers in a different font). In addition to scoring for accuracy, each test was timed to provide an estimate of task efficiency. Raw scores were then converted into age scaled scores, and higher scores represented higher levels of attention ability.

A composite score was created based on the mean age scaled scores across neuropsychological test data that measure areas of attention. Items in this composite score included all subtests from the TEA-Ch (i.e., Score!, Sky Search, Score DT, Sky Search DT) and the Number Detection subtest from the CAS. Adequate internal consistency was demonstrated across these items ($\alpha = .72$).

Measures of Parenting Behaviors

Observed Parenting Behaviors. Four family interaction tasks were coded using a macro coding system developed by Holmbeck, Zebracki, Johnson, Belvedere, and

Hommeyer (2007a, 2007b) and adapted from previous coding systems developed by Holmbeck, Belvedere, Gorey-Ferguson, and Schneider (1995), Johnson and Holmbeck (1999), and Smetana, Yau, Restrepo, and Braeges (1991). Also refer to Kaugars and colleagues (2011). Coders viewed an entire family interaction task and rated the family members across several behavioral dimensions including interaction style, conflict, affect, control, parenting behaviors, collaborative problem solving, and the general family atmosphere and impairment. Each item was scored on a five-point Likert scale, in which higher scores represented behaviors that were very often present and lower scores represented behaviors that were never present. The coders included undergraduate- and graduate-level research assistants that were blind to the specific hypotheses of this study. In general, all coders received a minimum of 10 hours of training before beginning the coding process. During the first round of training, the trainer provided feedback (e.g., types of errors made) to the trainee. This was followed by a reliability trial, and a minimum agreement of 90% between the rater and the response key was required. Trainees were given a total of two rounds to reach this criterion. If the trainee continued to fall short of 90% reliability after round two, they were dropped as a coder. For each task, two coders rated dyadic and family behaviors, and their scores were averaged to yield a single score.

Given the interest in parental acceptance, psychological control, and behavioral control, several parenting behavior codes were formed rationally (as opposed to empirically) by selecting items from the complete list of codes that reflect the definitions of each parenting construct as previously discussed in the literature. These parenting scales were developed separately for mothers and fathers. Parental acceptance was

assessed using the following codes: listens to others, humor and laughter, warmth, anger (reverse-scored), and supportiveness. Parental behavioral control was assessed using the following codes: confidence in stating opinions, parental structuring of the task, parental promotion of dialogue and collaboration, and parental dominance. Parental psychological control was assessed using the following codes: pressures others to agree, tolerates differences and disagreements (reverse-scored), receptive to statements made by others (reverse-scored), and parent promotes autonomy in child (reverse-scored). Composite scores were based on the mean across items.

To assess interrater reliability of the observed parenting behavior constructs, intraclass reliability correlations (ICCs) were computed, with .60 or above considered adequate (Kieffer, Cronin, & Fister, 2004). Adequate interrater reliability was obtained for maternal acceptance ($r = .86$), behavioral control ($r = .86$), and psychological control ($r = .74$), and paternal acceptance ($r = .87$), behavioral control ($r = .88$), and psychological control ($r = .68$). In addition, adequate scale reliability was obtained for maternal acceptance ($\alpha = .81$), behavioral control ($\alpha = .88$), and psychological control ($\alpha =.68$), and paternal acceptance ($\alpha = .84$), behavioral control ($\alpha = .91$), and psychological control ($\alpha = .68$).

Perceived Parenting Behaviors. The Child Report of Parent Behavior Inventory – Parent Report (CRPBI-P) was adapted from Schludermann and Schludermann’s (1970) 108-item child version. The CRPBI is the most widely used measure of parenting behavior in the literature to date (e.g., Holmbeck et al., 2002b). Due to time considerations, only 44 items from the larger 108 items were administered to mothers and

fathers. Parents were instructed to rate each parenting behavior on a three-point scale from 1 (*not like me as a parent*) to 3 (*a lot like me as a parent*). A total of sixteen items comprised the acceptance scale: 8 items from the acceptance subtest (e.g., I almost always talk to my child with a warm and friendly voice) and 8 items from the rejection subtest (reverse scored; e.g., I forget to help my child when s/he needs it) subscales were used for the acceptance scale. Fifteen items from the behavioral control scale: 5 items from the control subtest (e.g., I see to it that my child knows exactly what s/he may or may not do), 5 items from the enforcement subtest (e.g., I am very strict with my child), and 5 items from the lax discipline subtest (reverse scored; e.g., I am easy with my child). Thirteen items comprised the psychological control scale: 5 items from the intrusiveness subscale (e.g., I want to know exactly where my child is and what s/he is doing) and 8 items from the hostile control subtest (e.g., I am always telling my child how s/he should behave). It is important to note that Schaefer (1965) originally referred to the construct behavioral control as firm control. The term behavioral control is utilized in this study as a substitute for firm control, because this term more adequately defines the target of parental control. Moreover, the term behavioral control is more up to date with recent research (e.g., Barber, 1996; Gray & Steinberg, 1999; Holmbeck et al., 2002b). Mean scores across items were computed for each scale and higher scores represent higher levels of the specified parenting behavior. Adequate scale reliability was obtained for the maternal acceptance (α = .81), behavioral control (α = .67), and psychological control scales (α = .70), and the paternal acceptance (α = .81), behavioral control (α's = .76), and psychological control scales (α = .72).

Medical Adherence. Spina Bifida Self-Management Profile (SBSMP; Wysocki & Gavin, 2006) is a 14-item assessment of several dimensions of spina bifida self-care, based on parent-report, which assesses adherence to medical regimen. The dimensions include appointment keeping, bowel control, skin and wound care, exercise, medication management, catheterization, and urinary tract infections. The SBSMP is administered in a questionnaire format, as opposed to the prior use of this assessment measure in an interview format. Parents were instructed to report how well in the past six months their child has taken care of each self-care task. For example, to assess the child's adherence to their bowel program the parent was asked, "In the past 6 months, how often has your child stayed within the diet recommendations that the doctor has given to you?" Then, parents rated their child's behavior on a five-point scale from Always eats according to the recommendations (100%) to Rarely or never eats according to the recommendations (0-10%). Each item score was computed into standardized z-scores due to variability in the item's rating scale (e.g., 4-point-scale versus 5-point-scale versus 6-point-scale). A total score was computed using the mean item z-scores across the 14-items. Higher scores represented higher levels of medical adherence. Because the mother- and father-reported scores on the SBSMP were moderately correlated ($r = .49$), the mean across reporters was used when mother- and father-reports were available. Internal consistency could not be computed due to a low number of participants that completed all test items. Nonetheless, prior studies have demonstrated adequate internal consistency ($\alpha = .66$; Wysocki & Gavin, 2006).

Medical Autonomy. The Sharing of Spina Bifida Management Responsibilities (SOSBMR) scale was adapted from the Diabetes Family Responsibility Questionnaire (DFRQ; Anderson et al., 1990), and Barbara Anderson was consulted during measurement development. The DFRQ consists of 17 items that include diabetes regimen and general health-related tasks, in which the parent and child identify the family member who is responsible for a specified task on a three-point scale: child responsibility, parent responsibility, and shared responsibility. Higher scores indicate greater child responsibility. Additionally, a box marked N/A is provided for tasks that are not relevant for the child's care. Items on the DFRQ fall into three subscales including general health maintenance, regimen tasks, and social presentation of diabetes. The SOSBMR is similar to the DFRQ, however the SOSBMR consists of 34 items regarding spina bifida-related responsibilities (e.g., catheterization, bowel programs). An item mean score was computed for each reporter. Mother-, father-, and child-report scores were moderately correlated ($r = .65$ to $.76$). Thus, the mean across reporters was used when parent- and child-reports were available. Internal consistency could not be computed due to a low number of participants that completed all test items. Nonetheless, prior studies have demonstrated adequate internal consistency on the DFRQ ($\alpha = .85$; Anderson et al., 1990).

Approach to Data Analyses

Means, standard deviations, and ranges were computed for each of the control, independent, and dependent variables. To test Hypothesis 1, several analyses were conducted to determine whether children and adolescents with spina bifida would

demonstrate higher levels of inattention and executive dysfunction as compared to typically developing youth. Specifically, t-test analyses were computed for the attention and executive function measures when normative data was available (i.e., test data, BRIEF) in order to compare mean attention and executive function ability in comparison to data from a normative population. For the SNAP-IV, the percentage of individuals with spina bifida that demonstrated inattentive and hyperactive/impulsive symptoms above 95% of the general population were computed based on the criteria of Swanson and colleagues (1983).

In order to investigate Hypotheses 2 through 6, a series of hierarchical regression analyses were conducted to examine the association between neuropsychological function (attention, executive function), parenting behaviors (acceptance, behavioral control, psychological control), and healthcare behaviors (medical adherence, medical autonomy). Separate hierarchical regression analyses were run for each of the six maternal (three observed, three perceived) and six paternal (three observed, three perceived) parenting behaviors for the attention data predicting medical adherence and autonomy outcome variables. Similarly, separate hierarchical regression analyses were run for each of the six maternal (three observed, three perceived) and six paternal (three observed, three perceived) parenting behaviors for the executive function data predicting medical adherence and autonomy outcome variables. Thus, a total of 24 regression analyses were computed for the medical adherence outcome and a total of 24 regression analyses were computed for the medical autonomy outcome. The same 48 hierarchical regression analyses were run again including only youth with WASI scores above 85, in order to rule out the effects of low cognitive function on study findings.

Prior to running regression analyses, continuous predictor variables were centered by subtracting the appropriate sample means, resulting in a revised sample mean of 0 (Aiken & West, 1991; Holmbeck, 2002). For each regression analysis, independent variables and interactions among the independent variables were entered in the following order: (Step 1) IQ, age, and level of disability control variables, (Step 2) parenting behavior main effect, attention/executive function test data main effect, and attention/executive function questionnaire data main effect, and (Step 3) parenting behavior X attention/executive function test data and parenting behavior X attention/executive function questionnaire data interactions (Aiken & West, 1991; Holmbeck, 2002). More specifically, IQ, age, and disability level were entered as the first step to control for the effects of these variables for all regression analyses. Next, the main effects were entered, followed by the interaction variables, based on guidelines established by Aiken and West (1991) and Holmbeck (2002). For example, to examine the influence of attention and perceived maternal acceptance on medical adherence, after controlling for age, IQ, and level of disability, the following steps were entered into the hierarchical regression model: (Step 1) IQ, age, and level of disability control variables, (Step 2) perceived maternal acceptance main effect, attention test data main effect, and attention questionnaire data main effect, and (Step 3) perceived maternal acceptance X attention test data interaction and perceived maternal acceptance X attention questionnaire data interaction. In general, if a significant 2-way interaction emerged in the regression analyses, then simple slopes and relevant significance tests were computed for the different levels of the parenting behavior variables to determine the nature of the

association between neuropsychological functioning and healthcare behaviors (Aiken & West, 1991; Holmbeck, 2002).

Power analyses were conducted based on guidelines established by Cohen (1992). Cohen (1992) recommends that quantitative behavioral science research strive to obtain power of .80. Given the number of predictors in the multiple regression models (i.e., eight) and an alpha value set at .05, a sample size of 107 is required to detect a significant medium effect size ($f^2 = .15$) at .80 power. The sample size was sufficient to detect a medium effect size in all regression analyses (n's = 110 to 119), except for regression models that included paternal parenting behaviors. For these analyses, the sample size was only sufficient to detect a large effect size (*n*'s = 88 to 95). Analyses were continued with the awareness that a smaller number of fathers reduced the power to detect medium level effects for these analyses.

CHAPTER FOUR

RESULTS

Preliminary Analyses

Means, standard deviations, and scale ranges for variables utilized in the analyses are presented in Table 1. Outlier and skewness analyses were conducted for all variables using guidelines established by Tabachnick and Fidell (2001). First, univariate descriptive statistics were inspected to assess for out-of-range variables, plausible means and standard deviations, and univariate outliers. Two scores with extremely low z-scores on the perceived maternal acceptance variable were found to be univariate outliers (z-score < -3.29). In order to reduce the impact of the outliers on data analyses, the raw score for each outlier variable was changed to reflect a new raw score that was one unit larger than the next most extreme score in the distribution (Tabachnick & Fidell, 2001). Second, skewness analyses were conducted to identify non-normal variable distributions. Conservative alpha levels (.001) were employed to evaluate the significance of skewness, in which z-score values greater than 3.29 were considered significantly skewed and transformations were conducted to create approximate normal distributions. These analyses revealed that the following variables were significantly skewed: perceived maternal acceptance (z-score = -5.72), observed maternal behavioral control (z-score = -3.35), and parent-report of child medical adherence (i.e, SBSMP; z-score = -4.26). First

Table 1. Means, Standard Deviations, and Ranges for Control, Attention, Executive Function, Parenting, and Outcome Variables.

Variable	N	Mean	SD	Range
Control Variables				
IQ (WASI)	132	85.68	19.68	82
Age	139	11.43	2.46	7
Level of Disability	132	2.89	1.08	3
Attention Variables				
Neuro Test Data	129	6.53	2.74	11.60
Parent/Teacher-Report (SNAP-IV)	136	1.09	.59	2.56
Executive Function Variables				
Neuro Test Data	126	7.00	3.15	13.60
Parent/Teacher-Report (BRIEF)	136	1.70	.32	1.67
Perceived Parenting Variables (CRPBI-P)				
Maternal Acceptance	127	2.66	.24	1.29
Paternal Acceptance	100	2.54	.27	1.25
Maternal Behavioral Control	127	2.03	.27	1.50
Paternal Behavioral Control	100	2.01	.30	1.40
Maternal Psychological Control	127	2.06	.30	1.40
Paternal Psychological Control	100	1.92	.33	1.40
Observed Parenting Variables (Macro Data)				
Maternal Acceptance	132	3.48	.34	1.55
Paternal Acceptance	104	3.33	.37	1.84
Maternal Behavioral Control	133	3.67	.41	2.25
Paternal Behavioral Control	104	3.27	.53	2.62
Maternal Psychological Control	134	2.28	.35	1.69
Paternal Psychological Control	105	2.30	.34	1.54
Outcome Variables				
Medical Adherence (SBSMP)	123	-.01	.45	3.01
Medical Autonomy (SOSBMR)	124	1.82	.41	1.87

Notes. SD = standard deviation; WASI = Wechsler Abbreviated Scale of Intelligence; SNAP-IV = Swanson, Nolan, and Pelham – Fourth Edition; BRIEF = Behavioral Rating Inventory of Executive Function; CRPBI-P = Child Report of Parent Behavior Inventory – Parent Report; SBSMP = Spina Bifida Self-Management Profile; SOSBMR = Sharing of Spina Bifida Management Responsibilities.

square root transformations were conducted on these variables. The perceived maternal acceptance variable continued to be significantly skewed after square root transformations (z-score = 4.43). Thus, logarithm transformations were computed on this variable only, and this transformed variable was no longer significantly skewed.

Preliminary analyses were conducted to determine the degree of association among the attention and executive function variables (see Table 2). Correlations across the neuropsychological test data and parent/teacher-report data (i.e., BRIEF, SNAP-IV) for attention (r = -.31) and executive function (r = -.29) were modestly associated with each other. The correlations within the parent/teacher-report (r = .85) and neuropsychological test data (r = .66) for attention and executive function were higher than the correlations across methods. Thus, for psychometric reasons, associations between neuropsychological functioning and healthcare behaviors were expected to be more similar depending on the method of assessment (i.e., parent/teacher-report versus neuropsychological test data), rather than the construct being assessed (i.e., attention, executive function).

Pearson's correlation coefficients were also conducted to determine the degree of association among the parenting behavior constructs (see Table 2). For the questionnaire data (CRPBI-P), correlations between the perceived maternal parenting behaviors were all less than r = .40. The correlations between the perceived paternal parenting behaviors were also less than r = .40, except for the association between behavioral control and psychological control (r = .46). Correlations among the observational data were higher than those for the questionnaire data. For maternal and paternal parenting behaviors, correlations between acceptance and behavioral control were .48 and .56, correlations

Table 2. Pearson Correlations for Control, Attention, Executive Function, Parenting, and Outcome Variables.

Variables	1	2	3	4	5	6	7	8	9	10	11
1. IQ (WASI)	---										
2. Age	-.24**	---									
3. Disability	-.20*	.11	---								
4. Attention Test Data	.63**	.02	-.07	---							
5. SNAP-IV	-.27**	-.05	.08	-.31**	---						
6. Executive Function Test Data	.75**	-.24**	-.17	.66**	-.36**	---					
7. BRIEF	-.23**	-.13	.06	-.32**	.85**	-.29**	---				
8. Per. Acceptance (M; LOG)	-.05	-.14	.01	.07	-.02	.01	-.13	---			
9. Per. Acceptance (F)	-.03	-.25*	.02	-.10	-.08	-.00	-.13	.37**	---		
10. Per. Beh. Cont. (M)	.13	.02	-.04	.22*	-.07	.14	-.10	-.19*	-.22*	---	
11. Per. Beh. Cont. (F)	.05	-.20	-.06	.07	.12	.20	.21*	-.22*	-.21*	-30**	---
12. Per. Psych. Cont. (M)	-.26**	.03	.05	-.28**	.16	-.20	.12	-.09	-.10	.36**	.27**
13. Per. Psych. Cont. (F)	-.32*	-.08	-.06	-.21*	.15	-.06	.23*	-.14	.03	.01	.46**
14. Obs. Acceptance (M)	.22*	-.09	-.03	.18	-.02	.14	-.13	.35**	.20	-.15	-.18
15. Obs. Acceptance (F)	.15	-.06	.04	.07	-.05	.12	-.13	.12	.27**	-.18	-.27**
16. Obs. Beh. Cont. (M; SQRT)	.10	-.05	.07	.14	.03	.10	.05	.30**	.07	-.12	-.08
17. Obs. Beh. Cont. (F)	.07	-.24*	-.01	-.02	.09	.08	.02	.08	.24*	-.15	-.03
18. Obs. Psych Cont. (M)	-.27**	.02	-.01	-.18*	.13	-.19*	.20*	-.19*	.10	.04	.16
19. Obs. Psych Cont. (F)	-.15	-.06	-.15	-.17	.12	-.15	.18	-.06	-.06	.06	.30**
20. SBSMP (SQRT)	-.17	.08	.24**	-.16	-.24**	-.17	-.35**	.21*	.10	-.16	-.23*
21. SOSBMR	.30**	.41**	-.20*	.37**	-.11	.25**	-.18*	-.12	-.24*	.13	-.23

Notes. WASI = Wechsler Abbreviated Scale of Intelligence; SNAP-IV = Swanson, Nolan, and Pelham – Fourth Edition; BRIEF = Behavioral Rating Inventory of Executive Function; Per. = Perceived; Obs. = observed; M = parenting behavior of mothers; F = parenting behaviors of fathers; Beh. Cont. = behavioral control; Psych. Cont. = psychological control; SQRT = square root transformation conducted on variable; LOG = logarithm transformation conducted on variable; SBSMP = Spina Bifida Self-Management Profile; SOSBMR = Sharing of Spina Bifida Management Responsibilities.

*p < .05; **p < .01; ***p < .001.

Table 2 cont. Pearson Correlations for Control, Attention, Executive Function, Parenting, and Outcome Variables.

Variables	12	13	14	15	16	17	18	19	20	21
1. IQ (WASI)										
2. Age										
3. Disability										
4. Attention Test Data										
5. SNAP-IV										
6. Executive Function Test Data										
7. BRIEF										
8. Per. Acceptance (M; LOG)										
9. Per. Acceptance (F)										
10. Per. Beh. Cont. (M)										
11. Per. Beh. Cont. (F)										
12. Per. Psych. Cont. (M)	---									
13. Per. Psych. Cont. (F)	.27**	---								
14. Obs. Acceptance (M)	-.32**	-.14	---							
15. Obs. Acceptance (F)	-.32**	-.18	.60**	---						
16. Obs. Beh. Cont. (M; SQRT)	-.15	-.06	.48**	.11	---					
17. Obs. Beh. Cont. (F)	-.26*	-.14	.16	.56**	-.27**	---				
18. Obs. Psych Cont. (M)	.28**	.18	-.66**	-.59**	-.07	-.26**	---			
19. Obs. Psych Cont. (F)	.20	.28**	-.58**	-.74**	-.16	-.20*	.77**	---		
20. SBSMP (SQRT)	-.01	-.02	.31**	.06	.30**	-.19	-.08	-.16	---	
21. SOSBMR	-.12	-.24*	-.03	.06	-.05	-.01	-.13	-.10	-.19*	---

Notes. WASI = Wechsler Abbreviated Scale of Intelligence; SNAP = Swanson, Nolan, and Pelham – Fourth Edition; BRIEF = Behavioral Rating Inventory of Executive Function; Per. = perceived; Obs. = observed; M = parenting behavior of mothers; F = parenting behaviors of fathers; Beh. Cont. = behavioral control; Psych. Cont. = psychological control; SQRT = square root transformation conducted on variable; LOG = logarithm transformation conducted on variable; SBSMP = Spina Bifida Self-Management Profile; SOSBMR = Sharing of Spina Bifida Management Responsibilities.
*p < .05; **p < .01; ***p < .001.

between acceptance and psychological control were -.66 and -.74, and correlations between behavioral control and psychological control were -.07 and -.20, respectively. Thus, the association between parenting behaviors and healthcare behaviors were expected to be more similar for the observational data than for the questionnaire data, particularly for analyses investigating acceptance and psychological control. Higher correlations between the observational data versus questionnaire data have also been evident in other studies investigating these parenting constructs (e.g., Holmbeck et al., 2002b). Pearson's correlation coefficient analyses were also computed to determine the degree of association across methods of measuring parenting behaviors. None of the correlations between observational and questionnaire data exceeded r = .40 for any of the following parenting behaviors: maternal acceptance (r = .35), behavioral control (r = -.12), and psychological control (r = .28) and paternal acceptance (r = .27), paternal behavioral control (r = -.03), and paternal psychological control (r = .28).

In addition, the association between the healthcare behavior outcomes was also investigated (see Table 2). Pearson correlations indicated only a weak association between medical adherence and medical autonomy (r = -.19).

T-Test Analyses

T-test analyses were computed to assess Hypothesis 1, which predicted that children and adolescents with spina bifida would demonstrate higher levels of inattention and executive dysfunction, as compared to normative data. Mean scaled scores, standard deviations, and ranges for the attention and executive function test data are presented on Table 3. Higher scaled scores represent higher levels of functioning. In comparison to the normative sample mean scaled score of 10, performance on the TEA-Ch, CAS, and

Table 3. Means, Standard Deviations, Ranges, and t-Test Analyses for Attention and Executive Function Neuropsychological Subtests.

Variable	N	Mean	SD	Range	t-Test
TEA-Ch					
Sky Search	124	6.55	3.71	16	-10.36***
Score!	124	7.60	3.56	14	-7.50***
Sky DT	121	6.01	4.57	18	-9.60***
Score DT	122	7.06	3.71	14	-8.76***
CAS					
Planned Connections	120	6.15	3.53	13	-11.95***
Number Detection	122	6.13	3.33	14	-12.82***
D-KEFS					
Letter Fluency	126	7.00	3.70	17	-9.11***
Category Fluency	126	7.12	3.81	15	-8.50***
Switch – Correct	125	7.26	3.92	18	-7.82***
Switch – Accuracy	125	7.66	3.83	18	-6.83***

Notes. Means reflect scaled scores, with higher scores representing higher cognitive ability; t-tests are based on comparisons with published norms (Mean Scaled Score = 10; Standard Deviation = 3); TEA-Ch = Test of Everyday Attention for Children; CAS = Cognitive Assessment System; D-KEFS = Delis Kaplan Executive Function System. ***$p < .001$.

D-KEFS subtests were low average among youth with spina bifida (i.e., scaled scores between 6 and 7). T-test analyses were conducted to determine whether mean scores on the neuropsychological subtests among youth with spina bifida and mean scores based on normative data for same-aged peers were statistically different from each other. Consistent with study hypotheses, youths' performance on neuropsychological measures of attention and executive function was statistically lower than normative data across all analyses (i.e., $p < .001$ for all t-test analyses).

Mean T-scores, standard deviations, and ranges for the BRIEF subtests and indices are presented on Table 4 for parent- and teacher-reports. Higher T-scores

Table 4. Means, Standard Deviations, Ranges, and t-Test Analyses for BRIEF Subtests.

	Parent-Report					Teacher-Report					
BRIEF Subtest	N	Mean	SD	Range	Parent-Norms[1]	N	Mean	SD	Range	Teacher-Norms[1]	Parent-Teacher[2]
Initiate	123	56.34	9.49	38.00	7.41***	119	65.69	15.57	59.00	10.99***	-5.67***
Working Memory	123	57.29	10.13	47.50	7.98***	119	67.44	18.28	69.00	10.40***	-6.16***
Plan/Organize	123	56.09	9.71	46.00	6.96***	119	65.41	14.46	56.00	11.63***	-6.21***
Org. of Materials	123	50.39	8.85	36.50	.49	118	67.51	21.65	95.00	8.78***	-8.47***
Monitor	123	54.23	9.47	41.00	4.95***	120	60.57	13.57	64.00	8.53***	-4.89***
Metacog. Index	123	55.82	9.35	44.50	6.91***	118	67.05	16.85	67.00	11.04***	-7.03***
Inhibit	123	50.87	8.37	38.00	1.16***	118	53.20	12.49	73.00	2.79**	-1.80
Shift	123	55.70	9.70	47.00	6.52***	119	59.52	17.22	90.00	6.03***	-2.14*
Emotional Control	123	53.51	10.24	48.00	3.80***	118	55.04	15.56	84.00	3.52**	-.68
Beh. Reg. Index	123	53.31	9.32	43.50	3.94***	118	55.98	15.17	76.00	4.28***	-1.66
Global Exec. Comp.	123	55.26	9.28	46.00	6.29***	118	63.84	16.05	76.00	9.37***	-5.53***

Notes. N's vary for teacher-report due to missing data. Scores listed are T-scores, with higher scores indicating greater impairment; Mean T-scores based on published norms = 50; [1] = one-sample t-test; [2] = paired-samples t-test; BRIEF = Behavioral Rating Inventory of Executive Function; SD = standard deviation; Org. = organization; Metacog. = metacognitive; Beh. Reg. = behavioral regulation; Global Exec. Comp. = global executive composite.
*p < .05; ***p<.001

represent higher levels of executive dysfunction. In comparison to a normative sample T-score mean of 50, youth with spina bifida in this sample had T-scores ranging from 50.39 (50th percentile) to 57.29 (77th percentile) based on parent-report, and T-scores ranging from 53.20 (63rd percentile) to 67.55 (96th percentile) based on teacher-report. T-test analyses were conducted to determine whether mean scores on the BREIF subtests and indices among youth with spina bifida and mean scores based on normative data were statistically different from each other. Consistent with study hypotheses, parent-report of youth executive dysfunction was statistically higher among youth with spina bifida, in comparison to normative data (i.e., $p < .001$), except for the Organization of Materials subtest. Teacher-report of youth executive dysfunction was also statistically higher among youth with spina bifida, in comparison to normative data (i.e., $p < .001$ for t-test analyses). Paired sample t-test analyses were also conducted to compare mean T-scores based on parent-report and mean T-scores based on teacher-report. Across all analyses, teachers reported higher levels of executive dysfunction among youth with spina bifida, as compared to parents' report of executive dysfunction (i.e., $p = .00$ to $.03$), except for the Inhibit and Emotional Control subtests and the Behavioral Control Index.

Normative data were not provided for the SNAP-IV subtest, thus it was not possible to compare parent- and teacher-report of inattention and hyperactivity/ impulsivity with a normative population. However, item mean score for determining clinical significance (95th percentile) was provided. The percentage of youth that fell above 5% of the population was computed for the Inattentive, Hyperactive/Impulsive, and Combined scales (see Table 5), based on criteria established by Swanson, Nolan, and Pelham – Fourth Edition (SNAP-IV; Swanson et al., 1983). For the inattentive subtest,

11.2% and 6.6% of the spina bifida sample's scores fell above the 5% cut-off, based on
parent- and teacher-report respectively. For the hyperactive/impulsive subtest, 0.8% and 3.3% of the spina bifida sample's scores fell above the 5% cut-off, based on parent- and teacher-report respectively. Lastly, 0.0% and 2.5% of the spina bifida sample's, for parent- and teacher-report respectively, fell above the 5% cut-off for the combined scale.

Table 5. Percentage of Children with Spina Bifida in the Clinical Range for Symptoms of ADHD, Based on the SNAP-IV.

	Parent-Report		Teacher-Report	
SNAP-IV Subtest	N	Above 95th Percentile Cut Off (n)	N	Above 95th Percentile Cut Off (n)
Inattentive	125	11.2%(14)	122	6.6%(8)
Hyperactive/Impulsive	125	0.8%(1)	122	3.3%(4)
Combined	125	0.0%(0)	122	2.5%(3)

Notes. SNAP-IV = Swanson, Nolan, and Pelham – Fourth Edition.

Regression Analyses

Attention, Maternal Parenting Behaviors, and Medical Adherence.

A series of hierarchical regression analyses were conducted for each of the three perceived and three observed maternal parenting behaviors, resulting in a total of six hierarchical regression analyses (see Tables 6 and 7). Analyses were computed to examine the influence of attention (based on test data and parent/teacher-report data; Hypothesis 2) and maternal parenting behaviors (Hypotheses 3 and 4) on medical adherence, after controlling for age, IQ, and level of disability. In addition, analyses were

Table 6. Multiple Regression Analyses: Attention and Perceived Maternal Parenting Behaviors as Predictors of Medical Adherence.

Step and variable	R	β	FΔ
Perceived Maternal Acceptance			
(N = 110)			
Step 1: Disability Level	.23	.23	6.00*
IQ	.25	-.10	1.16
Age	.25	-.01	.00
Step 2: SNAP-IV	.41	-.33	13.39***
Acceptance	.45	.18	4.11*
Attention Test Data	.47	-.17	2.38
Step 3: Acceptance X SNAP-IV	.47	-.08	.61
Acceptance X Attention Test Data	.47	.01	.01
Perceived Maternal Behavioral Control			
(N = 110)			
Step 1: Disability Level	.23	.23	6.00*
IQ	.25	-.10	1.16
Age	.25	-.01	.00
Step 2: SNAP-IV	.41	-.33	13.39***
Beh. Control	.45	-.18	4.02*
Attention Test Data	.45	-.11	.88
Step 3: Beh. Control X SNAP-IV	.46	.06	.36
Beh. Control X Attention Test Data	.46	.03	.08
Perceived Maternal Psychological Control			
(N = 110)			
Step 1: Disability Level	.23	.23	6.00*
IQ	.25	-.10	1.16
Age	.25	-.01	.00
Step 2: SNAP-IV	.41	-.33	13.39***
Attention Test Data	.43	-.15	1.74
Psych. Control	.43	-.08	.67
Step 3: Psych. Control X SNAP-IV	.43	-.03	.11
Psych. Control X Attention Test Data	.43	.01	.02

Notes. Logarithm transformations for the maternal acceptance variable and square root transformations for the medical adherence variable (i.e., Spina Bifida Self-Management Profile) were utilized in the above analyses; IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; SNAP-IV = Swanson, Nolan, and Pelham – Fourth Edition; Beh. Control = behavioral control; Psych. Control = psychological control.

*p < .05; ***p < .001.

Table 7. Multiple Regression Analyses: Attention and Observed Maternal Parenting Behaviors as Predictors of Medical Adherence.

Step and variable	R	β	FΔ
Observed Maternal Acceptance			
(N = 112)			
Step 1: Disability Level	.24	.24	6.61*
IQ	.26	-.11	1.40
Age	.26	.00	.00
Step 2: Acceptance	.46	.39	19.48***
SNAP-IV	.56	-.34	16.84***
Attention Test Data	.58	-.17	2.96
Step 3: Acceptance X SNAP-IV	.58	.02	.05
Acceptance X Attention Test Data	.58	.00	.00
Observed Maternal Behavioral Control			
(N = 113)			
Step 1: Disability Level	.25	.25	7.60**
IQ	.28	-.13	2.08
Age	.28	.01	.00
Step 2: Beh. Control	.44	.35	15.57***
SNAP-IV	.55	-.33	16.16***
Attention Test Data	.57	-.22	4.53*
Step 3: Beh. Control X Attention Test Data	.59	.13	2.69
Beh. Control X SNAP-IV	.60	.15	3.07
Observed Maternal Psychological Control			
(N = 113)			
Step 1: Disability Level	.25	.25	7.60**
IQ	.28	-.13	2.08
Age	.28	.01	.00
Step 2: SNAP-IV	.43	-.33	14.19***
Attention Test Data	.45	-.17	2.42
Psych. Control	.46	-.10	1.29
Step 3: Psych. Control X SNAP-IV	.48	-.14	2.16
Psych. Control X Attention Test Data	.48	.03	.14

Notes. Square root transformations for the maternal behavioral control and medical adherence (i.e., Spina Bifida Self-Management Profile) variables were utilized in the above analyses; IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; SNAP-IV = Swanson, Nolan, and Pelham – Fourth Edition; Beh. Control = behavioral control; Psych. Control = psychological control.

*p < .05; **p < .01; ***p < .001.

also computed to determine whether the nature or magnitude of the association between attention and medical adherence differed as a function of maternal adaptive (Hypothesis 5) and maladaptive (Hypothesis 6) parenting behaviors. Separate hierarchical regression analyses were run for each of the maternal parenting behaviors including perceived acceptance (after logarithm transformation), behavioral control, and psychological control and observed acceptance, behavioral control (after square root transformation), and psychological control. The square root transformation of the medical adherence outcome variable was utilized in all regression analyses. Analyses were also run without transformations on the skewed variables (i.e., perceived acceptance, observed behavioral control, medical adherence). No significant differences emerged between analyses run with transformed variables versus non-transformed variables. As such, analyses run without transformations will not be discussed further.

Perceived Maternal Parenting Behaviors. After controlling for age, IQ, and level of disability, a significant positive main effect emerged for perceived maternal acceptance predicting medical adherence [$t(105) = 2.03$, $p < .05$; see Table 6]. In other words, consistent with study hypotheses, higher levels of perceived maternal acceptance were associated with higher levels of medical adherence. A significant main effect also emerged for higher levels of perceived maternal behavioral control predicting higher levels of medical adherence [$t(105) = -2.00$, $p < .05$]. It is important to note that the Pearson correlation coefficient for the association between perceived maternal behavioral control and medical adherence variables was not significant ($r = -.16$; see Table 2). Thus, the significant main effect that emerged in the regression model is likely the result of a suppression effect. Given that the perceived maternal behavioral control variable was not

significantly associated medical adherence, this finding represents a classical suppression effect, in which the inclusion of additional variables into the hierarchical regression model suppressed the error variance and improved the predictive utility of the behavioral control variable (Gaylord-Harden, Cunningham, Holmbeck, & Grant, 2010). Thus, this finding will not be further interpreted.

Consistent with study hypotheses, a significant negative main effect emerged for parent/teacher-report of child inattention (SNAP-IV) predicting medical adherence, after controlling for age, IQ, and level of disability [$t(106) = -3.66$, $p < .001$; see Table 6], such that higher levels of inattention were associated with lower levels of medical adherence. Lastly, level of disability significantly predicted medical adherence [$t(109) = 2.45$, $p < .05$], such that greater impairment in gross motor functioning was associated with higher levels of medical adherence. The association between gross motor functioning and medical adherence was similar across all subsequent analyses and, thus, will not be repeated.

Observed Maternal Parenting Behaviors. Significant positive main effects emerged for observed maternal acceptance [$t(108) = 4.41$, $p < .001$] and observed maternal behavioral control [$t(109) = 3.95$, $p < .001$] for predicting medical adherence, after controlling for age, IQ, and level of disability (Table 7). In other words, consistent with study hypotheses, higher levels of maternal acceptance and higher levels of maternal behavioral control were associated with higher levels of medical adherence.

Further supporting study hypotheses, lower levels of parent/teacher-report of child inattention (SNAP-IV) was a significant predictor of higher levels of medical adherence, after controlling for age, IQ, and disability [$t(107) = -4.10$, $p < .001$; $t(108) = -4.02$, $p <$

.001; $t(109) = -3.77$, $p < .001$; Table 7]. A significant negative main effect also emerged

for better performance on attention test data predicting higher levels medical adherence [$t(107) = -2.13$, $p < .01$]. However, given the non-significant association between the attention test data and medical adherence variables based on Pearson correlation analyses ($r = -.16$, see Table 2), the significant negative main effect that emerged in the regression model is likely due to a suppression effect. Similar to the previously discussed suppression effect, the non-significant association between the attention test data and the medical adherence variable suggests that this finding represents a classical suppression effect. As such, it will not be further interpreted.

Summary of Analyses. Taken together, several maternal parenting behaviors and disability factors emerged as significant predictors of medical adherence. Consistent with Hypothesis 2, lower levels of inattention (based on parent/teacher-report only) significantly predicted higher levels of medical adherence, after controlling for age, IQ, and level of disability. Consistent with Hypothesis 3, higher levels of both observed and perceived maternal acceptance and higher levels of observed maternal behavioral control significantly predicted higher levels of medical adherence, after controlling for age, IQ, and level of disability. No significant effects emerged for the impact of maternal psychological control on medical adherence (Hypothesis 4) or maternal parenting behaviors moderating the relation between inattention and medical adherence (Hypothesis 5 and 6). Lastly, greater impairment in gross motor functioning significantly predicted higher levels of medical adherence.

A series of hierarchical regression analyses were conducted for each of the three perceived and three observed paternal parenting behaviors, resulting in a total of six hierarchical regression analyses (see Tables 8 and 9). Similar to the previously discussed analyses, regression analyses were computed to examine the influence of attention (based on test data and parent/teacher-report data; Hypothesis 2) and paternal parenting behaviors (Hypotheses 3 and 4) on medical adherence, after controlling for age, IQ, and level of disability. In addition, analyses were also computed to determine whether the nature or magnitude of the association between attention and medical adherence differed as a function of paternal adaptive (Hypothesis 5) or maladaptive (Hypothesis 6) parenting behaviors. Separate hierarchical regression analyses were run for each of the paternal parenting behaviors including perceived acceptance, behavioral control, and psychological control and observed acceptance, behavioral control, and psychological control. The square root transformation of the medical adherence outcome variable was utilized in all regression analyses. Analyses were also run without a transformation of the medical adherence variable. No significant differences emerged between analyses run with the transformed versus the non-transformed adherence variable. As such, only the analyses including the transformation will be discussed below.

Perceived Paternal Parenting Behaviors. No significant main effects emerged for perceived paternal parenting behaviors predicting medical adherence (see Table 8). Nonetheless, consistent with study hypotheses, significant negative main effects emerged for the association between parent/teacher-report of inattention (SNAP-IV) and medical adherence, after controlling for age, IQ, and level of disability [$t(84) = -2.67$, $p < .01$].

Table 8. Multiple Regression Analyses: Attention and Perceived Paternal Parenting Behaviors as Predictors of Medical Adherence.

Step and variable	R	β	FΔ
<u>Perceived Paternal Acceptance</u>			
(N = 88)			
Step 1: Disability Level	.33	.33	10.48**
IQ	.34	-.08	.64
Age	.34	.04	.12
Step 2: SNAP-IV	.43	-.28	7.11**
Attention Test Data	.47	-.24	3.37
Acceptance	.47	-.02	.05
Step 3: Acceptance X SNAP-IV	.48	-.11	1.06
Acceptance X Attention Test Data	.48	-.05	.18
<u>Perceived Paternal Behavioral Control</u>			
(N = 88)			
Step 1: Disability Level	.33	.33	10.48**
IQ	.34	-.08	.64
Age	.34	.04	.13
Step 2: SNAP-IV	.43	-.28	7.11**
Attention Test Data	.47	-.24	3.37
Beh. Control	.48	-.13	1.74
Step 3: Beh. Control X Attention Test Data	.52	.22	4.05*
Beh. Control X SNAP-IV	.52	-.01	.01
<u>Perceived Paternal Psychological Control</u>			
(N = 88)			
Step 1: Disability Level	.33	.33	10.48**
IQ	.34	-.08	.64
Age	.34	.04	.12
Step 2: SNAP-IV	.43	-.28	7.11**
Attention Test Data	.47	-.24	3.37
Psych. Control	.47	.03	.06
Step 3: Psych. Control X SNAP-IV	.47	.05	.28
Psych. Control X Attention Test Data	.47	.02	.02

Notes. Square root transformations for the medical adherence variable (i.e., Spina Bifida Self-Management Profile) was utilized in the above analyses; IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; SNAP-IV = Swanson, Nolan, and Pelham – Fourth Edition; Beh. Control = behavioral control; Psych. Control = psychological control.
*p < .05; **p < .01.

Table 9. Multiple Regression Analyses: Attention and Observed Paternal Parenting Behaviors as Predictors of Medical Adherence.

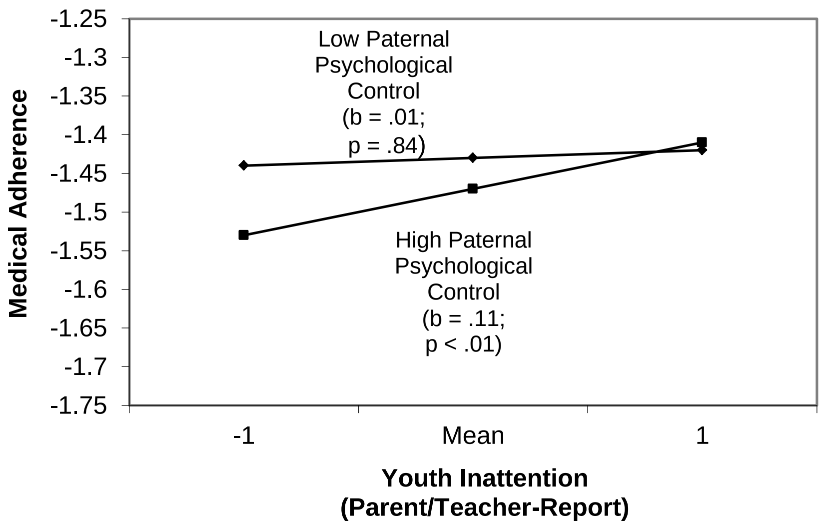
Step and variable	R	β	FΔ
<u>Observed Paternal Acceptance</u>			
(N = 89)			
Step 1: Disability Level	.38	.38	14.37***
IQ	.39	-.10	.96
Age	.39	.00	.00
Step 2: SNAP-IV	.45	-.24	5.53*
Attention Test Data	.47	-.18	1.95
Acceptance	.47	.05	.25
Step 3: Acceptance X Attention Test Data	.49	-.13	1.63
Acceptance X SNAP-IV	.49	.04	.11
<u>Observed Paternal Behavioral Control</u>			
(N = 89)			
Step 1: Disability Level	.38	.38	14.37***
IQ	.39	-.10	.96
Age	.39	.00	.00
Step 2: SNAP-IV	.45	-.24	5.53*
Beh Control	.48	-.18	3.37
Attention Test Data	.50	-.18	2.05
Step 3: Beh. Control X SNAP-IV	.53	-.18	3.23
Beh. Control X Attention Test Data	.56	-.20	3.45
<u>Observed Paternal Psychological Control</u>			
(N = 90)			
Step 1: Disability Level	.38	.38	15.44***
IQ	.39	-.09	.73
Age	.39	-.01	.01
Step 2: SNAP-IV	.46	-.24	5.62*
Attention Test Data	.48	-.19	2.14
Psych. Control	.49	-.12	1.53
Step 3: Psych. Control X SNAP-IV	.53	-.22	5.17*
Psych. Control X Attention Test Data	.53	.02	.04

Notes. Square root transformations for the medical adherence variable (i.e., Spina Bifida Self-Management Profile) was utilized in the above analyses; IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; SNAP-IV = Swanson, Nolan, and Pelham – Fourth Edition; Beh. Control = behavioral control; Psych. Control = psychological control.
*p < .05; ***p<.001

Specifically, lower levels of inattention based on parent/teacher-report were associated with higher levels of medical adherence. A significant perceived paternal behavioral control X attention test data interaction also emerged [t(81) = 2.01, p < .05], but follow-up simple slope analyses were non-significant.

Observed Paternal Parenting Behaviors. No significant main effects emerged for observed paternal parenting behaviors predicting medical adherence (see Table 9). Consistent with study hypotheses, significant negative main effects emerged for parent/teacher-report of inattention (SNAP-IV) predicting medical adherence, after controlling for age, IQ, and level of disability [t(85) = -2.35, p < .05; t(86) = -2.37, p < .05]. In other words, lower levels of inattention based on parent/teacher-report were associated with higher levels of medical adherence. This association was qualified by a significant observed paternal psychological control X SNAP-IV interaction [see Figure 2; t(83) = -2.27, p < .05].

Figure 2. Parent/Teacher-Report of Youth Inattention by Observed Paternal Psychological Control 2-Way Interaction for Predicting Medical Adherence



Follow-up simple slope analyses revealed a significant negative relationship between attention and medical adherence among children with fathers who demonstrated higher levels of observed psychological control [$t(86) = -3.40$, $p < .01$], such that lower levels of parent/teacher-report of attention predicted higher levels of medical adherence. Among children with fathers who demonstrated lower levels of observed psychological control, there was no significant relation between parent/teacher report of inattention and medical adherence [$t(86) = .21$, $p = .84$]. In other words, in contrast to study hypotheses, higher levels of inattention was associated with higher levels of medical adherence if fathers displayed higher levels of psychological control.

Summary of Analyses. Taken together, several disability factors emerged as significant predictors of medical adherence. Consistent with Hypothesis 2, lower levels of inattention based on parent/teacher-report significantly predicted higher levels of medical adherence, after controlling for age, IQ, and level of disability. Contrary to Hypotheses 3 and 4, no significant direct effects emerged for paternal parenting behaviors predicting medical adherence. However, observed paternal psychological control moderated the relation between inattention and medical adherence, such that lower levels of parent/teacher-report of attention predicted higher levels of medical adherence only among children with fathers who displayed higher levels of psychological control. This finding is in contrast to Hypothesis 6,which predicted that higher levels of paternal psychological control would exacerbate the negative effects of inattention on medical adherence. In other words, among children with fathers who demonstrated higher levels of psychological control, higher levels of inattention were significantly associated with

higher levels of medical adherence. No significant moderating effects emerged for paternal acceptance or behavioral control (Hypothesis 5).

Associations between Executive Functioning, Maternal Parenting Behaviors,and Medical Adherence.

A series of hierarchical regression analyses were conducted for each of the three perceived and three observed maternal parenting behaviors, resulting in a total of six hierarchical regression analyses (see Tables 10 and 11). Analyses were computed to examine the influence of executive function (based on test data and parent/teacher-report data; Hypothesis 2) and maternal parenting behaviors (Hypotheses 3 and 4) on medical adherence, after controlling for age, IQ, and level of disability. In addition, analyses were also computed to determine whether the nature or magnitude of the association between executive function and medical adherence differed as a function of maternal adaptive (Hypothesis 5) or maladaptive (Hypothesis 6) parenting behaviors (Hypotheses 5 and 6). Separate hierarchical regression analyses were run for each of the maternal parenting behaviors including perceived acceptance (after logarithm transformation), behavioral control, and psychological control and observed acceptance, behavioral control (after square root transformation), and psychological control. The square root transformation of the medical adherence outcome variable was utilized in all regression analyses. Analyses were also run without transformations on the skewed variables (i.e., perceived acceptance, observed behavioral control, medical adherence). No significant differences emerged between analyses run with transformed variables versus non-transformed variables. As such, analyses run without transformations will not be discussed further.

Table 10. Multiple Regression Analyses: Executive Function and Perceived Maternal Parenting Behaviors as Predictors of Medical Adherence.

Step and variable	R	β	FΔ
Perceived Maternal Acceptance			
(N = 113)			
Step 1: Disability Level	.21	.21	5.40*
IQ	.23	-.09	1.01
Age	.24	.03	.08
Step 2: BRIEF	.47	-.42	23.21***
Exec. Func. Test Data	.50	-.26	3.91
Acceptance	.51	.12	1.97
Step 3: Acceptance X BRIEF	.51	-.04	.19
Acceptance X Exec. Func. Test Data	.51	-.03	.10
Perceived Maternal Behavioral Control			
(N = 113)			
Step 1: Disability Level	.21	.21	5.40*
IQ	.23	-.09	1.01
Age	.24	.03	.08
Step 2: BRIEF	.47	-.42	23.21***
Beh. Control	.50	-.17	3.93
Exec. Func. Test Data	.52	-.24	3.34
Step 3: Beh. Control X BRIEF	.52	.04	.27
Beh. Control X Exec. Func. Test Data	.52	-.02	.05
Perceived Maternal Psychological Control			
(N = 113)			
Step 1: Disability Level	.21	.21	5.40*
IQ	.23	-.09	1.01
Age	.24	.03	.08
Step 2: BRIEF	.47	-.42	23.21***
Exec. Func. Test Data	.50	-.26	3.91
Psych. Control	.50	-.04	.19
Step 3: Psych. Control X Exec. Func. Test Data	.51	-.11	1.51
Psych. Control X BRIEF	.51	-.01	.01

Note. Logarithm transformations for the maternal acceptance variable and square root transformations for the medical adherence variable (i.e., Spina Bifida Self-Management Profile) were utilized in the above analyses; IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; BRIEF = Behavioral Rating Inventory of Executive Function; Exec. Func. = executive function; Beh. Control = behavioral control; Psych. Control = psychological control.
*p < .05; ***p < .001.

Table 11. Multiple Regression Analyses: Executive Function and Observed Maternal Parenting Behaviors as Predictors of Medical Adherence.

Step and variable	R	β	FΔ
<u>Observed Maternal Acceptance</u>			
(N= 115)			
Step 1: Disability Level	.22	.22	5.96*
IQ	.25	-.10	1.22
Age	.25	.03	.13
Step 2: BRIEF	.47	-.42	23.44***
Acceptance	.58	.34	18.26***
Exec. Func. Test Data	.59	-.21	2.82
Step 3: Acceptance X BRIEF	.60	.08	1.04
Acceptance X Exec. Func. Test Data	.60	.06	.45
<u>Observed Maternal Behavioral Control</u>			
(N= 116)			
Step 1: Disability Level	.24	.24	6.88*
IQ	.27	-.13	1.82
Age	.27	.04	.17
Step 2: BRIEF	.49	-.42	24.56***
Beh. Control	.59	.33	17.73***
Exec. Func. Test Data	.61	-.24	4.04*
Step 3: Beh. Control X Exec. Func. Test Data	.63	.16	4.59*
Beh. Control X BRIEF	.67	.24	9.40**
<u>Observed Maternal Psychological Control</u>			
(N= 116)			
Step 1: Disability Level	.24	.24	6.88*
IQ	.27	-.12	1.82
Age	.27	.04	.17
Step 2: BRIEF	.49	-.42	24.56***
Exec. Func. Test Data	.52	-.27	4.46*
Psych. Control	.52	-.05	.39
Step 3: Psych. Control X BRIEF	.53	-.07	.71
Psych. Control X Exec. Func. Test Data	.53	.03	.11

Notes. Square root transformations for the maternal behavioral control and medical adherence (i.e., Spina Bifida Self-Management Profile) variables were utilized in the above analyses; IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; BRIEF = Behavioral Rating Inventory of Executive Function; Exec. Func. = executive function; Beh. Control = behavioral control; Psych. Control = psychological control.

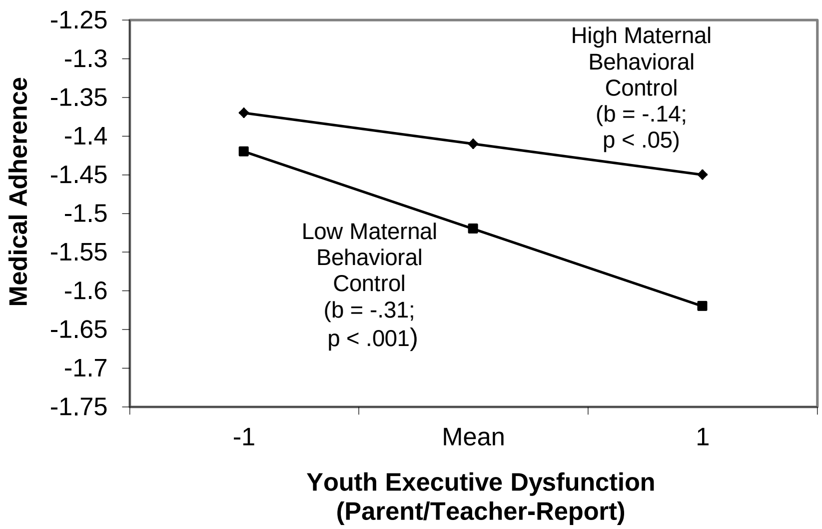
*$p < .05$; **$p < .01$; ***$p < .001$.

Perceived Maternal Parenting Behaviors. No significant main or interaction effects emerged for perceived maternal parenting behaviors predicting medical adherence (see Table 10). However, consistent with study hypotheses, significant negative main effects emerged for lower levels of parent/teacher-report of executive dysfunction (BRIEF) predicting higher levels of medical adherence, after controlling for age, IQ, and level of disability [$t(109) = -4.82$, $p < .001$].

Observed Maternal Parenting Behaviors. Consistent with study hypotheses, significant positive main effects emerged for observed maternal acceptance [$t(110) = 4.27$, $p < .001$] and observed maternal behavioral control [$t(111) = 4.21$, $p < .001$] predicting medical adherence, after controlling for age, IQ, and level of disability (see Table 11). Specifically, higher levels of observed maternal acceptance and observed maternal behavioral control were associated with higher levels of medical adherence. A significant negative main effect also emerged for parent/teacher-report of child executive dysfunction (BRIEF) predicting medical adherence, after controlling for age, IQ, and level of disability [$t(111) = -4.84$, $p < .001$; $t(112) = -4.96$, $p < .001$]. Consistent with study hypotheses, lower levels of executive dysfunction based on parent/teacher-report were associated with higher levels of medical adherence. Significant main effects also emerged for performance on executive function test data predicting medical adherence. However, the Pearson correlation coefficient for the relation between executive function test data and medical adherence was not significant (-.17; see Table 2). Thus, the significant main effect that emerged in the regression model is likely the result of a suppression effect. Given that the executive function test data variable was not significantly associated with medical adherence, this finding again represents a classical

suppression effect. Thus, this finding will not be further interpreted. A significant observed maternal behavioral control X executive function test data interaction emerged, but follow-up simple slope analyses were not significant. In addition, the association between parent/teacher-report of executive dysfunction (BRIEF) and medical adherence was qualified by a significant observed maternal behavioral control X BRIEF interaction [see Figure 3; $t(108) = 3.07$, $p < .01$].

Figure 3. Parent/Teacher-Report of Youth Executive Dysfunction by Observed Maternal Behavioral Control 2-Way Interaction for Predicting Medical Adherence



Follow-up simple slope analyses revealed that the relationship between lower levels of parent/teacher-report of executive dysfunction and higher levels of medical adherence was magnified among children with mothers who demonstrated lower levels of observed behavioral control [$t(110) = -5.24$, $p < .001$]. Yet, there was also a significant negative association between lower levels of parent/teacher-report of executive dysfunction and

higher levels of medical adherence among children with mothers who demonstrated higher levels of observed behavioral control [$t(110) = -2.46$, $p < .05$]. In other words, consistent with study hypotheses, maternal behavioral control partially buffered against the negative effects of executive dysfunction on medical adherence, such that the association between lower levels of executive dysfunction based on parent/teacher-report and higher levels of medical adherence was less salient among children with mothers who demonstrated higher levels of observed behavioral control.

Summary of Analyses. Taken together, several disability factors emerged as significant predictors of medical adherence. Consistent with Hypothesis 2, lower levels of executive dysfunction based on parent/teacher-report significantly predicted higher levels of medical adherence, after controlling for age, IQ, and level of disability. Analyses also provided support for Hypothesis 3, such that higher levels of observed maternal acceptance and observed maternal behavioral control were associated with higher levels of medical adherence. Contrary to Hypothesis 4, no significant effects emerged for maternal psychological control predicting medical adherence. Analyses did provide support for Hypotheses 5, which predicted that higher levels of maternal behavioral control would buffer against the negative effects of executive dysfunction on medical adherence. Specifically, the association between higher levels of executive dysfunction based on parent/teacher-report and lower levels of medical adherence was buffered among children with mothers who demonstrated higher levels of observed behavioral control, as compared to children with mothers who demonstrated lower levels of observed behavioral control. No support was provided for Hypotheses 6, which predicted

that maternal psychological control would moderate the relation between executive dysfunction and medical adherence.

Associations between Executive Functioning, Paternal Parenting Behaviors, and Medical Adherence.

A series of hierarchical regression analyses were conducted for each of the three perceived and three observed paternal parenting behaviors, resulting in a total of six hierarchical regression analyses (see Tables 12 and 13). Similar to previously discussed analyses, regression analyses were computed to examine the influence of executive function (based on test data and parent/teacher-report data; Hypothesis 2) and paternal parenting behaviors (Hypotheses 3 and 4) on medical adherence, after controlling for age, IQ, and level of disability. In addition, analyses were also computed to determine whether the nature or magnitude of the association between executive function and medical adherence differed as a function of maternal adaptive (Hypothesis 5) or maladaptive (Hypothesis 6) parenting behaviors. Separate hierarchical regression analyses were run for each of the paternal parenting behaviors including perceived acceptance, behavioral control, and psychological control and observed acceptance, behavioral control, and psychological control. The square root transformation of the medical adherence outcome variable was utilized in all regression analyses. Analyses were also run without a transformation of the medical adherence variable. No significant differences emerged between analyses run with the transformed versus the non-transformed adherence variable. As such, only the analyses including the transformation will be discussed below.

Perceived Paternal Parenting Behaviors. No significant main or interaction effects emerged for perceived paternal parenting behaviors predicting medical adherence (see

Table 12. Multiple Regression Analyses: Executive Function and Perceived Paternal Parenting Behaviors as Predictors of Medical Adherence.

Step and variable	R	β	FΔ
<u>Perceived Paternal Acceptance</u>			
(N= 90)			
Step 1: Disability Level	.33	.33	10.96**
IQ	.35	-.10	.95
Age	.35	.04	.17
Step 2: BRIEF	.46	-.31	9.81**
Exec. Func. Test Data	.49	-.30	3.43
Acceptance	.49	-.02	.06
Step 3: Acceptance X BRIEF	.50	-.10	.89
Acceptance X Exec. Func. Test Data	.50	-.03	.06
<u>Perceived Paternal Behavioral Control</u>			
(N= 90)			
Step 1: Disability Level	.33	.33	10.96**
IQ	.35	-.10	.95
Age	.35	.04	.17
Step 2: BRIEF	.46	-.31	9.81**
Exec. Func. Test Data	.49	-.30	3.43
Beh. Control	.50	-.10	.94
Step 3: Beh. Control X Exec. Func. Test Data	.52	.16	2.38
Beh. Control X BRIEF	.52	-.06	.32
<u>Perceived Paternal Psychological Control</u>			
(N = 90)			
Step 1: Disability Level	.33	.33	10.96**
IQ	.35	-.10	.95
Age	.35	.04	.17
Step 2: BRIEF	.46	-.31	9.81**
Exec. Func. Test Data	.49	-.30	3.43
Psych. Control	.50	.11	.93
Step 3: Psych. Control X BRIEF	.51	.08	.62
Psych. Control X Exec. Func. Test Data	.51	-.00	.00

Note. Square root transformation for the medical adherence variable (i.e., Spina Bifida Self-Management Profile) was utilized in the above analyses; IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; BRIEF = Behavioral Rating Inventory of Executive Function; Exec. Func. = executive function; Beh. Control = behavioral control; Psych. Control = psychological control.
*$p < .05$; **$p < .01$.

Table 13. Multiple Regression Analyses: Executive Function and Observed Paternal Parenting Behaviors as Predictors of Medical Adherence.

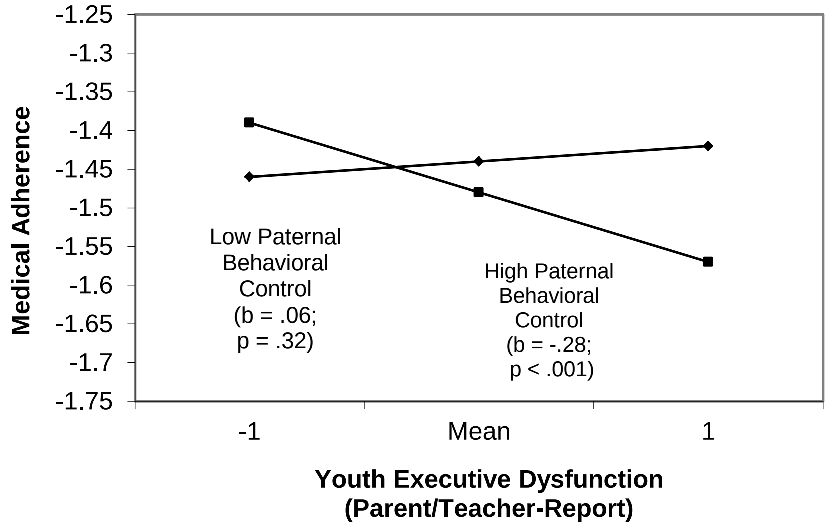
Step and variable	R	β	FΔ
Observed Paternal Acceptance			
(N = 91)			
Step 1: Disability Level	.38	.38	14.91***
IQ	.39	-.11	1.25
Age	.39	.01	.01
Step 2: BRIEF	.48	-.29	9.01**
Exec. Func. Test Data	.51	-.30	3.12
Acceptance	.51	.03	.11
Step 3: Acceptance X BRIEF	.52	.07	.51
Acceptance X Exec. Func. Test Data	.52	.10	.72
Observed Paternal Behavioral Control			
(N = 91)			
Step 1: Disability Level	.38	.38	14.91***
IQ	.39	-.11	1.25
Age	.39	.01	.01
Step 2: BRIEF	.48	-.29	9.01**
Beh. Control	.52	-.19	3.89
Exec. Func. Test Data	.54	-.29	3.16
Step 3: Beh. Control X BRIEF	.58	-.23	6.12*
Beh. Control X Exec. Func. Test Data	.59	-.05	.24
Observed Paternal Psychological Control			
(N = 92)			
Step 1: Disability Level	.39	.39	15.98***
IQ	.40	-.10	.98
Age	.40	-.01	.00
Step 2: BRIEF	.49	-.29	9.17**
Exec. Func. Test Data	.51	-.28	2.81
Psych. Control	.52	-.09	.95
Step 3: Psych. Control X BRIEF	.55	-.18	3.60
Psych. Control X Exec. Func. Test Data	.55	.01	.02

Notes. Square root transformation for the medical adherence variable (i.e., Spina Bifida Self-Management Profile) was utilized in the above analyses; IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; BRIEF = Behavioral Rating Inventory of Executive Function; Exec. Func. = executive function; Beh. Control = behavioral control; Psych. Control = psychological control.
*p < .05; **p < .01; ***p < .001.

Table 12). However, consistent with study hypotheses, significant negative main effects emerged for the association between parent/teacher-report of executive dysfunction (BRIEF) and medical adherence, after controlling for age, IQ, and level of disability t(86) = -3.13, p < .01], such that lower levels of executive dysfunction based on parent/teacher-report was associated with higher levels of medical adherence.

Observed Paternal Parenting Behaviors. No significant main effects emerged for observed paternal parenting behavior predicting medical adherence (see Table 13). However, consistent with study hypotheses and prior discussed analyses, higher levels of parent/teacher-report of executive dysfunction (BRIEF) was significantly associated with lower levels of medical adherence, after controlling for age, IQ, and level of disability [t(87) = -3.00, p < .01; t(88) = -3.03, p < .01]. This association was qualified by a significant observed paternal behavioral control X BRIEF interaction effect [see Figure 4; t(84) = -1.47, p < .05]. Follow-up simple slope analyses indicated that the relationship between lower levels of parent/teacher-report of executive dysfunction and higher levels of medical adherence was magnified among children with fathers who demonstrated higher levels of observed behavioral control [t(85) = -3.96, p < .001], as compared to children with fathers who demonstrated lower levels of observed behavioral control [t(85) = 1.01, p = .32]. Thus, in contrast to the maternal behavioral control analyses, the association between lower levels of executive dysfunction based on parent/teacher-report and higher levels of medical adherence was particularly salient among children with fathers who demonstrated higher levels of observed behavioral control.

Figure 4. Parent/Teacher-Report of Youth Executive Dysfunction by Observed Paternal Behavioral Control 2-Way Interaction for Predicting Medical Adherence



Summary of Analyses. Consistent with Hypothesis 2, higher levels of executive dysfunction based on parent/teacher-report predicted higher levels of medical adherence, after controlling for age, IQ, and disability. No support was provided for a significant association between paternal parenting behaviors and medical adherence (Hypotheses 3 and 4). However, analyses did provide partial support for paternal behavioral control moderating the relation between executive dysfunction and medical adherence. Yet, in contrast to maternal behavioral control analyses and Hypothesis 5, the relation between executive dysfunction based on parent/teacher-report and medical adherence was particularly salient among children with fathers who demonstrated higher levels of observed behavioral control. In other words, lower levels of paternal behavioral control buffered against the negative effects of higher levels of executive dysfunction on medical

adherence. No significant moderating effects emerged for paternal acceptance (Hypothesis 5) or psychological control (Hypothesis 6).

Associations between Attention, Maternal Parenting Behaviors and Medical Autonomy

A series of hierarchical regression analyses were conducted for each of the three perceived and three observed maternal parenting behaviors, resulting in a total of six hierarchical regression analyses (see Tables 14 and 15). Analyses were computed to examine the influence of attention (based on test data and parent/teacher-report data; Hypothesis 2) and maternal parenting behaviors (Hypotheses 3 and 4) on medical autonomy, after controlling for age, IQ, and level of disability. In addition, analyses were also computed to determine whether the nature or magnitude of the association between attention and medical autonomy differed as a function of maternal adaptive (Hypothesis 5) or maladaptive (Hypothesis 6) parenting behaviors. Separate hierarchical regression analyses were run for each of the maternal parenting behaviors including perceived acceptance (after logarithm transformation), behavioral control, and psychological control and observed acceptance, behavioral control (after square root transformation), and psychological control. Analyses were also run without transformations on the skewed variables (i.e., perceived acceptance, observed behavioral control). No significant differences emerged between analyses run with transformed variables versus non-transformed variables. As such, analyses run without transformations will not be discussed further.

Perceived Maternal Parenting Behaviors. Consistent with study hypotheses, significant positive main effects emerged for attention test data predicting medical autonomy, after controlling for age, IQ, and disability [$t(110) = 2.44$, $p < .05$; see Table

Table 14. Multiple Regression Analyses: Attention and Perceived Maternal Parenting Behaviors as Predictors of Medical Autonomy.

Step and variable	R	β	FΔ
Perceived Maternal Acceptance			
(N = 114)			
Step 1: Age	.49	.49	35.36***
IQ	.60	.36	21.83***
Disability Level	.62	-.13	2.95
Step 2: Attention Test Data	.64	.23	5.97*
SNAP-IV	.65	.08	1.21
Acceptance	.65	.01	.00
Step 3: Acceptance X Attention Test Data	.67	-.17	4.96*
Acceptance X SNAP-IV	.67	.06	.51
Perceived Maternal Behavioral Control			
(N = 114)			
Step 1: Age	.49	.49	35.36***
IQ	.60	.36	21.83***
Disability Level	.62	-.13	2.95
Step 2: Attention Test Data	.64	.23	5.97*
SNAP-IV	.65	.08	1.21
Beh. Control	.65	.03	.15
Step 3: Beh. Control X Attention Test Data	.65	.01	.01
Beh. Control X SNAP-IV	.65	.00	.00
Perceived Maternal Psychological Control			
(N = 114)			
Step 1: Age	.49	.49	35.36***
IQ	.60	.36	21.83***
Disability Level	.62	-.13	2.95
Step 2: Attention Test Data	.64	.23	5.97*
SNAP-IV	.65	.08	1.21
Psych. Control	.65	-.02	.10
Step 3: Psych. Control X Attention Test Data	.66	-.12	2.78
Psych. Control X SNAP-IV	.66	.06	.50

Notes. Logarithm transformation for the maternal acceptance variable was utilized in the above analyses; IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; SNAP-IV = Swanson, Nolan, and Pelham – Fourth Edition; Beh. Control = behavioral control; Psych. Control = psychological control.
*$p < .05$; **$p < .01$; ***$p < .001$.

Table 15. Multiple Regression Analyses: Attention and Observed Maternal Parenting Behaviors as Predictors of Medical Autonomy.

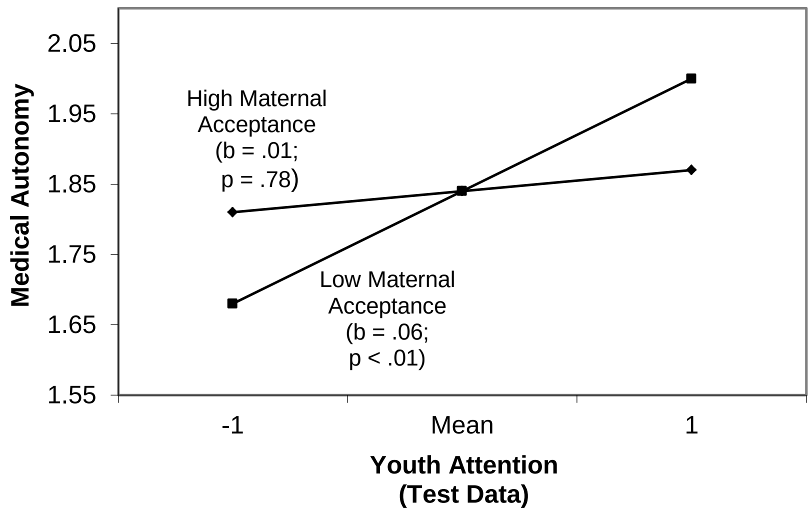
Step and variable	R	β	FΔ
<u>Observed Maternal Acceptance</u>			
(N = 115)			
Step 1: Age	.46	.46	29.88***
IQ	.59	.38	23.74***
Disability Level	.60	-.14	3.50
Step 2: Attention Test Data	.64	.28	8.81**
Acceptance	.64	-.04	.26
SNAP-IV	.64	.03	.19
Step 3: Acceptance X SNAP-IV	.64	.01	.03
Acceptance X Attention Test Data	.64	.01	.01
<u>Observed Maternal Behavioral Control</u>			
(N = 116)			
Step 1: Age	.44	.44	28.31***
IQ	.59	.40	25.84***
Disability Level	.61	-.15	3.82
Step 2: Attention Test Data	.64	.28	9.19**
Beh. Control	.65	-.07	.90
SNAP-IV	.65	.04	.26
Step 3: Beh. Control X SNAP-IV	.65	-.08	1.00
Beh. Control X Attention Test Data	.65	-.03	.12
<u>Observed Maternal Psychological Control</u>			
(N = 116)			
Step 1: Age	.44	.44	28.31***
IQ	.59	.40	25.84***
Disability Level	.61	-.15	3.82
Step 2: Attention Test Data	.64	.28	9.19**
Psych. Control	.65	-.05	.42
SNAP-IV	.65	.04	.29
Step 3: Psych. Control X SNAP-IV	.65	-.08	.97
Psych. Control X Attention Test Data	.65	-.04	.23

Notes. Square root transformation for the maternal behavioral control variable was utilized in the above analyses; IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; SNAP-IV = Swanson, Nolan, and Pelham – Fourth Edition; Beh. Control = behavioral control; Psych. Control = psychological control.
**p < .01; ***p < .001.

14]. Specifically, higher levels of attention ability were associated with higher levels of

medical autonomy. This relationship was qualified by a perceived maternal acceptance X attention test data interaction [see Figure 5; t(107) = -2.23, p < .05].

Figure 5. Youth Performance on Attention Test Data by Perceived Maternal Acceptance 2-Way Interaction for Predicting Medical Autonomy



Follow-up simple slope analyses revealed that the association between higher levels of attention ability based on test data and higher levels of medical autonomy was only significant among children with parents who reported higher levels of acceptance [t(108) = 3.46, p < .01]. The association between attention test data and medical adherence was not significant among children with mothers who perceived higher levels of acceptance [t(108) = .28,   p = .78]. In other words, consistent with study hypotheses, maternal acceptance buffered against the negative effects of inattention on medical autonomy. However, it is important to note that among higher functioning youth in the sample (i.e.,

attention test data scores above one standard deviation), the youth who also had mothers who perceived higher levels of acceptance displayed less autonomous behavior as compared to youth with mothers who perceived lower levels of acceptance. Lastly, positive significant main effects also emerged for age [$t(113) = 5.95$, $p < .001$] and IQ [$t(112) = 4.67$, $p < .001$]. Specifically, older children and children with higher scores on the WASI demonstrated higher levels of medical autonomy. The relation between IQ and age on medical autonomy was similar across all subsequent analyses and, thus, will not be repeated.

Observed Maternal Parenting Behaviors. No significant main or interaction effects emerged for observed maternal parenting behavior variables predicting medical autonomy (see Table 15). Consistent with study hypotheses, significant positive main effects again emerged for higher levels of attention ability based on test data predicting higher levels of medical autonomy, after controlling for age, IQ, and disability [$t(111) = 2.97$, $p < .01$; $t(112) = 3.03$, $p < .01$].

Summary of Analyses. Taken together, several factors emerged as significant predictors of medical autonomy. Consistent with Hypothesis 2, higher levels of attention ability based on test data was significantly associated with higher levels of medical autonomy, after controlling for age, IQ, and disability. Contrary to Hypotheses 3 and 4, no support was provided for maternal parenting behaviors predicting medical autonomy. Partial support was provided for Hypothesis 5, such that higher levels of perceived maternal acceptance buffered against the negative effects of inattention based on test data on medical autonomy. No support was provided for Hypotheses 6, which predicted that maternal psychological control would moderate the relation between attention and

medical autonomy. Lastly, being older and higher scores on the WASI were also associated with higher levels of medical autonomy.

Associations between Attention, Paternal Parenting Behaviors and Medical Autonomy

A series of hierarchical regression analyses were conducted for each of the three perceived and three observed paternal parenting behaviors, resulting in a total of six hierarchical regression analyses (see Tables 16 and 17). Analyses were computed to examine the influence of attention (based on test data and parent/teacher-report data; Hypothesis 2) and paternal parenting behaviors (Hypotheses 3 and 4) on medical autonomy, after controlling for age, IQ, and level of disability. In addition, analyses were computed to determine whether the nature or magnitude of the association between attention and medical autonomy differed as a function of paternal adaptive (Hypothesis 5) or maladaptive (Hypothesis 6) parenting behaviors. Separate hierarchical regression analyses were run for each of the paternal parenting behaviors including perceived acceptance, behavioral control, and psychological control and observed acceptance, behavioral control, and psychological control.

<u>Perceived Paternal Parenting Behaviors.</u> Contrary to study hypotheses, a significant negative main effect emerged for perceived paternal behavioral control predicting medical autonomy, after controlling for age, IQ, and disability [$t(86) = -2.71$, $p < .01$; see Table 16]. In other words, lower levels of perceived paternal behavioral control was associated with higher levels of medical autonomy. Consistent with the study hypotheses, a significant positive main effect emerged for higher levels of attention ability based on test data predicting higher levels of medical autonomy, after controlling

Table 16. Multiple Regression Analyses: Attention and Perceived Paternal Parenting Behaviors as Predictors of Medical Autonomy.

Step and variable	R	β	FΔ
Perceived Paternal Acceptance			
(N = 91)			
Step 1: Age	.41	.41	17.65***
IQ	.58	.43	23.39***
Disability Level	.62	-.23	7.33**
Step 2: Attention Test Data	.67	.30	8.22**
Acceptance	.67	-.06	.42
SNAP-IV	.67	.03	.09
Step 3: Acceptance X Attention Test Data	.67	-.03	.09
Acceptance X SNAP-IV	.67	-.01	.01
Perceived Paternal Behavioral Control			
(N = 91)			
Step 1: Age	.41	.41	17.65***
IQ	.58	.43	23.39***
Disability Level	.62	-.23	7.33**
Step 2: Attention Test Data	.67	.30	8.22**
Beh. Control	.70	-.22	7.60**
SNAP-IV	.70	.07	.78
Step 3: Beh. Control X SNAP-IV	.71	.08	.84
Beh. Control X Attention Test Data	.71	.00	.00
Perceived Paternal Psychological Control			
(N = 91)			
Step 1: Age	.41	.41	17.65***
IQ	.58	.43	23.39***
Disability Level	.62	-.23	7.33**
Step 2: Attention Test Data	.67	.30	8.22**
Psych. Control	.68	-.13	2.15
SNAP-IV	.68	.05	.31
Step 3: Psych. Control X SNAP-IV	.69	.16	3.78
Psych. Control X Attention Test Data	.70	-.08	.62

Notes. IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; SNAP-IV = Swanson, Nolan, and Pelham – Fourth Edition; Beh. Control = behavioral control; Psych. Control = psychological control.
**p < .01; ***p < .001.

Table 17. Multiple Regression Analyses: Attention and Observed Paternal Parenting Behaviors as Predictors of Medical Autonomy.

Step and variable	R	β	FΔ
Observed Paternal Acceptance (N = 92)			
Step 1: IQ	.37	.37	14.33***
Age	.59	.48	30.22***
Disability Level	.64	-.24	8.59**
Step 2: Attention Test Data	.66	.23	4.77*
Acceptance	.67	.07	.67
SNAP-IV	.67	-.00	.00
Step 3: Acceptance X Attention Test Data	.67	.08	.82
Acceptance X SNAP-IV	.67	-.00	.00
Observed Paternal Behavioral Control (N = 92)			
Step 1: IQ	.37	.37	14.33***
Age	.59	.48	30.22***
Disability Level	.64	-.24	8.59**
Step 2: Attention Test Data	.66	.23	4.78
Beh. Control	.67	.11	1.77
SNAP-IV	.67	-.01	.02
Step 3: Beh. Control X SNAP-IV	.68	.09	1.15
Beh. Control X Attention Test Data	.68	.07	.53
Observed Paternal Psychological Control (N = 93)			
Step 1: Age	.37	.37	15.00***
IQ	.59	.47	29.39***
Disability Level	.64	-.26	9.80**
Step 2: Attention Test Data	.67	.24	5.10*
Psych. Control	.67	-.03	.15
SNAP-IV	.67	.00	.00
Step 3: Psych. Control X Attention Test Data	.68	-.10	1.44
Psych. Control X SNAP-IV	.68	.06	.37

Notes. IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; SNAPIV = Swanson, Nolan, and Pelham – Fourth Edition; Beh. Control = behavioral control; Psych. Control = psychological control.
*p < .05; **p < .01; ***p < .001.

for age, IQ, and disability [t(87) = 2.87, $p < .01$]. Lastly, significant main effects also emerged for level of disability [t(88) = -2.71, $p < .01$], such that children with lower levels of gross motor functioning impairment demonstrated higher levels of medical autonomy. The association between level of disability and medical autonomy was similar across all subsequent analyses including paternal caregivers and, thus, will not be repeated.

Observed Paternal Parenting Behaviors. No significant main or interaction effects emerged for observed paternal parenting behavior variables predicting medical autonomy (see Table 17). However, consistent with study hypotheses, significant positive main effects emerged for higher levels of attention ability based on test data predicting higher levels of medical autonomy, after controlling for age, IQ, and disability [t(88) = 2.19, $p < .01$; t(89) = 2.26, $p < .05$].

Summary of Analyses. Taken together, several variables emerged as significant predictors of medical autonomy. Consistent with Hypothesis 2, higher levels of attention ability based on test data predicted higher levels of medical autonomy, after controlling for age, IQ, and level of disability. Contrary to Hypothesis 3, lower levels of perceived paternal behavioral control was a significant predictor of higher levels of medical autonomy. In addition, no support was provided for Hypothesis 4, which predicted that higher levels of paternal psychological control would be associated with higher levels of medical autonomy. No significant interaction effects emerged for paternal parenting behaviors moderating the association between attention ability and medical autonomy

(Hypothesis 5 and 6). Lastly, older age, higher IQ, and higher levels of gross motor functioning emerged as significant predictors of higher levels of medical autonomy.

Associations between Executive Functioning, Maternal Parenting Behaviors, and Medical Autonomy

A series of hierarchical regression analyses were conducted for each of the three perceived and three observed maternal parenting behaviors, resulting in a total of six hierarchical regression analyses (see Tables 18 and 19). Analyses were computed to examine the influence of executive function (based on test data and parent/teacher-report data; Hypothesis 2) and maternal parenting behaviors (Hypotheses 3 and 4) on medical autonomy, after controlling for age, IQ, and level of disability. In addition, analyses were computed to determine whether the nature or magnitude of the association between executive function and medical autonomy differed as a function of maternal adaptive (Hypothesis 5) or maladaptive (Hypothesis 6) parenting behaviors. Separate hierarchical regression analyses were run for each of the maternal parenting behaviors including perceived acceptance (after logarithm transformation), behavioral control, and psychological control and observed acceptance, behavioral control (after square root transformation), and psychological control. Analyses were also run without transformations on the skewed variables (i.e., perceived acceptance, observed behavioral control, medical adherence). No significant differences emerged between analyses run with transformed variables versus non-transformed variables. As such, analyses run without transformations will not be discussed further.

Table 18. Multiple Regression Analyses: Executive Function and Perceived Maternal Parenting Behaviors as Predictors of Medical Autonomy.

Step and variable	R	β	FΔ
<u>Perceived Maternal Acceptance</u>			
(N = 117)			
Step 1: Age	.44	.44	28.42***
IQ	.59	.40	26.76***
Disability Level	.61	-.13	3.17
Step 2: Exec. Func. Test Data	.62	.21	3.58
Acceptance	.62	-.01	.03
BRIEF	.62	.01	.00
Step 3: Acceptance X BRIEF	.62	.06	.56
Acceptance X Exec. Func. Test Data	.63	.06	.51
<u>Perceived Maternal Behavioral Control</u>			
(N = 117)			
Step 1: Age	.44	.44	28.42***
IQ	.59	.40	26.76***
Disability Level	.61	-.13	3.17
Step 2: Exec. Func. Test Data	.62	.21	3.58
Beh. Control	.62	.05	.44
BRIEF	.62	.01	.01
Step 3: Beh. Control X Exec. Func. Test Data	.62	-.04	.29
Beh. Control X BRIEF	.62	-.02	.05
<u>Perceived Maternal Psychological Control</u>			
(N = 117)			
Step 1: Age	.44	.44	28.42***
IQ	.59	.40	26.76***
Disability Level	.61	-.13	3.17
Step 2: Exec. Func. Test Data	.62	.21	3.58
Psych Control	.62	-.05	.34
BRIEF	.62	.01	.02
Step 3: Psych. Control X BRIEF	.63	.10	1.57
Psych. Control X Exec. Func. Test Data	.63	.03	.12

Notes. Logarithm transformations for the maternal acceptance variable was utilized in the above analyses; IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; BRIEF = Behavioral Rating Inventory of Executive Function; Exec. Func. = executive function; Beh. Control = behavioral control; Psych. Control = psychological control.
***p < .001.

Table 19. Multiple Regression Analyses: Executive Function and Observed Maternal Parenting Behaviors as Predictors of Medical Autonomy.

Step and variable	R	β	FΔ
Observed Maternal Acceptance			
(N= 118)			
Step 1: Age	.41	.41	23.92***
IQ	.58	.42	28.60***
Disability Level	.60	-.15	3.68
Step 2: Exec. Func. Test Data	.62	.23	4.27*
Acceptance	.62	-.05	.40
BRIEF	.62	-.02	.09
Step 3: Acceptance X BRIEF	.62	-.05	.35
Acceptance X Exec. Func. Test Data	.62	.01	.01
Observed Maternal Behavioral Control			
(N= 119)			
Step 1: Age	.40	.40	22.75***
IQ	.58	.43	30.62***
Disability Level	.60	-.15	3.96*
Step 2: Exec. Func. Test Data	.62	.24	4.42*
Beh. Control	.62	-.06	.57
BRIEF	.62	-.01	.02
Step 3: Beh. Control X BRIEF	.63	-.09	1.54
Beh. Control X Exec. Func. Test Data	.63	-.09	1.29
Observed Maternal Psychological Control			
(N= 119)			
Step 1: Age	.40	.40	22.75***
IQ	.58	.43	30.62***
Disability Level	.60	-.15	3.96*
Step 2: Exec. Func. Test Data	.62	.24	4.42*
Psych. Control	.62	-.05	.50
BRIEF	.62	-.00	.00
Step 3: Psych. Control X Exec. Func. Test Data	.62	.04	.26
Psych. Control X BRIEF	.62	-.01	.02

Note. Square root transformation for the maternal behavioral control was utilized in the above analyses; IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; BRIEF = Behavioral Rating Inventory of Executive Function; Exec. Func. = executive function; Beh. Control = behavioral control; Psych. Control = psychological control.
*$p < .05$; ***$p < .001$.

Perceived Maternal Parenting Behaviors. No significant main or interaction effects emerged for executive functioning or perceived maternal parenting behavior variables predicting medical autonomy (see Table 18).

Observed Maternal Parenting Behaviors. No significant main or interaction effects emerged for observed maternal parenting behavior variables predicting medical autonomy (see Table 19). Consistent with study hypotheses, higher levels of executive functioning ability based on test data was associated with higher levels of medical autonomy, after controlling for age, IQ, and level of disability [$t(114)$ 2.07, $p < .05$; $t(115) = 2.10$, $p < .05$].

Summary of Analyses. Consistent with Hypothesis 2, higher levels of executive function ability based on test data was a significant predictor of higher levels of medical autonomy. No significant effects emerged for the impact of maternal parenting behaviors on medical autonomy (Hypothesis 3 and 4) or maternal parenting behaviors moderating the relation between inattention and medical adherence (Hypothesis 5 and 6).

Associations between Executive Functioning, Paternal Parenting Behaviors, and Medical Autonomy

A series of hierarchical regression analyses were conducted for each of the three perceived and three observed paternal parenting behaviors, resulting in a total of six hierarchical regression analyses (see Tables 20 and 21). Analyses were computed to examine the influence of executive function (based on test data and parent/teacher-report data; Hypothesis 2) and paternal parenting behaviors (Hypotheses 3 and 4) on medical autonomy, after controlling for age, IQ, and level of disability. In addition, analyses were computed to determine whether the nature or magnitude of the association between

Table 20. Multiple Regression Analyses: Executive Function and Perceived Paternal Parenting Behaviors as Predictors of Medical Autonomy.

Step and variable	R	β	FΔ
Perceived Paternal Acceptance			
(N= 93)			
Step 1: IQ	.36	.36	13.35***
Age	.58	.47	28.49***
Disability Level	.62	-.23	7.53**
Step 2: Acceptance	.63	-.11	1.59
BRIEF	.64	-.13	2.13
Exec. Func. Test Data	.64	.08	.38
Step 3: Acceptance X Exec. Func. Test Data	.65	.09	1.17
Acceptance X BRIEF	.65	.04	.23
Perceived Paternal Behavioral Control			
(N= 93)			
Step 1: IQ	.36	.36	13.35***
Age	.58	.47	28.49***
Disability Level	.62	-.23	7.53**
Step 2: Beh. Control	.64	-.16	3.61
Exec. Func. Test Data	.65	.20	2.45
BRIEF	.65	-.01	.02
Step 3: Beh. Control X Exec. Func. Test Data	.65	.04	.23
Beh. Control X BRIEF	.65	-.03	.08
Perceived Paternal Psychological Control			
(N = 93)			
Step 1: IQ	.36	.36	13.35***
Age	.58	.47	28.49***
Disability Level	.62	-.23	7.53**
Step 2: BRIEF	.63	-.09	1.85
Psych. Control	.63	-.07	.66
Exec. Func. Test Data	.64	.15	1.03
Step 3: Psych. Control X BRIEF	.64	.10	1.30
Psych. Control X Exec. Func. Test Data	.65	-.04	.18

Notes. IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; BRIEF = Behavioral Rating Inventory of Executive Function; Exec. Func. = executive function; Beh. Control = behavioral control; Psych. Control = psychological control.

**p < .01; ***p < .001.

Table 21. Multiple Regression Analyses: Executive Function and Observed Paternal Parenting Behaviors as Predictors of Medical Autonomy.

Step and variable	R	β	FΔ
Observed Paternal Acceptance			
(N = 94)			
Step 1: IQ	.40	.40	18.18***
Age	.60	.46	27.39***
Disability Level	.64	-.25	8.98**
Step 2: BRIEF	.65	-.08	.81
Acceptance	.65	.04	.18
Exec. Func. Test Data	.65	.03	.06
Step 3: Acceptance X Exec. Func. Test Data	.65	.08	.76
Acceptance X BRIEF	.65	.00	.00
Observed Paternal Behavioral Control			
(N = 94)			
Step 1: IQ	.40	.40	18.18***
Age	.60	.46	27.39***
Disability Level	.64	-.25	8.98**
Step 2: BRIEF	.65	-.08	.81
Beh. Control	.65	.06	.56
Exec. Func. Test Data	.65	.03	.06
Step 3: Beh. Control X BRIEF	.65	.05	.38
Beh. Control X Exec. Func. Test Data	.65	.05	.29
Observed Paternal Psychological Control			
(N = 95)			
Step 1: IQ	.38	.38	16.23***
Age	.59	.47	29.16***
Disability Level	.65	-.26	10.24**
Step 2: BRIEF	.65	-.07	.75
Psych. Control	.65	-.05	.30
Exec. Func. Test Data	.65	.01	.01
Step 3: Psych. Control X Exec. Func. Test Data	66	-.11	1.54
Psych. Control X BRIEF	.66	.12	.02

Notes. IQ based on Wechsler Abbreviated Scale of Intelligence; β = standardized beta coefficient; FΔ = F – Change; BRIEF = Behavioral Rating Inventory of Executive Function; Exec. Func. = executive function; Beh. Control = behavioral control; Psych. Control = psychological control.
**$p < .01$; ***$p < .001$.

executive function and medical autonomy differed as a function of maternal adaptive

(Hypothesis 5) or maladaptive (Hypothesis 6) parenting behaviors. Separate hierarchical regression analyses were run for each of the paternal parenting behaviors including perceived acceptance, behavioral control, and psychological control and observed acceptance, behavioral control, and psychological control.

Perceived Paternal Parenting Behaviors. No significant main or interaction effects emerged for the executive function or perceived paternal parenting behaviors variables predicting medical autonomy (see Table 20).

Observed Paternal Parenting Behaviors. No significant main or interaction effects emerged for the executive function or observed paternal parenting behaviors variables predicting medical autonomy (see Table 21).

Summary of Analyses. In contrast to study hypothesis, no significant effects emerged for the direct impact of executive function (Hypothesis 2) or paternal parenting behaviors (Hypotheses 3 and 4) predicting medical autonomy. Moreover, no support was provided for paternal parenting behaviors moderating the relation between inattention and medical adherence (Hypotheses 5 and 6).

Regression Analyses: IQ Scores Above 85

A series of hierarchical regression analyses were conducted including only participants with WASI scores above 85 in order to rule out low general cognitive ability as an explanation for study findings. A total of 64 participants had a WASI score above 85. Identical to previously discussed regression analyses, analyses were computed to examine the influence of attention/executive function (based on test data and parent/teacher-report data; Hypothesis 2) and parenting behaviors (Hypotheses 3 and 4)

on medical adherence and medical autonomy, after controlling for age, IQ, and level of disability. In addition, analyses were also computed to determine whether the nature or magnitude of the association between attention/executive function and healthcare behaviors differed as a function of adaptive (Hypothesis 5) or maladaptive (Hypothesis 6) parenting behaviors. Separate hierarchical regression analyses were run for each of the maternal and paternal parenting behaviors including perceived acceptance (after logarithm transformation on maternal scale), behavioral control, and psychological control and observed acceptance, behavioral control (after square root transformation on maternal scale), and psychological control. First analyses for the medical adherence outcome will be discussed, followed by analyses for the medical autonomy outcome.

Medical Adherence

Across regression analyses for the medical adherence outcome, higher levels of disability predicted higher levels of medical adherence (p's < .05). This finding is consistent with previously discussed regression analyses that included the entire sample of youth with spina bifida. In contrast to Hypothesis 2 and previously discussed regression analyses, parent/teacher-report of youth inattention was not significantly associated with medical adherence among youth. In other words, once youth with WASI scores less than 85 were removed from the sample, there was no longer a significant main effect for inattention. However, consistent with Hypothesis 2 and analyses including the entire sample, parent/teacher-report of youth executive dysfunction continued to be significantly associated with medical adherence among youth, after controlling for age, IQ, and level of disability (p's < .05). Analyses also continued to provide support for Hypothesis 3, such that higher levels of observed maternal acceptance (p's < .05) and

observed maternal behavioral control (p’s < .01) were associated with higher levels of

medical adherence. Contrary to Hypothesis 3 and study findings for the entire sample, no significant main effects emerged for the association between the perceived parenting behaviors and medical adherence. Moreover, consistent with prior analyses, no significant effects emerged for psychological control predicting medical adherence (Hypothesis 4).

Partial support was provided for Hypothesis 5, which predicted that maternal parenting behaviors would moderate the relation between executive function and medical adherence. Specifically, a significant observed maternal behavioral control X executive function test data interaction emerged [$t(53) = 2.58$, $p < .05$]. Follow-up simple slope analyses revealed that the association between executive function ability based on test data and medical adherence was only significant among children with mothers who reported lower levels of behavioral control [$t(51) = -2.08$, $p < .05$]. The association between executive function test data and medical adherence was not significant among children with mothers who demonstrated higher levels of behavioral control [$t(51) = 1.71$, $p = .09$]. However, the direction of these findings was in contrast to study hypotheses. Namely, higher levels of executive function ability based on test data predicted lower levels of medical adherence among children with mother who demonstrated lower levels of behavioral control. This finding is also in contrast to previously discussed interaction effects with the entire sample.

Lastly, no support was provided for Hypotheses 6, which predicted that maladaptive parenting behaviors would exacerbate the negative effects ofinattention/ executive dysfunction on medical adherence. Yet, it is important to note that by only

including youth with a WASI score above 85 resulted in a small sample size (n’s = 53 for analyses including mothers and– 45-46 for analyses including fathers). This reduced the statistical power of the regression analyses, and thus, the likelihood of detecting significant main and interaction effects.

Medical Autonomy

Across regression analyses for the medical autonomy outcome, being older predicted higher levels of medical autonomy (p’s < .001). In contrast to previously discussed regression analyses including the entire sample of youth with spina bifida, scores on the WASI and level of disability were not significantly associated with medical autonomy. In contrast to Hypothesis 2 and previously discussed regression analyses, youth performance on executive function test data was not significantly associated with medical autonomy. In other words, once youth with WASI scores less than 85 were removed from the sample, there was no longer a significant main effect for executive function. However, consistent with Hypothesis 2 and analyses including the entire sample, higher levels of attention ability based on test data was significantly associated with higher levels of medical autonomy, after controlling for age, IQ, and level of disability (p’s < .05). Also consistent with previously discussed analyses and providing support for Hypotheses 3, lower levels of perceived paternal behavioral control predicted higher levels of medical autonomy (p’s < .05). No significant effects emerged for psychological control predicting medical autonomy (Hypothesis 4). In addition, no support was provided for Hypotheses 5 or 6, which predicted that parenting behaviors would moderate the relation between inattention/executive dysfunction and medical autonomy. Yet, it is important to note that by only including youth with a WASI score

above 85 resulted in a small sample size (n's = 56 for analyses including mothers and 47-48 for analyses including fathers). This reduced the statistical power of the regression analyses, and thus, the likelihood of detecting significant main and interaction effects.

CHAPTER FIVE

DISCUSSION

The purpose of this multisource, multimethod study was to examine the impact of neurocognitive deficits, namely inattention and executive dysfunction, and parenting behaviors on the healthcare behaviors of preadolescents and adolescents with spina bifida. Several hypotheses were investigated. First, this study explored inattention and executive dysfunction among youth with spina bifida, after controlling for age, IQ, and level of disability. Both parent/teacher-report questionnaires and test data were utilized. Second, it was predicted that youth with spina bifida who demonstrated higher levels of attention and executive function ability would also exhibit higher levels of medical adherence and autonomy. Illness-specific questionnaire data were collected from multiple reporters to obtain a measurement of medical adherence and autonomy among youth in this population. Specifically, mothers and fathers completed questionnaires regarding their child's medical adherence behaviors, and mothers, fathers, and youth completed questionnaires regarding youth's level of autonomy on medical tasks.

This study aimed to understand how environmental factors, specifically parenting behaviors, interact with neurocognitive factors to influence healthcare behaviors among youth with spina bifida. A developmental psychopathology framework was employed to explore both protective (i.e., parental acceptance, parental behavioral control) and vulnerability factors (i.e., parental psychological control). To do so, perceived and

observed parenting behaviors were investigated among mothers and fathers separately. It was hypothesized that higher levels of acceptance, higher levels of behavioral control, and lower levels of psychological control among mothers and fathers would predict higher levels of medical adherence and autonomy. The moderating role of these parenting behaviors on the association between neurocognitive functioning and healthcare behaviors was also investigated. Adaptive parenting behaviors (i.e., acceptance, behavioral control) was expected to buffer against the negative effects of inattention and executive dysfunction on healthcare behaviors, and maladaptive parenting behaviors (i.e., psychological control) was expected to exacerbate the negative effects of inattention and executive dysfunction on healthcare behaviors. The following sections highlight the findings for each of the study hypotheses.

Hypothesis 1

Hypothesis 1 predicted that children and adolescents with spina bifida would demonstrate higher levels of inattention and executive dysfunction, as compared to typically developing youth, after controlling for age, IQ, and level of disability. Consistent with prior research (e.g., Mahone et al., 2002; Rose & Holmbeck, 2007), youth with spina bifida demonstrated higher levels of inattention and executive dysfunction as compared to normative sample data. First, study findings for the test data will be discussed, followed by study findings for the parent/teacher-report questionnaire data.

Test Data

Mean scores on tests of attention and executive function among youth with spina bifida was low average, with mean scaled scores between 6.53 (around the 13th

percentile) and 7.00 (16th percentile), respectively. Similarly, mean IQ score within this population was low average, which is similar to other studies of youth with spina bifida (e.g., Brookshire et al., 1995; Mahone et al., 2002; Wills et al., 1990).

There was a great deal of variability in the attention and executive function test data. For example, standard deviations on the attention and executive function subtests ranged from 3.33 to 4.57 and the total sample demonstrated scores that ranged from the impaired to above average range. This is not surprising given the variability of neurologic impairment among youth with this condition and, specifically, within the population utilized in this study. In general, there is great variability regarding the severity of CNS damage among youth with spina bifida, such as the presence of brain malformations (e.g., Chiari II malformation), hydrocephalus, and/or seizure activity (e.g., del Bigio, 1993; Dennis et al., 2006; Fletcher et al., 2004). The number of shunt infections and malfunctions and the type and location of the spinal lesion also contributes to neurocognitive outcomes of youth with this condition (e.g., Fletcher et al., 2005). More specific to this study, youth with a broad range of impairment were included in the sample. For example, this study included youth with and without hydrocephalus, such that 21.6% (30 participants) of the sample did not have any documented history of hydrocephalus or shunt treatment. This is noteworthy because children with spina bifida, but without hydrocephalus, often do not exhibit as severe of impairment in comparison to children with spina bifida and hydrocephalus (e.g., Fletcher & Dennis, 2010). In addition, the majority of the sample was comprised of youth with the more severe form of spina bifida, known as myelomeningocele, but individuals with less severe types of spina bifida were also included in the sample (e.g., 9.4% diagnosed with lipomeningocele). There was

also variability in regards to the location of spinal lesions of participants in this

sample (18.0% sacral, 63.3% lumbar, 15.1% thoracic). As previously discussed, this has implications for the neurocognitive outcomes of youth in this sample. In sum youth with spina bifida demonstrate deficits on tests of attention and executive function, but there is a great deal of variability within the population.

Prior studies among youth with spina bifida tend to include only youth with the more severe illness presentation (i.e., myelomeningocele and hydrocephalus; e.g., Ammerman et al., 1998; Burmeister et al., 2005). However, by including youth with spina bifida with a broad range of disability levels increased the variability among youth in this sample. As a result, this increased generalizeability of study findings to youth with spina bifida in the general population. Moreover, the broad range of functioning among youth in this population on the neurocognitive measures increased the likelihood of detecting significant effects in regression analyses.

Questionnaire Data

On the questionnaire data, parents and teachers also report impairment in the areas of attention and executive function among youth with spina bifida. Specifically, the SNAP-IV was utilized in this study to provide an assessment of inattentive symptoms. This measure is based on the DSM-IV diagnostic criteria for ADHD. Percentage of participants that reached clinically significant levels of inattention and hyperactivity/ impulsivity was computed (above 95^{th} percentile). Based on parent-report, a substantially higher number of youth with spina bifida were reported to exhibit clinically significant levels of ADHD inattentive type (11.2%, n = 14), as compared to ADHD hyperactive/impulsive type (0.8%, n = 1). Yet, no participant met criteria for ADHD,

combined type. This trend was also noted for teacher-report of youth symptoms, such that 6.6% (n = 8) of children met criteria for clinically significant levels of ADHD inattentive type, as compared to 3.3% (n = 4) and 2.5% (n = 3) of youth reaching clinically significant levels of ADHD hyperactive/impulsive type and combined type, respectively. This finding is consistent with prior studies of youth with spina bifida that document higher rates of only ADHD inattentive type in this population (e.g., Ammerman et al., 1998; Burmeister et al., 2005). However, it is important to consider that mobility limitations may also contribute to lower levels of reported hyperactivity within this population.

It is noteworthy that the percentage of youth reaching clinically significant levels of ADHD inattentive type based on parent-report (11.6%) greatly exceeds rates of ADHD within a normative population (rates ranging from 3% to 7%; APA, 2002). However, this percentage is lower than in prior studies investigating ADHD among youth with spina bifida. For example, several researchers have found rates of ADHD diagnoses ranging from 31-33% among youth in this population (e.g., Ammerman et al., 1998; Burmeister et al., 2005). Yet, as previously discussed, these studies utilized samples of youth with both spina bifida and hydrocephalus, rather than including individuals with a wider range of disability levels (i.e., spina bifida without hydrocephalus). Thus, the higher levels of CNS damage among youth with both spina bifida and hydrocephalus are associated with greater neurocognitive deficits within these study populations (e.g., del Bigio, 1993; Dennis et al., 2006; Fletcher et al., 2004), which in turn also impacts symptomatology of inattention and hyperactivity/impulsivity.

It is also important to consider that the SNAP-IV does not currently provide aged-based or gender-based norms. Thus, the cut-off scores for clinical significance does not account for variability in symptoms that are typically demonstrated in a normative population (e.g., higher rates of symptomatology among males and younger children; APA, 2002). Perhaps utilizing a sample of preadolescents and adolescents in this study, rather than younger children, contributed to the lower percentage of youth meeting diagnostic criteria for ADHD.

In regard to executive function, the BRIEF was utilized in this study as an assessment of several domains of executive dysfunction. Study findings indicate that parents and teachers perceive higher levels of executive dysfunction in their child across all subtests, as compared to normative data, except for parent-report on the Organization of Materials subtest. However, similar to the test data findings, there was a great deal of variability in scores on each subtest of executive dysfunction, particularly for teacher-report.

It is also noteworthy that teachers of youth with spina bifida tend to report higher levels of executive dysfunction on the BRIEF. For example, scores on the BRIEF subtests ranged from the 50th to 77th percentile for parents, where-as percentile scores ranged from 63rd to 96th for teachers. Moreover, statistical tests comparing mean scores on the individual subtests between parents and teachers suggest that teachers perceive higher levels of executive dysfunction across all domains of the BRIEF, except for the Inhibit and Emotional Control subtests. There are several possible explanations for higher rates of executive dysfunction based on teacher-report versus parent-report. For example, classroom environments place increased demands on children that often require higher

order cognitive function. Children must follow multi-step classroom directions, manage classroom assignments and projects, keep classroom materials organized, and inhibit increased distractions of classmates. Teachers may more accurately report executive function deficits among youth with spina bifida due, in part, to increased opportunity to observe these children in environments that demand such higher order cognitive function. In addition, teachers have a comparison group of other children in the classroom to compare the child's behaviors. In contrast, parents may have less experience with typically developing youth and, thus, may under report their child's symptoms of executive dysfunction. However, it is noteworthy that while teachers report higher levels of executive dysfunction, parents report higher levels of inattention. These findings suggest that teachers are more likely to identify the presence of additional behaviors (e.g., impulsivity), whereas parents are more likely to identify the absence of behaviors (e.g., not attending to a task).

In comparison to other studies, parent-report of executive dysfunction was somewhat lower (e.g. mean T-scores on BRIEF subtests ranging from 50.4 – 57.3). Mahone and colleagues (2002) found mean subtest T-scores ranging from 54.0 (68th percentile) to 67.0 (96th percentile) on the BRIEF. However, it is again important to consider that Mahone and colleagues (2002) only included participants with both spina bifida and hydrocephalus. Thus, it is not surprising that samples of individuals with higher levels of illness severity, would exhibit greater neurocognitive deficits. Despite this disparity across studies, there was also a great deal of similarities. For example, both studies indicate that parents perceive youth to have the highest level of impairments on the Working Memory, Initiate, and Plan/Organize subtests and the lowest levels of

impairment on the Inhibit subtest. Similarly, Rose and Holmbeck (2007) found that parents of youth with spina bifida endorsed significantly higher levels of deficits on the Working Memory and Initiate subtests than a matched comparison sample.

Taken together, youth with spina bifida demonstrate higher rates of inattention and executive dysfunction in comparison to children without spina bifida, based on both questionnaire and test data. Yet, in contrast to other studies of youth with spina bifida (e.g., Mahone et al., 2002) the degree of impairment was relatively less severe. This is likely due to increased variability in illness severity among youth in this sample.

Hypothesis 2

Hypothesis 2 predicted that lower levels of attention and executive function among children with spina bifida would be associated with higher levels of medical autonomy and adherence, after controlling for age, IQ, and level of disability. Results for the medical adherence outcome will be discussed first, followed by findings for the medical autonomy outcome.

Medical Adherence

Study findings provide partial support for Hypothesis 2. Specifically, higher levels of inattention and executive dysfunction (based on parent/teacher-report only) was associated with lower levels of medical adherence among youth with spina bifida, after controlling for age, IQ, and level of disability. Moreover, the association between higher levels of executive function and higher levels of medical adherence continued to be significant when investigated only among children with an IQ score of above 85. Thus, lower general cognitive ability could not explain for this significant association in regression analyses. These study finding are not surprising given the complexity of

treatment tasks these youth must follow. In addition to managing typical adolescent healthcare demands (e.g., hygiene behaviors), youth with spina bifida must learn to catheterize, manage a bowel program, coordinate multiple doctor visits, identify signs of shunt malfunction, check for pressure sores, and many other healthcare demands. All of these tasks require higher order cognitive ability, such as planning, organizing, attending to detail, and problem solving. These findings are also in line with prior research indicating that youth with less advanced cognitive functioning often have greater difficulty managing their medical regimen (Dunbar-Jacob et al., 2000).

Yet, contrary to Hypothesis 2, no significant effects emerged for attention and executive function test data predicting medical adherence among youth. In other words, the relation between neurocognitive functioning and medical adherence varied depending on the source of the attention and executive function data. It is important to note that although there was a significant association between parent/teacher-report and test data, this association was only moderate (r's = -.31 and -.29 for attention and executive function, respectively). In contrast, there was a stronger association between parent/teacher-report of attention and executive functions (r = .85) and attention and executive function test data (r - .66). Thus, for psychometric reasons, it is not surprising that study findings were more similar based on assessment method rather than the construct being assessed (i.e., attention, executive function).

There are several other possible explanations for the non-significant associations between the attention and executive function test data and the medical adherence outcome. For example, this study created a composite score across several areas of adherence (e.g., catheterization, bowel program). Perhaps some treatment tasks rely more

heavily on higher order cognitive function (e.g., managing bowel program, catheterization), in comparison to other treatment tasks (e.g., taking oral medication). Thus, collapsing across treatment tasks may have reduced the likelihood of detecting significant effects. In addition, the medical adherence measure does not account for the degree of assistance youth with spina bifida received from family members to complete each treatment task. For example, somewhat contradictory findings emerged for disability level predicting medical adherence. Specifically, youth with higher levels of disability were more likely to adhere to their treatment regimens. This finding suggests that youth with higher levels of disability were likely receiving increased support from family members and healthcare providers to complete their treatment tasks. Moreover, as will be further discussed below, youth with spina bifida who exhibit higher levels of inattention and executive dysfunction were also less autonomous on treatment tasks. Thus, youth with spina bifida who were more severely impaired cognitively were also receiving increased parental support and scaffolding with their daily medical tasks. As a result, these youth were likely more adherent to their regimen. Interestingly, prior researchers have found that less parental involvement and supervision in adolescents' medical management is associated with worse adherence outcomes (Ellis, Podolski, Naar-King, Grey, Want, & Moltz, 2007; Naar-King et al., 2009). In addition, when adolescents with chronic health conditions view their parents as "collaborators" in resolving treatment-related issues, they are more likely to exhibit higher levels of adherence during adolescence (Wiebe et al., 2005).

Partial support was also provided for attention and executive function predicting medical autonomy. Specifically, lower levels of inattention and executive dysfunction (based on test data only) were associated with higher levels of autonomy on healthcare tasks, after controlling for age, IQ, and level of disability. In addition, the association between lower levels of attention and higher levels of medical autonomy continued to be significant when investigated only among children with an IQ score of 85 and above. Thus, lower general cognitive ability could not explain for this significant association in regression analyses. No significant effects were found based on parent/teacher-report of attention and executive function.

As previously discussed, the tasks required to manage the healthcare needs of youth with spina bifida are often quite complex and, thus, healthcare is a particularly challenging area for autonomy development. Study findings support prior research indicating that acquisition of medical autonomy skills is more challenging for youth with spina bifida (e.g., Zukerman et al., 2011). It is also noteworthy that age was significantly associated with medical autonomy in this study, such that older youth exhibited higher levels of medical autonomy than younger youth. This is also consistent with prior research that has found higher levels of responsibility for treatment tasks among adolescents as compared to preadolescents (e.g., Anderson et al., 1990; Devine et al., 2011; McQuaid et al., 2003).

There are several possible explanations for the non-significant association between the parent/teacher-report of inattention and executive dysfunction and medical autonomy. As previously discussed, parent/teacher-report of youth cognitive function

was only moderately associated with performance on tests of attention and executive function. This suggests that parents and teachers do not always adequately report attention and executive function ability in children. In addition, given that more severely impaired children often receive increased scaffolding and support from their parents to complete treatment tasks, these youth likely have fewer demands and/or opportunities to demonstrate their performance on tasks that require increased attention and executive function ability. As such, despite increased impairments as compared to typically developing youth, parents and teachers fail to endorse and/or recognize some symptoms of inattention and executive dysfunction.

Taken together, partial support was provided for Hypothesis 2, which predicted that attention and executive function would predict healthcare behavior outcomes among youth with spina bifida. Higher levels of attention and executive function based on questionnaire data only was significantly associated with higher levels of medical adherence, and attention and executive function based on test data was significantly associated with higher levels of medical autonomy.

It is somewhat surprising that questionnaire measures were associated with medical adherence, whereas performance-based measures were associated with medical autonomy. One reason for this finding may be that these different instruments are measuring different aspects of attention and executive function ability. Whereas the test data measures the youth's ability to rapidly execute problem-solving strategies and selectively attend to and/or divide attention across auditory and visual tasks, the BRIEF and SNAP-IV measure social and behavioral manifestations of attention and executive function abilities. In other words, social and behavioral manifestations of these

neurocognitive deficits have greater implications for medical adherence outcomes, whereas medical autonomy outcomes rely more heavily on youth's performance on tasks. Another explanation for this discrepancy between medical adherence and medical autonomy outcomes may be that the medical adherence outcome is heavily influenced by caregiver bias, and the medical autonomy outcome is more objective. For example, parents who perceive their child to have greater difficulty with medical tasks may over report symptoms of inattention and executive dysfunction (or vice versa). Nonetheless, it is important to note that teacher-report of attention and executive function was also obtained, which reduces the likelihood of single-source bias.

Hypotheses 3 and 4

Observed and perceived parenting behaviors were investigated as predictors of healthcare behaviors among youth with spina bifida, after controlling for age, IQ, and level of disability. Specifically, Hypothesis 3 predicted that adaptive parenting behaviors (i.e., higher levels of acceptance and higher levels of behavioral control) would predict higher levels of medical adherence and autonomy. Hypothesis 4 predicted that maladaptive parenting behaviors (i.e., higher levels of psychological control) would predict lower levels of medical adherence and autonomy. Results for the medical adherence outcome will be discussed first, followed by findings for the medical autonomy outcome.

Medical Adherence

In support of Hypothesis 3, higher levels of maternal observed and perceived acceptance and observed maternal behavioral control were significantly associated with higher levels of medical adherence. The association between higher levels of observed

maternal acceptance and behavioral control and higher levels and medical adherence remained significant when analyses were run for youth with IQ scores above 85 only. Thus, the degree in which mothers are emotionally supportive, affectionate, approving, and expect and enforce age-appropriate behavior is associated with higher levels of medical adherence among preadolescents and adolescents with spina bifida. This finding is in line with prior work documenting parental acceptance and behavioral control as significant predictors of positive adjustment outcomes among youth (e.g., Ainsworth et al., 1978; Barber & Harmon, 2002; Greenley et al., 2006; Holmbeck et al., 2002b).

Nonetheless, no significant direct effects emerged for perceived maternal behavioral control predicting medical adherence. Similarly, Holmbeck and colleagues (2002b) found that in comparison to the acceptance construct, associations with behavioral control and adjustment outcomes among youth with spina bifida were sparse. There are several possible explanations for these findings. For example, as highlighted by Holmbeck and colleagues (2002b), perhaps the construct of perceived behavioral control employed in both studies lacks construct validity. The non-significant association between the observed and perceived behavioral control constructs (-.12 for mothers and -.03 for fathers) further calls into question the validity of this measure. Moreover, perhaps the impact of behavioral control on adjustment outcomes does not appear until later adolescence or early adulthood. Future longitudinal research is needed to investigate the impact of behavioral control on healthcare behavior during these later developmental years when individuals are taking on more responsibility for their medical care.

Study findings also did not provide support for Hypothesis 4. Hypothesis 4 predicted that maladaptive parenting behaviors (i.e., psychological control) would be

associated with lower levels of medical adherence. The non-significant association between psychological control and medical adherence is in contrast to a great deal of research documenting the negative effects of psychological control on adjustment outcomes of youth (e.g., Barber, 1996; Steinberg, 1990) and particularly youth with spina bifida (Holmbeck et al., 2002b). Although increased intrusiveness and dominance has been linked to poor adjustment outcomes among youth with spina bifida, these parenting behaviors do not seem to have detrimental effects on healthcare behaviors of these youth. Perhaps having a complex and challenging medical condition, such as spina bifida, serves as a buffer against the possible negative effects these behaviors have on healthcare behaviors of preadolescents and adolescents. Another explanation is that the negative effects of psychological control on medical adherence outcomes may not appear until later in adolescence or early adulthood.

Lastly, no significant effects emerged for the effect of any of the paternal parenting behaviors predicting medical adherence. However, it is important to note that a small sample size of fathers (n’s = 88 - 95) reduced the statistical power of the regression analyses, and thus, the likelihood of detecting small to medium effects.

Medical Autonomy

Contrary to Hypotheses 3 and 4, study findings did not provide support for parenting behaviors predicting medical autonomy outcomes among youth with spina bifida. Instead, other factors seem to be more salient predictors of medical autonomy among preadolescents and adolescents in this population including age, level of disability, general cognitive functioning (i.e., IQ), and attention and executive function. Moreover, this study investigated youth during the preadolescent and early adolescent

years. Perhaps the effects of parenting behaviors on medical autonomy are not particularly salient during this developmental period. Rather, the effects of parenting behaviors may only become predictive after an accumulation of several years and/or after youth have begun to enter the later adolescent years. Prior research has found the youth with spina bifida often acquire autonomy skills two to five years after typically developing youth (Davis et al., 2006). Youth during the earlier adolescent and preadolescent years may not be fully prepared to take on responsibility for medical tasks, irrespective of variations in parenting behaviors. Future research is necessary to follow these youth longitudinally into the later adolescent and young adult developmental period when youth are expected to take on more responsibility for their healthcare needs.

Hypotheses 5 and 6

In addition to examining the direct effects of attention, executive function, and parenting behaviors on healthcare behaviors, this study also explored the moderating role of parenting behaviors on the relation between neurocognitive functioning and medical adherence and autonomy, after controlling for age, IQ, and level of disability. Specifically, Hypothesis 5 predicted that adaptive parenting behaviors (i.e., higher levels of acceptance, higher levels of behavioral control) would buffer against the negative impact of inattention and executive dysfunction on medical autonomy and adherence. In addition, Hypothesis 6 predicted that maladaptive parenting behaviors (i.e., psychological control) would exacerbate the negative impact of inattention and executive dysfunction on medical autonomy and adherence. Although there were relatively few significant interaction effects, partial support was obtained for Hypotheses 5 and 6.

For maternal parenting behaviors, there was partial support for Hypotheses 5, such that higher levels of observed maternal behavioral control buffered against the negative effects of executive dysfunction on medical adherence. Specifically, the association between higher levels of executive dysfunction based on parent/teacher-report and lower levels of medical adherence was buffered among children with mothers who demonstrated higher levels of observed behavioral control, as compared to children with mothers who demonstrated lower levels of observed behavioral control. In other words, as predicted, maternal parenting behaviors that promote age-appropriate structure, supervision, and expectations, can buffer against the negative effects of youth impairments on tasks of planning, organizing, initiating, and other tasks involving higher order cognitive functions on medical adherence outcomes. Yet, somewhat contradictory findings emerged when analyses were conducted among only youth in the sample with an IQ score 85 and above. Specifically, higher levels of executive function ability based on test data predicted lower levels of medical adherence among children with mother who demonstrated lower levels of behavioral control. This finding suggests that among higher functioning youth with IQs above 85, higher levels of executive function ability was associated with worse healthcare behavior outcomes if parents demonstrate lower levels of behavioral control. Perhaps mothers who display lower levels of behavioral control are more likely to provide even less structure, support, and supervision among youth who demonstrate higher levels of executive function. Thus, these youth are taking on more autonomy for treatment tasks than youth with lower levels of executive function ability.

Although maternal acceptance was directly related to medical adherence, no support was provided for the moderating role of this variable. This finding suggests that both children who display higher and lower attention/executive function benefit from increased maternal acceptance for predicting medical adherence. In addition, maternal parenting behavior did not provide support for the buffering role of psychological control (Hypotheses 6) on medical adherence outcomes, suggesting that other parenting behaviors are more important during these developmental years for promoting medical adherence.

Several paternal parenting behaviors moderated the relation between youth cognitive function and adherence outcomes among youth with spina bifida. Specifically, the relation between executive dysfunction based on parent/teacher-report and medical adherence was moderated by observed paternal behavioral control. Interestingly, the relation between executive dysfunction and medical adherence was particularly salient among children with fathers who demonstrated higher levels of behavioral control. In other words, study findings were in contrast to Hypothesis 5, such that lower levels of observed paternal behavioral control buffered against the negative effects of higher levels of executive dysfunction on medical adherence. In contrast, it was predicted that higher levels of paternal behavioral control would buffer against the negative effects of higher levels of executive dysfunction on medical adherence.

Study findings also conflicted with Hypothesis 6. Specifically, observed paternal psychological control moderated the relation between inattention and medical adherence, such that higher levels of parent/teacher-report of inattention predicted higher levels of medical adherence only among children with fathers who displayed higher levels of

psychological control. Thus, higher levels of psychological control seemed to serve as a protective factor among youth with higher levels of inattention based on parent/teacher-report. These findings are in contrast to prior research which highlight the detrimental effects of parental psychological control on child adjustment outcomes (e.g., Barber, 1996; Barber, Olsen, & Shagle, 1994; Holmbeck et al., 2002b; Maccoby & Martin, 1983; Steinberg, 1990). However, none of these studies explored medical adherence as an outcome variable. Psychological control may be detrimental in some domains of adolescents' adjustment (e.g., internalizing and externalizing behaviors), yet may also have some positive effects. It is possible that fathers who are more intrusive and domineering may simply take over medical adherence tasks among more impaired youth and, thus, facilitate adherence to treatment regimen.

There are several other possible explanations for these findings that warrant further exploration. For example, the majority of prior research investigating the impact of parenting behaviors on adjustment outcomes has only included maternal caretakers (e.g., Ainsworth et al., 1978; Barber & Harmon, 2002). Perhaps the validity of the behavioral control variable varies depending on gender of the parent. For instance, maternal parenting behaviors that facilitates and reinforces age-appropriate behaviors in children, when displayed by paternal caretakers, might be associated with intrusiveness and over protectiveness. Moreover, gender biases may have influenced the coding of this variable. The majority of research assistants involved in coding parenting behaviors were female. As such, female coders may have been more likely to code non-stereotypically maternal parenting styles (e.g., high levels of warmth) as negative in paternal caregivers. Another explanation is the interacting effect of both maternal and paternal parenting

behaviors. For example, children with fathers who displayed higher levels of behavioral control may have mothers who, in turn, displayed lower levels of behavioral control. As such, the effects of lower levels of maternal behavioral control may have more detrimental effects on healthcare outcomes as compared to the effects of paternal behavioral control. Future research is necessary to explore the simultaneous effects of both maternal and paternal parenting behaviors (e.g., both parents with high levels of behavioral control versus one parent with high levels and one parent with low levels of behavioral control).

Medical Autonomy

For maternal parenting behaviors, analyses provided partial support for Hypothesis 5. Specifically, higher levels of perceived maternal acceptance buffered against the negative effects of inattention based on test data on medical autonomy. In other words, maternal parenting behaviors that were characterized by warmth and supportiveness buffered against the negative effects of inattention on medical autonomy outcomes.

These findings suggest that maternal acceptance supports autonomy development among youth who demonstrate higher levels of inattention. However, it is also important to consider that higher levels of maternal warmth and support may have detrimental effects on the autonomy development of youth. For example, there was no significant difference in level of medical autonomy among youth who demonstrated higher versus lower levels of inattention. Perhaps warm and supportive mothers of youth who demonstrate higher levels of attention provided more support and scaffolding than is developmentally appropriate and, thus, hinder autonomy development. It is also

important to further explore the higher levels of medical autonomy among youth who were higher functioning and had a mother who demonstrated lower levels of acceptance. Perhaps these mothers granted higher levels of responsibility than was developmentally appropriately. Future research is necessary to investigate the interaction between autonomy development and medical adherence, in order to determine whether youth who are granted increased autonomy are actually completing their treatment tasks as prescribed.

No significant findings emerged for Hypothesis 6, based on maternal parenting behavior analyses, suggesting that maternal psychological control does exacerbate the effects of neurocognitive deficits on medical autonomy outcomes. In addition, analyses for paternal parenting behaviors did not provide support for Hypothesis 5 or 6. Thus, no support was provided for paternal parenting behaviors moderating the relation between neurocognitive deficits and medical autonomy. However, it is important to note that a small sample size of paternal caregivers (*n*'s = 88 - 95) reduced the power of the analyses.

Limitation and Future Research

There were some limitations of this study that should be addressed in future research. First, as is common in pediatric samples, the sample size was small, particularly for paternal caregivers. This limited the statistical power of the analyses and the likelihood of detecting larger effects. Second, the majority of the population was Caucasian. Given the higher rates of spina bifida within the Hispanic population (Lary & Edmonds, 1996), there was increased effort to include Hispanic, Spanish-speaking youth with spina bifida in this study. For example, parent questionnaires, video tasks, and all

family communication letters were translated into Spanish and Spanish-speaking research assistants participated in in-home sessions. Nonetheless, despite significantly higher rates of Hispanics in this study (28.1%) as compared to other studies investigating youth with spina bifida (e.g., Holmbeck et al., 2003), 54% of the sample was Caucasian. This limits the generalizeability of study findings to other ethnic groups. Future research should continue to strive for a more representative sampling of Spanish-speaking families, as well as other ethnic groups (e.g., African Americans). Third, this study sampled youth within a single illness group. Although there are several advantages to conducting research within a single illness group (e.g., Holmbeck et al., 2003), this methodology limits the degree to which we can generalize our findings to groups with other chronic health conditions. Fourth, study findings were based on cross-sectional data only, thus causality cannot be determined. As such, the influence of neurocognitive functioning and parenting behaviors on healthcare behaviors across time and the directionality of the findings cannot be determined. For instance, adherence and autonomy may directly influence parenting behaviors. One example is that parents might adapt their parenting style to a child who struggles to adhere to their medical regimen by increasing structure and becoming more overprotective. Moreover, among children who have the ability to be independent, these parents may develop higher expectations for mature behaviors and, thus, are more likely to enforce age appropriate behavior. Lastly, future research is necessary to determine factors that impact medical adherence and autonomy across the life span among individuals with spina bifida.

There were also several limitations regarding the measurement of medical adherence in this study. First, given the complexity of these children’s healthcare needs, a

questionnaire is not sufficient to fully understand medical adherence within the spina bifida population. Moreover, questionnaire data often overestimates adherence and can be influenced by reporter bias (e.g., social desireability; Rapoff, 1999). Nonetheless, comprehensive assessments are not always feasible due to financial and time constraints. Furthermore, the questionnaire utilized in this study allowed for the measurement of a complex array of medical adherence behaviors (e.g., catheterization, medication, bowel programs) and for data to be collected from multiple of individuals (i.e., mothers, fathers), reducing the likelihood of bias. An additional limitation of the adherence measure utilized in this study is that it does not account for the child's prescribed medical regimen. Although a "not applicable" option was included in the questionnaire to account for tasks not included in the child's regimen, this study cannot fully account for whether the child's medical behaviors correspond with medical providers' prescribed medical regimen. Lastly, the adherence questionnaire evaluates the management of treatment tasks among children and their families. As such, this measure does not take into account the amount of assistance youth are receiving from their families to complete their treatment tasks. Understanding whether youth can appropriately and autonomously complete their treatment tasks is particularly important as these individuals transition into adolescence and then adulthood. Future research is necessary to determine the impact of autonomy on healthcare behavior outcomes among youth with spina bifida, and how autonomy impacts parent-report of adherence behaviors on this measure.

There were also some limitations regarding the measurement of parenting behaviors. First, the methodology utilized in this study does not provide evidence for the simultaneous impact of both maternal and paternal parenting behaviors. For example,

high levels of maternal acceptance may buffer against the negative impact of high levels of paternal psychological control on adolescent healthcare behaviors, or low levels of paternal acceptance may exacerbate the negative impact of low levels of maternal acceptance. Second, this study does not offer information regarding factors that contribute to parenting behaviors (e.g., sociocultural factors) or children's perceptions of their parents' behaviors. For example, child characteristics (e.g., defiance) may also influence the parenting behaviors of mothers and fathers. Cultural factors may also influence how youth interpret their parents' acceptance, behavioral control, and psychological control, which will likely influence their response to these parenting behaviors. Future research is necessary to further understand the simultaneous effects of both maternal and paternal parenting behaviors, as well as factors that contribute to mothers' and fathers' style of parenting.

In addition, several suppressor effects emerged in the regression analyses which require increased attention. Further research is necessary to determine whether these suppressor effects are replicable. These studies would increase our understanding of how child (e.g., attention, executive function) and parent (e.g., parenting behaviors) factors work together to predict outcomes and the interdependence of such parent-child factors.

Lastly, his study did not directly explore neuroanatomical correlates associated with inattention and executive dysfunction of youth with spina bifida. Future research that investigates specific neuroanatomical correlates based on imaging data among youth in this population will provide valuable information to isolate children who are particularly at risk.

Conclusions

Despite the potential limitations of this study, there were also several strengths. This study utilized a multisource and multimethod design to provide evidence for the influence of both neurocognitive and environmental factors, namely parenting behaviors, on the healthcare behaviors of youth with spina bifida. For example, test data, mother-report, father-report, and teacher-report were obtained to assess attention and executive function, and child-report, mother-report, and father-report were obtained to assess healthcare behaviors. In addition, observational and questionnaire data were utilized to assess parenting behaviors among both mothers and fathers. By including mothers and fathers, this study was able to highlight the important role of both parents in the healthcare outcomes of youth with physical disabilities. In addition, this study focused specifically on the preadolescent and adolescent years. This developmental period is particularly important to study in regards of healthcare behaviors for several reasons. Most notably for this study, healthcare roles are often negotiated between parent and child during the early adolescent years and responsibility for medical tasks often begin to transfer from parent to child. In addition, as previously discussed, there was increased effort to recruit Hispanic, Spanish-speaking youth with spina bifida, given the higher rates of spina bifida within the Hispanic population (Lary & Edmonds, 1996). As such, this increased the generalizeability of the findings of this study, as compared to other studies of youth with spina bifida.

The results of this study have important clinical implications. First, youth with spina bifida are at higher risk for symptoms of inattention and executive dysfunction. For example, these youth demonstrate clinically significant difficulties with tasks of working

memory, initiation, planning, and organizing. Moreover, youth with spina bifida demonstrate increased levels of inattention, based on questionnaire and test data. As such, they are at an increased risk for a diagnosis of ADHD, predominately inattentive type.

Second, this study provides support for utilizing both questionnaire and test data to evaluate symptoms of inattention and executive dysfunction. Both measures are valuable for identifying youth at risk for adjustment difficulty. Third, deficits in attention and executive function are associated with adherence and autonomy outcomes, as well as potentially other areas of functioning. Fourth, this study highlights the differing factors that predict medical adherence versus medical autonomy outcomes, and the importance of fully investigating both of these constructs for understanding healthcare behaviors of youth with spina bifida. These findings have important implications for treatment. Clinically, skills training may be helpful for these youth to manage their executive and attention deficits and ultimately experience greater success with autonomy and adherence to their treatment regimen. In addition, medical interventions commonly used to treat attention difficulties in youth, such as stimulants, may be efficacious for the treatment of inattention in youth within this population. Nonetheless, future research is necessary to further explore the clinical utility of such medical treatments.

This study also highlights the important role of parenting behaviors on the healthcare outcomes of youth with spina bifida, particularly among youth with higher order cognitive deficits. Study findings were most salient for the role of parenting behaviors predicting medical adherence. Given the significant effect of both mother and father parenting behaviors on healthcare behaviors of youth with spina bifida, this study

provides support for including both parents in treatment. In addition, mothers and fathers of children with physical disabilities, such as spina bifida, would benefit from increased psychoeducation regarding the positive impact parental acceptance and behavioral control has on medical adherence and autonomy outcomes. Interventions would be particularly beneficial as parents navigate the preadolescents and adolescent years, when medical tasks are typically transferred from parent to child.

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